A CONSTRUCTIVIST COUNSELLING PROGRAMME
FOR ASSISTING LEARNERS INFECTED WITH
HIV/AIDS TO COPE IN SCHOOLS

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"It really doesn't matter what your conscious mind does because it is your unconscious mind that will find new possibilities that your conscious mind may not be aware of."

Milton Erickson
SUMMARY

The aims of this study were to investigate what the ‘lived’ experiences of HIV infected school-going learners are, determine how their psychological and physical well being are affected by HIV occurrences; investigate how their general functioning at school is, investigate the type of social support they get from their families, schools, communities and the society in general, and develop a constructivist counselling programme to assist these learners to realize their psychological and social strengths in order to succeed at school and in general life.

The findings from the proceedings of the literature review indicated that HIV attacks the immune system, that is, the human body’s defence against infection, and reduces the resistance of the body to all kinds of 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 which seriously affect the psychological and the physical well-being of human beings.

Constructivism formed the theoretical framework of this research. Constructivist theory propounds that people create meaning from the interaction between their existing knowledge or beliefs and the new ideas and situations that they encounter, ideas and situations that can only be effectively found in social settings. The constructivist theory postulates that attending to counsellee’s socio-cultural factors in the counselling processes provides counsellors with a cognitive framework for understanding the major tasks and crises of each stage of human functioning development. Self-efficacy was highlighted in the literature review as an important psycho-social variable that may influence coping among persons with HIV/AIDS as it refers to personal
judgements concerning the ability to engage successfully in specific behaviours that lead to specific desired outcomes.

The findings from the proceedings of the empirical research revealed that living with HIV becomes a burden which infected individuals carry wherever they go and they find it difficult to separate themselves from the virus; learners suffering from HIV/AIDS do not seem to be doing well at school because of continual sickness due to being infected with HIV, their high rate of absenteeism, their fear of being stigmatised and being socially discriminated against, hopelessness and helplessness, poverty, lack of social support and care by educators which all contribute to their poor scholastic performance; lack of support from family members, members of the community and the school makes it difficult for these learners to live positively; and that those learners who became infected with HIV/AIDS as a result of sexual abuse seem to be eager to spread the disease, instead of using preventative measures.

Based on the literature study on HIV/AIDS and constructivist counselling for assisting learners suffering from HIV/AIDS, as well as feedback on the interviews conducted with learner participants who were suffering from HIV/AIDS, recommendations, which could prove useful to implementation of effective constructivist counselling services in schools, were suggested.
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CHAPTER ONE

ORIENTATION

1.1 INTRODUCTION

As the world moves from one of perceived uniformity to one of perceived diversity, it is important that models of counselling science, practice and profession have the flexibility to work within unique social, educational, psychological and schooling situations. For this reason, a counselling science, practice and profession of the twenty-first century needs to develop a socially contextualised approach to collaboration and consultation through situational analysis (Freedman & Combs, 2002:34). Such an approach is dynamic and interactive, allowing counsellors to study educational, psychological and schooling situations systematically in order to:

- determine the main social influences on learning and psychological well-being problems of children and adolescents;

- ascribe meaning to the teaching and learning situation;

- collaboratively plan, design and build supportive educational and psychological interventions;

- implement counselling interventions both at the individual and systems level; and


The interactiveness of the socially contextualized approach to educational and psychological problems integrates cognitivist (information processing), socio-cultural and social cognitivist theoretical frameworks (Dattilio & Castaldo, 2001:46). Socio-cultural and social cognitivism theoretical frameworks form social constructivism. Cognitivist, socio-cultural and social cognitivist
theoretical frameworks developed because constructivist theorists such as Piaget, Vygotsky and Bandura, to mention the most prominent ones, disagreed with the behaviourism theory which postulated that the best way to study learning and counselling was through observable phenomena and strict focus on observable behaviour only without taking into consideration the role of cognitive processes, that is, the thinking processes (Neimeyer & Raskin, 2000:56; Reinecke, Dattilio & Freeman, 2002:21). Piaget, a cognitive psychologist did not agree with this theory. In reaction to the behaviourist theory, Piaget developed a cognitivist theory. The cognitivist theory in essence basically penetrates the thinking process of the learner to determine what mental processes are activated and changed during the course of learning. In cognitive theories, knowledge is viewed as symbolic mental constructs in the learner’s mind, and the learning process is the means by which these symbolic representations are committed to memory (Ellis, 2000:168; Dattilio, 2000:35; Bertolino & O’Hanlon, 2002:48). A change in behaviour is observed, as an indicator to ascertain elements of thinking processes. The cognitivist version of the human mind is an input/output model of information or symbol processing.

In the light of the foregoing paragraph, it is clear that cognitivists are concerned with the study of individuals’ perceptual processes, problem-solving abilities, and reasoning abilities. Cognitive counselling and learning programmes, in fact, are often organized in large sections, and have built-in or learner-generated memory devices to help learners retain and use the information in the future and give learners control by introducing conceptual frameworks, and by relying on both experiential and discovery learning (Beck & Weishaar, 2000:244; Leahy, 2002:418). Cognitivists hold the idea that information is more likely to be acquired, retained, and retrieved for future use if it is learner-constructed, relevant, and built upon prior knowledge.

In contrast to both behaviourism and cognitivism, social constructivism is not an objectivist theory in which reality is viewed as external to the learner where the mind acts as a processor of input from reality (Prochaska & Norcross, 2003:40). Rather, social constructivism presents a new view on how reality is
perceived and the nature of knowledge internal to the learner. When comparing social constructivism to both behaviourism and cognitivism, Yalom (2003:22) summarizes:

'The social constructivist...sees reality as determined by the experiences of the knower. The move from behaviourism through cognitivism to social constructivism represents shifts in emphasis away from an external view to an internal view. To the behaviourist, the internal processing is of no interest; to the cognitivist, the internal processing is only of importance to the extent to which it explains how external reality is understood. In contrast, the social constructivist views the mind as a builder of symbols, the tools used to represent the knower's reality. External phenomena are meaningless except as the mind perceives them....Social constructivists view reality as personally constructed, and state that personal experiences determine reality, not the other way round.'

The integration of socio-culturalism, social cognitivism and cognitivism allows for a balance between external experiences and internal processes, between the need for basic facts/concepts and problem solving, and instills the desire to create informed individuals and life-long learners (Corey, 2001:18; Mikulas, 2002:36; Prochaska & Norcross, 2003:42). For this reason the theoretical framework of this research assumes that the infusion of the theories of cognitivism, socio-culturalism and social cognitivism in the science and practice of counselling school-going children and adolescents, who in this research are referred to as learners, infected with the human immunodeficiency virus (HIV) and the acquired immune-deficiency syndrome (AIDS) can provide a rich, real and authentic learning and counselling experience.

In most parts of the world the human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) have become the most commonly diagnosed diseases among learners (Crepaz & Marks, 2002:135). Many schools in South Africa are likely to experience a huge increase in the prevalence of infection and manifestation of this pandemic among learners over the next few years (Hepburn, 2002:2). This escalation of the prevalence
of the disease is subsequently caused by a number of factors, *inter alia* the learner's temptation to explore their sexual identities and often not only to experiment with sex but also with drugs (Mitchell & Linsk, 2001:393). Learners' sexual behaviour also tends to be impulsive and greatly influenced by peer pressure, which requires being sexually active at a very tender age, but is counteracted by ignorance and illiteracy concerning the way HIV is contracted (Wenger, 2001:1849).

1.2 SIGNIFICANCE OF RESEARCH

As most researchers have pointed out, HIV/AIDS has a disastrous impact on the physical and psychological health and human functions such as physical indisposition, memory, concentration, and creativity of learners (Anderson & Schartlander, 2002:73). Subsequently, behavioural efficiency and effectiveness, interpersonal relationships and personal productivity are also limited (Barnett & Schueller, 2002:43). Because of the physical and psychological demands involved in coping with this incurable disease, it is not surprising that physicians and psychologists have suggested that an HIV positive learner will show evidence of a negative effect on his or her general functioning at school (Clinton, 2003:1800).

Unlike in the past where the schools' responsibility was only to provide teaching and learning, the prevalence of HIV/AIDS has now created the following two-fold responsibilities, which are to provide:

- appropriate education in an inclusive, constructive, ecosystemic and health promoting school climate and atmosphere that is helpful and supportive of learners infected with HIV/AIDS (Kelly, 2002:53); and

- professional counselling in spite of policies dealing with sensitivity to both the social and physical impact of HIV/AIDS and providing a curriculum designed to prevent the spread of this disease and foster risk-reducing behaviours (Mohlala, 2002:6).

Many HIV infected learners, come from disrupted or disorganized homes such as, families headed by juveniles because of parental death from AIDS or the
incidence of divorce that provide little or no structure to lead a normal life and to develop coping skills (Badcock-Walters, 2001:8). The school counsellor can, therefore be, the only adult on whom an infected learner can consistently rely upon not only for affection and support, but also for assistance. The counsellor often becomes the learner's advocate in dealing with a variety of institutions, including the school, welfare agencies, the courts (in cases of rape and abuse) and the medical community (Wild, 2001:20; Mendel, 2002:34; Hepburn, 2002:130).

Despite the HIV/AIDS infected learners' need for support, many individuals find it difficult to speak to relatives and friends and reveal their status and their fears. The disclosure of their positive status to immediate family members is also often received with negativity, which does not only cause personal discomfort but also is subjected to discrimination and stigmatization (Rugamela & Akoulouze, 2003:23; UNAIDS, 2002:1).

The diagnosis of a terminal illness such as HIV/AIDS can be a traumatic event paralyzing an individual's mind and in most cases, those diagnosed are often overwhelmed by negative thoughts and fears (Cullinan, 2002:11). It is in situations such as these that constructivist counselling is highly recommended as it is more of an attitude changing activity, rather than a technique of counselling (Neimeyer & Raskin, 2000:46). It is not simply a way of counselling but first and foremost, a way of thinking about human beings in their:

- social contexts such as families, communities and society;
- pain; and
- triumphs (Goldenberg & Goldenberg, 2004:65).

Constructivist counsellors are rooted in the positive belief that infected learners are as academically competent as any other children and adolescents. They believe that the goal of counselling is to understand the infected individual, his/her family and the larger systems that may create barriers or bridges to academic competency (Ellis, 2001:12).
1.3 STATEMENT OF THE PROBLEM

In this research the use of constructivist counselling at schools is considered of utmost importance in dealing with the psycho-somatic and spiritual problems that the children who are infected with HIV/AIDS experience. Constructivist counselling offers an ecosystemic approach where the immediate social systems such as families, communities, societies, cultural beliefs and the social interrelationships of the HIV/AIDS infected learners are taken into consideration (Neimeyer & Raskin, 2000:8). Constructivist counselling recognizes that individuals are part of many systems and take into account the possible relevance of one system to another as well as to the HIV/AIDS infected learner (Gergen & McNamee, 2000:35). Social systems are important in assisting infected learners and families, schools, communities, peer groups, as well as health agencies such as clinics and hospitals.

Taking the above mentioned in consideration, the following questions arise:

- What are the ‘lived’ experiences of HIV infected school-going learners?
- How are their psychological and physical well being affected by HIV occurrences?
- How is their general functioning at school affected?
- What type of social support do they get from their families, schools, communities and the society in general?
- Can a constructivist counselling programme be developed to assist these learners to realize their psychological and social strengths in order to succeed at school and in general life?

1.4 AIMS OF THIS STUDY

On the basis of the above questions formulated for this research, the aims of this study were to:

- investigate what the ‘lived’ experiences of HIV infected school-going learners are;
• determine how their psychological and physical well being are affected by HIV occurrences;
• investigate how their general functioning at school is;
• investigate the type of social support they get from their families, schools, communities and the society in general; and
• develop a constructivist counselling programme to assist these learners to realize their psychological and social strengths in order to succeed at school and in general life.

1.5 RESEARCH METHOD

In order to realize the aims of this study a certain method of research has to be utilized. The study follows the qualitative research method according to the case study design. The qualitative research paradigm, and more specifically the case study design, is well suited to reveal the socially contextualized 'lived' experiences of children infected with HIV/AIDS. This study documents these experiences from the social context of the participants with a view to developing a programme, which could be used in dealing with cases of learners infected with HIV/AIDS. Through interviews and observations, this study investigated:

• what the 'lived' experiences of HIV infected school-going learners are;
• how their psychological and physical well being are affected by HIV occurrences;
• how their general functioning is at school; and
• the type of social support they get from their families, schools, communities and the society in general

To understand the experiences of HIV/AIDS infected learners, the researcher observed the participants while interviewing them with the intention of noting expressions such as anger, sadness, frustrations and other feelings.
The findings from investigations and from interviews and observations are used to develop a constructivist counselling programme to help these learners realize their psychological and social strengths in order to succeed at school and in general life.

Miles and Huberman (1994:14) note that one of the major features of the qualitative data design is that it focuses on naturally occurring and ordinary events in natural settings so that researchers are able to develop conceptualizations of what 'real life' is like. They further note the richness and holism of such data, which provide strong potential for revealing complexity, since such data provide 'thick descriptions' which are vivid, nested in real context, and have a 'ring of truth' that has a strong impact on the reader.

1.5.1 The case study method

By analyzing the present database of interviews of the three case studies of learners infected with HIV/AIDS together with their next-of-kins (the health worker, aunt and grandmother of one of the participants) and conducting follow-up interviews of her own, the researcher sought to create a study that added to the literature on the 'lived' experiences of learners infected with HIV/AIDS. The interviews formed part of the three cases of three HIV/AIDS infected learners, a grandmother, an aunt and a healthworker.

Creswell (1998:18) is of the opinion that the case study is a research method in the qualitative paradigm, which involves the in-depth study of a single event or entity bounded in space or time. This method follows an inductive model of thinking and reasoning about the elements of the case being studied which will allow the findings to emerge from the data. The four key parameters of case studies, as defined by Miles and Huberman (1994:56), are:

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

1.5.2 Sampling

The research used a purposeful sampling design. There are different types of purposeful sampling designs (Merriam, 1998). The researcher decided to utilise network sampling, which is one of the types mentioned in Merriam (1998:26). Patton (1990:182) argues that this strategy involves identifying cases of interest from people who know what cases are rich in information, that is, good examples for the study and good interview participants. The researcher used her network of friends who are managers of Non-Governmental Organizations (NGOs) who work with children infected with HIV/AIDS, social workers, and health workers (both professionals and paraprofessionals) to conduct network sampling of six participants (n=6), three learners infected with HIV/AIDS, one of the learner’s grandmother, an aunt and a healthworker, for participation in this research.

1.5.3 Data analysis and interpretation

This research followed the constructivist grounded theory approach (Charmaz, 2000:21) in the analysis and interpretation of data. According to Charmaz (2000:23), constructivism recognizes the mutual creation of knowledge by the researcher and the participants, and aims at an interpretive understanding of participants' experiences. A constructivist approach to grounded theory re-affirms studying people in their natural settings, and a focus on meaning while using grounded theory furthers interpretative understanding (Charmaz, 2000:34).

In an interpretative study, there is no clear point when data collection stops and analysis begins. Collecting, analyzing and interpreting the data coincide as a process that unfolds as the research progresses. The researcher intended to interpret data from a position of empathetic understanding, which is one of the key principles of interpretative analysis. Charmaz (2000:16) supports this view by stating that one of the strategies of constructivist grounded theory is the simultaneous collection and analysis of data.
1.6 ETHICAL ISSUES

In order to facilitate the participants giving their fully informed consent, all the necessary information pertaining to the research including the nature, purpose and usefulness, procedures, confidentiality and the protection of anonymity and the voluntary nature of participation in the research was given.

This exercise was carried out with the participants rather than just what Terre Blanche and Durrheim (1999:11) refer to as “gatekeepers”.

1.7 OVERVIEW OF THIS STUDY

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

Chapter two presents the literature review on constructivist counselling.

Chapter three presents the literature review on HIV/AIDS.

Chapter four presents the empirical design.

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

Chapter six presents the summary of research findings, conclusions and recommendations of the study.

1.8 CONTRIBUTION OF THE STUDY

Although considerable research has been conducted on assisting and counselling HIV infected learners, insufficient research has been conducted on how constructivist counselling can be used to assist learners in question. Existing studies suggest that learners infected with HIV/AIDS are failing to cope with the demands of learning in schools, and consequently drop out of schools. Additionally, a small number of, if any, constructivist counselling programmes and models for assisting HIV/AIDS infected learners to cope in schools exist in South Africa. The purpose of this study is to contribute to the inconsistent body of research on HIV/AIDS and constructivist counselling.
More specifically, the study should contribute to the knowledge of the relationship between counselling and the significance of the theories of constructivism and ecosytems in assisting HIV/AIDS infected learners.

1.9 SUMMARY

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 constructivist counselling.
CHAPTER TWO

LITERATURE REVIEW ON CONSTRUCTIVIST COUNSELLING

2.1 INTRODUCTION

Post-modern counselling is founded on constructivism theories. Such theories assume that:

- meaning is actively created rather than discovered by humans (Bertolino & O'Hanlon, 2002:23);
- meaning is constructed in reflection through dialogue with the self and the environment (Murdock, 2000:12); and
- the individual comes to phenomena with pre-understandings that shape the meaning that is created (Guttman, 2000:185).

What these theories actually imply is that life is constituted of many different 'realities' in the same way as there are as many people, although some realities are more viable and preferable than others. Each person sees the world through his/her particular lens and speaks to the world through his/her unique voice.

The theories of constructivism came about as a direct antithesis of traditional and positivist theories of behaviourism, which disregarded the role of cognition, that is, mental processes and capacities, in the development of human functioning (see 2.3 below). Constructivism, on the other hand, implies that knowledge is metacognitively constructed and that the development of human functioning is a motivationally, metacognitively and behaviourally proactive process which is influenced by past knowledge gained from a particular environment in the form of 'lived' experiences of the individual (Greenberg, Pascual-Leone & Juan, 2001:166). According to the constructivists, the socio-cultural and social cognitive contexts of the individual, which are provided by a particular environment, are significant in
his/her effective psycho-social development and functioning (Prager, Savaya & Bar-Tur, 2000:56). The main proponents of the constructivism theories are Piaget with his cognitivism theories, Vygotsky with his socio-cultural theories and Bandura with his social cognitive theories (see 2.3) These theories developed from learning theories and developmental psychology of which both have to do with the development of children and adolescents. The post-modern counselling theories and practices, are founded on constructivism theories, and therefore, post-modern constructivist counselling represents a transformation in the history of counselling (De Jong & Berg, 2002:22; Nichols & Schwartz, 2002:61). It deviates from a traditional, positivist, modern, reductionist and partialed view of social life and the accompanying view of counselling as driven by a need to correct human deficit toward a view of the person as holistic, self-organizing, and maker of meaning. It is a deflection from ‘psychopathogenic self’ toward ‘psychofortigenic and storied self’ which is a solution-focused, strength-based and collaborative process (St. Clair & Wigren, 2004:12; Yalom, 2003:39; Schultz & Schultz, 2001:10). The constructivist approach offers counsellors and clients a method of collaboration and co-participation in meaning-making counselling activities. This method enables clients to construct the self and to make sense of life in the world, whereby ‘lived’ experiences of clients are narrated in the form of ‘lived’ stories (Yalom, 2000:22; Ellis & Crawford, 2000:37; Wubbolding & Brickell, 2001:16).

The following sections present constructivism as a metatheory of post-modern counselling and how its sub-theories of cognitivism (see 2.3.1), socio-culturalism (see 2.3.2) and social cognitivism (see 2.3.3) influence the counselling practice. Some concepts, which are used throughout the chapter, are also clarified (see 2.2). It is also necessary to present the theory of behaviourism (see 2.4) as a traditional, modern and positivist approach to learning and counselling in order to provide a clearer comparison between it and the theories of constructivism as a post-modern approach to learning and development (see 2.3) and counselling.
2.2 CLARIFICATION OF CONCEPTS

The following concepts, which are used throughout this research, are clarified in order to define the way in which they are used in this research.

2.2.1 Post-modernism

In his book 'Historical analysis of the changing nature of knowing', Chan, (2001:31) divides human history into three distinct eras:

- pre-modern;
- modern; and
- post-modern.

Each of these periods emphasized a particular ontological perspective that shaped how people dealt with events, problems, and solutions. In this sense:

- the pre-modern era (from the sixth century B.C. through the Middle Ages) emphasized dualism, idealism, and rationalism. Faith and religion played central roles, and effective efforts of change were prayer, faith, thinking, and/or reasoning (Palmeri, 2001:56);
- by comparison, the modern era (roughly from the Renaissance to the end of the nineteenth century, though modern thought still dominates much of current discourse) stressed empiricism, logical positivism, scientific methodology, the identification of objective truths, and validity. One consequence of the modern era was to solidify scientific and professional knowledge as the legitimate source of understanding the world. Through the logical process of science, individuals could discover what was true and what was not. Scientific knowledge was assumed to be a mirror image of objective reality (Sexton, 1997:7);
- the third (and present) era is labelled by Sexton (1997:7) as post-modern/constructivist and depicts it as accentuating the creation, rather than the discovery, of personal and social realities. The post-modern/constructivist era stresses the viability, as opposed to the
validity, of knowledge claims. It also pays special attention to epistemological issues through which investigators and theorists become concerned with 'how people know' as well as 'what they know'. Compared to modernism (wherein truths independent of subjective bias are revealed to neutral scientists), post-modernism/constructivism highlights human participation in the construction of knowledge, that is:

- the perspective of the observer and the object of observation are inseparable;
- the nature of meaning is relative;
- phenomena are context-based; and
- the process of knowledge and understanding is social, inductive, hermeneutical, and qualitative (Combs & Freedman, 1998:406; Coward, 2000:157), which serves as basis of grounded theory.

2.2.2 Theory

The concept 'theory' is derived from the word 'theoria' which in late Latin and Greek means to view, to examine, inspect and speculate. Most definitions of the word 'theory' have in common the elements of reality and belief. 'Belief' refers to the way in which theorists see and strive to explain, and 'reality' is the data or behaviour that theorists see and strive to explain. A theory may metaphorically be seen as a map (for the practice of counselling, in the case of this research) on which a few points are known and the road between points is inferred (Burke, 1994:2). A sound theory according to Burke (1994:9) and Sharf (1986:2) is:

- **consistent and clear**, and there is agreement among its general principles (philosophy), and agreement of it with observation. It is communicable as an easily read map and not too complex;

- **comprehensive**, and it has a broad scope and accounts for much behaviour. It approaches all-purpose utility;
explicit, about its rules, terms and theories - it is precise. Concepts can be translated into denotative statements in order to be checked against clear referents in the real world;

parsimonious, and does not overexplain phenomena. A theory should be precise about the limitations of its predictions; and

generates useful research. Theories need to be continually tested.

The counsellor needs to apply general principles to judge how appropriate the theory is. This research applies the theories of constructivism as postulated by Piaget, Vygotsky and Bandura (see 2.3).

2.3 CONSTRUCTIVISM AS A THEORETICAL FRAMEWORK OF THIS RESEARCH

The theoretical framework for this research is embodied in the literature that focuses on constructivism as a meta-theory, and Piagetian cognitivism, Vygoskian socio-culturalism and Banduran social cognitivism as sub-theories. Cognitivism, socio-culturalism and social cognitivism become core sub-theories of this theoretical framework because of their emphasis on the significance of the environment or social context, mental (cognitive, motivational and behavioural) capacities of human beings, and culture in the holistic development and psycho-physical and social well being of human functioning, unlike behaviourism which did not heed the significance of cognitions in human development and functioning (Butt, 2000:90).

Constructivism consists of the theory of cognitivism and the theory of social constructivism. The next section discusses each of these sub-theories of constructivism.

2.3.1 The theory of cognitivism

Cognitivism is a constructivist theory, which postulates that knowledge is a collection of abstract symbolic representations that exist in the mind of the learner (Dattilio, 2001:26). Underlying, internal mental, or cognitive processes are responsible for the behaviour of an individual. Amrhein (2004:69)
describes cognitivism as the general paradigm that explains behaviour by reference to cognitive or mental states.

Cognitivism considers that the role of 'what goes on in the head' is to map the 'real world' (Dattilio & Freeman, 2000:35). Piaget, whose theories are often contrasted with those of Vygotsky, considered that mental constructions are representations of the 'real world' which learners must 'accommodate' (Bruner, 1996:12). Piaget and Inhelder (2000:43) describe three processes that are instrumental to learners adapting to their environment through learning. They are assimilation, accommodation and equilibration.

- **Assimilation** - This is the process through which learners use their existing mental structures or schemas to take in new information. Learners need to have an existing schema (idea, concept), that is, prior knowledge to relate to the new information in order to assimilate it. Learners learn something by connecting new information to something they already know. In order to acquire new ideas or knowledge, they activate, integrate and thereby build upon prior knowledge, as in the case of reading (Dattilio, 2001:76).

- **Accommodation** - This is the process through which learners' existing mental structures or schemas change as they take in new information. They revise these existing schemas (ideas, concepts) and if new information does not coincide, that is, if they experience something that is new or different, it modifies their existing knowledge. The mental representations they previously had, are changed to accommodate the new experience (Leahy, 2002:418).

- **Equilibration** - This refers to internal self-efficacy or self-regulation, that is, the balancing in the minds, between assimilation and accommodation. When learners start to take in or assimilate new information or experiences, they relate this to what they already know. A discrepancy or misfit occurs, and the new knowledge creates disequilibrium, which the cognitivists refers to as cognitive dissonance. Equilibration is the self-regulatory process through which learners
balance new experiences with what they already know to achieve a state of equilibrium (Cain & Seeman, 2002:263).

Piaget's theory of cognitive development is a constructivist theory (Beck & Weishaar, 2000:250). That is, his view of the growth of human thought is that it occurs through the construction of knowledge by the individual through various experiences. Individuals contribute to these experiences and make sense, by using their mental schema to interpret, assimilate new information and accommodate mental structures (Applefield, Huber & Moallem, 2001:40).

Fundamental to Piaget's constructivism is the notion that knowledge is not something that learners gain from the outside. Rather, it is something that they gain through their own active experiences, their own acting up on the world physically or mentally to make sense of it (Beck & Weishaar, 2000:250). Active engagement in experiences is necessary for cognitive growth to occur. Two learning support principles in this regard are that:

- understanding occurs through interactions with the environment; and
- cognitive conflict (disequilibrium) or 'puzzlement' is the stimulus for learning (Sewell & Williams, 2001:300).

Cognitivists consider the 'real world' to be a knowable and single reality. This single reality is known through mental activities involving the mental processing of information. For the cognitivist, learners must be supported to effectively process information. This information processing involves acquiring information, organizing it, storing it, and retrieving it when necessary or desirable (Kazdin, 2001:30).

It must be pointed out that cognitivism makes certain assumptions about learning and about the human mind in general. For the cognitivist, all human beings are pre-wired with inclinations towards certain acquiring, encoding, and retrieving practices. Whatever might interfere with any of these processes may be regarded as barriers to effective learning. Activating, or helping learners to access or retrieve prior knowledge and make use of individual learning strategies is viewed as the primary role of learning support
Cognitivists also support the use of 'discovery learning' in education and psychocounselling. This is supported by the view that learners approach learning with individual strategies. Schema or semantic fields should be activated by educators and counsellors and by the learners themselves for effective learning to take place. The structures or arrangements of information in the mind should be understood so that educators and counsellors may structure or arrange content appropriately (Morgan & Macmillan, 1999:159; Tanaka-Matsumi, Higginbotham & Chang, 2002:324).

To support effective learning in the case of knowledge of mental processing, cognitivists developed learning style inventories that attempt to assess learners’ individual learning styles (Wilson, 2000:207). Personality type indicators were also developed on the basis of the work of counsellors such as Carl Gustav Jung. Concept mapping and brainstorming were devised as means to activate schema or semantic structures. Taxonomies of learning stages were also developed to describe the levels of learning, understanding, or awareness the majority of learner’s experience (Lazarus & Lazarus, 2002:220; Prochaska & Norcross, 2003:45).

Piaget’s theory has the following impacts on learning and teaching:

- the learning environment should support the activity of the child - children acquire knowledge through their actions, and thinking is considered to be action-based. Thus, a learning environment as follows should be created which encourages children to initiate and complete their own activities:
  - an active, discovery-oriented environment;
  - feedback from the actions, there should be concrete manipulable material; and
  - active self-discovery - playing effectively represents the total of the requisite characteristics of Piagetian-inspired instruction.
• children's interactions with their peers are an important source of cognitive development - peer interactions are essential in helping children move beyond egocentric thought (Beck & Weishaar, 2000:245);

• adopt instructional strategies to make children aware of conflicts and inconsistencies in their thinking - equilibration, for example children should experience disequilibrium, or an imbalance between their current cognitive structures and new information to be assimilated, to be able to move to a new stage of development (Dattilio, 2000:60). Educators should be able to:
  
  o use problems to confront learner's prior knowledge structure;
  
  o use Socratic dialogue to help learners to bring out misconceptions and faulty reasoning;
  
  o critically diagnose what children already know and how they think. Content is not introduced until the child is cognitively ready to understand it; and
  
  o questions or experience designed to induce conflict can only be effective when the logical structures on which they depend have been or are being developed (Beck & Weishaar, 2000:13; Dattilio, 2001:77)

2.3.2 The theory of social constructivism

The theory of social constructivism is the brain-child of Vygotsksky. The basic idea of social constructivism is premised on the socio-cultural approach to cognition which is expressed in the ‘general law of cultural development’, where Vygotsky (1986:16) proposes that the higher mental function appears “twice, or on two planes.” First it appears on the social plane and then on the psychological plane. It appears between people as an inter-psychological category and then within the individual child (learner) as an intra-psychological category (Prochaska & Norcross, 2003:24). That is, higher mental functioning
is characterized by 'voluntary control, conscious realization, social origins and nature, as well as mediation by psychological tools' (Freedman & Combs, 1996:56). Social origins and mediation through tools are two highly interconnected concepts in this basic idea.

The first concept of social origins draws special attention to the 'adults' power to arrange juveniles' environments. This arrangement can help to optimize juveniles' development according to existing norms (Butt, 2000:85). The second concept emphasizes the consequence of 'tools' mediating the activity. That is, 'instead of applying directly its natural function to the solution of a particular task, the child puts between that function and the task a certain auxiliary means ... by the medium of which the child manages to perform the task' (Reker, 2000:40)

The social constructivists emphasize the role of culture in learning. Vygotsky (1986:34) considered meaning to be a cultural construct at a time when behaviourism was still developing. However, his ideas about the cultural construction of meaning have been re-discovered by both modern and post-modern constructivists respectively. The emphasis on culture in the constructivist paradigm coincides with post-modern ideas of multiculturalism and a concern with fostering diversity and multiple perspectives as resources for the support of learning (Morgan & Macmillan, 1999:157).

The following reflect Vygotsky's contributions to the understanding of learning and development, namely:

- in what way different cultures affect the way learners learn and the cultural expectations surrounding learning and learning support;
- in what ways interactions between learners and other learners and adults support and assist learning;
- what optimal level for presenting new information, concepts or ideas when teaching exists; and
what role social experience and collaboration play in learning (Dissanayake, 2001:342).

The value of Vygotsky's (1986:17) theory is that he sought to find alternate views than other counsellors such as Piaget who contends that human development occurred in stages and that learners did not or could not see the world through the eyes of others (Bruner, 1996:63). Vygotsky (1986:38) argues that Piaget over-emphasizes the intellectual, the biological, the evenness and universality of developmental stages, the evolutionary character of development, the centrality of the individual, and the essential independence of thought and language. Vygotsky (1986:34) argued that development was not a cognitive process that occurred inside a person's head and was separate from the external world in which people lived (Dattilio, 2000:15). Rather he saw development as a continuous learning process that linked a person's current mental networks of association with new experiences gained through contact in, observations about, and reflections about the activities of everyday life (Ellis, 2001:28). To Vygotsky (1986:38) teaching and learning are an integrated process in human development. During the teaching and learning process learners are expected to actively participate in their own learning through the use of language and interactions with their peers and educators. In describing the Vygotskian concept of the teaching and learning process, Ochsner and Lieberman (2001:28) state that learning takes place in the context of a purposeful and meaningful activity as learners and educators work together to create a product that has its own intrinsic value. This purposeful and meaningful activity is viewed as a social process; with the learners bringing to the process their own 'lived' experiences to the process as grounded in their own socio-cultural contexts.

According to George, Thornton, Touyz, Waller and Beumont (2004:82) Vygotsky conceptualized the zone of proximal development (ZPD) as a way of viewing what children are coming to know. He noted that children were able to solve problems beyond their actual development level if they were given guidance in the form of prompts or leading questions from someone more advanced. This person, should be capable, it could be another learner, a
parent, a mentor, a coach, a guide or an educator. Vygotsky defined the ZPD as the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance or in collaboration with more capable peers.

### 2.3.2.1 Scaffolding

For Vygotsky (1986:58), 'scaffolding' is the process of providing a child or adolescent with a good deal of support during the time s/he is learning something. This support is reduced as the learner becomes able to deal with the task independently, resulting in the taking on of increasing responsibility for learning (Sheldon & Kasser, 2001:38). Support for a learner can take the form of co-operative learning among peers, guidance from adults, well-structured learning environments, or strategies for helping learners organize new material and relate it to prior knowledge (Leahy, 2002:420). Vygotsky (1986:38) particularly emphasized the ways in which adult support and learning among peers could assist children and adolescents to master concepts they could not learn alone.

Vygotsky's concept of scaffolding involves social support for learning (Schiralli, 1999:17). Collaborative learning strategies, in which learners work together in heterogeneous groups to solve problems, are consistent with scaffolding. Scaffolding can include many different approaches, all of which assist the learner in moving from assisted to unassisted success in a task (Mikulas, 2002:35).

**2.3.2.2 Socio-cultural context of knowledge**

Vygotsky emphasized the important role of culture in influencing how individuals learn and think. His thinking has had a significant impact on research demonstrating that cognition is "situated", that is, occurs in a context. Educators have learned from Vygotsky's work that they need especially to understand and respond to the cultural contexts which surround children's knowledge and which significantly affect their expectations about their roles as learners and what Schiralli (1999:15) refers to as their funds of knowledge.
Vygotsky particularly emphasized the role of culture in mediating learning, that is, in providing the tools (words, conventions, symbols and signs) through which knowledge is mediated and communicated. This means that learning and knowledge are to a large extent culturally and socially influenced (Schneider, 2001:260).

Vygotsky and his followers consider that learning is a culturally and socially mediated process. For educators, this means that each child is equipped with knowledge as well as a conception of learning from his/her family and cultural background and to succeed, children need connections between in-school learning and cultural foundations of knowledge (Prager et al., 2000:59).

Vygotsky believed that cognitive structures 'originate in social activity and, as they develop, are inextricably linked with language, which is in itself a social construct. It is through social interaction that children learn the cognitive and communicative tools and skills of their culture' (Searle, 1995:6; Steffe & Gale, 1995:26).

While Piaget focused on metacognitive knowledge which is an individual's knowledge about her/his own knowledge, skills and abilities, and the processes associated with their development (Butt, 2000:90), Vygotsky focused on meta-development. Meta-development may be seen as the development of individuals' cognitive structures and processes to understand how they develop their own way of thinking, problem solving, and other higher order cognitive processes (Dattilio & Freeman, 2000:46).

Vygotsky's message is profound - performing is how individuals learn and develop. It is through performing - doing what is other than and beyond - that the very young learn to do the varied things they do not know how to do. But what happens, as individuals perform their way into cultural and societal adaptation, is that they also perform their way out of continuous development (Bozarth, Zimring & Tausch, 2002:150).

A lot of what has been learned through performing becomes routinized and rigidified. People become so skilled at acting out roles that they no longer keep creating new performances of themselves. They develop an identity as
'this kind of person' - someone who does certain things (and does them in certain ways) and feels in certain ways. Most individuals think, as they forget that they also are whom they are becoming, would not be 'true' to 'whom they are' (Glauser & Bozarth, 2001:146).

Performative counsellors, therefore, work to build environments for children and adults to create new performances and reinitiate growth. Participating in creating the performance 'stage' and performing on it is how an individual can go beyond themself to create new experiences, new skills, new intellectual capacities, new relationships, new interests, new emotions, new hopes, new goals, which is, after all, what learning and developing are all about (Gibson et al., 2002:36), which can be termed self efficacy.

2.3.2.3 Self-efficacy

Self-efficacy, a principal component of social cognitive theory, reflects humans' ability to formalize operations. These beliefs about a person's capabilities to organize and perform specific courses of action often serve as predictors of people's ability and motivation because of their function in forethought. Just as efficacy beliefs are themselves examples of formalized operations, Bandura (1997:116) believes that most courses of action are initially shaped as thought. Cognitive constructions then, serve as guides to action in the development of proficiencies. People's beliefs about their efficacy influence how they construe situations and the types of anticipatory scenarios and visualized futures they construct (Watson, 2002:450; Baumeister, Campbell, Kreuger & Vohs, 2003:34). People's subjective beliefs, one of the most important being self-efficacy, will be further examined for their own constructivist origins in the next section.

2.3.3 Self-regulatory practices

capability of individuals to control their thoughts, feelings, motivations and actions. The self has an influence over the behaviour individuals choose, their motivation and persistence toward a goal, and their emotional reaction to the environment. Bandura's description of self-regulation accentuates people's ability to recognize when their actions are not producing the desired results and to change their behaviour to ensure success (Bandura, 1997:105). When people contemplate the likely results of their actions, one of their considerations becomes how they will construe the perceived outcome. More than the negative reactions of others, what keep people from acting out of accordance with society's expectations are their own self-regulatory skills, the functional basis of morality (Twenge & Campbell, 2001:322).

Arkowitz and Westra (2004:56) conceptualise self-regulation in terms of a triadic process by which individuals bring their influence to bear on their health habits. In their goal-guidance model, goal adoption sets the stage for self-directed change; implementation strategies convert goals into productive actions; and maintenance strategies help to sustain achieved behavioural changes.

People who have been diagnosed with chronic illness need to adapt to the situations they find themselves in. This adaptation does not occur automatically and also depends on the person, his/her self-efficacy and resilience (Bernard, Hutchison, Lavin & Pennington, 1996:43). Adaptation requires recognizing conditional relations between environmental events and between actions and outcomes. Because people have the ability to influence the environments in which they work, constructing a person's surroundings to best suit his/her goals is an important component of self-regulation. Bandura (1997:65) highlights how self-regulation contributes to improved capacities for human action. Skilled performances are usually achieved by repeated corrective adjustments of enactments to the guiding conception, as the skills are being behaviourally constructed and improved. By observing their actions, people eventually construct conceptions of new behavioural patterns and the circumstances in which it is appropriate to perform them (Bundy, 2004:24).

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The primacy of self-regulation in individuals continuously presides over their own behaviour. Hence, they are a key locus in the development and successful maintenance of health promotive habits. Whatever other factors may serve as guides and motivators, they are unlikely to produce lasting behavioural changes unless individuals develop the means to exercise control over their motivation and health-related behaviour (George et al., 2004:34).

Subsequently, the self system entails the notion that people can exercise some influence over their thoughts, feelings, and actions (Broadley, 2000:139). This idea is central to this research in the extent that self-regulatory processes - implemented through self-efficacy beliefs or proactive attitude - may act in favour of the promotion of better suited coping strategies (actions) to deal with the effect of being diagnosed HIV positive and consequently to get benefits in terms of health, emotional experience (feelings), and quality of life over the time. Given that the above theories offer the chance to be proactive instead of being reactive in coping with HIV, the mechanisms by which people remain engaged in goal-oriented actions (proactive coping) versus the anti-goal oriented ones (avoidance coping) are of relevance. Accordingly, Piaget, Vygotsky and Bandura’s theories may offer some inputs to further understand how people infected with HIV/AIDS tend to be negative instead of being positive in their dealing with demands of being ill over the time.

2.4 BEHAVIOURISM

Behaviourism is the term used to describe the theory that postulates that behaviour, or the actions of an individual being, are determined by external conditions (stimuli) that cause (cue) consequential responses (Miltenberger, 2004:264). From a behaviourist perspective learning is viewed as a set of acquired tendencies of action. For the behaviourist, the learner is trained to respond in a pre-determined manner to a particular set of circumstances. The behaviour of the learner is shaped. A behaviourist is not concerned with what is going on in the heads of the learner, this is viewed as irrelevant. What a learner does is important and not what a learner thinks. Learning is behaviour modification (Tanaka-Matsumi et al., 2002:69). The behaviourist counsellor
would then attempt to provide means to modify the behaviours, responses, and actions of learners. For the behaviourists, this should be accomplished through repetitive exercises that seek to automate responses (Watson & Tharp, 2002:23; Lazarus, 2000a:108).

From the behaviourist perspective, all actions may be described as responses to external stimuli. Stimuli may be described as unconditioned, neutral, or conditioned. Unconditioned stimuli are those that occur naturally as biological events and consequences. Neutral stimuli are those that produce no specific responses. Conditioned stimuli are those that do not initially produce a particular response but with repetition become associated with a particular response or responses. The process of contiguity is the association between stimuli that regularly occur together or in close proximity or succession (Shapiro, 2002:15).

Skinner (1974:123), one of the most famous proponents of behaviourism, coined the term operant conditioning, which refers to the use of stimulus response reinforcement to shape desired behaviours. He also used the term operant behaviours to describe voluntary behaviours that are not provoked by specific stimuli used by the subject to "operate" on the environment. The process of making use of operant conditioning to produce desired behaviours is contingent reinforcement. Reinforcement in operant conditioning is accomplished through positive reinforcement or reward, negative reinforcement or allowing avoidance of a negative situation, extinction or non-reinforcement, and punishment. This process allowed behaviour shaping (Nye, 2000:32; Wilson, 2000:205). Contingent reinforcement could also produce stimulus discrimination and response discrimination. These processes describe the subject’s learning to ascertain the difference between a variety of stimuli and responding to particular stimuli in with a particular behaviour.

For Skinner (1974:23), teaching human learners follows the same principles as training animals. Stimuli should be associated with desired behaviours through operant conditioning. The desired behaviours should be strengthened through schedules of reinforcement. Behaviour should be shaped through
successive approximations and fading may occur when the stimulus response association becomes well established.

Behaviours of learners not thoughts are important to behaviourists. The goal of learning and education is a set of behaviours not hidden thoughts. Behaviourists also consider descriptions of mental processes unscientific, as they are not observable (Kazdin, 2001:46). Behaviourism has been associated with logical positivism, which is the doctrine that postulates that theories that cannot be proven empirically are irrelevant. Modern defenders of behaviourism point out that the association between behaviourism and logical positivism was never as strong as many believe (Arkowitz & Westra, 2004:17).

Behaviourism has had many "incarnations" or applications. Emphasis on objectives as behaviours, instantaneous feedback, sequencing, drill and practice, and shaping are features found in learning support materials described as behaviourist (Cummings, 2002:4). Teaching machines, which involved devices that could hide and reveal answers to question items by the turn of some knob, were developed in the 1930s. By providing immediate feedback, the concept of reinforcement of desired behaviours in response to stimuli was fulfilled (Fishman & Franks, 1997:131). Programme books were used in which feedback could be immediately provided to the learner. Answers to questions would be provided on the same page as the question or in some other easily accessible area. Programme books became very popular since they were less expensive to produce than teaching machines. Film, slides, television, audio reproductions and film strips were also produced and experimented with as learning aids in the hope that eliciting desired responses by controlling stimuli. This emphasis on desired actions or behaviours corresponded well with behaviourist emphasis on observable actions as opposed to thought processes (Morgan & Macmillan, 1999:155).

Evident from the above discussion is that constructivism has evolved dramatically over the years. It has evolved from a purely reactive function to a responsive and proactive function.
Although constructivism is a complex paradigm consisting of tightly interwoven explanations for phenomena and explanations that resist categorization, analysis of existent research and theories reveals the following five principles of constructivist thought:

2.4.1.1 The active construction of meaning

A key tenet of constructivism is that learners actively construct meaning (Guttmann, 2000:185; Gergen & McNamee, 2000:333; Coward, 2000:160; Neimeyer & Raskin, 2000:34; Greenberg & Pascual-Leone, 1995:166; Freedman & Combs, 1996:56; Piaget & Inhelder, 2000:27; Vygotsky, 1986:132). Active agency, likely the single most influential and widely held belief amongst constructivist thinkers, is centred around Piaget and Inhelder's (2000:54) concept of equilibration. All people organize their experiences into cognitive structures called schemata, which adapt and change with mental development (Sewell & Williams, 2001:295). Experiences or concepts that are encountered for the first time undergo one of two processes, namely:

- assimilation, subsuming a new idea into an existing schema, or
- accommodation, creating new schema to contain novel information.

This organization and re-organization takes place constantly within the human mind, thus learning and development build on themselves to create more complex cognitive structures.

2.4.1.2 Social influences on construction

A second tenet of constructivism is that development is a socially situated activity that is enhanced in meaningful contexts (Applefield et al, 2001:35; Gregory, Schwer, Lee, Wise & Gregory, 2004:36; Butt, 2000:33; Fosnot, 1996:38). Constructivism emphasizes the role of the other in the development process. Individuals develop at different rates due both to their in-born characteristics (personal factors) and to the external factors that affect them (i.e., environment, including other people). Concepts that might otherwise not be created by a person until later in life can be created with assistance from
another individual who has already developed those skills (Carlson & Kjos, 2002:32). Language is one of many symbols that humans use to facilitate development. Therefore, it is possible for an individual to learn without the efforts of other people, and certainly without symbols, as the environment will act on a person regardless of others' or the self's participation. Constructivist thought contends that people create meaning from the interaction between their existing knowledge or beliefs and the new ideas and situations that they encounter and that can only be effectively found in social settings (Hong, Morris, Chi-Yue & Bebet-Martinez, 2000:709).

2.4.1.3 Importance of self-regulatory practices

Another critical principle of constructivism is that learning and development are self-regulated processes (Kukia, 2000:22; Searle, 1995:17; Vygotsky, 1986:76; Piaget & Inhelder, 2000:48). Constructivism emphasizes the role of self-regulation in learning and development, providing for the capability of individuals to control their thoughts, feelings, motivations and actions. The self has an influence over the behaviour individuals choose, their motivation and persistence toward a goal, and their emotional reaction to the environment. Behaviourism, conversely, views the learner as a relatively moldable object that can be shaped by examples, practice, and above all, re-inforcement (Gregory, Schwer, Lee, Wise & Gregory, 2004:275).

To that end, what individuals learn and how they develop can be regulated by the environment in which they live. The self would not be able to regulate the actions if it were not first able to identify that a state of disequilibrium has been reached. Once individuals are aware of cognitive conflict, they must decide how much, and in what ways, to expend their efforts to return to balance (Krabbendam & Aleman, 2003:376). Finally, after these actions have been taken, the self analyzes the outcome of the situation, concluding if those actions were sufficient to return to equilibrium, or if more actions are necessary.

One example of self-regulation in constructivist theory is Vygotsky's (1986:59) conception of the zone of proximal development. Interactions with others can
cause an individual to realize that his or her understanding of a given concept is insufficient. This person must then seek out the assistance of individuals who are more knowledgeable about this concept, who will, in turn, provide the information and instruction required to allow the learner to return to a balanced state. Therefore, people are able to return themselves as a mental operation to equilibrium only until the processes of self-regulation are again required (DeGrandpre, 2000:721).

2.4.1.4 The role of mental operations

A fourth principle of constructivism is that individuals are capable of formalized operations and abstract thought (Piaget & Inhelder 2000:231). To solve complex problems, people must first determine what skills or information are relevant to finding the solution. This process also helps people discover needs for further learning. Inhelder, Piaget and Inhelder’s (2000:121) conception of formal operations include an emphasis on hypothesis building and scientific reasoning as well as a highly developed understanding of causation. Individuals who have obtained formal operations can operate on the logic of a problem independent of its content, which serve to motivate individuals toward future goals. Finally, individuals are able to construct entirely new knowledge based only on information already available.

2.4.1.5 Constructivism, truth and experience

Although it may be considered controversial, the fifth tenet of constructivist thought is that cognition serves the organization of the experiential world, not the ontological reality. Reality represents an interpretation, so truth is viewed as viability, not validity (Franklin & Jordan, 1996:45; Cummings, 2002:4). As conceptions of modern constructivism grew during the middle of the twentieth century, theorists attempted to reconcile the subjectivity of Freud’s (1960:24) psychoanalytic school with the strict stimulus-response model of behaviourism.

Thus, constructivism came to hold that because all individuals lead different lives, the purpose of learning is to allow people to organize what they have experienced (Green & Gredler, 2002:60). Rather than "knowing" cold facts
about 'reality,' learning provides humans with beliefs about the world in which they live (Wubbolding, 2001:12). Furthermore, the individual can scrutinise information to create beliefs from interpretations of self-referent information and environmental contingencies (Wubbolding & Brickell, 2001:12). Behaviourism has no such subjective component - the environment acts on individuals, causing them to learn. There is, of course, a real world to be known, but every individual's knowledge of that world is always under construction and never fully constructed (Granvold, 1996:345). This phenomenological viewpoint is exemplified in the philosophy of Hoyt (2002:279), who contends that people have a common surrounding to be defined by their common interests.

As Hong et al. (2000:709) wrote, 'only an uncovering of the horizon of experience ultimately clarifies the 'actuality' and the 'transcendency' of the world, at the same time showing the world to be inseparable from transcendental subjectivity, which constitutes actuality of being and sense.' Three people who witness a car accident would all agree that there was an objective, real event. However, each of the witnesses will likely provide divergent descriptions. To distinguish constructivist thought from absolute relativism, it is essential to note that the disparate ways that those three individuals construct the meaning of an accident are coloured by their beliefs and their previous experiences (Mahoney & Marquis, 2002:794). People's beliefs, motivations, and actions are dependent primarily on their interpretations of their experiences and that of the world around them. Construction is linked to interpretation.

Constructivists postulate that knowledge is "constructed" by the "learner" (Neimeyer, Ray, Hardison, Raina, Kelley & Krantz, 2003:250). For them, knowledge is not a collection of facts but rather a synthesis that has been formulated by the very individual who takes on this knowledge. For the constructivist, individuals do not perceive reality in the same way.

Green and Stiers (2002:236) assert that constructivism is relativistic. Knowledge and indeed the individual's very perception of reality are variable, or relative. Knowledge, for the constructivist is also fallible. That is, inherently
prone to error. It is fallible and therefore "facts" can never be taken for granted. Instead they must incessantly undergo a process of evaluation and change. This flux can be considered a constant construction and reconstruction on the part of the learner (Moradi & Yoder, 2001:201).

The foregoing paragraphs have highlighted that a fundamental principle of constructivism is that what human beings learn is associated with the interpretation of their 'lived' experiences in relation to new information and in what way it connects to old information. This principle propounds that learning occurs as individuals construct their own new understandings or knowledge through interaction with and reflection on what they already know and believe, balanced against the ideas, events, people and activities they have contact with in their day-to-day activities. In fact, constructivist approaches produce greater internalization and deeper understanding than behaviouristic approaches.

2.5 THE INFLUENCE OF CONSTRUCTIVISM ON COUNSELLING

The constructivist perspective in counselling supports the idea that children and adolescents learn through interaction with others. Children and adolescents work together as peers, applying their combined knowledge to the solution of the problem. The dialogue that results from this combined effort provides children and adolescents with the opportunity to test and refine their understanding in an on-going process, called collaboration.

There is another aspect on collaboration in a constructivist counselling environment which involves the role of the counsellor, that is, facilitation or guidance. Vygotsky's theory of social constructivism, as opposed to Piaget's individualistic approach to constructivism, emphasizes the interaction of children with others in cognitive development (Vygotsky, 1986:39). His theoretical concept of the zone of proximal development embodies his belief that counselling is directly related to social development (Ochsner & Lieberman, 2001:717).

This is congruent to the idea that constructivists advocate that counselling interventions should not only match but also accelerate children and
adolescents’ cognitive development. According to Berlin (1996:328), constructivism requires a counsellor who acts as a facilitator and whose main function is to guide children and adolescents become active participants in their own counselling and make meaningful connections between prior knowledge, new knowledge, and the processes involved in counselling.

As Gregory (2002:397) described, a constructivist counselling environment is characterized by:

- shared knowledge among counsellors and children and adolescents;
- shared authority and responsibility among counsellors and children and adolescents;
- the counsellors new role as guide in counselling; and
- heterogeneous and small groupings of children and adolescents.

Resonant with the idea that the counsellor is a guide instead of an expert, constructivist counselling has always been likened to an apprenticeship (Schultz & Schultz, 2001:44; Prochaska & Norcross, 2003:32; Yalom, 2003:56) in which counsellors participate with children and adolescents in the solution of meaningful and realistic problems. Here, the counsellors serve as models and guides, showing children and adolescents how to reflect on their evolving knowledge and providing direction when the children and adolescents are experiencing problems. Learning and counselling are shared and responsibility for the learning and counselling processes is shared. The amount of guidance provided by the counsellor will depend on the knowledge level and experience of the children and adolescents (Walter & Peller, 2000:32; Corey, 2005:12).

Lewis and Osborn (2004:40) conceive a constructivist counsellor as someone who will:

- encourage and accept child and adolescent autonomy and initiative;
• use a wide variety of materials, including raw data, primary sources, and interactive materials and encourage children and adolescents to use them;

• inquire about children and adolescents’ understandings of concepts before sharing his/her own understanding of those concepts;

• encourage children and adolescents to engage in dialogue with the counsellor and with one another;

• encourage child and adolescent inquiry by asking thoughtful, open-ended questions and encourage children and adolescents to ask questions to each other and seek elaboration of children and adolescents’ initial responses;

• engage children and adolescents in experiences that show contradictions to initial understandings and then encourage discussion;

• provide time for children and adolescents to construct relationships and create metaphors; and

• assess children and adolescents’ understanding through application and performance of open-structured tasks (Lewis & Osborn, 2004:42; Rubak, Sandboek, Lauritzen & Christensen, 2005:305; Rubak, 2005:33).

From the foregoing paragraph it can be deduced that constructivism involves the active creation and modification of thoughts, ideas and understandings as the result of experiences that occur within a psycho-socio-cultural context.

Piagetian cognitivism, Vygostkian socio-culturalism, and Banduran social cognitivism theories are founded on the principles that:

• thinking and learning are social processes, not merely individual processes;
- Learning is an active process fueled by the desire to regulate cognitive dissonance experienced in everyday learning tasks. Through assimilating and accommodating new information, individuals restructure their thinking and experience cognitive growth;

- Learning requires active participation and engagement in which individuals construct knowledge, not only passive processing;

- Meaningful learning is situated in the context of everyday teaching and learning settings and in everyday problem-solving activities - these vary by cultural context, socio-economic status, and other socio-cultural and socio-political factors; and

- School failure is a product of the interaction of several factors - including the environment, the relationship between the learner and the educator, the educator's cultural and pedagogic competency, and school leadership - not just the learner (Miller & Moyers, 2005:267; De Jonge, Schippers & Schaap, 2005:10; Lewis & Osborn, 2004:45)

Hence, from a constructivist perspective, the primary responsibility of the counsellor is to create and maintain a collaborative problem-solving environment, where children and adolescents are allowed to construct their own knowledge, and the counsellor acts as a facilitator and guide.

Founded on the constructivism theory, constructivist counselling differs from behavioural counselling, which is founded on behavioural theories by eluding the past in favour of both the present and future. It is so focused on what is possible that it has little or no interest in gaining an understanding of the problem. Richards and Bergin (2004:135) suggest that it is not necessary to know what causes the problem in order to solve it and that no necessary relationship between problems and their solutions exists. Gathering information about a problem is not necessary for a change to occur. If knowing and understanding problems are unimportant, so is searching for "right" solutions (Slife & Reber, 2001:213; Corey, 2005:44). Any person might consider multiple solutions, and what is right for one person may not be right
for others. In constructivist counselling people choose the goals they wish to accomplish in counselling, and insufficient attention is given to diagnosis, history taking, or exploration of the problem (Cobb & Yackel, 1995:20; Gergen, 1995:44; Sexton & Alexander, 2002:238; Lock, 1997:56).

Constructivist counselling is grounded on the optimistic assumption that people are healthy and competent and have the ability to construct solutions that can enhance their lives. Regardless of what condition people are in when they enter counselling, Isaacs and Stone (1999:258) believe people are competent and that the role of the counsellor is to help people recognize the competencies they possess. The counselling process provides a context whereby individuals focus on recovering and creating solutions rather than talking about their problems. Applefield et al. (2001:40) describe this positive orientation: 'grow the solution-life enhancing part of people's lives rather than focus on the pathology-problem parts and amazing changes can happen pretty rapidly.'

Because people often come to counselling in a 'problem-oriented' state, even the few solutions they have considered are wrapped in the power of the problem orientation. People often relate what is rooted in a deterministic view that what has happened in the past will certainly shape their future (Ryan & Deci, 2000:68). Constructivist counsellors counter this individual presentation with optimistic conversations that highlight their belief in achievable, usable goals. Counsellors can be instrumental when assisting people in making a shift from a fixed problem state to a world with new possibilities. The counsellor can encourage and challenge people to write a different story that can lead to a new ending (Fosnot, 1996:51; Isaacs & Stone, 1999:258; Beck & Weishaar, 2000:250; Cormier & Nurius, 2003:18).

Individuals bring accounts of personal encounters to counselling. Some are used to justify their belief that life cannot be changed or, worse, that life is moving them further and further away from their goals. Constructivist counsellors assist people to pay attention to the exceptions to their problem patterns (Sewell & Williams, 2001:300). Constructivist counselling focuses on what people are doing that is effective and helps them to apply this knowledge.
to eliminate problems in the shortest amount of time possible. As Beck and Weishaar (2000:250) state: 'It encourages people to move out of analyzing the nature of the problem and how it arose and instead begin to find solutions and take action to solve it.'

There are various ways to assist people in thinking about what has worked for them. Alberti and Emmons (2001:36) prefer to engage people in conversations that lead to progressive narratives whereby people create situations in which they can make steady gains towards goals. Lazarus and Lazarus (2002:31) contends: 'Tell me about times when you felt a little better and when things were going your way.' It is in these narrations about a life worth living that the power of problems is deconstructed and solutions are established and made possible.

Greenberg and Pascual-Leone (1995:165) think of constructivist counselling as a model that explains how people change and how they attempt to reach their goals. Here are some of their basic assumptions about constructivist counselling:

- there are advantages to a positive focus on solutions and on the future. If people can re-orient themselves in the direction of their strengths using 'solution-talk,' there is a good chance that counselling can be brief (Watts & Pietzak, 2000:442);

- individuals who seek counselling do have the capability of behaving effectively, even though this effectiveness may be temporarily blocked by negative perceptions. Problem-focused thinking prevents people recognizing effective ways to deal with problems (Goldenberg & Goldenberg, 2004:15);

- there are exceptions to every problem. By speaking about these exceptions, people can get control over what have seemed to be insurmountable problems. The undertone of these exceptions allows for the possibility of creating solutions (Moyers, Martin, Manuel, Hendrickson & Miller, 2005:19);
people often present only one side of themselves. Constructivist counsellors invite people to examine the other side of the story they are presenting (Rubak, 2005:12);

small changes pave the way for larger changes. Any problem is solved one step at a time (Wahab, 2005:50);

people want to change, have the capacity to change, and should do their best to make change happen. Counsellors should adopt a co-operative stance with people rather than devising strategies to control resistive patterns (Sharf, 2004:11); and

people should trust their intuition to solve their problems. There are no “right” solutions to specific problems that can be applied to all people. Each individual is unique and so, too, is each solution (Gillespie, Birdthistle, Jones, Bundy, Hoffman, Pigozzi, Draxler, Whitman, Fouilhoux & Drake, 2003:55).

Mitchell (2000:21) and Yalom (2003:64) have moved away from the term counselling and refer to what they do as personal consultation. They facilitate conversations around the preferences and possibilities of individuals to help them create a positive future. By avoiding the stance of the expert, Stiles (2002:605) believe they can be interested, curious, and encouraging in jointly exploring the desires of individuals.

Moursund and Erskine (2004:12) stress the importance of creating collaborative counselling relationships and see doing so as necessary for successful counselling. Acknowledging that counsellors have expertise in creating a context for change, they stress that people are experts on their own and often have a good sense of what has or has not worked in the past and, as well, what might work in the future. If people are involved in the counselling process from beginning to end, the chances are increased that counselling will be successful. In short, collaborative and co-operative relationships tend to be more effective than hierarchical relationships in counselling.
Corey (2004:34), Cormier and Nurius (2003:11) describe four steps that characterize the process of constructivist counselling:

- determine what people want, rather than search for what they do not want;

- do not look for symptoms, and do not attempt to reduce people by giving them a diagnostic label. Instead, look at what people are doing that is already working and encourage them to continue in that direction;

- if what people are doing is not working, then encourage them to experiment with doing something different; and

- keep counselling brief by approaching each session as if it were the last and only session.

Although these steps seem fairly obvious, the collaborative process of the individual and counsellor constructing solutions is not merely a matter of mastering a few techniques. The solution-focused model requires a philosophical stance of accepting people where they are and assisting them in creating solutions. The attitude of the counsellor is crucial to the effectiveness of the counselling process.

Cummings (2002:4) believes people can generally build solutions to their problems without any assessment of the nature of their problems. Given this framework, the structure of solution building differs greatly from behavioural approaches to problem solving as can be seen in the following brief description of the steps involved (Lazarus, 2000b:32):

- people are given an opportunity to describe their problems. The counsellor listens respectfully and carefully as people give an answer to the counsellor’s question, ‘How can I be useful to you?’

- the counsellor works with people in developing goals as soon as possible. The question is posed, ‘What will be different in your life when your problems are solved?’
• the counsellor asks individuals to recall times when their problems were not present or when the problems were less severe. People are assisted in exploring these exceptions, with special emphasis on what they did to make these events happen;

• at the end of each solution-promoting conversation, the counsellor offers feedback, provides encouragement, and suggests what people might observe or do before the next session to attempt to solve their problems; and

• the counsellor as well as the individual evaluate the progress being made in reaching satisfactory solutions by using a ratings scale. People are also asked what needs to be done before they see their problem as being solved and also what will be their next step.

Constructive counselling reflects some basic notions about change, about interaction, and about reaching goals. The constructive counsellor believes people have the ability to define meaningful personal goals and that they have the resources required to solve their problems. Goals are unique to each individual and are constructed by the person to create a richer future (Prochaska & Norcross, 2003:43). A lack of clarity regarding individual preferences, goals, and desired outcomes can result in a rift between counsellor and individual. Thus, it is essential that the initial stages of counselling address what people want and what concerns they are willing to explore (Ellis & Crawford, 2000:56; Reinecke et al., 2002:34).

Constructive counsellors concentrate on small, realistic, achievable changes that may lead to additional positive outcomes (Ginerich & Eisangart, 2000:480). Because success tends to build upon itself, modest goals are viewed as the beginning of change. Constructive counsellors adhere to the language of individuals, using similar words, pacing, and tone (De Jong & Berg, 2002:75). Counsellors use questions that presuppose change, posit multiple answers, and remain goal-directed and future-oriented such as:

• ‘What did you do and what has changed since your visit last’ or
- ‘Did you notice any improvement since your last visit?’ (Walter & Peller, 2000:39).

Winslade and Monk (2000:19) emphasize the importance of assisting people in creating well-defined goals, which are:

- stated in the positive in the person’s language;
- process or action-oriented;
- structured in the here-and-now;
- are attainable, concrete and specific; and
- controlled by the individual.

However, Corey and Haynes (2005:23) caution against too rigidly imposing an agenda of achieving precise goals before people have a chance to express their concerns. People must firstly experience that their concerns are heard and understood before they formulate meaningful personal goals. In a counsellor’s zeal to be solution-focused, it is possible to get lost in the mechanics of counselling and not attend sufficiently to the interpersonal aspects (Yalom, 2000:11).

In constructivist counselling, there are several forms of goals which comprise changing the:

- viewing of a situation or a frame of reference; and
- course of problematic situations and tapping people’s strengths and resources (Neimeyer & Raskin, 2000:53).

A main goal of constructivist counselling involves helping people adopt attitudinal and a language shift from talking about problems to talking about solutions (Fredrickson, 2000:578). People are encouraged to engage to change or solution-talk, rather than problem-talk, on the assumption that what they talk about most will be what they create (Sewell & Williams, 2001:300). Talking about problems will create on-going problems. Talk about change will
produce change. As soon as individuals learn to speak in terms of what they are able to do competently, what resources and strengths they have, and what they have already done that has worked, they have accomplished the main aim of counselling (Ferch, 2000:160; Butt, 2000:90; Messer & Warren, 2001:70).

People are much more likely to fully participate in the counselling process if they perceive themselves as determining the direction and purpose of the conversation (Schultz & Schultz, 2001:45). Much of what the counselling process is about involves people's thinking about their future and what they want to be different in their lives. Constructive counsellors adopt a "not knowing" position as a route to putting people into the position of being experts about their lives. Counsellors do not assume that they know by virtue of their expert frame of reference, the significance of the individual's actions and experiences (Watts & Shulman, 2003: 30). This design casts the role and functions of a counsellor in quite a different light from behaviourally oriented counsellors who view themselves as experts in assessment and treatment.

Constructivist counsellors strive to create collaborative relationships because of their belief that doing so opens up a range of possibilities for present and future change (Greenberg et al., 2001:175). They create a climate of mutual respect, dialogue, inquiry, and affirmation in which people are free to create, explore, and co-author their evolving stories (Sheldon & Kasser, 2001:48). Their main counselling task consists of helping people imagine how they would like things to be different and what it will take to bring about these changes (Watts & Pietzak, 2000:445). Some of the questions that Watson (2002:450) find useful are:

- 'What do you expect by coming here?'
- 'How would that make a difference to you?' and
- 'What might be a sign to you that the changes you want, are happening?'
As with any other counselling orientation, the quality of relationship between the counsellor and individual is a determining factor in the outcomes of constructivist counselling. It is essential to create a sense of trust so people will return for further sessions and will follow through on homework suggestions (Corey, 2005:34). Constructivist counselling is designed to be brief, which suggests that the counsellor should shift the focus as soon as possible from talking about problems to exploring solutions (Bitter & Nicoli, 2000:44; Dinkmeyer & Sperry, 2002:23). Indeed, one way of creating an effective counselling partnership is for the counsellor to show people in what way they can use the strengths and resources they already have to construct solutions (Lazarus & Zur, 2002:36).

Watts (2003:12), Yalom (2000:27) and Bozarth et al. (2002:150) describe three kinds of relationships that may develop between counsellors and individuals:

- **Customer** - the person and counsellor jointly identify a problem and a solution to work toward. The person realizes that to attain his goals, personal effort will be required.

- **Complainant** - the person describes a problem but is not able or willing to assume a role in constructing a solution, believing that a solution is dependent on someone else's actions. In this situation, the person generally expects the counsellor to change the other person to whom the problem is attributed.

- **Visitor** - the person who comes for counselling because someone else such as a spouse, parent, educator, or probation officer thinks the person has a problem. This person may not agree that he or she has a problem and may be unable to identify anything to explore in counselling.

De Jong and Berg (2002:45) recommend using caution in order for counsellors not to "box" people into static identities. Rather than categorizing people, counsellors can reflect on the kinds of relationships that are developing between individuals and themselves. For example, people
(complainants) who tend to place the cause of their problems on another person or persons in their lives may be helped by skilled intervention to begin to see their own role in their problems and the necessity for taking active steps in creating solutions (Strumpfel & Goldman, 2002:190). A visitor person may be willing to work with the counsellor to create a customer relationship by exploring what the person needs to do to satisfy the other person or 'get them off their back.' Initially, some people will feel powerless and overwhelmed by their problems (Cummings, 2002:4; Kazdin, 2001:33). Even people who are unable to express a problem may change as the result of developing an effective counselling alliance. The manner in which the counsellor responds to different behaviours of people, is imperative in bringing about a shift in the relationship. In short, both complainants and visitors have the capacity for becoming customers (Lazarus & Lazarus, 2002:220; Prochaska & Norcross, 2003:18).

2.6 CONCLUSION

This chapter explored the role constructivism and its sub-theories can play in the counselling of learners infected with HIV/AIDS. The next chapter will review literature on HIV/AIDS.
CHAPTER THREE

LITERATURE REVIEW ON HIV/AIDS

3.1 INTRODUCTION

The latest universal statistics on the epidemic of HIV/AIDS published by UNAIDS/WHO in December 2004 are alarming. UNAIDS and the WHO estimated that between 36 and 44 million people around the world were living with HIV in December 2004 (UNAIDS, 2004:10). It was also estimated that during 2004 alone, between 4.3 and 6.4 million people were newly infected with HIV and between 2.8 and 3.5 million people died of AIDS related illnesses. More than 23 million people suffering from AIDS have died since 1981 worldwide the year in which the disease was first recognized as a unfamiliar disease in the United States when clinicians in New York, Los Angeles, and San Francisco diagnosed young homosexual men with Pneumocystis carinii (now P jiroveci) pneumonia (PCP) and Kaposi's sarcoma (KS), which were found to be unusual diseases for young adults were not immuno-suppressed (Lamptey, Wigley & Carr, 2002:34).

According to UNAIDS (2004:24), Sub-Saharan Africa remains by far the worst-affected region, with 23.4 million to 28.4 million people infected by HIV at the end of 2004. Just under two thirds (64%) of all people in the world who are HIV positive in sub-Saharan Africa, and more than three quarters (76%) are women. An estimated 25.4 million Africans are infected HIV and approximately 3.1 million new infections occurred in 2004. In 2004 alone the epidemic claimed the lives of an estimated 2.3 million Africans. Around two million children under fifteen are HIV positive and more than twelve million children have been orphaned by AIDS. A combination of social factors seems to be responsible for this state of affairs, which are:

- poverty and social instability;
- high levels of sexually transmitted infections;
- the low status of women;
- sexual violence;
- high mobility (particularly migrant labour); and
- lack of leadership (Wilson, 2003:14; Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001:82).

South Africa has the fifth highest prevalence of HIV in the world, with 21.5% of the population estimated to be infected. The UNAIDS Global Report estimate the number of AIDS related deaths in South Africa in 2004 to have ranged anywhere between 270 000 and 520 000 (UNAIDS, 2004:18). Given the numbers of people infected and dying, South Africa is regarded as having the most severe HIV epidemic in the world. In South Africa, women face a greater risk of HIV infection. The infection rates involving males and females are most pronounced in the age group: thirteen – twenty four years, and the infection ratio is twenty female for every ten males. Young women tend to have partners much older than themselves, and have other girlfriends and are more likely to be HIV infected (Berkman, 2001:1; Dorkenoo, 2001:23).

This chapter provides the literature review on the human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) and how these maladies affect the general health, that is, both the physical and psychological wellness and well being of individuals, which has a bearing on the epidemiology of HIV/AIDS, its transmission and treatment.

3.2 THE EPIDEMIOLOGY OF HIV/AIDS, ITS TRANSMISSION AND TREATMENT

This section includes the epidemiology, transmission and treatment of HIV/AIDS.

3.2.1 The epidemiology of HIV/AIDS

AIDS is an acronym for Acquired Immunodeficiency Syndrome or Acquired Immune Deficiency Syndrome and is defined as a collection of symptoms and
infections resulting from the depletion of the immune system caused by infection with the human immunodeficiency virus (HIV). HIV is a very small germ or organism which infects people through contact with infected body fluids. It cannot be seen by the naked eye, only can be detected under an electron microscope. It only survives and multiplies in body fluids such as sperms, vaginal fluids, breast milk, blood and saliva (Furler, Walmsley & Millson, 2001:160). HIV attacks the immune system, which serves as the body's defence mechanism against infection (Gayle & Lange, 2004:6), and reduces the resistance of the body to all kinds of illness, including influenza, diarrhoea, pneumonia, TB and certain cancers. It eventually weakens the body to such an extent that it cannot fight sicknesses and causes death after a period of five to ten years after becoming infected, but some HIV-infected people live longer if they receive the right psychocounselling and medication (Gillespie et al., 2003: 80). This means that this malady attacks the immune system that protects the body from illnesses and it damages the ability of the body to protect itself from tuberculosis (TB), chest infections, sores, upset stomachs and other infections, and the body loses its ability to fight infections after the immune system has been weakened (Cross, 2001:132). After many years the damages are serious and the person contracts serious illnesses which develop to a syndrome known as AIDS, which is the final stage of infection with HIV, and this is what causes the person to die (Dean & Moalusi, 2002:24).

HIV is a retrovirus that primarily infects vital components of the human immune system such as CD4+ T cells, macrophages and dendritic cells. It also directly and indirectly destroys CD4+ T cells (Anderson & Schartlander, 2002:74). As CD4+ T cells are required for the proper functioning of the immune system, when enough CD4+ cells have been destroyed by HIV, the immune system barely works, leading to AIDS. For infection to take place, the virus causing AIDS enters the blood and quickly penetrates certain white cells (called 'CD4' cells or 'T4 cells') in the body (Benell, Hyde & Swainson, 2002:23). HIV also directly attacks certain human organs, such as the kidneys, the heart and the brain leading to acute renal failure, cardiomyopathy, dementia and encephalopathy. Many of the problems faced
by people infected with HIV results from the failure of the immune system to protect them from certain opportunistic infections and cancers (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002:16).

3.2.2 Transmission

The literature review reveals that HIV is transmitted through penetrative and oral sex whether vaginal or anal, blood transfusion, the sharing of contaminated needles through drug injection, in health care settings, and between mother and infant during pregnancy, child-birth and breastfeeding (Coombe & Kelly, 2001:18). The use of physical barriers such as the latex condom is widely advocated to reduce the sexual transmission of HIV (Brown, 2003:50).

Children and adolescents can also contract HIV/AIDS through being sexually abused. Thus a sexual offence can be defined as discovered sexual abuse that is perceived as serious enough to warrant an official response (James, 2001:16).

At the end of the year 2004, there were between 36 and 44 million people living with HIV, of whom twenty five million are in sub-Saharan Africa. Global estimates for new HIV infection in 2004 were 4.3 to 6.4 million (UNAIDS, 2004:38). Around half of the people who acquire HIV become infected before they turn twenty five years of age and die of AIDS before their 35th birthday. This age factor makes AIDS uniquely threatening to children. In 2004, an estimated 640,000 children aged fourteen or younger, became infected with HIV. Over 90% of newly infected children are babies born to HIV-positive women, who acquire the virus at birth or through their mother's breast milk. Almost nine-tenths of such transmissions occur in sub-Saharan Africa (WHO, 2004:35; Kalichman & Simbayi, 2004:36). Africa’s lead in mother-to-child transmission of HIV is firmer than ever despite the evidence that HIV ultimately impairs women’s fertility, once infected, a woman can be expected to bear 20% fewer children than she otherwise would. Drugs are available to minimise the dangers of mother-to-child HIV transmission, but these do not
often reach the destinations where they are most needed (Department of Health, 2004:15).

3.2.3 Treatment

HIV infection is a chronic infectious disease that can be treated, but not yet cured. There are effective means of preventing complications and delaying, but not preventing, progression to AIDS. At the present time, not all persons infected with HIV have progressed to AIDS, but it is generally believed that the majority will (Van Aard, 2002:12). The rate of clinical disease progression varies widely between individuals and has been shown to be affected by many factors such as host susceptibility, immune function, health-care, the presence of co-infections and other peculiarities of the viral strain (UNAIDS, 2002:10). People with HIV infection, therefore, need to receive education about the disease and treatment in order to be active partners in decision making together with their health care provider (Lamptey et al., 2002:20).

The South African Government’s response to the epidemic is grounded in the HIV/AIDS and Sexually Transmitted Diseases Strategic Plan for the period 2000 - 2005. The purpose of this plan is to provide a broad national framework around five priority areas:

- prevention;
- treatment;
- care and support;
- research, monitoring and evaluation; and

This plan has led to the South African Government adopting the operational plan for comprehensive HIV and AIDS treatment and care, in November 2003, which includes the provision of antiretroviral (ARV) counselling in the public health sector. The progression of the ARV programme is proving a slow process though, because the Department of Health needs to address major
capacity and infrastructure constraints but also because they should be educating South Africans about the role of nutrition and traditional medicine, and the safety and efficacy of registered drugs that have been provided in the private sector for many years. By early 2005 only approximately 30 000 HIV/AIDS infected people were receiving ARV counselling through the state programme. The Operational Plan commits the Government to provide ARV treatment to 1 650 000 people who should need it by March 2008 (Department of Health, 2004:12).

Ebersohn and Elloff (2002:23) posit that the counselling situation can be an excellent place to explore the benefits and disadvantages of HIV/AIDS disclosure. Counsellors could assist HIV/AIDS infected individuals decide which person to inform initially. The optimal way to disclose status (for example, in person, by letter, by phone), and the optimal time to inform such individuals. They suggest that role playing can help facilitate the disclosure process and reduce anxiety. Counselling can help HIV-positive learners cope with school-related discrimination. Counsellors can assist them in distinguishing between realistic paranoia (fact based) and exaggerated paranoia (fear based) with regards to discrimination.

According to Dean and Moalusi (2002:24), support groups and group psycho-counselling can be vital forums for addressing stigmatization. Group facilitators can help members to identify the social function of stigmatization, examine their own internalized stigma, and experience the catharsis of their pain and shame. These groups also provide HIV positive people with an empowering sense of belonging. An important goal of psychocounselling is to help HIV/AIDS infected persons learn how to become good consumers of treatment. Counsellors can encourage HIV/AIDS infected persons to assert their right to know as much as possible about any proposed course of action. HIV/AIDS infected persons who find this difficult may need interventions to help them develop skills in assertiveness. Support groups such as mothers of people living with AIDS (which also welcomes fathers and siblings) or other AIDS service agencies may be very effective in helping family members feel less isolated (Ginwalla, 2002:707).
3.2.3.1 Psychological issues related to treatment decisions

Gupta (2001:46) posits that initiating medical treatment often confronts people with a deeper acknowledgment of their HIV-infected status. Strong denial mechanisms and hopefulness may weaken, leaving HIV/AIDS infected individuals vulnerable to bouts of fear and anxiety which may result in suicidal ideation.

The advent of new antiretrovirals and drug combination treatment revised many physicians' and HIV/AIDS infected individuals' approaches to treatment. Early reports of improved and extended lifespan resulted in widespread optimism. However, Harker (2002:12) maintains that the recent therapies offer great uncertainties in exchange for hope, but prospects of continued improvement can be shattered overnight with side effects, drop-offs in efficacy, and unforeseen consequences.

Harries (2002:38) note five psycho-social repercussions of new combination therapies:

- many people may be (or are being) excluded from access to these therapies. At a cost of about R105,000 per year it is questionable whether medical aids will pay or will continue to pay for treatment;

- adherence to the new regimens can be extremely difficult. Combination therapies require many tablets be taken on a strict schedule coordinated with meal and fasting times. Poor compliance with directions may increase the possibilities of viral mutations and lead to drug-resistant strains of HIV;

- people who in the past have been unable to take medications consistently, such as individuals who are severely mentally disabled, are chemically dependent, or have mental retardation, may be excluded from available therapies;

- the side effects of these drugs may preclude some people from taking them; and
the long-term effects of this treatment is undetermined. In their study of long-term survivors, Kelly (2002:80) and James (2001:23) describe the characteristics of the 'good' HIV infected person as the one who:

- takes responsibility and charge of his or her health;
- acknowledges that HIV illness has an uncertain course and makes plans based on a variety of contingencies;
- is informed about the natural history of HIV disease and keeps abreast about changing treatment recommendations;
- observes and reports symptoms to the physician promptly;
- considers the physician a trustworthy working partner with whom he or she is honest and open;
- complies with agreed on treatment regimens;
- keeps track of prescriptions and understands their purpose;
- utilizes medical appointments efficiently by preparing a list of concerns and questions;
- accepts and seeks help when necessary; and
- devotes sufficient time to medical care.

Some individuals turn to alternative treatments which may not have had the same reliability and rigorous testing that pharmaceutical drugs receive. It is always prudent to inform primary health care providers about diverse treatments to prevent harmful drug interactions (Kalichman & Simbayi, 2004:572).
3.2.3.2 Psycho-social issues related to the management of chronic illness

The onset of HIV-related symptoms to patients signals the progression of HIV disease and can cause considerable stress, which can result in fear of death. Similarly, personal anniversaries for testing HIV-positive declines in CD4 cell counts, rising viral loads, hospitalizations, and deaths of other people with AIDS all raise fears and concerns that can cause stress and treatment failures (Keeton, 2002:28).

Pain management is a central part of coping with HIV. Patients often feel bewildered when confronted with physical pain and may need assistance to keep in mind that the subjective nature of pain does not make it less legitimate. At the same time, patients may have to realize that there are limitations to their physicians' ability to mitigate pain. Patients' adherence to treatment regimens is critical since the advent of complex treatment with inhibitor drugs that require constant attention through out each day (Bradshaw et al., 2002:32).

Counsellors working with HIV-positive clients will need to employ a broad range of professional skills. Gibson et al. (2002:14) maintain that the counsellor at times will have to be an educator, as well as a case manager. While the counsellor does not need to discontinue counselling in order to facilitate case management tasks (for example, helping a client negotiate the welfare system), continued counselling might not be possible if such tasks are not performed.

3.3 THE EFFECTS OF HIV/AIDS ON PSYCHO-PHYSICAL WELL BEING

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 (Hurting, Pande, Baral, Newell, Porter & Bam, 2002:80).

Hepburn (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.

3.3.1 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). The 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).

3.3.2 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 (Lemma, 2003:29). However, during this latent phase, HIV can be found in large quantities in lymph nodes, spleen, adenoid glands and tonsils (Mekonnen, 2003:49). 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 (Minuye, 2003:18). 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 (Nyblade, Kidanu & Mbambo, 2003:16).

The next stage of HIV begins when the immune system starts to break down (Hanson, 2002:71). This is often preceded by subtle mutations in the virus, during which it becomes more aggressive in damaging white cells (Fox, Fawcett, Kelly & Ntlabati, 2002:33). 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 (Floyd, Creese & Alban, 2002:30).

Cooper-Arnold, Stover & Bollinger (2001:28) say 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, 2004:4).

3.3.3 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 in the fluid covering the brain and spinal cord, requiring a needle to be inserted in 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.

The most common HIV/AIDS related illnesses which accompany the late stage are chest infections, damage to the nervous system, skin rashes and growths and problems in the gut, eyes and other organs. These illnesses will be discussed below.
3.3.3.1 Chest infections are common

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 (Hargreaves & 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 (Harris & Schubert, 2001:10). Latent TB infection is common in the general population.

3.3.3.2 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 (Ainsworth & Teokul, 2000:60).

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 (Petersen & Swartz, 2002:13). 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, 2004:39).

3.3.3.3 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, 2004:21). 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 (Bennett & Fairbank, 2003:39).

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).

3.3.3.4 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 (Hanson, 2002:13). 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 (Brugha, 2003:36; Blower & Farmer, 2003:21).

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, inter alia:

- *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.
3.4 THE EFFECTS OF HIV/AIDS ON PSYCHO-SOCIAL ADJUSTMENT OF INFECTED PERSONS

HIV/AIDS infected persons are at risk to experience psycho-social adjustment problems in a number of areas which include those that are discussed below.

3.4.1 Stigmatization

HIV/AIDS infection is a highly stigmatizing disease. Stigma refers to a visible mark used to distance, shame, condemn, or socially ostracize a person. Stigmas, therefore, communicate social disapproval. HIV infection is stigmatizing because it is difficult to conceal as the disease progresses, is disruptive to the person's life and relationships and can cause physical disfigurement as part of its degenerative course (Anderson & Schartlander, 2002:75).

AIDS-related stigmas result in discrimination, prejudice, and isolation. Social stigmas are a major factor in limiting social support and assistance for coping with HIV (Wilson, 2003:24). AIDS-related stigmatization is complicated by other socially stigmatizing characteristics of the groups most afflicted by the epidemic. Homosexuality, drug abuse, poverty, and minority group membership are all characteristics that carried significant social adversities prior to the HIV epidemic and have now become associated with HIV/AIDS (Bennel et al., 2002:44).

Social stigmas are a source of chronic stress for people living with HIV and AIDS. Victim blame is common because people often contract the virus through behaviours that are socially sanctioned (Clinton, 2003:43). Also, people infected with HIV can internalize blame, believing that they 'should' have known better and should have taken precautionary steps against getting infected (Bradshaw et al., 2002:23).

A serious outcome of social stigmatization experienced by people with HIV is their reluctance to disclose their HIV status to others. Fears of being ostracized, isolated, and abandoned create a shroud of secrecy around having HIV. An inability to disclose being HIV positive to others limits the resources and supports that are available to a person living with HIV.
According to Clinton (2003:33), acts of discrimination against people suffering from HIV/AIDS are frequent. People have been denied services, residence, and employment because they are HIV infected. Although laws that protect people against discrimination exist in many areas, these problems still persist.

In the light of the above paragraphs, 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. In his landmark book Stigma: Notes on the management of spoiled identity, Crepaz and Marks (2002:11) 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' (Cullinan, 2002:30). Dean and Moalusi (2002:31) 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; and

- **tribal stigma of race, nation, and religion** - beliefs that are transmitted through lineages and equally contaminate all members of a family.

According to Goffman and other researchers, diseases associated with the highest degree of stigma share common attributes:
• the person suffering from 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 (Dorrington et al., 2001:71). Initially, 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 (Gwatkin & Deveshwar-Bahl, 2002:12). 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. 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 (James, 2001:33; Kelly, 2002:12).

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 (Lemma, 2003:38). HIV-positive individuals, their loved ones, and even their care-givers are often subjected to rejection by their social circles and communities 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 (James, 2001:32).

HIV-related stigma has been further divided into the following categories:
- **instrumental HIV-related stigma** - a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness (Hanson, 2002:70);

- **symbolic HIV-related stigma** - the use of HIV/AIDS to express attitudes toward the social groups or "lifestyles" perceived to be associated with the disease (Gupta, 2001:52); and

- **courtesy HIV-related stigma** - stigmatization of people connected to the issue of HIV/AIDS or HIV-positive people (Gregson et al., 2001:468).

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 (Dorkenoo, 2001:32). Early detection of HIV infection is important. Knowledge of a person's HIV seropositivity can lead to earlier treatment and improved outcomes (Dean & Moalusi, 2002:25). Knowledge of seropositivity also can lead to changes in risk behaviours that can reduce or eliminate the risk of HIV transmission.

Coombe and Kelly's report (2001:48) 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, eight percent 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 (Clinton, 2003:45). 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 suffering from HIV and said it was a reason for not getting tested (Brown, 2003:50).

Earlier 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) (Bertozzi et al., 2002:67). HIV/AIDS-related stigma also influences individuals' responses to testing positive. It aggravates the psychological burden of receiving a positive HIV test (Berkman, 2001:46). Earlier in the epidemic, there were reports of severe psychological responses to notification, including denial, anxiety, depression, and suicidal ideation (Benatar, 2002:165). 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 afterwards (Barnett & Schueller, 2002:47).

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 seropositivity to partners, friends, family, colleagues, employers, and health care providers (Badcock-Walters, 2001:8). At each level, a decision to disclose seropositivity may either enhance access to support and care or expose the individual to stigmatization and potential discrimination.

Psycho-social factors related to disclosing HIV status are:

- the potential for prejudice and stigma;
- the possibility of having the integrity of one's sexual relationships called into question or of losing a relationship;
- the potential of being labeled an unfit parent;
- vulnerability to violence, particularly for women who wish to disclose to their partner;
- reactions from family and the fear of hurting parents;
- shame (particularly for members of some cultural communities);
• loss of friendships;
• loss of health insurance; and
• fear of employer's reactions.

3.4.2 Psycho-social issues related to coping, death and dying

Persons who receive a diagnosis of HIV or AIDS often react with a mixture of emotions, including shock, depression, hopelessness, grief, anger, and fear. Psycho-social factors such as coping and social support may affect both disease progression and quality of life. For example, a study of 736 individuals with AIDS noted that these individuals practiced a variety of coping behaviors categorized as positive coping, social support seeking, and avoidance coping. The coping behaviors were associated with health behaviors, affect, and disease progression in both cross-sectional and longitudinal analyses (Gayle & Lange, 2004:36). Similar findings were reported in a phenomenological pilot study conducted by MacIntyre (2001:18) which explored the experiences of five HIV-infected African American women. Audiotaped interviews from these women were examined. Twelve themes emerged from the data: violence, addiction, it couldn't happen to me, shock and denial, education, time, uncertainty, cycles, secretive nature of their lives, someone, survival, and children. It is evident, even from this small pilot study, that these individuals have complex experiences and that the complexities of stress has an effect on coping and psychological well being.

Many people suffering from HIV fear dying, in particular, the anticipation of a painful or lengthy death. This is particularly the case when they have seen friends, lovers or colleagues die after suffering from severe pain or dementia from AIDS-related causes. Crepaz and Marks (2002:140) and Dorkenoo (2001:42) identify a number of challenges facing HIV-positive people close to death, which indicates that they should:

• attempt to find self-acceptance;
• clarify their wishes for final medical treatment;
- attempt to deal with and hopefully heal rifts with family and friends; and

- find ways to say goodbye and yield to death.

Those close to the dying person must also prepare for his or her death. Doing so often involves attempting to accept the person as he or she is. In addition, they must come to accept the person's wishes for medical care, as well as any wishes related to activities after his or her death.

### 3.5 SUMMARY

From the foregoing paragraphs it has been apparent that learners infected with HIV face specific problems which are related to the infection and others related to everyday living. Awareness alone that a person is a carrier of a dangerous and lethal virus is a stress factor impacting the major functioning levels of a human being - physical, psychological - emotional, social. Common strategies for overcoming anxiety and fear of death are not sufficient. It is apparent that every person living with HIV/AIDS desperately needs the presence and availability of other people.

The next chapter will present the empirical design employed in this study.
CHAPTER FOUR

EMPIRICAL DESIGN

4.1 INTRODUCTION

This chapter provides details of the methodology employed in the design of this research. It focuses, inter alia, on the procedure for the design, methods of data collection, data analysis, selection of cases as well as the design of the interview research.

4.2 AIMS OF THE RESEARCH DESIGN

The aim of any research design is to select or choose and utilise the methods and techniques that the researcher considers imperative to yield a better attainment of the aims and objectives of the study. There are numerous research methods in literature, which researchers employ for the specific nature and kind of research to be undertaken (Berg, 2003:16). It is difficult to find one single research method suitable for carrying out every type of research problem at all times. There are a great number of other factors that implicate the choice of research methods for any given research problem such as, the nature and dynamics of the problem being researched, costs and time (Creswell, 2003:16) to mention only a few. As such, it is imperative that a specific research problem be solved through relevant research methodology (DeMarrais & Lapan, 2004:29). For these reasons, researchers have to consciously and purposefully select and utilise only those research methods that would permit better, convenient and successful attainment of specific research aims (Denzin & Lincoln, 2005:32). This research is not an exception and therefore the research method and techniques considered by the researcher to be relevant are utilised as presented in sections that follow.

4.3 RESEARCH DESIGN AND METHODOLOGY

A qualitative research methodology was used in this study. Miles and Huberman (1994:12) note that one of the major features of qualitative data
analysis is that it focuses on naturally occurring, ordinary events in natural settings so that researchers are able to develop robust conceptualizations of what 'real life' is like. They further note the richness and holism of such data, which provides strong potential for revealing complexity, since such data provides 'thick descriptions' that are vivid, nested in real context, and have a 'ring of truth' that has a strong impact on the reader. Maxwell (2004:24) contends that the 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. This research therefore seeks primary data from people who are directly involved with the subject matter in focus.

On the basis of the foregoing paragraph, the use of qualitative research in this research can be justified as follows:

- firstly, it is a type of formative research that could offer specialized techniques for obtaining in-depth responses about what learners suffering from HIV/AIDS think, 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 reality of the learner suffering from HIV/AIDS; and

- secondly, qualitative research provides a rich texture and context through which to learn about the learner suffering from HIV/AIDS as an individual without losing the rich descriptions of his/her attitudes and feelings and the essence of his/her 'lived' experiences.

The constructivist foundation of this research investigation fits in with a qualitative research approach, because constructivist researchers believe in the narratives and stories of the individuals being interviewed. This research is investigative and exploratory, and the interviews with learners suffering from HIV/AIDS were designed to encourage them to tell their stories. According to Patton (2001:16), this is consistent with the idea that people make sense of and communicate their experiences through stories. Shank (2002:16) explains that narrative or story telling represents a distinctive 'way of knowing' quite
different from the theoretical, propositional or paradigmatic knowledge that has historically been the trademark of the scientific community. According to Shank (2002:11), narratives are vehicles for expressing the consciousness of the narrator. How a person constructs meaning is believed to be unique to the person. The positivist assumptions are that ‘everyone shares the same meaning system’ and experiences ‘the world in the same way’ (Merriam, 1998:28). Rather than searching for universals that can be applied to the analysis of all humans, the aim is to undertake the subjective world of the participants, which is best realized through a qualitative research approach.

A discussion of the design type, types of interviews used and the interview setting follows.

4.3.1 Design type

The design type identified for this research is thus a case study design, following a qualitative approach. The case study design was selected in order to preserve uniqueness and social context of each case. An instrumental case study, which is used to provide insight into the issue of constructivist counselling is conducted (Barton, 2000:19). This study is qualitative in nature and the researcher is to give an in-depth description of a small number of bounded system cases (Tellis, 1997:36). The basic strategy of this design is to describe thoroughly a single unit during a specific period of time. The researcher worked with three learners suffering from HIV/AIDS, two relatives (an aunt and a grand mother) and a health worker (see 4.6). Yin (1998:26) states that the case (learner suffering from HIV/AIDS) is selected to advance an understanding of that other interest (constructivist counselling). Tellis (1997:51) supports this by stating that the case study is an ideal methodology when a holistic, in-depth investigation is needed. Case studies can be characterized in qualitative research as the researcher spending extended time, on site - personally in contact with the activities and operations of each case, reflecting, revising meanings of what was occurring (Rowley, 2003:17).

The use of interviews in this research is recommended by different researchers in the field, including the works of Gillham (2000:18). The aim of
interviews in this research was to obtain primary information from the participants who were selected to participate in this study (see 4.6). Interviewing takes the investigation one step further by focusing in considerable detail on the life experience and social behaviour of selected individual respondents (Anderson, 1998:37).

Barton (2000:19) suggests that the interview may be likened to a conversation. It is an interaction, which takes place in the context of a relationship. This interaction offers a rich data source of human structures of experience. DeMarrais and Lapan (2004:36) propose the use of certain skills, in facilitating an atmosphere conducive to openness and trust within an interview situation. They suggest that the interviewer be alert and listen actively to the participants’ verbal and non-verbal communications. Furthermore, they note that the researcher must engage in a non-judgemental, non-evaluative manner. DeMarrais and Lapan’s suggestions were kept in mind during the interviews.

Open-ended questions were used to focus on certain themes and probe a broad yet loosely defined area of importance that the researcher has previously identified. The task of the interviewer was to focus upon, or guide the participants towards certain themes, but not guide the participants towards certain opinions about those themes (Gillham, 2000:28). Due to the nature of the study, the researcher wanted to:

- ask numerous open–ended questions, or open ended probes;
- transcribe and audiotape the answers given by the respondents;
- encourage respondents to say what they think and to do so with great richness and spontaneity; and
- generate or attain an improved response rate by the interviewees and by so doing enhance the quality of the study. These aspects concur with the advantages of interview schedules stated by Maxwell (2004:38).
Furthermore, the researcher wanted to gain first-hand in-depth information from the participants on the items of the interview schedule (see Addendum A).

4.3.2 Types of interviews

Maxwell (2004:28) suggests various types of interviews, which range from the hostile interview to the humanist phenomenal interview where there is mutual respect and sharing of information between the interviewee and interviewer. The latter is characteristic of the interviews used in this study.

The researcher opted for semi-structured interviews which involve one-to-one interaction and are organized to encourage the respondent to talk freely and to express his/her experiences, feelings and ideas on the effects of HIV/AIDS on his/her psychological, social and physical well being, and how s/he generally functions and performs at school.

4.3.3 Interview setting

These interviews were conducted at the participant's homes with only the interviewer and the interviewee in the room and in other cases with their caretakers. The confidentiality of the conversation had to be maintained and it was assumed that there would be absence of peer pressure and that would allow for discussion of sensitive issues or highly personal matters. The interviews were conducted in a relaxed conversational style. The rapport that developed was important in helping to elicit more in-depth information by encouraging the infected learners to feel both safe and confident. The learners suffering from HIV/AIDS were encouraged to feel relaxed and were asked to discuss anything about their enjoyable life experiences generally before focusing on the questions on the interview schedule. This was done in order to keep the interviewees at ease and to build a rapport between the interviewer and the interviewee.

The responses were tape-recorded with the permission of the interviewees for later transcription analysis and interpretation.
4.4 METHODS OF DATA COLLECTION

Methods of data collection are hereby discussed in terms of participant observation, data documentation and data capturing.

4.4.1 Participant observation

Data sources of participant observation were used in this study to add a unique dimension to this qualitative research by observing and interpreting the social meanings of the everyday lives and actions of the infected learners. As the term suggests, participant observation means that the researcher directly observes the behaviour and activities of the learners under study. This commonly entails gaining the trust and confidence of research subjects and is invariably a time consuming activity. However, the rich contextual data that resulted were invaluable, both in confirming and validating self reports of learners suffering from HIV/AIDS and also in describing the events and situations in which social action took place (how they were infected, how they live with the infection, how they think they can cope in the midst of challenges and how they can be helped). This is particularly important for learners, where precise and detailed descriptions of the social context (societies), context of systems (education, health and communities) and context of culture (beliefs both traditional and Christian, norms and values) are needed for constructivist counselling.

4.4.2 Data documentation

Data is documented mainly as a historical record for oneself and other possible researchers. Keeping track of fieldwork as the process unfolded, created this historical record. The researcher relied on the field notes and the audiotaped messages of the interviews. Miles and Huberman (1994:28) suggest that there are essentially two kinds of field notes. Firstly there are notes that the researcher writes to describe as fully as possible what infected learners did and said. Secondly, there are notes that the researcher writes, called ‘soft’ notes that are concerned with unfolding analysis.
Every tape was dated clearly and transcribed into written format. Emergent themes were realized for the purpose of data analysis and interpretation.

### 4.4.3 Data analysis

Data analysis is the process whereby order, structure and meaning are imposed on the data that is collected in a qualitative research study (Patton, 2001:39).

An interpretive approach called hermeneutics was selected in order to understand the worldview of the participants. According to Seidman (1998:29) hermeneutics refers to a detailed reading or examination of a text, which could refer to conversational written words or pictures. The reading is to discover embedded meaning.

The term hermeneutics is a Greek word which means to interpret, and is derived from the story of Hermes, a mythological messenger who was tasked with changing the unknown to a form that humans could understand, via language and writing (Strauss & Corbin, 1998:35). As a contemporary research approach, hermeneutics involves understanding and interpretation. The aim is to understand how people experience the world pre-reflectively, without classifying or abstracting it (Tellis, 1997:39).

The goal of hermeneutics then is to discover meaning and achieve understanding, not to extract theoretical terms or concepts at a higher level of abstraction (Yin, 1998:28). It aims to interpret a person’s experiences through a text. The assumption is however, that the ‘lived’ experience is veiled. Thus the researcher’s task in collaboration with the participant is to uncover the shared common practices of the experience (Flick, 1998:29).

The principles of hermeneutics are in keeping with the constructivism paradigm on which this research is based, hermeneutics assumes that the meaning-giving process is influenced by social structures, shared practices, and language (Berg, 2003:46). Also in line with constructivism, the hermeneutic approach assumes that the process of interpretation is informed
by the interpreter's values. The notion of truth or a correspondence with reality is not considered to be an issue from this perspective.

It is acknowledged that the researcher cannot completely know or understand the participants' experiences. This would imply an objectivist ability to stand apart from the interview and make value-free observations. In addition, it must be kept in mind that the participants may censor their stories or simply may not be fully aware of, or able to articulate certain aspects of their experiences (Schram, 1999:39).

Although proponents of hermeneutics do not generally advocate the use of specified techniques, the following approach was adapted from Rapmund (1996:24) and was applied in this study:

- permission was obtained from participants before being interviewed. As most of them are still minor, permission from their parents/guardians was obtained;

- taped interviews were transcribed;

- the researcher carefully listened to the tape recordings while simultaneously reading the transcribed interviews;

- the researcher read the text repeatedly and immersed herself in each of the participant's stories in order to make sense of their worlds; and

- the researcher identified themes or patterns from each of the original texts and used excerpts from the original texts to support these proposed themes. Stories for each participant were constructed around identified themes.

At the commencement of data collection, the qualitative analyst becomes aware of meanings, patterns, regularities, explanations and possible configurations. The competent researcher should, however, be aware of 'early' conclusions and approach these conclusions with a sceptical, open mind (Stockdale, 2003:46). Final conclusions must not be made until data collection has been completed.
Dialoguing occurred between the researcher and the text, between the researcher and her supervisor, between the researcher and the account itself and her own values interpretations and impressions. During this process, the researcher searched for any possible misconceptions, deeper meanings, alternative connotations and changes over time as she examined elements of the text and the entire text. According to Yin (1998:37), analyzing is a circular progression between parts and whole, foreground and background, understanding and interpretation and researcher and narrative account.

Data analysis consisted of four phases. Phase one included reading through transcripts to confirm their accuracy and listening to audio-taped interviews in order to (re) familiarise the researcher with the discussion. Phase two involved a process of identifying the meanings hidden within the discourse. Barton (2000:96) states that there are two contexts to quotations - the interview from which it is taken and the 'pool of meanings' that arise from the discourse. In addition, interpretation of quotations throughout the analysis phase was based on the context of experience. Thus, quotations were highlighted from interview transcripts and discourse was interpreted within the scope of the meanings expressed by each participant across an entire interview.

Phase three involved the organisation of the results of analysis into themes based on similarity and difference in meaning. Quotations were sorted into groups and then organised on the basis of standard characteristics that defined each group. Phase four completed the analysis and involved a process of reduction in which groups of quotations were re organised into discrete themes.

4.5 SELECTION OF CASES - SAMPLING

The researcher used the sample design of purposeful sampling. There are different types of purposeful sampling. Network sampling is one of the types mentioned in Merriam (1998:24). Patton (2001:182) 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. 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.

As stated in 1.5.2, three learners suffering from HIV/AIDS, two relatives who were one of the respondent’s grandmother and aunt and a healthworker participated in this study (n=6). These learners are all from Gauteng Province of South Africa, living in three different townships in the Vaal Triangle, which are Sebokeng, Bophelong and Evaton.

4.6 DESIGN OF THE INTERVIEW RESEARCH

In his book ‘Interviews: An introduction to qualitative research interviewing’, Rowley (2003:36) discusses the seven stages of interview research which are: Thematizing, Designing, Interviewing, Transcribing, Analyzing, Verifying, and Reporting. The interviews were conducted in this manner and are discussed below.

4.6.1 Thematizing

In order to reach the aims of this research (Schram, 1999:28) the information that learners under investigation shared with the researcher helped in providing an understanding of ‘lived’ experiences of learners suffering from HIV/AIDS. These ‘lived experiences’ were converted into themes. A challenge for the researcher was to adequately represent the complexity of the ‘lived’ experiences of HIV/AIDS positive learners. In order to maintain the complexity without misinterpreting sensitivity was required to express data into words. The following themes were used to ascertain about:

- the infected learner’s feelings about suffering from HIV/AIDS;
- the effects of being infected with HIV/AIDS on their psychological and physical well being;
- their general functioning at school; and
- the nature and extent of support they get from their families, schools, communities and the society in general.
4.6.2 Designing

The learners that participated in this study were those who had reported their status either to the educators and/or the management of the school and/or the social workers, learners who fall into the category of those whose HIV positive status was not revealed to the educators at school but who frequently absent themselves because of illnesses, relating to opportunistic diseases, and those learners who are comfortable talking about their status, were considered as participants. Parents of two learner participants reported their children's positive status to the educator/s at their schools - the other infected learner's status had not been reported.

Two of the learner participants were infected through mother to child transmission (MTCT), and the other learner participant became infected through being sexually abused by an infected adult (uncle). Two of these participants are boys and the other one a girl.

In this study the most important criteria was that selected learners are infected, they have been tested, they know their status, parents know their status, they were willing to participate in the research and that learners are representative of diverse cases of HIV/AIDS in South African schools.

4.6.3 Interviewing

When learners gave permission for the researcher to interview them, interviews were scheduled. At that time the researcher indicated that the interview was designed to last between thirty and forty-five minutes. With the permission of those being interviewed, the interviews were taped. Most interviews were based on the pre-developed questions - however, the interviewer probed the responses and asked for clarification when needed. The researcher met and applied the criteria for interviewing as prescribed by Schram (1999:38), which are:

- knowledgeable - Has an extensive knowledge of the interview theme;
- structuring - Introduces a purpose for the interview, outlines the procedure in passing, and rounds off the interview by, for example, briefly telling what was learned in the course of the conversation;

- clear - Poses clear, simple, easy, and short questions, speaks distinctly and understandably and does not use academic language or professional jargon;

- gentle - Allows the subjects to finish what they are saying, lets them proceed at their own rate of thinking and speaking;

- sensitive - Listens actively to the content of what is said, hears the many nuances of meaning in an answer;

- open - Hears which aspects of the interview topic are important for the interviewee;

- steering - Knows what he or she wants to find out - is familiar with the purpose of the interview;

- critical - Does not take everything that is said at face value, but questions critically to test the reliability and validity of what the interviewees tell;

- remembering - Retains what a participant has said during the interview, can recall earlier statements and ask to have them elaborated; and

- interpreting - Manages throughout the interview to clarify and extend the meanings of the interview statements.

4.6.4 Transcribing

The oral interviews were transcribed into written text, and recorded on audiocassettes. As such the researcher had to make time to:

- play back each tape in chronological manner as the interviews had been conducted;
listen to all tapes very carefully; and

- add missing information in the transcripts.

All transcriptions were completed by the same transcriber to ensure that the same procedures were used for all interviews. The transcripts were prepared *verbatim*, but they had to be edited as the interviews were conducted in Sotho. This was because all respondents are Sotho speaking and could not understand English. In cases of grammatical mistakes in the sentences and the use of inappropriate terms/language, the researcher corrected with (own) suitable words.

4.6.5 Analyzing

Data from the interviews were stored in three forms, on hard copy, cassettes and on the computer. The researcher followed Miles and Huberman's (1994:26) suggested approach by looking at the text, 'trying out coding categories on it, then moving on to identify themes and trends, and then to testing hunches and findings, aiming firstly to delineate the 'deep structure' and then to integrate the data into an explanatory framework.' Data was displayed in the narrative form.

4.6.6 Verifying

Although some of the themes identified for this study indicated that other aspects are generalizable to the larger population of learners infected by HIV/AIDS, some are not generalizable. Those that are not generalizable include how psychological and physical wellness of these learners is affected by their HIV status. Findings can be said to be characteristic only of the population constituting the original interview pool. Creswell (2003:45) notes that in postmodern approaches to the social sciences, the goal of universal generalizability is being replaced by an emphasis on contextuality and heterogeneity of knowledge. Therefore, the goal was not so much to generalize but to describe the specifics within the context of this study. The issue of validity was addressed in two ways - the interview questions were posed to answer the research questions and the original question on the
'lived' experiences of infected learners was restated during the second interviews, to provide triangulation. Patton (1990:26) states that there are basically two kinds of triangulation that contribute to verification and validation of qualitative analysis, which are checking at the consistency of:

- findings generated by different data collection methods; and
- different data sources within the same method.

4.6.7 Reporting

The findings of the study are communicated in narrative form. The quotes, which relate to the general text, were conceptualized, and names and places that violate confidentiality were altered.

4.7 ETHICAL CONSIDERATIONS

Gunsalus (2002:28) note that the very nature of the aim of a research that attempts 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 has a responsibility to respect the rights, needs, values and wishes of the participants suffering from HIV/AIDS. In order to protect the participants' rights, the following safeguards as listed by Cresswell (1998:37) were employed:

- The research topic and objectives were articulated clearly in order to be well understood by the participants.
- Transcriptions, interpretations and reports were made available to the participants if they wish to see them.
- In any decision-making process in the study, the researcher considered the rights and protection of the participants.
- The researcher honoured confidentiality. The participants chose their pseudonym to be used in the texts to protect their anonymity.

It is anticipated that the discussion of the experience of these learners suffering from HIV/AIDS may prove to be emotionally distressing for some
participants. Participants, therefore, were monitored and debriefed. If necessary the researcher made recommendations for therapeutic interventions.

4.8 SUMMARY

This chapter explained the research methodology of the study, the nature of the database, the interviews and the method of analysis. The next chapter deals with analyses and interpretation of data collected during interviews.
CHAPTER FIVE

ANALYSES AND INTERPRETATIONS OF THE RESULTS

5.1 INTRODUCTION

This chapter provides analyses and interpretations of the responses that the interviewees that participated in this research gave to the questions that the interviewer posed. All three learners who are part of the interviewees who form cases of this research, are HIV/AIDS positive.

The verbatim transcripts of each case are placed first, followed by the researcher’s impression of each participant based on her observations, analysis and interpretation of each case’s responses to the questions asked by the researcher then follows. Lessons learned from each case and a set of planning questions and answers from each participant’s experience are placed last.

5.2 INDIVIDUAL ANALYSIS AND DISCUSSION OF EACH CASE STUDY

This first individual analysis centres around Tshepo’s case, his family background, the proceedings of the interview between Tshepo and the researcher and the researcher’s impressions of him based on her observations.

5.2.1 Case study 1: Tshepo’s case

This case presents a situation of a child who was prenatally infected with HIV, which in this research is referred to as mother-to-child transmission.

The brief introduction of Tshepo’s family background and the general impression that the researcher gained of this 11-year-old boy are given. The whole verbatim transcription of the interview that the researcher conducted with Tshepo and the health worker follows.
5.2.1.1 Introduction

The interviewer had three interviews with Tshepo (not his real name) and one with his aunt and his grandmother. Each session lasted about three hours.

The interviewer commenced the conversation by explaining that the interview was conducted for a doctoral degree research on school-going learners who are living with HIV/AIDS and that everything that the interviewees will reveal during the interviews will be kept confidential. The interviewer further requested the family’s permission to write down some some of the revelations and also to electronically record the conversation so as not to forget what was discussed.

5.2.1.2 Family background

Tshepo is a ten-year-old grade five learner who is the last-born in the family of three boys. They live with their grandmother and step-grandfather and the grandmother’s only surviving daughter, that is, Tshepo’s aunt. Tshepo’s grandmother had three children, Tshepo’s mother who passed away, a son who, after a short illness, passed away five years ago, and Tshepo’s only surviving aunt, Dipuo (not her real name). According to the grandmother both Tshepo’s parents died of HIV/AIDS. Tshepo’s mother died in April 2000 and his father in August 2001. Tshepo’s two brothers were born before their mother got married to their stepfather. Tshepo’s eldest brother is a, seventeen-year-old, grade eleven learner while his other brother is a fifteen-year-old, grade nine learner.

According to the information provided by Tshepo’s aunt, (his mother’s younger sister) Tshepo’s father was already HIV positive by the time he got married to her sister (Tshepo’s mother). They moved to live in the Reconstruction and Development Programme houses (houses meant for indigent people and those who earn salaries below R3 500.00 per month) but when they were both very sick they decided to come home. The father went to his home (where he was born) and the mother preferred to die among her own relatives. Tshepo is HIV positive, and infected through mother to child transmission. He knows that he is suffering from HIV/AIDS.
What follows is a word for word transcription of the actual conversation that took place between the interviewer, Tshepo, his aunt and his grandmother.

5.2.1.3 Additional information

The first visit to the family was a little bit tense because the family was not yet acquainted with the interviewer and they did not know what the interviewer wanted to know, which was the cause of interviewer not getting much information. She was not discouraged though, as she was hoping that they would open up eventually. The second time the family was visited, the interviewer and her promotor decided to buy the family vegetables. This made them willing to talk. They then told the interviewer about the problem of the boys' social grant. The interviewer realized that it is sometimes very difficult for other people to open up to a total stranger - one has to make regular visits until people start feeling free to tell him/her whatever s/he wants to know.

5.2.1.4 Transcription of interview with Tshepo, his grandmother and his aunt

This story is based on the transcribed interview between the researcher and Tshepo.

When did you come to stay with your grandmother and step-grandfather?

Tshepo: In August 2001 immediately after the death of my father. There was no one to take care of me where we 'lived' with my father. Before my father died we were staying with my grandmother (father’s mother) whose health deteriorated immediately after the death of her son, her only child and she died few months thereafter.

Who advised you to come and stay with your grandmother?

Tshepo: No one, I was used to visiting my grandmother and my mother whenever I felt like (my father was still alive) so it was the only thing to do. I was not close to other relatives on my father's side to go and stay with them.
How many people live in your grandmother's house?

**Tshepo**: We are eight in the house, it's my grandmother, step-grandfather, my two older brothers, my aunt and her two children aged eight and five.

In which area do you sleep at night?

**Tshepo**: My grandmother and my step grandfather use the main bedroom in the house, no one uses the other bedroom, then the rest of us use the two roomed shack adjacent to the house as our bedroom. The other room on the shack is used as a kitchen as well as bedroom at night.

Do you sleep in your own bed?

**Tshepo**: Yes there are two beds in the shack's bedroom, my aunt and her two kids use the other bed and I sleep on the single bed next to them. My two elder brothers sleep on the floor in the kitchen.

Are you comfortable at night?

**Tshepo**: Yes although when it is cold, I wish I could have another blanket. The shack is very cold when it is cold and very hot when it is hot. In winter my grandmother cooks in the shack most of the time, she uses the coal stove that is in our shack. This helps us a lot as the shack becomes warm.

When last did you become sick?

**Tshepo**: The whole of October and November 2004, the nurse at the clinic advised my grandmother to take me to hospital for an X-ray check up for TB. It was discovered that I had TB. I am still on TB treatment. At the hospital they told me to take the treatment for six months and this is my fifth month.

Is the TB treatment helping Tshepo in any way?

**Grandmother**: Yes it has helped, he recuperated immediately after he started using the treatment, and he eats a lot now. The tablets have given him a good appetite. I am not complaining but sometimes we do not have food and it is not right for him to drink his tablets on an empty stomach.
Is Tshepo still sick?

Grandmother: No, except that he developed a boil when he was sick in November, this has not healed ever since, I have to clean and dress it every day before he goes to school. Sometimes the principal of the school where Tshepo attends, helps with the cleaning and dressing of Tshepo’s wound. I only use Savlon as this is the only thing he was given at the clinic.

Is Tshepo on any other medication except for TB treatment?

Grandmother: Tshepo is not on any other medication except for the TB treatment. I cannot afford to buy him multivitamins or any other energy boosters for that matter, they are sometimes given free at the clinic but the clinic does not always have them.

Does Tshepo know that he is HIV positive?

Grandmother: Tshepo knows that he is HIV positive. One nurse in the health clinic told him about his status after an HIV test. I am still furious about the way this was revealed to him, because he was told in my absence. It was his aunt who took him to the clinic that day. After being tested, the nurse in charge said to him, ‘you have AIDS and you are going to die like your parents.’ (The grandmother was almost in tears when she was telling this to the interviewer. Her emotions as observed by the interviewer were a combination of anger, frustration and sadness). I feel that it was the way my grandchild was told about his status that made his health to deteriorate in October last year. Although he was not tested before I knew he was positive, he had all the signs, I did not want him to be told about his status the way the nurse did at the clinic, I was waiting for the right time and still contemplating on how this could be said.

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

Tshepo: Sad, I did not want any one telling me this - I have seen how both my parents suffered before they died. I knew deep down that I might be positive but I did not want anyone confirming this. My head started spinning, the nurse
kept on talking I could not hear what she was saying after she revealed my status in front of my aunt who was very quiet all this time. The nurse was the only person who seemed to be making a lot of noise, explaining things I couldn't grasp. The only thing that was on my mind was 'I am going to die.' I could not believe what I have just heard (with sadness).

What else can you tell me about that day?

Tshepo: I really do not remember what happened on the way home - my aunt never said anything the whole time. When we arrived home I went straight to my bed and slept. My grandmother waked me up during suppertime, I ate while she was asking me how I was and wanted to clean and dress the wound.

Were you counselled before you were tested?

Tshepo: I do not remember being counselled after the nurse spoke to my aunt about my health and my family history, the nurse just told me that they are going to do a blood test because I am sick - they wanted to know what was wrong with me so that they can be able to give me the right treatment. I agreed and we went to another room where the test was done.

Did this affect you with your studies in any way?

Tshepo: Yes it did, my writing became very bad, I no longer write the way I used to, my work is sometimes incomplete, I am not playing in class like the other learners but still I do not finish my work in time, when we are writing tests I have to be given extra time.

Are you checking Tshepo's schoolbooks?

Grandmother: Yes I usually check his books - he is not doing very well. I think being absent for lengthy periods of time from school disturbs him. He had to be absent from school for two months last year and it was towards the end of the year when others were writing the end of the year examinations. I was not worried about his performance at school then but one thing that was on my mind was if he can be better (Tshepo showed the interviewer his
books, Mathematics and Human and Social Sciences, his favourite subjects. Tshepo’s books were very neatly covered yet the work in his books was untidy. There were a lot of unfinished exercises in his books, he would write a date in others, write few questions, leave a big gap, draw a line and start another exercise that is also far from being complete).

**How do you feel about your status now?**

_Tshepo:_ I do not want to think about my status, whenever I think about it I become sick, it is better for me not to think about it. I forget about it when I am playing with my friends, when it is dark and we cannot play any more I come home to do my homework. After being cleaned and dressed I eat and go to sleep. I do not have much time to think about my status.

**How often does a nurse/ doctor/ health worker visit your school to advise you on HIV/AIDS issues?**

_Tshepo:_ Once a year we are visited by either a nurse or a health worker, this happens when we are celebrating the world AIDS day usually in September. This is a very big occasion - we prepare items to render that day, and educators prepare food for the visitors and us. This occasion usually takes us the whole day. The health workers inform us about how HIV/AIDS is transmitted, how we can help take care of people with HIV/AIDS, and the importance of knowing one’s status.

**What comes to your mind when they talk about the importance of knowing your status?**

_Tshepo:_ I wish I did not know about my status, life would have been easier, I think I would not be sick when I think about HIV/AIDS. I do not think learners at my school know about their HIV status and they live care-free, they have nothing to worry about.
Have you ever been counselled by a professional counsellor or by a educator at your school?

Tshepo: There are no professional counsellors at our school and educators do not have time to counsel us - they are teaching or always busy with their work.

Do you think being counselled can help you in understanding HIV/AIDS?

Tshepo: Maybe, I do not know much about counselling and how it can help me, what I think can help me is to know and talk to other learners that are HIV positive and maybe they can tell me how they live with the virus.

Do you still have dreams about your future Tshepo?

Tshepo: Yes I would like to be a doctor one day and help other people who are sick.

How do you make up for the time you have lost because of sickness?

Tshepo: There are a few friends whom I suspect they know that I am HIV positive. I have never told any of my friends about my status. I suspect that their parents, who live in the same street, told my friends. There is a very special friend who makes it a point to tell me everything that was done at school in my absence.

Grandmother: Tshepo's friends are very helpful. There is one day that my daughter (Tshepo's aunt) will never forget; the friend came and helped Tshepo until 22h00 in the evening. Tshepo's friend would give him time to relax as he would be tired after every question they finished answering. His aunt accompanied him home at night after they finished doing the schoolwork.

How is your relationship with Tshepo?

Tshepo's aunt: We have a very good relationship - he is free to come to me and talk about anything, but we never talk about his status or HIV/AIDS. I want to take care of Tshepo due to the fact that his mother loved me very much. I will never forget the fact that my sister took care of me after the birth
of my first child. She left her husband and decided to stay with us for a month just to take care of me and help me with the newly born baby. I help my mother (Tshepo’s grandmother) in taking care of my nephew, but I do not wash and dress him. I go to school to report if he is sick. I attend parents’ meetings on my mother’s behalf. I go and collect food parcels from the social workers if the principal of the school gives us a letter to take to the social workers. I always check his books in the evening and help him with his homework.

What do you think can be done to make Tshepo comfortable at home?

Aunt: I am not sure but one thing I am sure of, is the ill-treatment we get from my stepfather (Tshepo’s step grandfather) also affects him and is detrimental to his health. My stepfather is working, but hardly gives us money for groceries or for anything for that matter. He does not have children with my mother. He is not a friendly person. He is always angry and grumpy. He likes reprimanding us for things we did not do. Sometimes it becomes very difficult to live under the same roof with him. Most of the time when my stepfather is around all my nephews, my two children and myself prefer to sit in the two-roomed shack that is also our bedroom. This is very difficult for all of us, as we cannot even watch TV, which is in the lounge in the main house. The only time we enter the house on weekends is when we are fetching our food or when my stepfather is not around.

How do you get food now that your husband is not supportive?

Grandmother: I get a social grant from the welfare for all three of my grandchildren. There is no other source of income, as I do not qualify for the old-age grant, because that my husband is working. The grants for all three children have stopped, it has been two months now; this is due to the fact that I did not renew it earlier. For the whole of January 2005, we have been living on a food parcel we received from the social workers. This was organised by the school principal, who wrote a letter to the social workers, explaining the family’s plight. Tshepo’s aunt is also receiving a child’s grant for her two children. This money is too little to feed the whole family, she has to take care
of her own children buying them school uniforms and paying for their school-fees. (It is during this time that the interviewer met the family through a social worker who is working with abandoned street kids and those who are infected).

**How does the school support you?**

**Grandmother:** The principal of the school where Tshepo attends helps me with the washing and dressing of the wound sometimes. She also organises platex gloves for me to use when I am washing and dressing the boy. When the boy is sick, but is able to go to school, the principal fetches Tshepo and drives him back home after school. Sometimes when Tshepo becomes too weak at school, the principal brings him home before school is out or takes him to the nearest hospital. There are many other learners who are HIV positive within the school - this was revealed to us by the school principal in a parents' meeting. She was trying to encourage parents to come forward and tell her or the educator in charge about their children’s status in order for the school to help in whatever way. This information has helped Tshepo in accepting his status and also gave him strength to go to school everyday without fear of being discriminated against. The principal did not give us names of learners who are HIV positive - I think that is good because I do not want other people to know that my grandson is positive. I have a good relationship with my neighbours - I do not want it to be ruined by anything.

**Do you think infected learners are supported at school?**

**Grandmother:** There is a feeding scheme programme at school for all those children who are underprivileged. The principal allows all those who are on a feeding scheme programme to go to the staff-room (this is where the kitchen is) whenever they feel hungry. This is due to the fact that some of them are taking medication that makes them always hungry. Other learners are exempted from paying school fees, but I was surprised to receive a letter from the school reminding me of the outstanding fees. I am thinking of sending Tshepo’s aunt to go to talk to the principal so that Tshepo can be exempted from paying school fees.
Who else supports you as a family?

**Grandmother:** The social worker visits sometimes to 'check if everything is OK.' He has been of great help and it is easy to talk to him. I feel free to talk to him about anything. He has helped us a lot about the applications for grants and for giving us advice on what should be done when Tshepo is ill.

How did the principal get the information about Tshepo's status?

**Grandmother:** One of his friends made the principal aware that Tshepo was ill. He and the other boys went to the principal's office and told her that Tshepo was ill and that he has been like this for days, they even told the principal that Tshepo does not play - he is no longer the same person they know, he is always quiet, does not laugh even when they are passing jokes and that he becomes tired very easily. The principal requested me to come to school to discuss Tshepo's health - it was that time that I told him about Tshepo's status.

Do you ever talk about your status with your principal or one of the educators?

**Tshepo:** No we never talk about my status - no one has ever asked me about my status or talked about my being infected.

Would you like to discuss your positive status with either of them?

**Tshepo:** No I do not want to talk about my positive status I do not want people to know that I am HIV positive.

At the time of the third visit, Tshepo told the interviewer that he feels like he has control of his life, although he sometimes worried about his health. He does not blame himself for being ill, but is confused as to why he is the only one in the family who is living with HIV/AIDS. He does not understand why his brothers are negative whilst he is positive. He feels frustrated when he cannot go to school because of ill health.
5.2.1.5 Researcher's impressions of Tshepo based on her observations

Tshepo appeared to be in pain, his lymph glands were swollen in both armpits and neck. He looked undernourished although he was wearing neat and tidy but torn clothes. He is thin and shorter than children his age. He forced a smile sometimes when the researcher tried to crack a joke to clear the air, but he couldn't hide the sadness and pain in his life. It was the researcher's impression that Tshepo has not been given the opportunity to deal with the loss of both his parents and the fact that he himself is infected.

5.2.1.6 Analysis and interpretation of Tshepo’s case

Tshepo's experiences of living with HIV/AIDS will be analysed below. The analysis is divided into themes and will be discussed in terms of:

- how he feels about being infected;
• how his psychological and physical well being is because of being infected;

• his general functioning at school; and

• the nature and extent of social support he gets from his family, school, community and society.

The themes are not mutually exclusive and readers might find an overlapping of themes.

(a) How Tshepo feels about being infected

Each section has an analysis and interpretation. Where appropriate, statements will be illustrated by excerpts from the interview.

Analysis

It seems as if Tshepo has not come to terms with the fact that he is HIV positive. He is still in a stage where he is angry and frustrated. He wishes things could be normal - he refers to not knowing about his status as easier life and to knowing his positive status to difficult life. He said:

'I wish I did not know about my status, life would have been easier, I think I would not be ill when I think about HIV/AIDS.'

When Tshepo's status was revealed to him, he remembered feeling as though his life had come to an end. The only thing that came to his mind when his HIV positive status was revealed, was that he was going to die. He did not listen to other things that were said by the nurse, as the only thing that was in his mind was the fear of death. When asked about how he felt after the diagnosis he said:

'The only thing that was on my mind was that I am going to die.'

Tshepo felt a great sense of disbelief. Although Tshepo knew that both his parents died of HIV/AIDS, he did not believe that he could be HIV positive and his words were:
'I could not believe what I have just heard (with sadness).'

Tshepo's way of dealing with his positive status is by trying to forget that he is HIV positive, by focusing on playing and later on in the day on doing his homework. He makes sure he is always occupied so as not even think about his status. He said:

'I forget about it when I am playing with my friends. When it is dark and we cannot play any more I come home to do my homework and after being cleaned and dressed, I eat and go to sleep. I do not have much time to think about my status.'

Interpretation

It seems that Tshepo's knowledge about his HIV/AIDS positive status has become a burden he carries wherever he goes. He cannot separate himself from the virus. He appears to have an unrealistic perception that not knowing helps, as one does not have anything to worry about and that life would be easier. By wishing to stay ignorant about his status, instead of realizing that it is quite normal to feel that way, seems to heighten the anxiety. Just talking about his experiencing of HIV appeared to evoke the same emotional stress that Tshepo had when the HIV test results were revealed to him. Knowing one's status is the most important thing in one's life as those who are tested HIV negative could choose to stay so and those who are HIV positive can learn ways of looking after themselves (see 3.4.1). Tshepo's reaction is perhaps, an indication of his unresolved feelings in this regard.

It seems that being unemotionally prepared for positive HIV results, made Tshepo to think that being diagnosed with HIV/AIDS meant death. Tshepo, like most People Living With AIDS (PLWA) typically experiences the knowledge of impending death accompanying diagnosis of HIV/AIDS, as inconceivable. This is in line with the literature finding that for those who cannot find meaning and cannot find acceptance, suicide becomes an alternative (see 3.2.3.1). Concurringly, research suggests that individuals with HIV/AIDS are at an increased risk of suicide than comparable individuals without infection (see 3.2.3.1). From Tshepo's responses it can be deduced
that while for some individuals infected with HIV/AIDS, suicide represents their wish to die, for others, it emanates from pain and discomfort and may abate if the stressors were removed. For others, it reflects a need to re-establish mastery over the illness that has robbed their independence and dignity (see 2.3.2.3). It seems that the death sentence of being diagnosed HIV/AIDS positive may create space and opportunity for some individuals to redefine and commit to living life more fully.

Tshepo seems to have been in a state of shock when his positive HIV status was disclosed to him - his mind could not assimilate the positive results he had just heard. In terms of the experiences of shock and denial, the literature similarly reflects that the typical initial response to the news of infection may be of temporary shock, numbness and denial (see 3.2.3.1).

In a search for balance and normality within the abnormality of life with HIV, Tshepo seems to be engaged in an adaptive process, which attempts to integrate his life changing events into his everyday way of being.

Tshepo seems to be having feelings of loss of identity. The degree to which identity is disturbed appears to depend on the degree of lost aspects of self, the importance of these lost aspects and the possibility of regaining a sense of wholeness. This in the case of Tshepo can call for identity reconstitution, which could be an attempt to regain this wholeness. To proceed towards reintegration, there must be at every step a corresponding letting go, grieving for what has been lost, and closure. Meanwhile, the person is always moving toward a new self, a better self, even a transcendent self. The reintegration involves defining and redefining identity, refocusing direction and integrating identity. Each step hopes to hold onto significant parts of the self, at the same time focusing on and discovering new aspects of self. Literature indicates that in order to regain the sense of wholeness, a person must first be able to identify that a state of disequilibrium has been reached (see 2.4.3)

(b) Tshepo's psychological and physical well being

This aspect involves analysis and interpretation, as well.
Analysis

Tshepo’s sense of personal security appears ruptured and vulnerable, he also appears destitute. To him, what constitutes family, is having both his father and his mother as he used to. The death of both his parents left him vulnerable to stigma and poverty. When asked about who advised him to go and stay with his grandmother and his step grandfather he said:

‘There was no one to take care of me where I lived with my father.’

Tshepo appears helpless in the situation he finds himself in. There were not many options at his disposal - he appeared not to be sure whether he wanted to stay with his grandparents or rather with other people, he appeared not thrilled though to come and stay where he was. He found himself helpless to change the situation, and therefore experienced a sense of hopelessness and his answer was:

‘I was used to visiting my grandmother and my mother whenever I felt like when my father was still alive, so it was the only thing to do.’

Tshepo does not remember being counseled before he was tested. After the results from the test, the nurse revealed his status to him in the most insensitive manner, according to his grandmother. Tshepo’s grandmother was still angry and frustrated by the way the nurse handled Tshepo’s situation. Tshepo’s grandmother said about the incident:

‘After being tested, the nurse in charge said to him, you have AIDS and you are going to die like your parents.’

Tshepo appears to be traumatized by the death of both his parents. His fears are based on his experience of HIV/AIDS, the suffering, which may include pain and dying. He is affected by the death of both his parents, of which he witnessed their pain and the different stages they went through and he answered:

‘I have seen how both my parents suffered before they died. I knew deep down that I might be positive but I did not want anyone confirming this.’
Tshepo appears not to be aware of the fact that he will never be as healthy as the other learners who are not infected. Someone with HIV/AIDS can experience periods of illness as well as periods of well being over a long time. This affects his life as he would like to go out and play like all the other children. It is as if the TB treatment is going to solve all his health problems, he told the researcher proudly because he was in his fifth month of treatment and his words were:

'It was discovered that I had TB. I am still on TB treatment - at the hospital they told me to take the treatment for six months and this is my fifth month.'

Being infected with HIV/AIDS overwhelms Tshepo - the mere thought of it depresses him. He tries unsuccessfully not to think about his status. When Tshepo is asked about the way he copes with being infected and he said:

'I do not want to think about my status, whenever I think about it, I become sick, it is better for me not to think about it.'

The fact that Tshepo is ill most of the time affects his physical well being. Even his friends have noticed the change in his life. They said about him:

'Tshepo does not play - he is no longer the same person we know, he is always quiet, does not laugh even when we are passing jokes and he becomes tired very easily.'

**Interpretation**

Tshepo seems to be struggling to come to terms with the fact that he is HIV positive. This can be attributed to a lot of factors including lack of counselling before and after being tested, the fact that no one ever speaks to him about the virus or about him being infected, not knowing other learners or having spoken to other learners who are also infected (see 1.2). He seems to be in denial, which makes it difficult for him to deal with his emotions of being infected. He appears to be traumatized - the only thing that comes to his mind when HIV is mentioned is death, and this is because he saw both his parents
dying of AIDS. He seems not understand the stages of HIV/AIDS in a human body - he is not emotionally prepared for the times of sickness and changes in his body, because of the effect of the virus to his immune system (see 1.2).

Tshepo had to take a decision to stay with his grandparents although this appeared to be the most difficult decision to take. His idea of a family having been composed of his mother and a father had to change as he had to be taken care of by grandparents because of his age. This can mean that Tshepo's convention had been challenged and this has forced him to face things head on (see 5.2.1.6b).

It appears that the kinds of situations, which Tshepo finds himself in, can, occasionally, erode his sense of control and confidence as a learner. The researcher believes that Tshepo will perhaps need to acknowledge this paradox and recognize what options are open to him to help. At the same time he will have to acknowledge that certain factors cannot be changed. These are boundaries that will need to be clear to him in order to manage his feelings of uncertainty and helplessness (see 3.2.3.2).

It seems that being tested without having been counselled, can have devastating results on the health of the infected (see 5.2.1.6b). It appears that Tshepo could live his life with fear of death as the first thing that was said to him after being tested was that he was going to die. That coming from a health worker, could prevent him paying attention to anything positive that can be said about living with the HIV.

Tshepo's experience of having 'lived' with his parents who both died of HIV/AIDS seems not to have made him stronger than those who did not go through this experience. Instead his experiencing of his parents' suffering, appeared to have introduced feelings of shock, denial, anger, fear, depression and unfortunately it seems that Tshepo has not yet reached the stage of acceptance of his HIV positive status. The death of both Tshepo's parents because of HIV/AIDS seems to have left him vulnerable, destitute and insecure. He finds himself in a situation where he is both helpless and hopeless (see 1.2).
It seems that Tshepo will have to understand that he is going to experience periods of sickness as well as health. He will have to be informed about what to do in times of sickness. It seems that it is this lack of knowledge and understanding and the emotional ‘seesaw’ of getting sick and hoping for recovery and only to fall sick again, that causes infected people resort to suicide. While the importance of medication is not covered in the literature review, it seemed to yield an important finding, suggesting that medication has a major role to play in the physical and psychological well being of the infected (see 3.2.3.1).

It appears that if an individual has had adequate time working through the different stages, he/she will reach a stage of acceptance. He/she will have mourned the imminent losses of meaningful people and places and will regard his/her impending end with a degree of quiet expectation. This is not the case with Tshepo - his way of dealing with the situation is to suppress it in his mind.

Although Tshepo has not yet reached the final stages of the disease (full blown AIDS) there appears to be physical changes in his body. It is believed that when a person's pattern of thought or behaviour is unexpectedly disrupted he/she employs a problem solving strategy to reinstat and maintain balance (see 3.3.2). Tshepo's strategy appears to be that of withdrawal.

(c) Tshepo's general functioning at school

Analysis

Tshepo's work deteriorated ever since he was diagnosed HIV positive, he mentions the state of his writing, which the researcher agrees with. He is becoming slower in doing his work. Besides being slow, Tshepo's work is not orderly - he would start writing something, leave it, start another subject's work on the same page and does not complete anything. He comments that:

'Yes it did, my writing became very bad, I no longer write the way I used to, my work is sometimes incomplete. I am not playing around in class like other learners, but still I do not finish my work in time. When we are writing tests, I have to be given extra time.'
Being absent whenever he is ill, hinders Tshepo's progress at school. Sometimes it takes more than a month sometimes for his health to improve. He misses most things taught at school, whilst he is ill. His grandmother is aware of the fact that absenteeism is a contributory factor in Tshepo's performance at school. Asked about Tshepo's functioning, he said:

'I think he is disturbed by being absent for periods of time from school. He had to be absent from school for two months last year and it was towards the end of the year, when others were writing the end of the year exams.'

Tshepo's grandmother is not working and his step grandfather who is the sole breadwinner in the house does not provide food. They all depend on Tshepo and his half brother's grants. Sometimes it takes a long time for them to get a grant, if they did not renew it before the expiry date. During those times it is difficult to get food. For Tshepo, this is even worse as he is not supposed to take his treatment on an empty stomach, and the fact that he has to go to school without having eaten. His grandmother commented as follows:

'I am not complaining, but sometimes we do not have food and it is not right for him to drink his tablets on an empty stomach.'

**Interpretation**

It appears that Tshepo's positive status affected his performance at school. He seems to be slow in performing his tasks.

The high rate of absenteeism and lack of support from the educators in helping the child catch up lost work after he/she has recovered, seem to have negative effects on Tshepo's general functioning at school (see 1.2).

It appears that lack of food can contribute to poor attendance as Tshepo sometimes opts to stay home rather than go to school on an empty stomach. Research has proved that learners who go to school without food, lack concentration, they cannot participate in activities both in class and in extra-curricular activities. The situation becomes even worse to those on medication
who have to eat before they take their medication (see 3.2.3). Tshepo's school has a nutritional programme, but it seems Tshepo's grandmother does not want to rely on it. This may be due to the fact that the supply of food to schools is not regular, children go without it for sometime.

It seems that Tshepo is overwhelmed by being HIV infected and experiences periods of depression. This seems to affect his general functioning at school as his standard of work appears to be poor because of lack of concentration, high rate of absenteeism due to ill health, and being slow in completing tasks as the virus has affected him psychologically and physically. It can be deduced that cognitive disorders secondary to HIV infection may predominantly affect people's capacity to take initiative, to translate this initiative into appropriate actions and to adequately judge the consequences of their actions or lack of actions (see 3.3.5). This means that learners infected with HIV/AIDS may present themselves as competent, but are not. It appears as if other factors that contribute to Tshepo's failure to progress well at school are the relationships he has with other members of the family - for example, his step-grandfather and poverty.

(d) The nature and extent of support that Tshepo gets

Analysis

Tshepo's friends are very helpful. One of them visits Tshepo when he is sick and informs him about everything they did at school. This special friend also helps him with homework when he is sick. Tshepo said about his support:

'There is a very special friend who makes it a point that he tells me everything that was done at school in my absence.'

The social worker is also very helpful in giving advice on what should be done concerning Tshepo's health and also assists with applications for grants. Tshepo's grandmother is happy about the support they get from him. He said about the social worker:
'The social worker visits sometimes to check if everything is OK. He has been of great help and it is easy to talk to him. I feel free to talk to him about anything. He has helped us a lot with the applications for grants and for giving us advice on what should be done when Tshepo is sick.'

Health workers visit Tshepo's school once a year when the school is celebrating the World AIDS day. They then have the opportunity to listen to a nurse or a doctor talking about HIV/AIDS. There appears to be no time for discussions and questions concerning HIV/AIDS issues, as there are a lot of other activities that are scheduled for that day. Tshepo said about the event:

'Once a year we are visited by either a nurse or a health worker - this happens when we are celebrating the world AIDS day, usually in September. The health workers inform us about how HIV/AIDS is transmitted, how we can help take care of people with HIV/AIDS, and the importance of knowing one's status.'

Tshepo's step-grandfather is not supportive of Tshepo's positive status - he does not support the family in any way. His stepchild and all his step grandchildren fear him. Tshepo's aunt complains of the ill treatment they all get from her stepfather. She said about him:

'He is not a friendly person. He is always angry and grumpy. He likes reprimanding us for things we did not do. Sometimes it becomes very difficult to live under the same roof with him.'

Tshepo has never spoken to anyone about his being positive, he said when asked whether they discuss his health with his principal at school:

'No we never talk about my status - no one has ever asked me about my status or talked about my being infected.'

When Tshepo's aunt was asked about her relationship with Tshepo, she said:

'We have a very good relationship - he is free to come to me and talk about anything, but we never talk about his status or HIV/AIDS.'
Tshepo’s grandmother helps Tshepo with many things. She washes and dresses his wound daily, she provides food for him, she takes care of him when he is sick, she is just like a mother to him. Tshepo’s grandmother is happy that the principal did not give them names of other learners who are HIV positive within the school. She prefers to keep Tshepo’s positive status a secret. She is scared of the fact that this would ruin her relationship with her neighbours. She said:

"The principal did not give us names of learners that are HIV positive - I think that was good because I do not want other people to know that my grandson is positive. I have a good relationship with my neighbours - I do not want it to be ruined by anything."

The school principal helps Tshepo’s grandmother with the cleaning and dressing of the wound sometimes, she writes letters to social workers to ask for food for the family when the grants have stopped, she fetches and takes Tshepo back home when he is sick, she takes him to hospital when he becomes sick at school, she also organizes platex gloves for Tshepo’s grandmother and makes sure that learners received food from the school feeding programme whenever they need it. Tshepo relates the following:

"The principal allows all those that are on feeding scheme programme to go to the staff-room (this is where the kitchen is) whenever they feel hungry - this is due to the fact that some of them are taking medication that makes them always hungry."

**Interpretation**

Tshepo seems to enjoy the support he gets from his best friend - getting information on what is happening in the school during the periods of sickness gives Tshepo hope of joining his friends again. This is in line with the literature that social support is an important element in intercepting the stress experienced by HIV/AIDS positive individuals. The stress-buffering hypothesis of social support suggests that social support acts as protective mechanism in the face of the stressful situations that HIV/AIDS individuals experience. It is thought to operate 'both by contributing to the resources available to
individuals to cope with the stressor, as well as by reducing the stress response to the stressor'. The mere perception of availability of adequate support buffers situational stress as much as actual support.

The support that Tshepo and his family get from the social worker appears to be important to Tshepo. Having a health worker coming to visit seems to be very helpful as Tshepo's grandmother could ask him/her anything on the aspects she is uncertain of.

It seems that the information that Tshepo gets from school during HIV/AIDS days is valuable although there is no time for questions. For PLWA information about the stages of HIV/AIDS, treatment for opportunistic diseases becomes imperative as patients should know what to do and what not to do (see 3.2.3.1).

It appears that other than his positive HIV status Tshepo also has to deal with his step grandfather. It seems that Tshepo is not spared other problems he has to face because of his positive status, instead, in addition to living with the HIV virus, he has to live life like all the others with all its problems and obstacles (see 5.2.1.6d).

It seems that keeping silent about one's HIV positive status is regarded by Tshepo as something that is meant to be. Because he has never been asked about his status by anyone, he seems not to see any need to tell people about his status. This could be attributed to feelings of embarrassment, shame, and fear of judgment that PLWA have. Where there is silence about a person's positive status, there is no hope of him/her being supported (see 3.4.1).

The support Tshepo gets from his aunt seems to benefit his emotional well being, but not being able to talk about HIV/AIDS seems not to be good for Tshepo. He needs someone to talk to, someone who can understand (see 1.2).

It appears that Tshepo's grandmother is reluctant to disclose Tshepo's status, and does not want neighbours to know about his positive status as she thinks that this will affected their relationship. Instead of thinking that her neighbours
can help by means of giving the family support, she seems to anticipate the opposite. This could also be an indication of fear of being stigmatised (see 3.4.1)

Tshepo seems not to have received proper counselling which could have prepared him emotionally for the positive test results. It is the researcher’s opinion that Tshepo’s case illustrates a point of controversy in working with infected learners, namely, how does one help without doing more harm? The literature cautions that aggressive and insensitive treatments and evaluations can exacerbate patient’s symptoms and contribute to severe complications. Nonetheless, it is important to acknowledge that there may be times when proactive intervention is in the best interest of the patient (see 3.2.3.2). The support he gets from his grandmother, his aunt and the school principal, seems to give him comfort, but he does not talk about his fears and his feelings as there is no one around him who seems to be prepared to talk about HIV/AIDS. Tshepo’s survival can depend on the support he gets from his family members and other people in his immediate environment. It is worrying that the culture of silence about HIV/AIDS still prevails, as this adversely affect learners who desperately need the information for their survival.

5.3 INDIVIDUAL ANALYSIS AND INTERPRETATION OF NTSWAKI’S EXPERIENCES

This second individual analysis centres around Ntswaki’s case, her family background, the proceedings of the interview between Ntswaki and the researcher and the researcher’s impressions of her based on her observations.

5.3.1 Case study 2: Ntswaki’s case

This case presents a situation of a child who was infected with HIV through being sexually abused, which in this research is referred to as sexual transmission.
The brief introduction of Ntswaki's family background and the general impression that the researcher gained of this 12-year-old girl are given. The whole verbatim transcription of the interview that the researcher conducted with Ntswaki follows.

5.3.1.1 **Introduction**

The interviewer had two interviews with Ntswaki (not her real name). One of these interviews was conducted at her home and the next one in a Place of Safety. Each session lasted about two hours.

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

5.3.1.2 **Family background**

Ntswaki is a twelve-year-old grade seven learner who was born on 13\textsuperscript{th} June 1992. She is the first-born in the family of three; the other two siblings are six years old and one year old respectively. She lives with a foster parent in a Place of Safety. Her own home is not very far from where she has been placed. Her father, mother and the other two siblings live in his biological father's house.

Ntswaki's father did not father the second born child. Her mother gave birth to Ntswaki's younger sister when her husband was in jail. When Ntswaki's father was in jail Ntswaki and her mother moved out of the house to stay with Ntswaki's stepfather. Ntswaki's father was jailed for seven years. After he was released Ntswaki, her younger sister and her mother moved back to her father's house. Ntswaki's mother had her third-born after her husband came back from jail.
Ntswaki’s grandmother stays in another location with Ntswaki’s uncle (her father’s younger brother). Ntswaki’s mother, father and both her siblings are HIV positive.

What follows is a word-for-word transcription of the actual conversation that took place between the interviewer and Ntswaki.

5.3.1.3  Transcription of interview with Ntswaki

How old were you when you started being abused?

Ntswaki: I was seven years old, doing Grade two, when my father was still in jail.

Who abused you?

Ntswaki: I visited my grandmother in another location. My grandmother stays with my uncle (my father’s younger brother) and his wife. My uncle and my aunt do not have children. The day the abuse started, my uncle and my aunt had a fight - my uncle beat my aunt up and my aunt left the house. He raped me, and I could not tell anyone, I was scared of my grandmother; she is not a nice person, especially when she is drunk. Almost everybody in the area where my uncle lives, is scared of him - he told me that if I told anyone, he would kill me. Each time he would start a fight with my aunt and chase her away, and he would rape me. This happened for years, as I would visit them almost every holiday. I was afraid to tell my mother what was happening, or why I did not want to visit my grandmother.

When did this usually happen?

Ntswaki: Yes, most of the time, when I visited them as already said previously up until December 2003, my uncle decided to come to my home. There was no one except me, he sent me to buy a cigarette at the spaza shop, followed me to the spaza shop and told me that he is going to wait for me at the bus stop. I followed him. When I was about to cross the road he stopped a taxi and dragged me inside the taxi. He told the driver to stop at an open veld. He raped me there and gave me money to take a taxi back home.
Did you tell anyone?

Ntswaki: Yes, this time I could not take no more, I was also afraid of what my mother would say when she saw me after I was raped. I decided to tell my neighbours when I arrived home. As my mother was not at home they took me to the hospital, and the doctor who attended me called the police. I had to give a statement of what happened.

How many times did this happen to you?

Ntswaki: I cannot tell, it happened many times. Each time I visited my granny, it would happen two or three times.

How do you feel about the sexual abuse?

Ntswaki: I cannot describe how I felt when I was young, I wanted to be alone most of the time, I did not like playing with other children. I do not know what the reason was, but I couldn’t just go to other children and join them in their play, I couldn’t go even if they invite me to. Now I go out a lot. I am always out of the house with friends. I have managed to make a lot of friends, although we no longer play - we hang out a lot. I usually go home around eight or nine in the evening.

When you were playing alone were you thinking of the abuse?

Ntswaki: No, I never thought about the way I feel about the abuse. Even now I do not think about it, I think I have forgotten about it. One thing I sometimes think about is my positive HIV status.

What comes into your mind when sexual abuse is mentioned?

Ntswaki: Nothing. There is absolutely nothing in my mind concerning the abuse. I think that part of my life is gone and forgotten.

Where was your granny when it happened?

Ntswaki: Sometimes she was asleep, especially during weekends she would be drunk. During the day my uncle would tell me to come to their shack. All
these rapes would happen after a fight with my aunt. My granny knew about this and when she was drunk, she would tell me that I was going to get pregnant at a very early age, and that I should not go around spreading lies about her son.

**What were you given at the hospital?**

Ntswaki: I was given a lot of tablets that I am still using. I go for treatment at the hospital after every three months.

**What happened to your uncle?**

Ntswaki: He was caught, but he is out on bail, his wife bailed him out. A few days after my uncle came out of jail, my aunt died.

**Are you not afraid that he is going to come to your home again?**

Ntswaki: I told the social worker that I am living in fear, that he can come any time and kill me as he said, that is why they decided to take me to a Place of Safety until after the court proceedings.

**Do you know what your aunt was suffering from?**

Ntswaki: Yes, during the time when the family was busy with funeral arrangements, my granny told people that she had AIDS. I could believe her because pieces of flesh were falling off my aunt's body a few days just before she died. She was very ill.

**How did you feel when you were told about your positive HIV results?**

Ntswaki: I felt very bad, angry and confused. I cried, I thought of my aunt's body a few days before she died. I never thought I would have HIV, I thought that the worst thing that would happen to me was to get pregnant as my granny said. It was a shock, I have seen a lot of other people in our area who have AIDS, they don't look good.
Who did you tell about your status?

**Ntswaki:** I have not told anyone, but my mother told my class educator. My class educator was very concerned, she was always complaining about my poor work and the dropping standard of my performance. The social worker, the health worker and the foster parent also know, they were all told by my mother.

Why have you not told anyone, especially your friends?

**Ntswaki:** I do not want to do that, I do not know what they will think, they may reject me and I will end up having no one to talk to.

How does being infected affect your school work?

**Ntswaki:** I do not care about school, maybe, that is why I do not get good marks. Before I discovered that I am HIV positive, it was better, because I could concentrate on my work. Now, I really do not see any point why should I study. Why should I continue schooling for that matter? I am HIV positive and I am going to die. In class I only think of what is going to happen to me, I believe not even one of my classmates suffer the same affliction as I do. They all have a reason to joke and laugh about everything, prepare for tests and plan for the future, I don't!

Is it only lack of concentration that disturbs you in doing your work?

**Ntswaki:** Sometimes I am ill and the other days I do not go to school because of the discharge. They complain that I smell and I understand it is a very bad smell that I cannot do anything about. I tried washing my body three times a day but that does not help, so on the days when I am having a heavy discharge, which most of the time causes a musty, stale odor then I do not go to school. Then there are days when I bunk school because I just do not feel like going to school.
What are you using for discharge and herpes?

Ntswaki: I have been given tablets at the hospital, but I do not use them always. I prefer African potato.

Does it make you better?

Ntswaki: Sometimes, I am tired of using pills ever since I was tested, I wish there was something else to use besides pills.

How does the school support you?

Ntswaki: I am part of the school nutrition programme, sometimes the principal gives me money to fetch treatment from the hospital. My class educator counselled me the last time I was raped.

Who supports you most?

Ntswaki: At the moment it is the social worker and my uncle (my mother’s brother). My educator also supports me. She is concerned. She always asks me if there is anything she can help me with. My mother never says anything about the whole situation. To her I am responsible for the abuse and for dividing the family.

Who loves you most in the family?

Ntswaki: I do not think they love me. It is my uncle (my mother’s younger brother) who cares for me. My mother does not love me. If she did she would not be blaming me. I also think my father does not love me - he always asks when I am going to die so that they can have meat at my funeral. My grandmother (father’s mother) hates me, she knew about this all along. I was too young to tell people about what was happening. She didn’t talk to her son to stop what he was doing. She is blaming me for reporting this to the police - she says I am going to die first and her son is going to come out of jail free of charge.
Have you ever spoken to your mother or your father about your status or sexual abuse?

**Ntswaki:** We never sit down at my home and talk about things. My HIV status is only mentioned when I have done something wrong, like not cleaning the house. My father would say that I must get sick and die he wants to eat meat. My mother seldom talks about my life in general, we only talk about what I should prepare for supper, which rooms to clean after school and when she is asking me to baby sit for her while she is out of the house. I have sensed that she is blaming me for everything that has happened in my life. I overhead my mother asking my grandmother why I did not tell her about the sexual abuse if I was not enjoying it.

**Were you ever counselled?**

**Ntswaki:** Yes, by my educator after I was raped, the social worker also counselled me once.

**How often does your educator counsel you?**

**Ntswaki:** We spoke about this once, immediately after my mother told her about my being raped. She does not have time to talk to me for a long time - sometimes she just asks me if I had eaten.

**How is life in this new home?**

**Ntswaki:** Things are different here, mama (as she prefers to be called) is a housewife, they have three children, one of them is married and the other two are still attending school at one of the high schools in the area. The father of the house is working - he does everything for his children, buying them clothes, food and even brings them chips and sweets in the evening when he comes back from work. I have never been in that situation. My father has been in jail most of the time. Now that he is out of jail, he is not working. Even before he went to jail, he had never worked. Mama always tells me she loves me she would like to take care of me - no-one ever told me that and I do not know whether to believe her or not. Sometimes mama gives me money to buy
sweets at school, I also eat when I return from school. I am not used to that. All in all, there are a lot of changes, including the fact that I have to be at home before 18h00.

**What dreams do you have for the future?**

**Ntswaki:** I do not have dreams, even if I can have dreams I will never accomplish them. I am going to be sick and die. I do not see any point of having dreams— if you are HIV positive, you can die any time.

**What if you live for another 10 to 15 years?**

**Ntswaki:** I do not think I can live that long, my grandmother says I am going to die soon. I will see then what I will do, for now, I just do not care.

**When last did you become sick?**

**Ntswaki:** I developed a rash in December, after some time it developed into sores, it covered my whole body, I had to go to the clinic to get an ointment to get better, I could not go to school for the whole week. I always have abdominal pains, herpes and a lot of discharge.

**What do you think can make you live longer?**

**Ntswaki:** Taking medication, living healthy, and exercising, I have been told. Not sleeping around with boys would also help.

**Do you believe that if you can follow this advice you can live a healthy, longer life?**

**Ntswaki:** No, they just say that to motivate you to take medication and exercise. If one has AIDS you are going to die eventually, whether you have taken medication or not.

**If you have a boyfriend would you tell him about your positive status?**

**Ntswaki:** No, not at all, firstly what would this boyfriend think, I think if I tell him, I will definitely lose him, besides I would ensure that we are both positive.
What do you mean by ensuring that you are both positive?

Ntswaki: By not telling the boyfriend about my status and making sure we never use a condom. As far as I know I am the only girl my age who is HIV positive in the area I live in. Going about telling people about my status is definitely going to cause problems for me. If I tell the first boyfriend that comes along he will tell other boys and they will never come to me, I will end up having no boyfriend. If I tell my boyfriend to use a condom, he would be suspicious and I would end up telling him the truth. No one will ever know that I am positive, except for those who already know.

5.3.1.4 Researcher's impression of Ntswaki based on her observations
The researcher accidentally met Ntswaki at a street corner. She was expecting her to be home as it was 7h00 in the morning and the researcher had made an appointment a day before to see her. When the researcher asked her what she was doing at the street corner so early in the morning, she just smiled and said nothing. Ntswaki was wearing a very short and tight skirt - one could wonder how she was able to walk in such a tight skirt. She was clean wearing only a little bit of lipstick and makeup. She looked older and more mature than children her own age. The researcher could not believe she was twelve, she looked as if she was sixteen.

5.3.1.5 Analysis and interpretation of Ntswaki's case

Ntswaki's experiences will be analysed below. The analysis is divided into themes and will be discussed in terms of:

- how she feels about being infected;
- how her psychological and physical well being is because of being infected;
- her general function at school; and
- the nature and extent of support she gets.

The themes are not mutually exclusive and readers might find an overlapping of themes.

(a) The way Ntswaki feels about being infected

Each section has an analysis and an interpretation. Where appropriate, statements will be illustrated by excerpts from the interview.

Analysis

Sexual abuse is traumatic for the child victim. It appears that Ntswaki's uncle as the abuser took advantage of Ntswaki's innocence, trust or affection. Ntswaki was sexually abused several times for more than five years before
she had the nerve to tell the neighbours. This is what she said, when she was asked how many times she was sexually abused:

'I cannot tell - it happened many times - that is each time I visited my granny. It would happen two or three times.'

Ntswaki is not able to express her feelings concerning the abuse and this is what she said about the way she feels:

'No, I never thought about how I feel about the abuse - even now I do not think about it - I think I have forgotten about it.'

Ntswaki felt awful about being diagnosed HIV positive. She appears angry and confused. Ntswaki could not believe that she was HIV positive - the news came as a shock to her because she has been told many times that she was going to be pregnant. She appears to be sad. She experiences the fear that has been dominating her life in the past seven years, but this time it is fear of death and said:

'I felt very bad, angry and confused. I cried, I thought of my aunt's body a few days before she died. I never thought I would have HIV, I thought that the worst thing that would happen to me was to get pregnant as my granny said.'

Ntswaki claims never to use a condom as she wants her boyfriends to be positive like her. When asked if she would tell a boyfriend about her positive status, she said:

'No, not at all. Firstly what would this boyfriend think. I think if I can tell him, I will definitely lose him, besides, I would ensure that we are both positive.'

Ntswaki does not want to tell anyone about her positive status. She is afraid of what her friends would say, she fears rejection and discrimination. Ntswaki appears to be ashamed of her status and what people would say about her and mentions:
‘I do not want to do that, I do not know what they will think, they may reject me and I will end up having no one to talk to.’

Ntswaki appears to have no hope for the future - she appears to have stopped living and is waiting for death. She does not have any plans for the future, she does not believe in living positively. When asked about her opinion on eating healthy and taking medication, she said:

‘No, they just say that to motivate you to take medication, there is no such. If one has AIDS you are going to die eventually, whether you have taken medication or not.’

Ntswaki tends to be most upset by the medical aspect of her HIV positive status, such as going to the hospital all the time and having to take a lot of nasty-tasting medicines and pills. She says:

‘I have been given pills at the hospital, but I do not use them always. I prefer African potato.’

‘Sometimes, I am tired of using pills ever since I was tested, I wish there was something else to use besides pills.’

**Interpretation**

Ntswaki had been sexually abused several times over a period of more than five years. She became infected through being abused.

Because of the threats, fear and embarrassment, Ntswaki did not tell anyone about the abuse. Keeping the secret of abuse, seems to only have caused her more emotional stress. Her way of dealing with her ordeal seems to have been to sit and play alone, which might be a way of hiding her pain and frustration or as avoidance-oriented strategy. This could mean that Ntswaki decided to totally avoid thinking about her painful situation (see 3.4.1).

The literature study supports the finding of anger as a typical response to HIV positive diagnosis (see 3.2.3.1). Being confused could be attributed to the fact
that she was not expecting to be HIV positive because her grandmother emotionally prepared her for pregnancy.

Ntswaki's appears to be vengeful and bitter about being HIV positive. It can be noted from Ntswaki's responses that when denial can no longer be sustained, it is transposed by feelings of anger, rage and resentment. In contrast to the denial stage, the stage of anger is very difficult to cope with from the perspective of family and friends, as anger is displaced and projected onto the environment randomly. It can be learned from Ntswaki's responses that a person must let go, grieve and achieve acceptance of lost aspects of the self before s/he can move on (see 1.2).

Anger, guilt and fear seem to be common feelings for Ntswaki as she has been sexually abused for more than five years (see 3.4.1). Being diagnosed with HIV/AIDS seems to have been the last straw for Ntswaki, although she did not completely break down, she mentions feeling bad about being diagnosed HIV positive, angry and confused (see 3.4.1). She seems not have expected HIV positive diagnosis - the least she expected was to fall pregnant. She claims never to use a condom so as to infect her boyfriend/s as well. This is an indication of the extent of vengeance Ntswaki has, not only towards the perpetrator, which happens to be her uncle, but to all men.

Ntswaki seems not to want to tell anyone about her HIV positive status, she mentioned being afraid of what her friends would say, she fears rejection and discrimination. Fear of discrimination and rejection are in most cases the cause of non-disclosure. A serious outcome of social stigmatization identified in the literature study is the reluctance to disclose a positive HIV status to others. This inability to disclose the positive status can limit the resources and support that are available to Ntswaki (see 3.4.1).

Ntswaki is demoralized and demotivated, her mind is fixed on the relationship between HIV/AIDS and death. Literature supports the notion that in some way suffering ceases to be suffering at the moment when it finds meaning. Ntswaki has not yet found meaning for her suffering. Man is willing to suffer, on condition that there is a meaning in the suffering. Research done concerning
coping with chronic illness supports the idea that PLWA felt that they were more able to cope with their situation once they had discovered a sense of purpose. Ntswaki seems to be in a 'problem-oriented state' where even a few solutions she has considered are wrapped in the power of the problem orientation (see 2.5).

Ntswaki does not take her medication, which would somehow alleviate the infection causing the discharge. The literature indicates that initiating medical treatment often confronts people with a deeper acknowledgement of their HIV status. For Ntswaki taking action such as making desired life changes and exerting control over medical decisions would have helped her to maintain a sense of hope. However, adaptive behaviour (such as medication adherence) is influenced by social factors such as environmental interactions (see 2.3.2.2), self-efficacy (2.3.2.3) and self-regulatory practices (2.3.3). It is also influenced by individual factors, internal physiological and cognitive states (see 2.3.1).

(b) Ntswaki's psychological and physical well being

Analysis

Ntswaki appears to be having one thing in mind and that is that she is going to die - she does not have dreams for the future, she appears to be waiting for the time she is going to be sick and die. She no longer has a life, her life is in a standstill. The trauma in her life has been unbearable - she appears not to have any strength left to face the problems in her life. She also appears to be suicidal and claims:

'I do not have dreams, even if I can have dreams, I will never accomplish them. I am going to be sick and die, I do not see any point of having dreams - if you are HIV positive, you can die any time'

Ntswaki cannot talk to her grandmother and mother about the abuse and was left vulnerable as a result. Ntswaki was still very young when she started being abused. She said:
‘I was seven years old, in Grade two, when my father was still in jail’

Ntswaki could not disclose the sexual abuse immediately following the first incident. This is what she said about why she could not tell anyone:

‘He raped me, and I could not tell anyone, I was afraid of my grandmother - she is not a nice person, especially when she is drunk’

Ntswaki decided to tell people about the abuse after five years of living in hell and in fear. She was almost afraid of everybody, afraid of her grandmother, afraid of her uncle and she said about the reason she decided to tell the neighbours about the abuse:

‘This time I was tired of this - I was also afraid of what my mother would say when she saw me after I was raped’

Ntswaki is not involved in any sporting activities at school and at home. She does not understand the benefits of being involved in sports. She said about keeping healthy:

‘No, they just say that to motivate you to take medication and exercise - there is no such a thing, if one has AIDS you are going to die eventually whether you have taken medication or not’

Interpretation

Ntswaki appears to be very pessimistic about the future and by so doing has lost all hope in everything. This implies that Ntswaki is not coping. Psychological beliefs such as optimism, personal control, and a sense of meaning are recognised to be advantageous to mental health, thus suggesting that psychological beliefs such as meaning, optimism and humour may act as buffers against mental and physical ill health. In the literature survey it has been discovered that self system entails the notion that people can exercise some control over their thoughts, feelings and actions. This idea implemented through a proactive attitude may act in favor of better suited coping strategies (see 2.3.3).
Ntswaki started being sexually abused at a very tender age, the time when she could trust almost everyone, especially family members. Ntswaki does not seem to only face an assault on the developing sense of her sexual identity, but a blow to her construction of the world as a safe enough environment and her developing sense of others as trustworthy. Ntswaki's sexual abuse seems to involve a breach of trust or an exploitation of vulnerability. This is in line with the literature where it indicates that many HIV infected learners come from disrupted or disorganised homes that provide little or no structure for them to lead a normal life and develop coping strategies (see 1.2).

Ntswaki suffered sexual abuse for more than five years, her reluctance to disclose abuse tends to stem from a fear of the perpetrators, who are her uncle (her father's brother) and her grandmother, who is her father's mother. These feelings of helplessness and Ntswaki's fear that no one will believe the disclosure of abuse, seem to have lead to accommodative behaviour. It is indicated in the literature that the disclosure can be recieved with negativity, which can cause personal discomfort, discrimination and stigmatization (see 1.2).

Ntswaki's responses indicate that sexual abuse disclosures are usually a process rather than a single event. Ntswaki did not mention other incidents of abuse to the neighbours, but only mentioned the rape. This indicates that a person can only disclose what s/he is comfortable disclosing. Literature indicates that role playing can help facilitate the disclosure process and reduce anxiety (see 3.2.3).

Ntswaki's emotional trauma of childhood sexual abuse seems to be compounded by the fact that the perpetrator of the abuse was a close, male family member. As is the case with Ntswaki, sexual abuse occurred in a family atmosphere of silence, secrecy, protection of the perpetrator and blaming of Ntswaki, the victim. The literature supports the idea of victim blame as people often contract the virus through behaviours that are socially sanctioned. Ntswaki also appears to frequently experience feelings of shame, guilt, isolation, powerlessness, embarrassment, and inadequacy. She appears to have accepted responsibility for the abuse by blaming herself. Internalising
blame makes people believe that they should have known better and should have taken precautionary measures against getting infected (see 3.4.1).

For infected learners, participation in sports, physical education classes, or any other type of regular exercise helps to build and maintain healthy bones and muscles, controls weight, and has positive psychological benefits. Infected learners who exercise, also improve their long-term health.

Ntswaki does not have hope for the future - she appears to have stopped living and is waiting for death. Ntswaki seems not to understand the fact that the medical aspect of her HIV positive status need to be taken care of, she appears to hate the medication she is given at the hospital, and prefers African potato. The literature review indicates that some individuals turn to alternative treatments, this for Ntswaki could have adverse effects on her health as some over the counter drugs may make her body resistant to antiretrovirals (see 3.2.3.1).

Ntswaki appears to be having only one thing in mind and that is that she is going to die. This fear is supported by the literature where it indicates that many people suffering from HIV fear dying (see 3.4.2). Ntswaki no longer trusts people, including her family and her home is no longer seen as safe. She feels vulnerable and destitute.

She seems to be in a situation where she is both helpless and hopeless. Ntswaki appears to be struggling to come to terms with the fact that she is HIV positive - her educator has counseled her only once. No one ever speaks to her at home or at school about the virus or about her being infected. Ntswaki is in denial, which makes it difficult for her to deal with her emotions (see 1.2).

Ntswaki appears to be questioning the meaning of life and specifically the larger world, the role she has to play, and the options and opportunities available to her. She seems to perceive her future to be bleak, with lack of care, hopelessness and lack of concentration. Feelings of being overwhelmed and overburdened, seem to contribute to her poor performance at school. Ntswaki seems to be disturbed by her health, which contributes to her being absent from school - she seems to be ashamed of the fact that her discharge
emits an odour, she has tried everything she could think of to no avail. Some days she appears depressed - these are the days she says she does not feel like going to school. A lack of concentration may refer to Ntswaki's inability to focus or devote attention to schoolwork. Initially, Ntswaki found it difficult to continue schooling without thinking about her plight (see 1.2).

(c) Ntswaki's general functioning at school

Analysis

Ntswaki's general functioning at school has deteriorated, as she reveals several factors that contribute to her inability to perform, and these include - lack of care, hopelessness, lack of concentration, and feelings of being overwhelmed and overburdened. She said when asked about her performance at school:

'I do not care about school - may be that is why I do not get good marks, before I discovered that I am HIV positive, it was better because I could concentrate on my work. Now, I really do not see any point, why should I study, why should I continue schooling for that matter? I am HIV positive and I am going to die. In class I only think of what is going to happen to me, I believe not even one of my classmates has suffered the same affliction as I have.'

Ntswaki is also disturbed by her health, which contributes to her being absent from school. Ntswaki appears to be ashamed of the fact that her discharge has an odour - she has tried every medicament she could think of, to no avail. She comments:

'Sometimes I am sick and other days I do not go to school because of the discharge - they complain that I smell and I understand it is a very bad smell that I cannot do anything about. I tried washing my body three times a day - that does not help, so on the days when I am having a heavy discharge, which is most of the time it causes a musty, stale odour, so I do not go to schools.'
The third contributory factor to her poor performance at school is being depressed some days - these are the days she says she does not feel like going to school. She loses a great amount of work during the days she is absent, and says:

‘Then there are days when I bunk school because I just do not feel like going to school.’

Initially, Ntswaki found it easy to continue schooling without thinking so much about her plight. However, she is finding it more difficult to concentrate on her schoolwork and school activities as she comments:

‘In class I only think of what is going to happen to me, I believe not even one of my classmates suffered the same affliction as I have. They all have a reason to joke and laugh about everything - prepare for tests and plan for the future - I don’t!’

**Interpretation**

Ntswaki appears to be questioning the meaning of life and specifically the larger world, the role she has to play in it, and the options and opportunities available to her. She perceives her future to be bleak because of the challenges she has to face (see 2.5).

Ntswaki observed that through her experience of a change in her body, her sense of self was impacted and in turn, altered. In this case a change in experience of self on a physical level, shifted the experience of others as well as experience of self, radically altering the experience of being in the world. Concerning HIV and its impact on identity, alterations in self can be experienced and in turn this revolves around issues of greater self-assuredness and self-understanding and a greater sense of maturity (see 2.3.2.3 & 2.4.3).

In terms of the experience of depression, the literature (see 3.4.2) similarly notes that depression must be regarded as an expected response to HIV/AIDS status. It has been found that depression is one of the most
common psychological reactions to HIV/AIDS diagnosis, particularly in the period following testing. In addition, because of the absence of a cure for HIV/AIDS, feelings of helplessness and hopelessness become prevalent. Depression in HIV/AIDS individuals may also be linked to wider society's negative perceptions and stigmatization of the illness, creating a sense of alienation and isolation as one is treated as a potential infectious threat to society. Depression develops as a reaction to this stigmatizing labeling, in turn leaving the PLWA feeling helpless, hopeless and depressed. Within this study, feelings of shame, isolation, stigma and prejudice were prevalent emotions linked to the experience of diagnosis and life for people living with HIV/AIDS (see 3.4.1).

A lack of concentration refers to Ntswaki's inability to focus or devote attention to schoolwork. Unfortunately her lack of concentration is relatively deep rooted, as she is unable to regain focus, even in spite of the support she gets from her educator. The literature indicates that learners suffering from HIV/AIDS will show evidence of a negative effect on their general functioning at schools (see 1.2).

(d) The nature and extent of support that Ntswaki gets

Analysis

Ntswaki appears not to be expecting any support from her grandmother, as she never supported her all the years she has been abused. Ntswaki appears not to trust her grandmother, she cannot confide in her. Ntswaki appears to be bearing a grudge towards her grandmother for siding with her son and not with her and said:

'My granny knew about this because when she was drunk, she would tell me that I was going to fall pregnant at a very early age, and that I should not go around spreading lies about her son.'

The principal and the school educator where Ntswaki attended school, seem to be caring and helpful. She has been identified as one of those learners who
should be part of the school nutrition programme. The principal also supports her financially. When asked about the support she gets from school, she said:

‘I am part of the school nutrition programme - sometimes the principal gives me money to fetch treatment from the hospital. My class educator counselled me the last time I was raped.’

Ntswaki appears not to be getting support from her family members including both her parents. The whole family, except for Ntswaki’s uncle (her father’s younger brother) appears not to be coping or using bad coping strategies concerning Ntswaki’s positive status. They never sit down as a family and discuss their problems. Other people, but not her own parents support Ntswaki. She feels that her family does not love her or even care about her, she mentions that:

‘My HIV status is only mentioned when I have done something wrong like not cleaning the house. My father would say that I must get sick and die, he wants to eat meat. My mother seldom talks about my life in general. We only talk about what I should prepare for supper, which rooms to clean after school and when she is asking me to baby sit for her while she is out of the house. I have sensed that she is blaming me for everything that has happened in my life. I overhead my mother asking my grandmother why I did not tell her about the sexual abuse if I was not enjoying it.’

Ntswaki gets support from a woman who is the owner of the home where she is kept until the trial is over. She had to be kept in a Place of Safety as her uncle has threatened to kill her. No one has ever told her she loved her, this is a new experience to her. She said about the support she gets from her mama:

‘Mama always tells me she loves me, she would like to take care of me. No-one ever told me that and I do not know whether to believe her or not. Sometimes mama gives me money to buy sweets at school. I eat when I come back from school and I am not used to that.’
Ntswaki appears to be aware of the love and care that other people are offering her. She seems to be aware that the social worker and her school educator are trying to help her. She appears to be grateful that at least one member of the family is supportive. She said about their support:

‘At the moment it is the social worker and my uncle (my mother’s brother). My educator also supports me. She is concerned, and she always asks me if there is anything she can help me with.’

Ntswaki has been counselled after the last incident of the sexual abuse, which she calls rape - she was also counselled by the social worker when they first met and commented about counselling:

‘Yes, by my educator after I was raped, the social worker also counselled me once.’

**Interpretation**

Lack of support from people who are closer to Ntswaki appears to have devastating effects on the way she copes with the disease. The support of her grandmother in the case of the sexual abuse and also in the case of the HIV is imperative and could have made a difference. Ntswaki does not get support from her family. The principal and the school educator where Ntswaki attends school seems to be caring and helpful. Ntswaki seems to respond positively to the love, care and support she gets from the woman who accommodates her until after the trial (Place of Safety) (see 1.2).

It is a commendable thing that her educator and the principal support Ntswaki at school. The stress-buffering hypothesis of social support suggests that social support acts as a protective mechanism in the face of the stressful situations that HIV/AIDS learners experience (see 1.2). It is thought to operate both by contributing to the resources available to individuals to cope with the stressor, as well as by reducing the stress response to the stressor (see 2.5).

The fact that Ntswaki’s family does not support her seems to have negative effects on her. She appears to feel unwanted by her father who only talks
about her status when she has done something wrong. Ntswaki's father as well as her mother, seems to be blaming Ntswaki for her HIV positive status. They both appear to distance themselves from the problem - they leave it to Ntswaki to deal with the problem herself, the way she sees fit. Without the support of both her parents, it is very difficult for Ntswaki to be positive about her status, adapt ways of coping and move on with her life. Furthermore, HIV at times introduces sadness, nonunderstanding and fear for those people close to the infected, this may be the case with Ntswaki's parents (see 3.4.1 & 1.2).

Ntswaki appears unsure of how to respond to the love, support and care she receives from the woman who is taking care of her. She seems overwhelmed by the love, care and support she gets from this lady. No one has ever told her s/he loves her - it appears she does not even believe in love, it also seems too good to be true.

It is commendable that Ntswaki is able to recognize and respond positively to the love and support she receives from other people. This could be an indication of the fact that all is not defeated, concerning change of attitude, behaviour, hopelessness and helplessness (see 1.2).

Constructivist counselling is meant to help the individual to deal with problematic areas in his/her life, but the counselling Ntswaki received, did not alter her understanding of her situation (see 2.5).

5.4 INDIVIDUAL ANALYSIS AND INTERPRETATION OF VUSI'S EXPERIENCES

This third individual analysis centres around Vusi's case, his family background, the proceedings of the interview between Vusi and the researcher, between the health worker and the researcher and the researcher's impressions of him based on her observations.
5.4.1 Case study 3: Vusi's case

This case presents a situation of a child who was infected prenatally with HIV, which in this research is referred to as Mother To Child Transmission (MTCT).

The brief introduction of Vusi's family background and the general impression that the researcher gained of this eight-year-old boy are given. The whole verbatim transcription of the interview that the researcher conducted with Vusi follows.

5.4.1.1 Introduction

The interviewer had two interviews with Vusi (not his real name). Both of these interviews were conducted at his home. Each session lasted about two hours.

5.4.1.2 Family background

Vusi is an eight-year-old grade three learner who was born on 1st September 1996. He is the last-born in the family of two; his elder sister is a seventeen-year-old grade eleven learner. He stays with his very sick mother and his sister. They all live in a very old house, a house that belonged to his great-grandparents. Vusi's grandparents had two daughters, his mother's older sister and his mother. According to their culture, his mother is the one who had to inherit the house, as she is the last-born. His stepfather stays with another wife in another location. His sister and himself visit his stepfather (his sister's biological father) sometimes. Vusi's mother never got married and her children are from different fathers. Since March last year his aunt (his mother's elder sister) visits them on a daily basis to take care of her younger sister (Vusi's mother). In 2002 and 2003, she would visit the family occasionally to wash their clothes and clean the house as Vusi's mother could not do either of those house chores. Vusi's mother has been sick and bedridden for a year now.
5.4.1.3 Additional information

The researcher first met Vusi at the health worker's house - he was thin and had a fine rash all over his face. He was wearing old torn shabby clothes, which were also dirty. When the researcher requested him for an interview he sat down in a corner of the house as if he was hiding. Although Vusi has a light complexion, he appears dark with darker patches all over his face. The interviewer felt that it was going to be very difficult to make Vusi feel relaxed, as he appeared agitated. The corner he was sitting in, was next to the door, it was as if he was expecting something painful and he was preparing himself for flight. Although the interviewer invited him for a drink and cookies, he drank and ate the cookies as fast as he could and looked more bewildered than he was before. Vusi's state made it very difficult for the interview to begin as the interviewer was trying to make him relax before they started.

What follows is a word for word transcription of the actual conversation that took place between the interviewer and the health worker.

5.4.1.4 Interview with the health worker

The interviewer decided to start interviewing the health worker firstly, to get background information on the case, secondly to get information on the assistance the health worker renders to Vusi's family and thirdly because Vusi's situation is different from others who know their status - no one told him that he was positive and his mother suffers memory losses and speech impairment.

How long have you been a health worker?

Health worker: It is three years now. I started at the beginning of March 2002. It was an advertised post. The NGO wanted volunteers to work with people who are HIV positive and those that are living with AIDS. After an interview, I was told that I got the job, and after being trained, I was allocated an area to work in.
How did you meet Vusi (not his real name)?

**Health worker:** My supervisor (the social worker) introduced me to schools and clinics in the location I was to work in. Vusi’s class educator phoned me one day requesting me to come to school concerning him. Apparently the educator was concerned about Vusi’s health - he was very thin, his shirt and trousers were torn and he looked shabby, and he was bunking school a lot - he had all the signs of being neglected. The educator tried to contact the parent but to no avail. The parent did not want to come to school and discuss Vusi’s problem. I went to Vusi’s home after the meeting with the educator. I found Vusi’s mother lying in bed, she had been sick for about three weeks, she was alone in the house. She told me that her sister comes and helps her sometimes. In the discussion we had about Vusi’s problem at school she agreed that she had been too sick for the past two weeks, she could not look after Vusi well, she was not even able to help him with his homework.

**How old was Vusi when you met him?**

**Health worker:** I met Vusi in July 2003. He was seven years old then, but he looked younger and smaller than children his age.

**Concerning this case - what were you expected to do?**

**Health worker:** As in all families where a parent or parents are unable to communicate with the school, I was expected to be a go-between, check what the educators were complaining about, see if I am able to solve the problem at home, if necessary involve a qualified social worker who is my supervisor. I was expected to counsel Vusi as the school does not offer counselling services, and to assist the family concerning Vusi's school uniform, provide them with food parcels and assist to obtain a grant for the mother and also for Vusi.

**What did you manage to do concerning this case?**

**Health worker:** I managed to get to Vusi's home, assess the situation, counsel Vusi, organize a school uniform for him, get food parcels for the
family, and also assist with the application of grants for Vusi and his mother. Vusi’s mother was not be able to apply for a disability grant before her CD4 count could be checked, so I had to take her to the nearest clinic and also have Vusi tested. Her CD4 count was below 200, so she qualified for the grant and, she is still receiving the grant as her health has never improved. Vusi’s mother was tested in December 2003, this was when we both agreed that her health is deteriorating and she has to know what the problem is. She would be better for a short period of time and be sick most of the time. I somehow failed to supply the family with food three times that year but as we usually do, we depend on the funds we have. If we no longer have funds, we cannot give them anything.

How has Vusi been after being counselled?

Health worker: There is an improvement, though slight. He has stopped bunking school, he still does not perform well at school, and the educators say he still does not do his homework and his class work.

Concerning being shabby and looking neglected, what does he look like now?

Health worker: He is clean and neat now, his aunt washes and prepares his food daily, but in the evening there is no one to see to it that he does his homework. The grant helped a lot - at least there is food for them. When his aunt cannot come she has to hire someone to take care of them.

When and where did you counsel Vusi?

Health worker: Vusi was counseled at his home once, immediately after the educator complained that there was no time to do counselling, we only do it once. It is very rare to do it twice with the same person - there is always so much to help the families with. I have to make sure that his mother is washed daily or at least three times a week, I have to arrange with people who work for the Red Cross to come and help with the cleaning of the house (Home Based Care Unit), see to it that they have food, train people to take care of
Vusi's mother and so on. Vusi was also counselled at the clinic before being tested.

What are the contents of the food parcels you give to people living with HIV/AIDS?

Health worker: We give families mealie-meal, tinned fish, sugar, coffee, vegetables such as cabbages, carrots, and potatoes. We encourage people to eat vegetables raw, we never buy them fish oil, it is not good for their health, and they should just boil the vegetables and eat them without salt. Too much salt is not only the cause of their swollen feet, it also aggrevates the situation.

How long does the food parcel last for one family?

Health worker: It is intended to last them for three months, but it depends on the composition of the family and whether everyone that co-resides with the patient depends on the food parcel. At Vusi’s home the food parcel lasts them for three months except for vegetables, which lasts for only a month. As I have said earlier, when we do not have enough funds, they starve. Our NGO, like all the other NGOs is at the mercy of the donors and it also depends on whether the number of people we feed, do not increase.

When was Vusi tested?

Health worker: Vusi was tested in January 2004. He was very sick and his mother agreed to take him to the clinic and the results were positive. Vusi was not told about the results. We agreed that he was still too young to know - that is the reason he does not know. He is older than he was then, he knows what HIV/AIDS is, he sees his mother suffering every day, and he is not only infected but also affected. He becomes sick sometimes although not as frequently as he used to. I feel he deserves to know what the problem is, unfortunately his aunt does not think that way and his mother has reached a point where she has memory losses and is speech impaired.
Do you think the social worker can tell Vusi about his status?

Health worker: I do not know, but there is nothing that the social worker or the health workers can do if not even one of the members of the family does not agree to be part of the disclosure. Vusi is also still young, I do not think he poses any threat to anyone's life at the age of eight, but I think the school deserves to know.

Children are often not told of their own HIV infection, or that of parents and siblings. Parents have indicated that they are uncomfortable discussing their HIV status with children for a variety of reasons. One of these is the fear that their children will be unable to keep the diagnosis a secret from peers and other the community or family members, resulting in social rejection of the child and the family. Parents also report a desire to protect the child from the knowledge that the parent and/or child has the illness. This is especially true if one or more close family members or friends have already died from AIDS. Additionally, parents report that they are uncomfortable and uncertain how to address questions regarding the way the virus was transmitted to parent and/or child. Parents may feel guilty or ashamed about the method by which they contracted HIV. Mothers, especially, may be trying to cope with their own feelings in having transmitted the virus to their child.

In general, it has been well established that children have better emotional adjustment if they are told of their diagnosis and allowed to discuss their condition openly with their family and medical care givers. This is true even in situations where the child is terminally ill.

Does the school know?

Health worker: I had to report back to the class educator. I had to tell her what the situation is - she deserves to know so that she can be able to assist Vusi. I told her after Vusi was tested.

What follows is a word-for-word transcription of the actual conversation that took place between the interviewer and Vusi.
5.4.1.5 Transcription of interview with Vusi

The interviewer had two interviews with Vusi (not his real name), one with his educator and one with the health worker. Both these interviews were conducted at his home. Each session lasted about two hours.

How is your life?

Vusi: My life is boring, there are no surprises, nothing new; I do same old boring things everyday.

What are those boring things you do every day?

Vusi: Waking up every morning, getting ready for school, getting to school, doing school work, coming back home, playing until it's dark and eating supper and going to sleep.

Is everything that you do boring?

Vusi: Yes, I do not go to town or visit other relatives. I see my sick mother, my sister and my aunt every day.

Why don't you try other things that you have never done, like playing with children you have never played with before?

Vusi: I have never thought of that.

Is school also boring?

Vusi: Yes, I feel like not going to school sometimes, I used to bunk school when I felt like it but I no longer do that, because whenever I am absent for two days or three, my class educator phones the health worker. It is easy for the health worker to check on me because we live in the same area.

What do you think can make your life less boring?

Vusi: I would like to go to town like other children in our neighbourhood. I have never been to town, I do not go and visit anywhere, except my stepfather in one of the locations in our area and that also happens after a very long
time. Other learners talk about journeys they took by train. I have never been on a train, although I do not live too far from the railway station. I miss my mother although she stays with me. We do not talk, sometimes I want to tell her something, I can’t, she doesn’t understand, she doesn’t talk back.

**How do you perform at school?**

**Vusi:** I do not know, I have not received this term’s report yet, but the last two years I did not perform well. My educator last year told me that I was promoted and she advised me to work harder in the next grade.

**Why was your performance bad in the last two years?**

**Vusi:** I was bunking school a lot, I did not do my homework and class work, I just did not care about school. There was no one supervising me at home as my mother was always sick and is now bedridden, my older sister always comes home late in the evening.

**Is there any change in your performance now?**

**Vusi:** Maybe, but I am still not interested in schoolwork. I attend school more regularly than last year, except for days when I am sick.

**When last did you become sick?**

**Vusi:** I was sick for two weeks in January this year - that was immediately after we reopened, I had flu and I also developed a rash all over my body. I was taken to the clinic and they gave me a medicine for flu and an ointment for the rash.

**Do you know your status?**

**Vusi:** No, I was tested when I was doing grade one, my mother and the health worker took me to the clinic. The nurses did not tell me the results, they were revealed to my aunt and the health worker.
Would you like to know your status?

Vusi kept quiet, he made a sound as if he wanted to say something but decided otherwise.

If you were told that you are HIV negative would that change your boring life?

Vusi also did not answer the question but just shook his head.

If you were a father, would you tell your child that s/he is HIV positive?

Vusi: Yes s/he deserves to know.

Were you counselled before you were tested?

Vusi: I was counselled before being tested. The nurse told me that I was about to do HIV test. She started asking me questions about HIV, what I know about it and explained what it means to be positive and negative.

Why were you taken for an HIV test?

Vusi: I was very sick then, grade one was my worst year, I couldn’t be well for more than two months, and I was in and out of the hospital for the whole year.

How is your health now?

Vusi: Better compared to that year, I still suffer from flu a lot and I always develop a rash and sometimes have mouth sores.

How do you feel about being sick?

Vusi: I hate being sick, when I am sick I have to sleep like my mother. I become worried whenever I am sick that I will end up like her. Although I do not care that much about school, it is better than sleeping the whole day and night hoping for a speedy recovery.
Do you know what your mother is suffering from?

**Vusi:** I do not know for sure, she has been ill for a long time. It is even worse now that she cannot even talk - people in the neighbourhood say she has AIDS.

**What do you think Vusi?**

**Vusi:** I also think she has AIDS, I have seen other people on TV who are HIV positive some of them are like her.

**What do you think about HIV/AIDS?**

**Vusi:** I think it is a very bad thing to happen to a person, when one is diagnosed HIV positive, it is like a death sentence - it also kills the whole family.

**Why do you think it kills the whole family?**

**Vusi:** I know people in our neighbourhood think we all have it, that is why my sister is always out of the house, she is afraid of them. I do not care whether I have it or not, because sometimes I suffer from the same things that my mother is suffering from.

**What are those?**

**Vusi:** Sores all over the body, flue, swollen lymph glands and gastro-enteritis.

**When did you meet the health worker who is taking care of your family?**

**Vusi:** I do not remember the month, but it was in 2003 when I was in Grade one. She came to see my mother, she asked me a lot of questions about why I am not attending school regularly, who helps me with homework, and so on. She told me that she is going to check on my schoolwork. She then spoke for a long time to my mother. After a few days she came back with a lot of groceries and brought me a school uniform. My mother was very happy, she thanked her, my mother could speak then, unlike now. Ever since, the health worker checks on us occasionally to see if we are still well, especially mother,
she always brings us something, like latex gloves for my aunt to use when she is washing my mother, diapers and food parcels.

**How does your aunt help you?**

**Vusi:** She washes and irons my school uniform, she cooks both lunch and supper for us, she cleans the house, she takes care of my mother, by washing, dressing and feeding her, she washes my mother’s clothes and especially her blankets which have to be washed daily if she has run out of diapers. She does not sleep over as she is married and has children of her own to take care of, she comes every morning before I go to school. She prepares breakfast for us and helps me get ready for school. My eldest sister helps her sometimes, but she is not always in the house, especially after school, she is a choir girl and her choir practices daily for their weekend performances.

**Who takes care of you after your aunt has left?**

**Vusi:** My aunt leaves round about five o’clock - she reports to our neighbours that she is leaving. Our neighbours take care of me - I sit and play with their child who is the same age as me, when it is dark the mother would accompany me to my home. She switches on the lights, checks on my mother, and after she is sure everything is okay, she dishes up for me. She does not dish up for my mother- my aunt makes sure she feeds my mother before she leaves. She and her husband take turns to check on us until it is time to sleep.

**What do you do when you are left with your mother?**

**Vusi:** Immediately after I have eaten I sleep, there is nothing I can do, and we do not have TV otherwise I could sit and watch TV. I do not switch off the lights, my sister switches the lights off when she is back, and she also locks up.
Why do you not use this time for doing your homework?

Vusi: I always forget that I have homework and even if I remember I am afraid to sit alone and do homework.

Are you worried about your health?

Vusi: Yes, when I am very sick, I think I am going to die, I do not like being sick but there is nothing I can do. I see every day how my mother suffers - I do not want to be as sick as she is.

If you were positive, would you like your educator to know about your status?

Vusi: No, I would not like her to know, she is a very kind person though - she takes care of all learners that are sick in the class, she is always concerned about our health and our performance in class. How would she treat me knowing that I am positive? I do not think a person who is positive can attend school normally, I think other learners would treat him/her badly.

Do you think counselling would help you in anyway?

Vusi: Yes, sometimes I feel as if I would like to talk to someone about my life and about the situation at home because I sometimes feel very lonely. If we were more close to my sister, maybe we could talk about what we were going to do when she dies. I am worried about what will happen to me, I even asked the health worker one day whether I could stay with her and her family.
5.4.1.6 **The researcher's impressions of Vusi based on her observations**

5.4.1.7 **Analysis and interpretation**

Vusi’s experiences are analysed below. The analysis is divided into themes and will be discussed in terms of:

- how he feels about being infected;
- how his psychological and physical well being is because of being infected;
- his general function at school; and
- the nature and extent of support he gets.

The themes are not mutually exclusive and readers might find overlap between themes. Where appropriate, statements will be illustrated by excerpts from the interview.
(a) How Vusi feels about being infected

Analysis

Unlike other infected learners who were interviewed in this research, no one ever told Vusi that he is HIV positive. His mother, the health worker and his schooleducator all know about his positive status - he is the only one who does not know. According to the health worker, this was done to protect him. His words were:

'Vusi was not told about the results, we agreed that he was still too young to know for that reason he does not know. Now he is older than he was then, he knows what HIV/AIDS is, he sees his mother suffering every day, and he is not only infected but also affected'

Vusi appears to think that children deserve to know about their status. This could refer to his own status, as he was tested without being told the results. He appears not to be happy about not knowing his status. When asked about whether he would tell his own child her/his status he said:

'Yes s/he deserves to know'

Vusi hates being sick, he associates being sick to having HIV/AIDS. Being sick worries him, he even prefers attending school, than being sick, he said:

'I hate being sick, when I am sick I have to sleep like my mother. I become worried whenever I am sick that I will end up like her. Although I do not care that much about school, it is better than sleeping the whole day and night hoping for a speedy recovery'

Vusi associates being HIV positive with death. He does not realise that a person can live for a long time after being diagnosed with HIV/AIDS, and mentions:

'I think it is a very bad thing to happen to a person, when one is diagnosed HIV positive. It is like a death sentence, it also kills the whole family'
Vusi suspects that he might be HIV positive because of what people are saying about their family, when he says:

'I know people in our neighbourhood think we all have it, that is why my sister always is out of the house because she is afraid of them. I do not care whether I have it or not, because sometimes I suffer from the same things that my mother is suffering from'

Vusi reported feeling great shame and embarrassment regarding disclosure. He is fearful of other people's judgement. This is what he said when asked if he would tell his educator when he found he was HIV positive:

'No, I wouldn't like her to know, she is a very kind person though. She takes care of all the learners that are ill in the class, she is always concerned about our health and our performance in class. How would she treat me, knowing that I am positive? I do not think a person who is positive can attend school normally - I think other learners would treat him/her badly'

**Interpretation**

Not knowing about one's status whilst other people know, appears to be devastating for Vusi. There are various reasons that could be attributed to this - the health worker said he was still too young to be told (see 3.2.2)

Vusi could be suspecting that he was HIV positive, he was tested and he is wondering what the results could have been. He knows what HIV/AIDS is, his idea of children being told about the results, could be referring to his own situation (see 3.2.2).

Vusi relates being sick to fears about death, as well as fears about the future and his functionality within that future. Accordingly, illness is experienced as more intense than a mere experience of physical symptoms. Research indicates that illness is experienced as a global sense of disorder - a disorder which involves the disruption of the body (with concurrent disturbance of self and the world) and changed relation between the body and the self. The loss
of wholeness brought on by illness is experienced not only as a threat to the body but also as a threat to the self. This disorder introduces disequilibrium to a person's way of being, creating feelings of fragmentation and chaos (see 2.5). Thus a great stressor related to the experience of HIV, is a fear for the future and illness.

Like many other people who have been diagnosed HIV positive, Vusi thinks of death. This further indicates that when individuals are diagnosed HIV positive they are confronted with their own fragility and transition, which launches them into a psychological and existential crisis (see 3.2.3.2).

Vusi shows signs of being frustrated and angry, his way of dealing with the situation is not to care whether he has HIV/AIDS or not (see 3.4.1).

PLWA are part of culture, environment, history, society and specific situations. It is only within these specific situations that they are able to exercise their freedom of choice. The impact of culture on HIV introduces the idea of various experiences of HIV, which are mediated by culture. For Vusi, culture determines the reactions of others towards him (see 2.3.4).

Vusi appears to be in denial as he says he does not care whether he has AIDS or not and yet he is aware that he sometimes suffers from the same ailments his mother suffers from. He feels ashamed and embarrassed regarding disclosing his positive HIV status. Vusi is bored and perceives life as meaningless to him, there is nothing new. Vusi seems to be longing for life to be normal. His boredom is caused by the fact that there is no one that takes him to town or to visit relatives, he misses going to town with his mother, and he appears to be tired of the life they are now living. This new life and the fact that he sees his sick mother every day, depresses him (see 3.4.1).

(b) Vusi's psychological and physical well being

Analysis

Vusi appears to be bored and perceives life as meaningless - to him there is nothing new, because he claims:
'My life is boring, there are no surprises, nothing new; I do the same old boring things every day'

Vusi would like to go out and visit relatives, he misses going to town with his mother, and he appears to be tired of the life they are now living, when he says:

‘Yes, I do not go to town or visit other relatives I see my sick mother, my sister and my aunt every day’

It does not appear as if Vusi has any skills in dealing with what he calls boredom in his life. When asked why he does not try other things that he has never done, such as playing with children, he has never played with before, he said:

‘I have never thought of that’

When asked what he thinks can make his life less boring, he said:

‘I would like to go to town like other children in our neighbourhood, I have never been to town, I do not go and visit anywhere except my stepfather in one of the locations in our area but that also happens a very seldomly. Other learners talk about journeys they took by train. I have never been on a train, although I do not live too far from the railway station. I miss my mother. Although she stays with me, we do not talk, sometimes I want to tell her something, I can’t, because she doesn’t understand, she doesn’t talk back’

Vusi appears to be worried about being sick, he appears to be helpless in the situation. He wonders what will happen to his mother and he appears to be aware of the suffering and pain his mother is going through, when saying:

‘Yes, when I am too sick I think, I am going to die. I do not like being sick but there is nothing I can do. I see every day how my mother suffers; I do not want to be as sick as she is’
Vusi does not think his educator should know about his status, should it happen he is HIV positive. He is afraid of the treatment he might get from other learners and he is not sure of how his educator would react. This is what he said about self-disclosure:

‘How would she treat me knowing that I am positive? I do not think a person who is positive can attend school normally, I think other learners would treat him/her badly’

Vusi appears to be lonely. He keeps things ‘bottled up’, not intentionally, but because he does not have anyone to talk to. He would like to talk to people about the situation, especially his family because he mentions:

‘Yes, sometimes I feel as if I could talk to someone about my life and about the situation at home, I sometimes feel very lonely. If we were close with my sister, maybe we would talk about what we are going to do if my mother can die. I am worried about what will happen to me. I even told the health worker one day that I would like to stay with her and her family’

For Vusi, the physical symptoms experienced, have been related to his weight - he was thin compared to children of his age.

‘The educator was concerned about Vusi’s health, he was very thin, his shirt and trousers were torn and he looked shabby, and he was bunking school a lot - he had all the signs of being neglected’

Vusi’s physical wellness is impacted by HIV/AIDS in the form of fine rash all over his body and mouth sores, as he revealed:

‘I still suffer from flu a lot and I always develop a rash and sometimes have mouth sores’

**Interpretation**

Vusi appears not to be coping with the fact that his mother is terminally ill. There is an emptiness in his life - he refers to this emptiness as a ‘boring life’.
Like all learners his age, he would like to do new and exciting things, but he realizes that this is not going to happen. Boredom could be a sign of being stressed and being depressed (see 3.4.1).

Vusi seems to be longing for things to be normal, this new life and the fact that he sees his sick mother every day depresses him. Vusi is thus lonely and depressed and he does not have anyone to talk to about his plight. Emotional suffering is probably the strongest effect of HIV and AIDS on children. Their worries can last for a long time, as they experience suffering on a daily basis (see 3.4.1).

Vusi reveals depression in emotional/affective and cognitive components such as sadness, crying, lack of pleasure or interest and negativistic beliefs. Infected learners need to be equipped with skills to deal with day-to-day problems they encounter (see 3.4.1).

For Vusi HIV seems to present an infinite source of anxiety which taxes his capacity to cope effectively. Literature suggests that every moment and situation in the individual’s life exhibits intentionality. Within this framework it suggests that the infected have a choice even in their difficult situation as to how to perceive and respond to their circumstance (see 2.4.3).

Discrimination, stigma, fear of treatment he might get, should it be revealed to him that he is HIV positive, are a cause of concern for Vusi (see 3.4.1).

Although the biological effect of HIV/AIDS cannot be ignored, there is a significant correlation between social support and emotional adjustment whereby social support functions in a mediatory role in buffering the effects of stress. This indicates that if Vusi can have someone to talk to, some of the problems could easily be solved, and different coping strategies could be explored for those problems that cannot be solved (see 1.2).

Through Vusi’s experience of a changed biological system, his sense of self was impacted and in turn altered. The educator realized that there was something wrong because of his health and the fact that he was very thin. Life becomes more difficult for learners who are infected and who stay with
parents who are also infected, especially those who have reached a stage of having full blown AIDS (see 3.3).

The impact of HIV/AIDS on Vusi’s physical well-being can make him ashamed of himself. This not only impacts on his emotions, but also on how he relates to others (see 3.3).

(c) Vusi’s general functioning at school

Analysis

Vusi is not performing well at school - this has been attributed to the fact that he does not do his work, because:

‘He still does not perform well at school, and the educators say he still does not do his homework and his class work’

Vusi appears to be demotivated and shows lack interest in school and schoolwork, when he says:

‘Maybe, but I am still not interested in schoolwork’

Being sick most of the time and not being able to attend school contributes to Vusi’s poor performance, when he mentions:

‘I was very sick then. Grade one was my worst year - I wouldn’t be well for more than two months, and I was in and out of the hospital for the whole year’

Lack of supervision at home because of his mother’s condition made Vusi not able to do his homework, as he said:

‘There was no one supervising me at home as my mother was always sick and is now bedridden. My older sister always comes home late at night’

Vusi has a problem of forgetting to do his schoolwork. When he was asked why he does not do his homework because he was not doing anything at night, he said:
‘I always forget that I have homework and even if I remember, I am afraid to sit alone and do homework’

Vusi appears not to see any value in attending school - he seems to have lost interest.

‘I just did not care about school’

**Interpretation**

Vusi lacks support at home to help him with his homework and classwork. He also is not making an effort to make sure that he progresses well.

There seems to be a shortage of counselling services in schools, a situation, which could lead to high failure rate, high drop out as infected learners lack guidance and support which is essential in this crucial time of their lives. HIV/AIDS can cause severe learning distress and cause demotivation to learners infected. With support, infected learners will remain in school for longer, thereby safe-guarding their future rather than being abandoned to premature dependence. Vusi is always worried about being sick, about his mother’s condition, concerned about opportunistic infections, uncertain about the future, should anything happen to his mother, health, and anticipating loss and his mother’s death - all these factors cause or exacerbate feelings of anxiety. Vusi experienced discrimination and stigma as the neighbours suspect that the whole family is infected (see 1.2).

Vusi has been absent from school for quite some time, he lost out on the work that was done in his absence. This also indicates that the school, which Vusi attends, makes little effort to organize extra classes for learners who miss classes because of their HIV/AIDS-related illness. Absence of extra classes for these learners could lead to high failure rate in classes and contribute to learners dropping out of school, because they cannot cope (see 1.2).

Learners who have no one to supervise them at home, perhaps having an adult to see to it that they are properly dressed and ready for school, monitor their progress by communicating with the school, supervise them in the
evenings when doing their homework, are likely to perform badly at school. The importance of parent involvement has always been valued (see 1.2)

The progression of HIV infection to AIDS infection has been associated with the central nervous system (CNS) dysfunction. The signs and symptoms of HIV-related dysfunctional nervous system infection to Vusi include cognitive impairment, such as short term memory deficits and confusion, changes in personality, as well as other factors that effect neuropsychological functioning. These factors include prescribed drug use, stress of living with a chronic/terminal illness, and nutritional deficiencies (see 3.3.5).

The conclusion is that Vusi has lost hope, nothing matters to him any more.

(d) The nature and extent of support that Vusi gets

Analysis

Apparently the educator was concerned about Vusi’s health, he was very thin, his shirt and trousers were torn and he looked shabby, and he was bunking school a lot - he had all the signs of being neglected. The educator tried to contact the parent but to no avail. This is what the health worker said about the way she became involved in this case:

‘Vusi’s class educator phoned me one day requesting me to come to school concerning Vusi’.

Vusi himself said of his educator:

‘She is always concerned about our health and our performance in class’

Vusi’s mother cannot render full support to him because she is very sick and bed-ridden. It became difficult for her to supervise him and to look after him and he appeared to be neglected. It was mentioned for instance:

‘In the discussion we had about Vusi’s problem at school, she agreed that she had been too sick for the past two weeks, she couldn’t look after Vusi well, she was not even able to help him with his homework’
The health worker and the social worker support Vusi and his family. The health worker counseled him although she feels that counselling him once is not enough, because she maintains:

‘Vusi was counseled at his home once, immediately after the educator complained, there is no time to do counselling, we only do it once. It is very rare to do it twice with the same person; there is always so much to help the families with’

Vusi's aunt takes care of him, she washes and cooks for him. After the aunt has left, the neighbours take care of Vusi. This is what he said about his aunt and the neighbours.

‘My aunt leaves round about five o’clock - she reports to our neighbours that she is leaving. Our neighbours then take care of me - I sit and play with their child who is the same age as myself, and when it is dark, the mother would accompany me to my home’

Interpretation

It helped Vusi to get support from his educator as he was referred to a health worker who could assist the whole family. Educators who are able to identify learners with problems and be able to deal with the situations learners find themselves in, do not only help learners, but also their families. For learners like Vusi that kind of support can make a big difference.

Vusi seem to be missing his mother, he sometimes shows signs of crying out for help, he cannot be supervised and be taken care of because his mother is sick. The fact that Vusi's mother is sick, affects Vusi at school. This is in line with literature as it indicates that learners suffering from HIV/AIDS will not perform well at school (see 1.2).

Although it seems that the counselling Vusi received from the health worker was not enough, it helped just to talk to someone and having someone who could listen to him. Vusi is not able to share his problems with his mother as
she is sick - he cannot talk to his sister because he says she always comes home late - at least the health worker offered a shoulder to cry on (see 1.2).

The mere perception of availability of adequate support buffers situational stress as much as actual support. Vusi is comforted to have people like his aunt who could offer assistance.

5.5 SUMMARY

This chapter analysed and interpreted ‘lived’ experiences of three HIV infected respondents who participated in this research. Themes that were identified were used in both the analysis and interpretation.

The next chapter deals with conclusions, findings and recommendations.
CHAPTER SIX

EVALUATIONS, RECOMMENDATIONS AND CONCLUSIONS

6.1 INTRODUCTION

This final chapter presents an overview of research findings and conclusions from the literature study as well as from the empirical research. Recommendations in terms of addressing the infected learner's personal 'lived' experiences will also be included, these will be based on:

- what the 'lived' experiences of HIV infected school-going learners are;
- how their psychological and physical well being are affected by HIV occurrences;
- their general functioning at school; and
- the type of social support they get from their families, schools, communities and the society in general

6.2 OVERVIEW OF THE PHENOMENON OF LIVING WITH HIV/AIDS

The study elicited central themes that were common to the participants regarding their experience of HIV/AIDS. These commonalities may be viewed in the context of this research, as the essence of the phenomenon of experiencing HIV/AIDS. The themes have been discussed in detail in chapter 5 and are summarized below in terms of the summary of findings and conclusions from both the literature study and the empirical investigation.

6.2.1 Summary of findings and conclusions from the literature study

The following findings were drawn from the proceedings of the literature studied in various chapters of the study:

- HIV attacks the immune system, that is, the body's defence against infection, and reduces the resistance of the body to all kinds of illness,
including influenza, diarrhoea, pneumonia, TB and certain cancers. It eventually weakens the body as much that it cannot fight sicknesses and causes death between five and ten years after becoming infected, but some HIV-infected people live longer if they receive the right psychocounselling and medication (see 3.2).

- 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 (see 3.3).

- Constructivist thought contends that people create meaning from the interaction between their existing knowledge or beliefs and the new ideas and situations that they encounter, ideas and situations that can only be effectively found in social settings (see 2.4).

- Constructivism involves the active creation and modification of thoughts, ideas and understandings as the result of experiences that occur within a psycho-socio-cultural context. The constructivist theory postulates that attending to counsellee's socio-cultural factors in the counselling processes provides counsellors with a framework for understanding the major tasks and crises of each stage of human functioning development (see 2.5).

- HIV infection fits the profile of a condition that carries a high level of stigmatization. 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. 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. 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 (see 3.4.1).

- Self-efficacy is one important psycho-social variable that may influence coping among persons with HIV/AIDS as it refers to personal judgements concerning one's ability to engage successfully in specific behaviours that lead to specific, desired outcomes. Infected people's beliefs about their efficacy can be developed by sources of influence. These sources of influence include mastery of experiences, vicarious experiences, social persuasion, and psychological state (see 2.3.3.1).

6.2.2 Summary of findings from the empirical investigation

The following findings were drawn from the proceedings of the empirical research conducted in this study:

- Living with HIV becomes a burden which infected individuals carry wherever they go, it becomes difficult to separate themselves from the virus ((see 5.2.5.1; 5.3.5.1; & 5.4.5.1).

- Being tested without being counselled, proved to have had devastating results to the participants of this research (see 5.2.5.1; 5.3.5.1; & 5.4.5.1).

- A person's sense of self is profoundly impacted as the understanding of self is linked and defined by disease progression and viral load (see 5.2.5.2; 5.3.5.2; & 5.4.5.2).

- Becoming HIV positive created feelings of shock, disbelief, anger, fear, suicidal ideation, depression, isolation, and shame. Unfortunately all respondents seem to have reached not the stage of acceptance (see 5.2.5.1; 5.3.5.1; & 5.4.5.1).

- All respondents indicated that after they had been diagnosed positive, conflict, fear and anxiety regarding self-disclosure became prevalent. While
responses of sadness, shock and prejudice appeared to be commonplace from those close to the participants. All respondents mentioned barriers like fear of being stigmatised, being discriminated against and about what other people would say about them being HIV infected (see 5.2.5.1; 5.3.5.1; & 5.4.5.1).

- Living with parents who are HIV/AIDS positive proved not to build resilience among the infected - children instead they live in fear of death. These children become traumatised by sickness and death of their own parents, which leaves them vulnerable and destitute (see 5.2.5.1; & 5.4.5.1).

- The study revealed a lack of information regarding issues of HIV/AIDS. Infected learners who are not informed about the progression of HIV/AIDS in human bodies, do not understand that they will experience periods of illness followed by periods of health. To these learners, sickness means that they are about to die (see 5.2.5.1; 5.2.5.1; & 5.4.5.1). Moreover, illness frustrates them when they are unable to attend school or play like other children. Lack of knowledge on other HIV/AIDS related matters such as precautionary measures, what to do in terms of keeping well and the importance of adherence to medication, indicated a hindrance in coping with and accepting the HIV positive status (see 5.2.5.3; 5.3.5.3; & 5.4.5.3).

- Learners infected with HIV/AIDS do not seem to be doing well at school. Sickness due to being infected, the high rate of absenteeism, fear of being stigmatised and being discriminated against, hopelessness and helplessness, poverty, lack of support and care by educators all contribute to their poor performance (see 5.2.5.3; 5.3.5.3; & 5.4.5.3).

- Lack of support from family members, members of the community and the school makes it difficult for these learners to live positively (see 5.3.5.4; & 5.4.5.4). Where there is support, infected learners seemed to reveal resiliency by successfully adapting in the face of adversity. Participants who have some sort of support, seemed to be optimistic about their future - they could even tell what they would like to be when they grow up. Those
that were not given enough support, questioned the meaning of life - they do not seem to be having any plans for the future and seem to be waiting for death (see 5.2.5.4; 5.3.5.4; & 5.4.5.4).

- A great stressor related to the experience of HIV, was described as being a fear for the future and illness (see 5.2.5.1; 5.3.5.1; & 5.4.5.1).

- Psychological beliefs such as meaning, optimism and humor may act as buffers against mental and physical illhealth. When respondents start worrying about something, they become ill. Infected learners who exercise also improve their long term health (see 5.3.5.2).

- Infection by being sexually abused, lead to lack of trust in human-kind by victims (see 5.3.5.2).

- Victims of sexual abuse who became infected with HIV/AIDS seem to be eager to spread the disease, instead of using preventative measures (see 5.3.5.2).

6.3 RECOMMENDATIONS

Based on the literature study on constructivist counselling for assisting learners suffering from HIV/AIDS, and feedback on the interviews conducted with these learners, the following recommendations, which could prove useful to implementation of effective constructivist counselling services in schools, are suggested.

6.3.1 Recommendations with reference to further research

The study hereby recommends the following aspects for research:

- Little or no research has been effected on the training of constructivist counsellors for schools in South Africa, particularly for black schools in historically disadvantaged areas, such as townships and farms where, because of ignorance, fear of being discriminated against and being stigmatised, HIV/AIDS infected learners decide to drop-out. Constructivist counselling takes social context into consideration in helping people deal
with the effects of HIV/AIDS in their psychological and physical well being. Future research should, therefore, focus on an effective application of the constructivist theory to counselling. Such a research can employ a larger sample than the one employed in this study. Such a research can thus serve as a vehicle for school counsellors and educators to more emphatically deal with HIV and AIDS pandemic and its impact on learners in schools.

- Since this research concentrated on school counselling, further research ought to be undertaken at national and provincial levels so that a national holistic picture of effectiveness of provision of care and support by school counsellors can be obtained.
- Research needs to be carried out and disseminated in regard to HIV/AIDS counselling/Voluntary Counselling and Testing in schools in South Africa. Institutes of higher education could partner with Voluntary Counselling and Testing centres in order for the partners to benefit in terms of research and human resource.

6.3.2 Recommendations for the practical implementation of findings

The recommendations made hereunder are drawn directly from the results of the literature studied and the proceedings of interviews. These are made as solutions or parts thereof with a view of addressing the research questions. It is contended that implementation of these recommendations would fulfil the aims of this study in yielding positive results to the problem of lack of constructivist counselling in schools in South Africa. The following recommendations are therefore made from the conclusions reached in section 6.2:

- 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.

- Training of counsellors - 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.

- Food and nutrition assistance - 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.

• Collaboration - 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 have 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.

- Health Advisory Committee - School systems should establish a health and education HIV/AIDS advisory committee that includes 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.

- 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.

6.4 THE UNIQUE CONTRIBUTION OF THIS STUDY

The unique contribution of this study lies in its provision of an in-depth exploration of the infected learners’ ‘lived’ experiences of the HIV/AIDS epidemic, contextualised within the social context of their environments and the impact these environments have had on their psycho-social well being. The responses of the participants as well as the researcher’s observations indicated that there is a link between the personal and the social issues, this can be observed on how finances determine access to resources and inevitably determine the experience of living with HIV. For the participants, finances as well as the nature of support that these participants get is the determining factor in terms of the possibility of coping and access to information, which inevitably determines their prognosis.

Furthermore, the research suggests that living with HIV is very different to life with other terminal diseases, as it is bound up with very potent, social and private constructions of disease linked with stigma, shame and prejudice. This becomes more difficult for learners as besides dealing with being infected they are also expected to perform well at school. This has implications for public and social education around HIV/AIDS in addressing ignorance and lack of education around transmission and also for provision of extra lessons to those who are frequently absent because of illness.

The participants indicated that although they are scared to initiate support groups for learners with HIV/AIDS because of age and fear of discrimination,
they feel it is important to have support groups either at school or at their homes.

The research further suggests that gender acts as an intercepting mediator in the experience of HIV. The participants observed a significantly altered experience of HIV based on gender relating to biological manifestations of the disease, responses to it, and responses from others.

6.5 PERSONAL REFLECTIONS

While writing the conclusions of the research and reflecting on the findings and research process, the researcher was astounded by how profoundly moved and deeply personally affected she became by this research. The literature and theory came alive and were given a deeply human voice and spirit through interactions with the infected learners. Their human struggles as well as their internal and external battles were generously shared. While living with HIV was by no means described as renowned, it was some infected learner's ability to find meaning and purpose that was undeniably renowned and admirable. In turn, our interactions have left a great impact and sense of admiration on my behalf for infected learners finding meaning and purpose in their struggles with life and death.

6.6 SUMMARY

In summary, it may be noted that the experience of living with HIV is one, which may be described as layered and perplexing. It may be understood as an experience embracing many contradictions and holding much ambivalence. In becoming HIV positive, individuals are faced with many tasks and transformations both on a physical as well as a psychic level. Thus, the experience of integrating a life-threatening disease into a person's way of being- in-the-world in relation to the self and others, involves a very complex process. This process consists of overwhelming and intense feelings. Invariably forcing issues of loss, limitation and death, to be carefully looked at and examined. Nonetheless, through death becoming more certain and in some ways expected, life is given a greater sense of meaning and focus. In turn, often creating the space for the rediscovery of spirituality, religion and
compassion, and in some way gaining a sense of meaning and sense. It is hoped that this research has managed to access the experience of living with and making meaning of HIV.
REFERENCES


BARNETT, T. & WHITESIDE, A. 2000. Guidelines for studies of the social and economic impact of HIV/AIDS. Best Practice Collection, UNAIDS.


171


DEPARTMENT OF HEALTH. See SOUTH AFRICA. DEPARTMENT OF HEALTH.


FREDRICKSON, G. 2000. Extracting meaning from past affective experiences: the importance of peaks, ends, and specific emotions.


181


MARTIN, J. & SUGARMAN, J. 1996. Bridging social constructionism and cognitive constructivism: a psychology of human possibility and constraint. A revised version of an invited address by the first author presented at the AERA annual meeting in New York. (Available from Jack Martin, Faculty of Education, Simon Fraser University, Burnaby, B.C. Canada V5A 1S6.)


REKER, G.T. 2000. Theoretical perspective, dimensions, and measurement of existential meaning. (In G.T. Reker & K. Chamberlain (Eds.),


WHO see World Health Organisation


ADDENDUM A

A CONSTRUCTIVIST COUNSELLING STRUCTURE

INTRODUCTION

This proposed constructive counselling structure uses the analogy of a human body to illustrate a socially contextualized approach to counselling learners suffering from HIV/AIDS. The human body functions very well when the blood, circulatory, respiratory, digestive, musculoskeletal, reproductive, nervous and excretory systems that constitute it are well co-ordinated.

In light of this understanding, a constructivist counselling 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 'lived' experiences.

An effective reciprocal interaction among all these social systems can be an effective ecosystemic and constructive way of co-ordinating social processes and services for helping children and adolescents suffering from HIV/AIDS to psychologically, socially and biologically develop in the environments that are health promoting, just as the effective symbiotic interactions between different biological systems of human beings enable its body to be lively, healthy and functional.

RATIONALE FOR USING THE HUMAN SYSTEMS

The human body is like a complex bureaucratic organization, such as in industries, schools and so on that has an important job to get done on a tight
deadline. In order to get everything done perfectly and on time, it has to use a co-ordinated system.

Actually, the human body uses many systems that work side by side. The ecosystem theory applied in constructivist counselling uses a similar approach where techniques are:

- joined (engaging and entering the family, school, communities and societal systems);
- assessed (identifying maladaptive interactions between schools, families and communities which have a bearing on the psychological, social and biological development of children and adolescents suffering from HIV/AIDS); and
- restructured (transforming maladaptive interactions for the benefit of children and adolescents who are suffering from HIV/AIDS).

Constructivist counsellors will assess and facilitate healthy family interactions based on socio-cultural values and norms of the child/adolescent and family being helped. Interactions with families and other social support systems within the communities such as non-governmental organizations that are oriented towards HIV/AIDS, social workers, educational psychologists, physiotherapists, occupational therapists, medical doctors, izinyanga and izangoma (traditional health practitioners), abathandazi (spiritualists) and so on are critical to helping school-going children and adolescents suffering from HIV/AIDS develop psychological, physical and social resilience which they so need in order to develop maximally.

The use of the ecosystems theory will, therefore, address dysfunctional social interactions in learners suffering from HIV/AIDS' families and broader ecosystems, and engage these systems to socially, psychologically and physically support and regulate these learners’ positive metacognitive, motivational and behavioural changes.
THE STRUCTURE OF THE HUMAN BODY DEPICTING THE STRUCTURE OF CONSTRUCTIVIST COUNSELLING

The structure of the human body that is presented on the next page represents the structure of constructivist counselling which the researcher proposes for assisting learners suffering from HIV/AIDS.
The table on the next page explains what each system of the human structure represents in the constructivist structure that is proposed in this research. The systems of the body illustrated in the above-mentioned structure represent the metatheory of constructivism (see chapter 2), ecological and systems theories, learning support, the theory of inclusion, counselling and psychotherapy which the researcher see as core constituent theories for effectively psycho-socially supporting learners suffering from HIV/AIDS and which should always be in the mind of the constructivist counsellor.
The above table can be explained as follows:

- Just as the brain regulates the thinking capacity of the human being, learning support provision at schools can assist learners suffering from HIV/AIDS to personally regulate their metacognitive, motivated and behavioural involvement in their own learning.

- Just like the lungs help the human body to breathe in refreshing oxygen and breath-out used-up carbon dioxide, the philosophy of inclusion of all stakeholders which have a direct influence on the psychological, social, and physical development of children and adolescents such as educational psychologists, physiotherapists, medical doctors, pastors, izinyanga and izangoma, social workers and so on can assist schools to develop new psycho-social programmes which educators and parents can use in helping children and adolescents suffering from HIV/AIDS to develop healthily and holistically.

- Just as the heart is responsible for transporting blood throughout the body and thereby providing life in the human body, counselling has the capacity to unfold the latent cognitive, affective and conative potentialities of children and adolescents suffering from HIV/AIDS and thereby develop strengths for meaningful and positive living. As the
heart is the 'engine' of the human body, constructivism as propounded by Piaget, Vygotsky and Bandura is the 'engine' of the post-modern era and twenty-first century counselling and education of learners because of its emphasis and focus on the significance of the environment and its social context in the psycho-social development of human beings.

- Just as the kidneys filter more than two litres of water and waste from the body every day and clean more than 225 litres of blood on a daily basis thus eliminating the wastes and the excess water from the body through urination, psychotherapy has the capacity to assist learners who are suffering from HIV/AIDS to cleanse themselves of all the psycho-social problems associated with this disease, thus developing solutions which will enhance their psychological, social and physical resilience.

- Just as capillaries are responsible for the free flow of blood in and out of the heart, ecological and systems theories are responsible for effective implementation of interactive and meaningful relationships among schools, families, communities, societies and the world.

The ecological and systems theories, which are premised on constructivism as a metatheory promote connectedness, inclusion and partnership among all social systems in communities. The ecological and systems theories’ structure of environments is as follows:

- the *microsystem* – this is the layer closest to the child and contains the structures with which the child has direct contact. The microsystem encompasses the relationships and interactions children have with their immediate surroundings (Berk, 2000). Structures in the microsystem include family, school, neighbourhood, or child-care environments. At this level, relationships have impact in two directions - both away from the child and toward the child. For example, a child's parents may affect his beliefs and behaviour - however, the child also affects the behaviour and beliefs of the parent. Bronfenbrenner calls these *bi-
directional influences, and he shows how they occur within among all levels of environment. The interaction of structures within a layer and interactions of structures between layers is key to this theory. At the microsystem level, bi-directional influences are strongest and have the greatest impact on the child. However, interactions at outer levels can still impact the inner structures;

- the mesosystem – this layer provides the connection between the structures of the child’s microsystem (Berk, 2000). The connection between the child’s teacher and his parents, between his church and his neighbourhood, serve as example of this system;

- the exosystem – this layer defines the larger social system in which the child does not function directly. The structures in this layer impact children’s development by interacting with some structure in their microsystem (Berk, 2000). Parent workplace schedules or community-based family resources are examples. The child may not be directly involved at this level, but they do feel the positive or negative force involved with the interaction with their own system;

- the macrosystem – this layer may be considered the outermost layer in the child’s environment. While not being a specific framework, this layer is comprised of cultural values, customs, and laws (Berk, 2000). The effects of larger principles defined by the macrosystem have a cascading influence throughout the interactions of all other layers. For example, if it is the belief of the culture that parents should be solely responsible for raising their children, that culture is less likely to provide resources to help parents. This, in turn, affects the structures in which the parents function. The parents’ ability or inability to carry out that responsibility toward their child within the context of the child’s microsystem is likewise affected; and

- the chronosystem – this system encompasses the dimension of time as it relates to a child’s environment. Elements within this system can be either external, such as the timing of a parent’s death, or internal, such
as the physiological changes that occur with the ageing of a child. As children get older, they may react differently to environmental changes and may be more able to determine the way that change will influence them.

The connectedness of social systems as explained in the latter paragraph can be depicted in the table below. This table illustrates a constructivist and ecosystemic approach that schools can adopt in dealing with the HIV/AIDS epidemic.

**Figure 7.1: Constructive counselling approach for dealing with HIV/AIDS at schools. (Donahue & Markman, 1999:3).**
The above table shows how parents (family systems), school systems, and community agencies can interact in their concerted effort to deal with the HIV/AIDS epidemic.

From the foregoing paragraphs it is apparent that the constructivist counselling process should encompass collaboration in order for it to be effective.

**Collaborative processes**

The reciprocal interaction of all the social systems will lead to the collaborative processes, which appear below:

- **Assessing learners' suffering** from HIV/AIDS in order to identify their psychological strengths, limitations and external and internal social barriers to learning.

- **Make recommendations** and initiate learning support programmes such as Individualised Educational Programmes; Key Skills support programmes, Vocational learning support programmes, Inclusive learning programmes and others.

- **Dynamic and continuous assessment** - some emergency situations arise when a learner suffering from HIV/AIDS is threatening to hurt him/herself or someone else. The constructivist counsellor may embark on an immediate risk assessment in appropriate circumstances. Attention to ensure safety will be reviewed and some short-term follow-up may occur. In some cases, the client will be referred to other community programs.

- **Link to systems including psychopathology** - Through personal or family counselling, liaising with educators or parents, and where necessary referring to outside agencies (who may then work with the constructivist counsellor).
Collaboration is the process whereby two individuals or groups work together for a common goal, a mutual benefit, or a desired outcome. Trust, respect, openness, active listening, clear communication, and risk taking are fundamental requirements for collaborative efforts. In order for collaboration to happen in a school system, participants (including community organizations, families, members of the health sector such as psychologists, nurses, general practitioners, pathologists, dietitians and members of the Social Development such as social workers, business and industry as well as members of neighbourhood organisations) must share a common vision and agree on a common mission - THAT OF ASSISTING AND SUPPORTING THE LEARNERS AND ADOLESCENTS SUFFERING FROM HIV/AIDS.

The motivation for a common mission may be the need to identify or solve a problem, to focus on the issues relating to HIV/AIDS and its impact on the school system and the effect on learners and adolescents suffering from HIV/AIDS, or to achieve consensus regarding strategies that need to be used to assist and support these learners. Initiating and maintaining collaborative efforts is an appropriate role of the school counsellor.

**EFFECTIVE COLLABORATION** is built on:

- the **STRONG PERSONAL CHARACTERISTICS** of the collaborator (which is the constructivist counsellor);

- a clearly defined system (the family, communities, societies and health sector); and

- administrative support for a change within the school system, administrative support coming from the local level (members of the School Management Teams and School Governing Bodies), district level (members of the learner support services), provincial and national level.
ROLES OF A CONSTRUCTIVIST COUNSELLOR

Just like the role of the excretory system and the digestive system is to cleanse the body of all the digested nutrients in the human body, the new role of the school system and school counsellors in the twenty-first century is also to cleanse the school system and its wider community of the negative perceptions and attitudes of community members towards people suffering from HIV/AIDS, stigma and discrimination, isolation, culture of silence towards HIV/AIDS which breeds non-disclosure of positive HIV/AIDS status and denial.

The roles of the constructivist counsellor, which are facilitation of positive change, effective use of counselling skills and building of a counselling relationship, will be discussed below:

Facilitation of positive change

The constructivist counsellor will work as a facilitator of positive change, a change agent and an expert in trans-theoretical theory, that is, application of various theories such as constructivism and ecosystems. All this will be possible by the use of the following:

- **Solution focused counselling** - Solution focused brief therapy (SFBT) is a short term goal-focused therapeutic approach which will focus on helping the learners change by constructing solutions rather than investigating problems. Articulating what the impact of positive changes will be like on their lives is often more important than understanding what led to the problem. The solution focused counselling is based on the premises that everyone has the ability to change and that the solutions are often already present in the individual's life which is the basis for ongoing change.

- **Narrative counselling** - Narrative therapy is premised on the idea that the lives and the relationships of persons are shaped by the knowledges and stories that communities of persons negotiate and
engage in to give meaning to their experiences and certain practices of self and of relationship that make up ways of life associated with these knowledges and stories.

- **Cognitive behaviour therapy** - Cognitive behavior therapy combines two very effective kinds of psychotherapy which are cognitive therapy and behavior therapy. Behavior therapy will help learners weaken the connections between troublesome situations and their habitual reactions to them. These reactions include fear, depression or rage, and self-defeating or self-damaging behavior. It will also teach them to calm their minds and body, so they can feel better, think more clearly, and make better decisions.

Cognitive therapy on the other hand will teach learners how certain thinking patterns are causing their symptoms by giving them a distorted picture of what’s going on in their lives, and making them feel anxious, depressed or angry for no good reason, or provoking them into ill-chosen actions; and

- **Postmodern approaches from multicultural perspective**

The skills to use the above approaches need to be acquired so that they can be appropriately implemented.

**THE FACILITATION OF POSITIVE CHANGE** can also be demonstrated by combining the above approaches, thereby adopting a trans-theoretical approach which helps the learner suffering from HIV/AIDS to:

- resolve emotional wounds that lead to anxiety, depression, addictive behaviours, spiritual pain, and self-defeating beliefs;

- understand the messages that the symptoms carry;

- regulate his/her own emotions; and

- explore connections between emotions and physical symptoms;

- develop harmony between thoughts and feelings;
• enhance **creativity**, and spiritual development; and

• explore issues in context of his/her spiritual, cultural, and political values.

The above postmodern approaches are valued in this research as they rest on the assumptions that **people are competent** and can be trusted to use their resources in creating better solutions and **more-life affirming stories**.

The eclectic approach also uses different approaches to counselling. These approaches are regarded as intertwined, as it becomes difficult sometimes to separate the one from the other.

**Use of counselling skills**

The constructivist counsellor shall have counselling skills such as:

• **Listening**

• **Empathy**

• **Respect**

These **counselling skills** are represented by the heart as an organ of the **blood circulatory system**, this is because the heart is the 'engine' of the human body - if a person's heart stops functioning, s/he dies. The implication here is that **skills in counselling** reinforce therapeutic processes for invigorating strong human psycho-social well being.
It is believed that when principles of life giving, cultural attunement, respect, authenticity and disciplined mindfulness are incorporated into one's own counselling practice, whether when working one-to-one, in groups, or in community development, it is possible to create one's own activities for those people with whom the counsellor works. These principles also enhance the building of a rapport between the counsellor and the counsellee. People come for counselling because they need to be assisted, some are depressed, they need the counsellor to empower them with life skills, build self-worth and help them to regain their dignity.

**USE OF DIFFERENT ROLES OF THE CONSTRUCTIVIST COUNSELLOR**

The constructivist counsellor shall be a:

- collaborator in the sense that s/he forms partnerships with families, community, and societal agencies that are oriented towards HIV/AIDS;

- consultant in the sense that his or her knowledge and skills of counselling within social contexts form the socio-cultural environment of human beings are always solicited by persons in psycho-social distress such as those suffering from HIV/AIDS;

- facilitator in the sense that s/he facilitates contextualized and solution-focused counselling; and

- advocate in the sense that s/he fights for human rights of all human beings including those of learners and adolescents who are experiencing psychological and social distress because of being infected with HIV/AIDS.

**Constructivist counselling** can be approached as a collaborative process whereby counselees have the opportunity to gather necessary skills for self-empowerment, gain awareness of their own psychological and behavioural process, learn ways to cope with overwhelming feelings, redirect patterns of ineffective behaviour and self-defeating thoughts.
The lungs indicate inclusion of learners suffering from HIV/AIDS. This calls for educators who are willing to accept these learners, deal with stigma and discrimination in schools and develop ways of assisting them to achieve their educational goals.

**These roles will assist in:**

- Whole School Development
- Building schools as learning communities
- Building health promoting schools

The presence of an effective constructivist counsellor within a school could be beneficial to its environment in creating an atmosphere that is conducive to the effective learning of a learner suffering from HIV/AIDS.

**Observation of counselling relationship**

The constructive counsellor will observe and consider the following

- counselling relationship;
- *ubuntu/botho* (African inherent human dignity);
- alternative healing; and
- social context and diversity.

Helping people to heal and grow in their relationships is the primary interest of the constructivist counselling.

The counselling relationship is a collaborative process in which both client and counsellor work to facilitate positive change in thoughts, feelings, relationships, and behaviour. The approach should be based on the Christian and Psychodynamic understanding that people heal and mature in the context of relationships that are safe, empathically attuned, and clarifying.
THE COUNSELLING RELATIONSHIP IS CRUCIAL TO THE HEALING PROCESS, whether the problem is with external relationships, traumatic experience, or one’s relationship with one’s self. Psychoanalytic principles and relational dynamics can be used to explore the internal conflicts and patterns that are at the root of emotional, psychological and relational problems. This also includes being sensitive to the existential problems inherent in being human, and how these affect people.

The 21st century counsellor

The above illustration represents an image of the relationship between the 21st century counsellor and the counsellee.
THE FUTURE OF THIS COUNTRY AND ITS NATION DEPENDS ON THE ABILITY OF THE SCHOOL SYSTEM TO LEAD AND TO ADAPT AS IT PREPARES LEARNERS FOR THE FUTURE.

The broad mission of the school health is thus, to fulfil society's interest in assuring conditions in which learners, families and members of the community and society can be healthy.

In order to assure these conditions, integration of new technologies and information from the public health programmes to target both educational and psychological intervention strategies within the school, that will prevent morbidity, mortality, and disability from a wide array of conditions, will have to be adhered to.

Counsellors can increasingly use these technologies and information in research, policy, and programme development. They thus need to be more actively involved in implementing technology.

The technology can significantly affect the work of school counsellors in the areas of information retrieval and dissemination, distance learning, counselling interventions, networking and support systems, and training and supervision.

CLASSROOMS AND COUNSELLING OFFICES IN THE 21ST CENTURY ARE NO LONGER TIED TO RESOURCES IN A TRADITIONAL SCHOOL BUILDING.

Learners can obtain information from virtually anywhere, as technology has opened the door to distance learning. In addition, school counselors can involve learners in the videoconferencing process by having them interview community members and business leaders regarding issues on HIV/AIDS that affect their school. Counsellors also need to be abreast of the latest occupational information and trends.

When counsellors share ideas, concerns and successes, we are to benefit!
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>When did you come to stay with your grandmother and step-grandfather?</td>
</tr>
<tr>
<td>Who advised you to come and stay with your grandmother?</td>
</tr>
<tr>
<td>How many people live in your grandmother's house?</td>
</tr>
<tr>
<td>In which area do you sleep at night? Do you sleep in your own bed?</td>
</tr>
<tr>
<td>Are you comfortable at night?</td>
</tr>
<tr>
<td>When last did you become sick?</td>
</tr>
<tr>
<td>Is the TB treatment helping Tshepo in any way?</td>
</tr>
<tr>
<td>Is Tshepo still sick?</td>
</tr>
<tr>
<td>Is Tshepo on any other medication except for TB treatment?</td>
</tr>
<tr>
<td>Does Tshepo know that he is HIV positive?</td>
</tr>
<tr>
<td>How did you feel when you were told you were HIV positive?</td>
</tr>
<tr>
<td>What else can you tell me about that day?</td>
</tr>
<tr>
<td>Were you counselled before you were tested?</td>
</tr>
<tr>
<td>Did this affect you with your studies in any way?</td>
</tr>
<tr>
<td>Are you checking Tshepo's schoolbooks?</td>
</tr>
<tr>
<td>How do you feel about your status now?</td>
</tr>
<tr>
<td>How often does a nurse/doctor/health worker visit your school to advise you on HIV/AIDS issues?</td>
</tr>
</tbody>
</table>
What comes to your mind when they talk about the importance of knowing your status?

Have you ever been counselled by a professional counsellor or by a educator at your school?

Do you think being counselled can help you in understanding HIV/AIDS?

Do you still have dreams about your future Tshepo?

How do you make up for the time you have lost because of sickness?

How is your relationship with Tshepo?

What do you think can be done to make Tshepo comfortable at home?

How do you get food now that your husband is not supportive?

How does the school support you?

Do you think infected learners are supported at school?

Who else supports you as a family?

How did the principal get the information about Tshepo’s status?

Do you ever talk about your status with your principal or one of the educators?

Would you like to discuss your positive status with either of them?

INTERVIEW QUESTIONS FOR NTSWAKI

How old were you when you started being abused?
Who abused you?

When did this usually happen?

Did you tell anyone?

How many times did this happen to you?

How do you feel about the sexual abuse?

When you were playing alone were you thinking of the abuse?

What comes into your mind when sexual abuse is mentioned?

Where was your granny when it happened?

What were you given at the hospital?

What happened to your uncle?

Are you not afraid that he is going to come to your home again?

Do you know what your aunt was suffering from?

How did you feel when you were told about your positive HIV results?

Who did you tell about your status?

Why have you not told anyone, especially your friends?

How does being infected affect your school work?

Is it only lack of concentration that disturbs you in doing your work? What are you using for discharge and herpes?

Does it make you better?

How does the school support you? Who supports you most?
Who loves you most in the family?

Have you ever spoken to your mother or your father about your status or sexual abuse?

Have you ever spoken to your mother or your father about your status or sexual abuse?

Were you ever counselled?

How often does your educator counsel you?

How is life in this new home?

What dreams do you have for the future?

What if you live for another 10 to 15 years?

When last did you become sick?

What do you think can make you live longer?

Do you believe that if you can follow this advice you can live a healthy, longer life?

If you have a boyfriend would you tell him about your positive status? What do you mean by ensuring that you are both positive?
INTERVIEW QUESTIONS FOR THE HEALTH WORKER

How long have you been a health worker?

How did you meet Vusi (not his real name)?

How old was Vusi when you met him?

Concerning this case - what were you expected to do?

What did you manage to do concerning this case?

How was Vusi been after being counselled?

Concerning being shabby and looking neglected, what does he look like now?

When and where did you counsel Vusi?

What are the contents of the food parcels you give to people living with HIV/AIDS?

How long does the food parcel last for one family?

When was Vusi tested?

Do you think the social worker can tell Vusi about his status?

Does the school know?
INTERVIEW QUESTIONS FOR VUSI

How is your life?

What are those boring things you do every day?

Is everything that you do boring?

Why don’t you try other things that you have never done, like playing with children you have never played with before?

Is school also boring?

What do you think can make your life less boring?

How do you perform at school?

Why was your performance bad in the last two years?

Is there any change in your performance now?

When last did you become sick?

Do you know your status?

Would you like to know your status?

If you were told that you are HIV negative would that change your boring life?

If you were a father, would you tell your child that s/he is HIV positive?

Were you counselled before you were tested?

Why were you taken for an HIV test?

How is your health now?

How do you feel about being sick?

Do you know what your mother is suffering from?

What do you think Vusi?
What do you think about HIV/AIDS?

Why do you think it kills the whole family?

What are those?

When did you meet the health worker who is taking care of your family?

How does your aunt help you?

Who takes care of you after your aunt has left?

What do you do when you are left with your mother?

Why do you not use this time for doing your homework?

Are you worried about your health?

If you were positive, would you like your educator to know about your status?

Do you think counselling would help you in anyway?