

**AN ECOSYSTEMIC INVESTIGATION OF THE PLIGHT
OF LEARNERS WHOSE PARENTS ARE SUFFERING
FROM HIV/AIDS**

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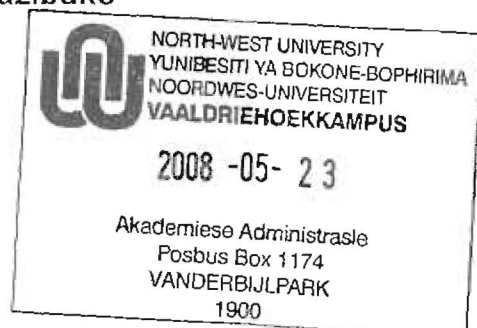
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ABSTRACT

The objectives of this research were to investigate the lived experiences of parents who are suffering from the HIV/AIDS disease, investigate the lived experiences of children whose parents are suffering from the HIV/AIDS disease and propose an ecosystemic intervention programme for supporting children whose parents are suffering from the HIV/AIDS disease.

The literature research investigation revealed that part of the burden that learners whose parents suffer from HIV/AIDS carry comes in the form of mental stress and experiences caused by, merely staying with a sick loved one whose condition deteriorates where hope of improvement was expected, prolonged sickness of a loved one, and witnessing the slow painful death of a loved one especially at home. These children often take on additional domestic tasks or care for sick relatives or younger siblings. The children's attendance can be compromised during this time. Their incentive to protect themselves against infection can be low when HIV is only one of many threats to health and life. Poverty may also breed low levels of respect for self and others, and thus a lack of incentive to value and protect lives. The mediating mechanisms act in ways which reduce the impact of risks, reduce negative chain reactions, maintain self-esteem and self-efficacy through relationships and task achievement and open opportunities for positive development.

Findings from the empirical research reveal that parents who are HIV-positive are unemployable because of their ill-health, a situation which makes their families to leave in dire poverty. The parents often blame each other for their HIV-positive status sometimes as a way of relieving stress, but when these parents blame each other their children are caught in the cross-fire.

Children of parents who suffer from HIV/AIDS are discriminated against and stigmatised by other children, friends and people from their communities. This situation affects these children both psychologically and emotionally. These children assume adult responsibilities at a very tender age, usually lack basic needs such as food, clothing, school uniform, school necessities etc. Their

scholastic performance gets negatively affected because of lack concentration, not having enough time to do homework and being frequently absent from school.

The children become vulnerable to verbal, emotional and physical abuse, do not get the necessary support they need from their family members, community, government institutions such the Department of Health and in schools where they attend. These children do not seem to be coping with the circumstances they find themselves in especially if they are also HIV-positive.

There is no communication between children of parents who suffer from HIV/AIDS and their parents concerning their experiences about the disease, how they feel and the future expectations. There is also no clear plan on what should these children do, in the case of their parents' death. At schools where these children attend there are no clear strategies to assist them to catch-up with their school work after a long absence and the children do not receive any work from school while they are at home sick or recuperating from illness as per the National Policy on HIV/AIDS.

An ecosystemic programme is proposed in this research.

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CHAPTER ONE

ORIENTATION

1.1 INTRODUCTION AND STATEMENT OF THE PROBLEM

It is generally accepted that the HIV/AIDS epidemic seriously has an enormous effect on the social, psychological and physical well being of children. An estimated twenty-two-point-five million people in Sub-Saharan Africa are living with HIV/AIDS (Barnett & Whiteside, 2000b:35). These are mainly adults who in the short, medium and long term are about to die and leave a frightening uncountable number of AIDS orphans exposed to socio-economic problems in their families and communities where they live.

According to Gupta (2001:14) report, there is a total of fifteen-point-two-million children around the world who have lost at least one parent to the HIV/AIDS epidemic. Most of these children are in sub-Saharan Africa, and one-point-two-million are in South Africa, with about four-hundred-and-fifty-thousand having lost both parents (Whiteside, 2003:67).

Most research in South Africa has been dealing with the HIV/AIDS infected children and adults. There is little research, if any, which has been conducted on the plight of children whose parents are suffering from the HIV/AIDS' opportunistic symptoms 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 (De Waal, 2003:64; Whiteside, 2003:67; Parker & Mundawarara, 2002:23).

It is a concern that there is no research that addresses the plight of the children mentioned above, who in all reasons will in the short, immediate or

long term be orphaned. In most cases, children orphaned by HIV/AIDS are often stigmatised and discriminated by members of the community or absent from school because of uncountable reasons that resulted from the burden that is put on them by the HIV/AIDS disease (Benell, Hide & Swainson, 2002:3). Part of the burden comes in the form of mental stress and experiences caused by:

- merely staying with a sick loved one whose condition deteriorates where hope of improvement was expected;
- prolonged sickness of a loved one; and
- witnessing the slow painful death of a loved one especially at home (Makgoba, 2000:16; Binswanger, 2000:32).

All this stresses the surviving children and hence affects their scholastic performance at school and worse still, brings about stigmatization in the survivor, way after the death of the sufferer (Achmat, 2004:17).

Death, especially of parents, often results in a growing number of orphans. Those orphans whose parents are from rural areas are pushed further down the poverty datum line (Tallis, 2002:15). All this has reversed family adulthood roles from parents to children who are still supposed to:

- do their homework exercises assigned by class teachers;
- write assignments;
- do class tests; and
- enjoy playing with others or joining into discussions in and out of school with their peers (Cullinan, 2002:421).

Indeed, research in this subject is needed if South Africa is to succeed in providing for their special needs.

This happens because of nowadays' poverty, unemployment, urbanisation and the nucleation of the family which have eroded the capacity of the

extended family to care for orphans, hence the much-needed societal sympathy on orphans has been eroded as such (Kelly, 2002:23). If the situation is left unrestrained, the poorly socialized children with poor education often run the risk of exposure to HIV/AIDS through prostitution at a younger age in the case of girls or street dwelling with all forms of criminal behaviour in the boy child (UNAIDS, 2001:80).

Different Governments and Non-Governmental Organisations have put in place various efforts in addressing the issue of orphaned and vulnerable children. This has included:

- social grants;
- paying of fees and provision of uniforms to such children;
- putting them in children's homes;
- the issue of foster parenting; and
- giving out food handouts (Hecht, Adeyi & Semini, 2002:37).

In the light of the above stated experiences and stresses these children have to endure because of their sick parents, there is a need for an ecosystemic intervention which has the efficacy to help these children cope both psychologically and socially at schools (Campbell, 2003:24). This means that broadening the scope of special educational interventions for children whose parents are suffering from the HIV/AIDS disease, requires new social collaborations across multiple social sectors and disciplines such as bringing together a range of expertise extending beyond the health field which can raise significant challenges for creating effective psychological and social synergy for dealing with the HIV/AIDS epidemic's effects on the psycho-social well-being of children (Phiri & Webb, 2002:59). Indeed, South Africa needs a synergistic system that connects schools, communities, churches, clubs and others, to one another with the purpose of socially preparing these children and their peers to deal with the HIV/AIDS epidemics' challenges (Hall, 2003:87).

An ecosystemic intervention mentioned in the latter paragraph implies moving away from individual-focused interventions to ecosystemic interventions shifts where the emphasis towards concepts of community participation, community mobilisation and empowerment in dealing with HIV/AIDS takes place. The importance of community-led peer education and the participation of local stakeholders are emerging as a guiding principle for ecosystemic interventions which seek to engage the broader socio-contextual factors relevant to children's psychological and social suffering from the HIV/AIDS epidemic (Dorrington, Bourne, Bradshaw, Laubscher & Timaeus, 2001:23). Yet, involving communities in the conceptualisation, implementation and/or evaluation of programmes dealing with the psychological and social well being of children affected by HIV/AIDS, can raise significant challenges, and there is little understanding about the process of community mobilisation or the techniques that best promote sustainable community participation in supporting children who are psychologically and socially suffering because of the HIV/AIDS epidemic (Beck, Miners & Trolley, 2001:17).

The questions that now come to mind are:

- What are the lived experiences of parents who are suffering from the HIV/AIDS disease?
- What are the lived experiences of children whose parents are suffering from the HIV/AIDS disease?
- Can an ecosystemic intervention programme be developed for children whose parents are suffering from the HIV/AIDS disease?

Having posed the above questions, the following section will state the objectives under-pinning this research.

1.2 OBJECTIVES OF THIS RESEARCH

The objectives of this research are to:

- investigate the lived experiences of parents who are suffering from the HIV/AIDS disease;

- investigate the lived experiences of children whose parents are suffering from the HIV/AIDS disease; and
- propose an ecosystemic intervention programme for supporting children whose parents are suffering from the HIV/AIDS disease.

1.3 ECOSYSTEMS AS THE THEORETICAL FRAMEWORK OF THIS RESEARCH

In this study, the theory of supporting children whose parents are dying of the HIV/AIDS through ecosystemic perspective formed the basis. This theory was formulated by Bronfenbrenner (1979:23), who identified the following four social systems of interrelationships that influence human development, which are the:

- microsystem;
- mesosystem;
- exosystem; and
- macrosystem.

Bronfenbrenner's (1979:37) ecosystemic theory focuses on the child and the influences of the above social systems have on his/her human development. When examining ways in which the effectiveness of the child's involvement with social spheres of influence such as families, schools, and communities actually influence his/her healthy development during the era of HIV/AIDS epidemic, Bronfenbrenner's model provides a framework to consider the interactions within the social systems and between the social systems and their psychological and social influence on the child.

On the basis of the latter paragraph, this research inquiry is focused on examining social relationships between three of the child's microsystem groups such as family members, educators, and community members who have direct contact with him/her in dealing with the effects of the HIV/AIDS epidemic on his/her psychological and social well being. When these groups

have direct interactions with the child, they are in the child's microsystem. However, when the groups interact with each other they are acting as members of the child's mesosystem.

An ecosystemic perspective that highlights the synergistic relationships that exist among families, schools and communities is significant in any programme that aims to promote school-family-community-society-world systems interrelationships and symbiosis in an endeavour to support children whose parents are suffering from the HIV/AIDS disease.

1.4 RESEARCH METHODS USED IN THIS RESEARCH

This section presents the research methods used during the proceedings of this research. It includes both the explanations of the literature review and the qualitative empirical research methods which this researcher employed to answer the questions highlighted in section 1.1 of this research and thereby achieve the objectives mentioned in 1.2.

1.4.1 Literature review method

International and national educational journal articles, books, papers presented at professional conferences, government policy documents, dissertations and theses written by graduate scholars and reports compiled by school researchers, university researchers and government agencies providing information and policies on HIV/AIDS and children affected by HIV/AIDS served as both primary and secondary sources.

1.4.2 Qualitative empirical research method and design

Qualitative empirical research methods focus on phenomena that occur in natural settings that are in the 'real world' and involve studying those phenomena in all their complexity (Leedy & Ormrod, 2005:133). According to White (2005:80), they deal with empirical research data that are principally verbal. White (2005:81) further posits that qualitative empirical research is more concerned with understanding social phenomena from the lived experiences of the participants. This happens through the researcher's

participation in the daily life activities of those involved in the research. Cresswell (2003:15) is of the opinion that qualitative empirical research is an inquiry process of understanding, based on distinct methodological traditions of inquiry that explore a social or human problem. In the process of his/her research, the researcher builds a complex, holistic picture, analyzes words, reports, detailed views of informants, and conducts the study in a natural setting.

De Vos (2001:240) sees qualitative empirical research as a multi-perspective approach to social interaction, aimed at describing, making sense of, interpreting or reconstructing this social interaction in terms of the meanings that the participants who form the population sample of the study attach to it. Denzin and Lincoln (2005:143) postulate that qualitative empirical research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.

From the foregoing paragraphs in this section it is clear that qualitative empirical research involves the studied use and collection of a variety of empirical materials such as case studies, personal experiences, introspections, life-stories, interviews, observations, historical, interaction, and visual texts that describe routine and problematic moments and meaning in individuals' lived experiences.

This researcher chose a qualitative empirical research method for this research because:

- it uses an inductive form of reasoning: develops concepts, insights and understanding from patterns in the data;
- it derives meaning from the subject perspective;
- it is ideographic: aims to understand the meaning that people attach to everyday life;

- it captures and discovers meaning once the researcher becomes immersed in data;
- its observations are determined by information richness of social settings, and types of observations used are modified to enrich understanding;
- its concepts are in the form of themes, motives and categories; and
- its data are analysed by extracting themes (Denzin & Lincoln, 2005:45).

Such a method seems appropriate in exploring the lived experiences of both the children whose parents are suffering from HIV/AIDS.

In exploring the lived experiences of both the children whose parents are suffering from the HIV/AIDS disease as well as their parents who are suffering from the HIV/AIDS disease who formed the population sample of this research, this researcher conducted a phenomenological qualitative empirical research. The term phenomenology refers to a person's perception of the meaning of an event, as opposed to the event as it exists externally to a person (Leedy & Ormrod, 2005:139). This study attempted to understand adult learners' and educator's perceptions, perspectives and understanding of adult basic education and training provisions in their social settings.

1.4.3 Population sample of this research

This section discusses the:

- way in which the participants who formed the population sample of this research were selected;
- ways in which the empirical research data were gathered and transcribed; and
- ways in which themes were deduced from the participants' personal responses.

Since this research is purely qualitative in nature, purposeful sampling was used. The qualitative approach was used, because the researcher wanted to be able to:

- record and understand the plight of children whose parents suffer from HIV/AIDS in their own terms;
- observe natural, ordinary 'lived' experiences of children whose parents suffer from HIV/AIDS; and
- generate detailed empirical research data about the children studied and also to provide contextual understanding (De Vos, 2001: 177).

There are different types of purposeful sampling, and network sampling is one of the types of purposeful sampling mentioned by Merriam (1998:137). The researcher decided to utilise network sampling. Patton (2001:182) argues that this strategy of purposeful sampling involves identifying cases of interest from people who know what cases are information-rich, that is good examples for the study, and good interview subjects. In purposeful sampling, size and specific cases depend on the study purpose. The researcher used her network of friends who are managers of Non-Governmental Organizations, social workers, members of the support groups for HIV-infected and -affected people and colleagues to conduct network purposeful sampling. The researcher decided to approach a social worker working with street, abandoned, orphaned and neglected children. The interviewer requested the social worker for assistance, as it was difficult to get this kind of information at schools because educators were not aware of children who have parents who are suffering from the HIV/AIDS disease. The social worker assisted the researcher with two case studies of children whose parents suffer from the HIV/AIDS disease, who happened to stay in Edenville and Kroonstad in the Fezile Dabi Education District of the Free State. In these case studies, one educator, a health-worker, two children, four parents and a grandmother were interviewed (N=9). Educators do not know which children have parents who suffer from HIV and they have to depend on whether parents are prepared to disclose their HIV/AIDS positive status or not.

1.4.4 Empirical research instrument

To elicit empirical research data from the participants who formed the sample of this research, an interview question schedule was used (see appendix A). This interview question schedule was used to conduct in-depth and semi-structured interviews which involved one-to-one interaction. In-depth and semi-structured interviews were conducted to encourage each participant to express himself/herself freely about his/her plight of learners whose parents suffer from HIV/AIDS. In-depth interviewing focuses in considerable detail on the plight and social behaviour of individual participants. An open-ended interview was used to explore each participant's thoughts and feelings about his/her plight of having parents who suffer from HIV/AIDS. In this open-ended interview, a group of questions was used to guide the interview (see Appendix A).

According to Patton (2001:75), open-ended interviewing is considered to be an effective way to obtain individual perspectives. Open and non-threatening questions, such as the first question, "Would you tell me about yourself?" were included in order to help establish rapport and to allow the interviewee to respond freely. In addition to developing rapport, the open-ended interview dialogue was selected, because it assisted with enhancing the communication level between the respondent and the interviewer.

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

Empirical research data collections and analyses are not independent processes in a qualitative research design. While data collection actually entailed the process of interviewing, informal analyses of the respondents were also conducted during the interview. Handwritten assessment notes taken during and after the interview, constituted part of the initial research design. Immediate review of audiotapes, a *verbatim* review of the interview

transcript and notes to the methodological log, were additional analysis steps that intertwined with data collection. Thus, analysis was ongoing and occurred during the process of data collection.

1.5 ETHICAL CONSIDERATIONS

Due to the charged and emotive nature of the HIV/AIDS epidemic's phenomenon, certain ethical considerations assumed particular importance. Denzin and Lincoln (2005:230) notes, that the very nature of the aim of a phenomenological study, namely to access the individual's life-world, is obtrusive. In this study, this obtrusiveness will further be exacerbated by the sensitivity of the topic under investigation. First and foremost, the researcher will have a responsibility to respect the rights, needs, values and wishes of the participants (Berg, 2003:112). In order to protect the participants' rights, the following safeguards as listed by Cresswell (2003:123), are employed, which are that:

- the research topic and objectives were expressed clearly in order to be well understood by the participants;
- each participant's consent was requested to participate in the study;
- transcriptions, interpretations and reports were made available to those participants who wished to see them;
- in any decision-making process in the study, the researcher considered the rights and protection of the participants; and
- the researcher honoured confidentiality. The participants chose their pseudonym to be used in the texts in order to protect their anonymity. It was anticipated, that the discussion of the experience of meaning in individuals with HIV, could prove to be emotionally distressing for some participants. If necessary, the researcher would make recommendations for therapeutic interventions (Merriam, 1998:67).

1.6 OVERVIEW OF THIS RESEARCH'S CHAPTERS

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

Chapter two presents the literature review on literature review on the HIV/AIDS epidemic and the ecosystems theory

Chapter three presents the empirical research design.

Chapter four presents the analyses and interpretations of the empirical research results.

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

1.7 CONCLUSION

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

The next chapter presents the literature review on the HIV/AIDS epidemic and the ecosystems theory

CHAPTER TWO

LITERATURE REVIEW ON THE IMPACT OF HIV/AIDS ON CHILDREN WHOSE PARENTS SUFFER FROM HIV/AIDS

2.1 INTRODUCTION

This chapter presents literature review on factors that affect children whose parents suffer from HIV/AIDS. In terms of section 28 of the South African Constitution (RSA, 1996), a child is defined as a person younger than 18 years old. This research has adopted this definition of a child.

2.2 STIGMA AND DISCRIMINATION

Stigma can be defined as the identification and recognition of a bad or negative characteristic in a person or group of persons, and treating them with less respect or worth than they deserve due to this characteristic. Stigma also generally refers to a negatively perceived defining characteristic, either tangible or intangible. It is an attribute used to set the infected or affected persons or groups apart from the normalized social order, and this separation implies devaluation (Barnett & Whiteside, 2002a:16). In regard to HIV/AIDS, the stigma may be the actual infection or it may be based on behaviours believed to lead to infection. The association with an incurable disease is then used as medical justification for established patterns of exclusion of groups already deemed morally questionable (Smart, 2000:12). Conversely, people living with HIV/AIDS may become implicitly associated with stigmatized behaviours, regardless of how they actually became infected (Hooper-Box, 2005:27). These pathways of stigma are difficult to disentangle, but mutually reinforce each other (Barnett, 2002:26).

Furthermore, stigma may be applied with varying degrees of force, depending on local moral judgements about means of acquisition (Sidley, 2000:47). In South Africa, a clear gradient of "guilt" and "innocence" has formed the discourse surrounding HIV/AIDS. Sex workers or injection drug users who contract HIV are classified as most guilty, with children of sex workers

following (Johnson & Dorrington, 2001:53). At the other end of the spectrum, monogamous wives infected by their husbands who use drugs or visit sex workers are considered to be “innocent” and “vulnerable,” while their HIV positive children, infected during pregnancy, birth, or breastfeeding become the ultimate “defenseless victims.” Varying degrees of stigma are applied to these groups of people living with HIV/AIDS, and often to their family members or immediate communities (Hellinger & Fleishman, 2000:183).

Discrimination is composed of the actions or treatment based on the stigma and directed towards the stigmatized (Wolitski, Valdiserri, Denning & Levine, 2001:884). The stigmatized find themselves ostracized, rejected, and shunned and may experience sanctions, harassment, scapegoating, and even violence based on their infection or association with HIV/AIDS (Fassin & Schneider, 2003:496). Discrimination may spring from social disapproval of the infection and its implied behaviors or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted. Because the HIV pandemic emerged so suddenly and progressed so quickly, in many countries discrimination could result from people’s belief that not enough time remains to weigh carefully the strengths and weaknesses of various alternative solutions to an AIDS-related problem (Pick, 2003:55) and the reaction is thus to err on the side of caution, even at the expense of individual rights.

Ultimately, however, the concepts of stigma and discrimination are closely linked. Some authors choose to refer to discrimination as “enacted stigma”. Because discrimination often includes public restrictions and punishing actions, however, it can frequently be more easily identified, and thus will remain separately defined in this review (Hellinger & Fleishman, 2000:187).

2.3 WAYS IN WHICH CHILDREN CAN BECOME INFECTED WITH HIV

2.3.1 Children infected by HIV/AIDS through unsafe health practices

Badcock-Walters (2001:6) notes that the second most frequent transmission route namely through blood transfusions, is the most efficient. When infected blood is transfused, the risk of acquiring HIV is remarkably high, ranging from 90 to 100 percent. Infection via blood transfusion occurs through the

transfusion of contaminated blood and through the use of contaminated needles and syringes (MacIntyre, 2001:170).

2.3.2 Negative attitudes of Blacks towards HIV/AIDS

The attitude towards HIV/AIDS among Black South Africans is different. Definitions of health, sickness and sexuality have different meanings in the traditional African context, than in the Western world. It has been very difficult to change Black people's attitude because all HIV/AIDS education and prevention programmes have mostly been based on Western principles, without understanding the diverse cultural and belief systems of Africa and incorporating them into such programmes (Arndt & Lewis, 2000:857).

James (2001:6) opines that illness among Black people is not a random event. Rather, every illness is a product of destiny and has a specific cause. For Blacks, in order to eliminate the illness, it is necessary to identify, punish, eliminate and neutralise the cause, the intention behind the cause and the agent of the cause of intention (Hooper-Box, 2005:32). Illness, according to Black cultural beliefs, can be a result of disharmony between a person and the ancestors, caused by God, spirits, witches and sorcerers, natural causes, or a breakdown in relationships between people (Hellinger & Fleischman, 2000:185).

Ancestors are seen to have an integral influence on the lives of Africans. They are believed to protect people against evil. However, ancestors could purportedly punish people by sending illness and bad luck if people are ignorant of observing traditions that keep the ancestors happy. People can also cause disharmony between themselves and the ancestors if certain social norms and taboos are violated (Parkhurst & Lush, 2004:16).

Scheinder (2000:12) believes that ancestors do not always send illness, but through the withdrawal of their protection, people become susceptible to illness, tragedy and spells cast by witches and sorcerers. Illness caused by ancestors is seldom serious or fatal, and through offerings and sacrifices, a positive relationship is restored between people and their ancestors. There is no available evidence that traditional Africans link AIDS to the anger of the

ancestors or to punishment from God. Some Christians do, however, believe that AIDS is God's punishment for immorality and sin (Tesa, 2001:80).

Bertozzi, Opuni and Bollinger (2002:50) state that witches and sorcerers are frequently blamed for illness and misfortune in traditional Black African societies. Because traditional Africans often use the services of witches and sorcerers to send illness and misfortune to their enemies, they in turn, believe that whatever bad luck or illness is incurred, is a product of witches or sorcerers.

Among many rural, poor and uneducated Africans, HIV/AIDS is seen as being caused by witchcraft. Many people ascribe sexually transmitted diseases (STD) to witchcraft (Kelly, 2002:17). They base this belief on the argument of why does one man become infected and the other remain uninfected when both men have had sexual contact with the same woman (Dorkenoo, 2001:23).

When relationships are in conflict, or threatened, accusations of witchcraft are raised against members of a group or a community (Johnson & Dorrington, 2001:58). In African societies, death is only accepted as natural when the elderly die. When younger people die, it is viewed as untimely and attributed to punishment or the work of evil spirits or witches (Hall, 2003:26). This psychological rationale of blaming witchcraft implies that Africans are not taking responsibility for their actions and are displaying an external locus of control. This viewpoint prevents people from exercising their personal initiative in preventing a fatal illness such as HIV/AIDS (Ebersohn & Eloff, 2002:18).

Bollinger, Opuni and Bertozzi (2002:60) posit that due to this misconception, many Africans cannot fully appreciate the need for engaging in HIV preventative methods. By blaming witches as the cause of illness, the victim's status suits those who are infected. However, this faulty belief has resulted in many witch-hunts and deaths. By ignoring or undermining traditional witchcraft beliefs, prevention efforts are hindered. Loudon (2002:10) and Mkandawire (2001:40) believe that these beliefs should be incorporated into HIV/AIDS prevention programmes at schools. Interventions should recognise the

personal or ultimate cause of an illness, which may be witchcraft, but the fact that the immediate cause is a “germ or virus” which is sexually transmitted should be emphasised.

Many traditional Africans believe that witches or sorcerers use sexual intercourse as the entry point for their medicines or spells to infect people with sexually transmitted diseases and HIV (Hecht, Adeyi & Semini, 2002:37). For many years, traditional Africans have worn charms which they believe have preventative and proactive powers (Sidley, 2000:140). If the use of these “protective” charms prevent misfortune and illness, Halpepirin (2001:13) asks why the introduction of condoms “blessed” by traditional healers cannot be used to increase their use among traditional people.

Traditional Africans believe that some causes of illness can be ascribed to a failure to “purify” themselves adequately through rituals (Gupta, 2001:30). Ritual impurities are usually associated with sexual intercourse (especially sex with a taboo person), with activities of the reproductive system or with coming into contact with corpses and death (Geeta, 2000:18). In order to cleanse oneself of these “impurities”, a person has to perform extensive cleansing rituals that involve washing, vomiting and purging (Friedman & Mottier, 2004:26).

Carr-Hill and Peart (2003:58) state that although HIV infection is not commonly thought to be a consequence of “ritual impurity,” some of the sexual prohibitions may be useful in HIV prevention programmes. For example, the prohibition against sexual intercourse with a woman during menstruation, with a widow before she is cleansed (her husband might have died of AIDS) or with women who have had an abortion or miscarriage should be encouraged because they can prevent HIV infection.

Traditional Africans believe that some diseases such as colds, influenza and diarrhoea in children, STD's and malaria are caused by natural causes such as germs and viruses (De Waal, 2003:23). Although it is believed that witches may sometimes use germs and sexual intercourse to cause illness, traditional Africans acknowledge that the immediate cause of sexually transmitted

diseases is virus-related, that is, it is transmitted through sexual intercourse and can be prevented by behavioural change (Geeta, 2000:16).

However, the link between STDs, AIDS and sexual behaviour change is often not made in traditional Africa. Many Africans do not understand that they have to alter their sexual behaviour to prevent HIV infection, since the disease affects all organs in the body besides the sexual organs. The AIDS message should therefore be strongly linked to STD prevention in Africa. The knowledge and assistance of traditional healers should be actively employed in the control and prevention of HIV (Gupta, 2001:24).

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

- to abstain from sex while undergoing STD treatment;
- not to have sex with prostitutes; and
- to locate and advise all recent sex partners to be treated (Dorkenoo, 2001:20).

Polygamy is also a way of life for most Africans. Polygamy is valuable to migrant labour, where men leave their wives in the rural areas to seek work in the cities. If a man has several wives, he could take one at a time to live with him in the city, while the other wife/wives remain behind to take care of the household (Sidley, 2000:149).

Parker and Mundawarara (2002:90) state that in some societies sexual intercourse between husband and wife is banned while she is pregnant and this abstinence is practiced until after child-birth or even until the child is weaned. In such situations, polygamy prevents husbands from turning to casual sex. Therefore, in areas where polygamy is practiced, AIDS educators cannot effectively preach monogamy. They need to emphasise loyalty and fidelity between a husband and all his wives and discourage sex outside that group.

James (2001:34) found that the resistance to condom use in Rwanda has nothing to do with ignorance, but relates to social and cultural dimensions of Rwandan sexuality. They believe that the flow of fluids involved in sexual intercourse and reproduction are indicative of “gifts of self” which Rwandans regard as vital in a relationship (Phiri & Webb, 2002:63). The use of condoms, according to them, blocks this vital flow between partners, and cause infertility and other illnesses. There is also fear that the condom may stay blocked in the vagina and cause “blocked beings.” In many parts of Africa, there is a widespread belief that repeated inseminations of semen are needed to form or “ripen” the growing foetus in the womb (Pick, 2003:58). It is also believed that semen contains important vitamins that are necessary for the continued physical and mental health, beauty and future fertility of women (Johnson & Dorrington, 2001:56; Makgoba, 2000:21).

This research intends to investigate whether the above-mentioned misconceptions have not been transmitted as values and norms to children who grow up in communities with such cultural beliefs and convictions. The literature review has revealed that there are children who believe that HIV/AIDS can be transmitted through forms of casual contact, such as kissing, sharing a drinking glass and contact with a toilet seat (Kelly, 2002:43). These lingering misconceptions are contributing factors that create prejudice against HIV-positive individuals, since children who believe that HIV can be transmitted in these ways are much more likely to express discomfort about attending schools with those children who are infected with HIV/AIDS.

The foregoing paragraphs highlight the socio-culturalness of aspects of HIV/AIDS in Africa. Research findings indicate that Africa has the largest number of people living with HIV/AIDS in the world, and the fastest growing epidemic. The reasons for this are complex; nevertheless, certain socio-cultural factors have been identified as responsible for the rapid spread of the disease.

2.3.3 Physical and sexual violence against children

Violence against girls is a major problem in South Africa, and is linked to its male-dominated culture. Men often use violence in an attempt to maintain their status in society and prove that they are “real men” by keeping women under their control (Barnett & Whiteside, 2002:17). Physically abusive relationships limit girl’s ability to negotiate safer sex: many men still do not want to use condoms, and some become violent if young women insist on protected sex (Badcock-Walters, 2001:8). These girls may not even raise the issue of safer sex for fear of a violent response (Achmat, 2004:36).

South Africa, where a girl has about a one in three chance of being raped in her lifetime, has the highest sexual violence statistics in the world with obvious implications for the spread of HIV/AIDS (Barnett, 2002:29). The genital injuries that result from forced sex increase the likelihood of HIV infection; when virgins and children are raped, the trauma is more severe, and risk of infection even higher (Cullinan, 2002:422).

Increasing numbers of rapes of female children may represent men’s attempts to seek sexual relations with young girls to avoid HIV infection or because of the belief that sex with a virgin will cure AIDS (Hall, 2003:87).

Young women with a history of being sexually abused are more likely to risk unsafe sex, have multiple partners, and trade sex for money (Loudon, 2002:36). Men who are violent to their partners are also more likely to have sexually transmitted infections (STIs) (Parkhurst & Lush, 2004:24). These factors combine to put women who suffer sexual violence at very high risk of contracting HIV/AIDS (Beck, Miners & Trolley, 2001:26).

2.3.4 Poverty

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

- The daily struggle for survival overrides any concerns people living in poverty might have about contracting HIV (Loudon, 2002:36).
- Strategies adopted by people made desperate by poverty, such as migration in search of work and “survival” sex-work, are particularly conducive to the spread of HIV/AIDS (Phiri & Webb, 2002:61).
- People living in deprived communities where death through violence or disease is commonplace tend to become fatalistic: the incentive to protect oneself against infection is low when HIV is only one of many threats to health and life. Poverty may also breed low levels of respect for self and others, and thus a lack of incentive to value and protect lives (Geeta, 2000:76).
- Poverty is generally associated with low levels of formal education and literacy. Knowledge about HIV and how to prevent it, as well as access to information sources such as schools or clinics, is subsequently low in poor communities (Schneider, 2000:56).

Ironically, socio-economic development and poverty relief can, in fact, sometimes drive the epidemic. This is particularly the case when development is linked to labour migration, rapid urbanisation, and cultural modernisation – all of which occur to a significant extent in South Africa. Thus, although poverty contributes to the spread of HIV/AIDS, alleviating poverty can do likewise. For example, improved infrastructure such as new transport routes and improved access are seen as positive developmental goals. However, this often results in a larger migrant population, and facilitates the spread of AIDS to previously inaccessible parts of the country (Whiteside, 2003:73).

2.3.5 Commercialisation of sex

According to Hooper-Box (2005:27) prominent aspect of South African culture that undoubtedly contributes to the HIV/AIDS epidemic is that sexuality is frequently seen as a resource that can be used to gain economic benefits.

The country has seen the rapid development of a relatively affluent black middle class with a desire for material goods, and a sexual culture that associates sex with gifts. Men gain social prestige by showing off material possessions and being associated with several women (Cambell, 2003:27).

Young women are often persuaded to have sex with “sugar daddies” older, wealthier men in exchange for money or gifts (Sheon & Crosby, 2004:8). Some girls enter the sex industry for similar reasons. Young women infected with HIV by “sugar daddies” then infect younger men, who in turn infect other young women and in time become HIV-positive older men themselves and so the cycle continues. Older men also infect older women, usually their wives. Both younger and older women give birth to children, some of whom will be HIV-positive (Mkandawire, 2001:27).

2.3.6 Lack of knowledge and misconceptions about HIV/AIDS

It appears that the majority of South Africans have heard about AIDS, and have a fairly good level of knowledge of the basic facts i.e. that the disease is spread sexually, and that condoms reduce risk. Nevertheless, there are still many people, especially those with low levels of formal education and who lack access to accurate, relevant information on HIV/AIDS and sexuality, who are unaware of the risks (Tallis, 2002:18).

Women, in particular, have high rates of illiteracy, and many girls do not complete basic education (Tallis, 2002:17). Also, women may be unaware of risks because their time is taken up with tending the home, and they have limited links with the outside world (Halperin, 2001:13).

Added to this is the problem that dangerous myths and misconceptions about HIV/AIDS abound. These include believing that the virus can be contracted by sharing food, that infected people can be recognised by their symptoms, and, perhaps the most notorious of all, the belief that sex with a virgin can cure the disease (Tesa, 2001:85). Beliefs such as this give people a false sense of their level of risk, and contribute to confusion about how HIV is transmitted (Ebersohn & Eloff, 2002:22).

People who do possess some knowledge about HIV often do not protect themselves because they lack the skills, support or incentives to adopt safe behaviours. High levels of awareness among the youth, a population group particularly vulnerable and significant as regards the spread of HIV/AIDS, have not led, in many cases, to sufficient behavioural change. Young people may lack the skills to negotiate abstinence or condom use, or be fearful or embarrassed to talk with their partner about sex. Lack of open discussion and guidance about sexuality is often lacking in the home, and many young people pick up misinformation from their peers instead (Hellinger & Fleishman, 2000:185).

2.4 WAYS IN WHICH CHILDREN ARE AFFECTED BY HIV/AIDS EPIDEMIC

Children are affected by HIV/AIDS in the following ways:

- **Being born to a mother who is HIV-positive.** Most children who are born to HIV-positive mothers are not HIV-positive themselves. Without prevention of mother-to-child transmission (PMTCT) interventions, 25 — 30% of children born to HIV-infected women are likely to be HIV-positive. Where available, current PMTCT interventions in South Africa reduce these figures to between 5% and 15% (Pick, 2003:56).
- **Living with sick parents, caregivers, or others who are sick of HIV/AIDS.** The times during which parents and caregivers are ill are often times of increased stress and difficulty for children. For example, children often take on additional domestic tasks or care for sick relatives or younger siblings. Children's school attendance can be compromised during this time (Hecht *et al.*, 2002:47).
- **The illness or death of someone who provides financial or other support** to children and their households (whether or not that person lives with the family). As increasing numbers of people depend on limited or decreasing income and resources, children are at greater risk (Butler, 2005:13).

- **Living in communities with high rates of illness and death.** Though it is not well documented, there is likely to be significant emotional impact on children who grow up surrounded by illness and death in their families, social networks, and neighbourhoods (Halpepirin, 2001:13).
- **Being orphaned.** It is estimated that South Africa has one-point-two-million AIDS orphans (Tesa, 2001:82).

This research focuses on children living with sick parents as a result of the HIV/AIDS disease.

2.4.1 Social issues for children affected by the HIV/AIDS epidemic

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

2.4.1.1 Changed notions of what constitutes family

On the socio-cultural level, the impact of HIV/AIDS has also challenged and broadened traditional notions of what constitutes a family. Many of those infected by the disease live in non-traditional arrangements, prompting reconsideration of who is and who functions as a family. For the purpose of this research family members are defined as individuals who by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need. Operationally the family includes the spouses, partners, children, parents, siblings, friends and caregivers of the person with AIDS (Benell *et al.*, 2002:7).

In terms of the systems theory, families are social systems. Consequently, the effect of a family member's infection will reverberate throughout that system and over time. According to Tallis (2002:17), the psychosocial impact of HIV/AIDS on families usually begins with the disclosure of HIV infection. The disclosure of HIV-positive status may be how parents first learn of their infected child's sex activities. Consequently, together with the prospect of

being infected themselves, the child's family life and/or pattern of denial may be shattered,

Reactions to and feelings of families of persons living with HIV/AIDS include social stigma and isolation, as secrecy cuts off potential sources of support, fear of contagion, which may limit intimacy and involvement of parents, fear of infecting others or straining their lowered immune system, fear of abandonment, as caregivers are unable to keep up with the physical and emotional demands of care-giving and of watching a loved one suffer and deteriorate, guilt by family members for having estranged themselves from the ill individual because of his/ her lifestyle and psychological and physical fatigue (Arndt & Lewis, 2000:859).

2.5 COPING AND SUPPORT RELATING TO HIV/AIDS

Ways in which human beings cope with the effects of the HIV/AIDS epidemic depends on many conditions, the following three deserve note:

- The first is the severity of the illness. The very sick must put all their energy into healing and may not have the luxury of energy left over for emotional growth.
- The second is the social support available. If one is willing to ask for help and has a wide support network, s/he will have an easier time than if s/he is isolated.
- The third condition is the pre-illness personality of the person. If one has always been pretty resilient, s/he is likely to have resilience in coping with the illness (Pakhurst & Lush, 2004:35; UNAIDS, 2001:78).

Wolitski, Valdiserri, Denning and Levine (2001:884) contend that personal meaning systems act to influence the manner in which individuals respond and cope with stress throughout the life span. They argue that individual 'patterns of commitment' determine the manner in which certain events are appraised in terms of their possible impact on both psychological and physical well being, and influence the manner in which these events are managed.

Events, which challenge important commitments, are generally perceived as threatening, increasing the individual's vulnerability to stress. However, they note that this vulnerability also propels the individual into action, which relieves the threat and maintains coping. Thus, patterns of commitment create a state of meaningfulness (Bertozzi *et al.*, 2002:36)

The coping mechanisms that are used in response to stress perform a vital role in determining the character and extent of the stress impact. Coping influences health both indirectly, through health and illness behaviour or directly through physiological responses. Thus, an individual's coping strategies have meaningful effects on their physiological responses to stressful situations and how individuals cope with stresses in turn effects overall health and mortality (Badcock-Walters, 2001:6). Coping can be defined as a person's cognitive and behavioural efforts to manage with internal and external stress (MacIntyre, 2001:166). According to this framework, problem-focused coping is understood as behavioural attempts at management of the external environment, and emotion-focused coping as the regulation of internal stress. Typically, people use both types of coping, although one type may be dominant depending on the context, appraisal of the situation and personal factors (Carr-Hill & Peart, 2003:59). Problem-focused coping tends to predominate when people feel that something constructive can be done, whereas emotion focused coping tends to prevail when people feel that the stressor is something that must be endured (Barnett, 2002:26). De Waal (2003:17) contends that meanings in situations influence human resilience and initiative. Thus in the case of HIV/AIDS, what determines the crisis of the disease is not the illness, but the meaning attributed to it in turn affecting one's coping style. Those who remain angry disconnect from the world with an attitude of 'nobody cares', prompting a chronic stress response. Those that imagine possibility, perceive change as a challenge, commit to engaging with the self and others and refuse to feel powerless and develop proactive coping styles (Fassin & Scheinder, 2003:497). It is expected that at varying points of the HIV/AIDS progression, different coping requirements will be made. Furthermore, the effectiveness of the types of coping strategies and the psychosocial resources used in meeting those demands may be dependent

on the disease stage. A number of studies exploring the role of coping styles and coping strategies in persons with HIV/AIDS disease have been conducted. One of these studies conducted by Celentano and Sonnega (1992) attempted to document ways of coping with HIV/AIDS (Friedman & Mottier, 2004:44).

Three methods of coping were addressed namely active cognition (re-assessing the situation to cast it in a more positive light), active behaviour (attempting to master the situation), and avoidance coping (avoiding thinking about it). Better emotional adjustment to HIV/AIDS has been found to be associated with an active behavioural coping style. Also coping strategies comprising of control, optimism and interpersonal coping have been found to be correlated with better adjustment to HIV/AIDS (Baylis & Bujra, 2000:16). Similar to these findings Dorrington *et al.* (2001:63) found avoidance coping to be associated with worse emotional adjustment to HIV/AIDS as opposed to more active coping strategies. Barnett and Whiteside (2002a:16) argue that there are three coping strategies that may be dysfunctional namely venting emotions, behavioural disengagement and mental disengagement. Use of emotional and behavioural disengagement by the individual may indicate an avoidance of satisfactory cognitive appraisal, which has been identified as being critical for coping with stress. They found that the venting of emotions suggests a reluctance to partake in cognitive appraisal or other coping responses that may alleviate stress. It was found that venting of emotions is in fact related to increased distress over a period of time. Research by Binswanger (2000:40) exploring the use of more avoidance and less support seeking was confirmed to be significantly related to lifetime suicidality, as determined by means of the Diagnostic Interview Schedule, in a sample of HIV-infected homosexual men. However contrary to these findings and despite much criticism, Butler (2005:11) observe that avoidant coping expressed through an ability to fantasize, correlates with fewer psychological symptoms, suggesting that this style may nevertheless, be useful. However, they note that when avoidant coping is expressed through withdrawn behaviour, it correlates with higher symptom levels. The results of these studies suggest that at times a more active style of coping may be beneficial,

while at others, a more avoidant style may be protective in buffering the stress of illness. It becomes evident then that the experience of diagnosis incorporates and facilitates a complex process involving the typical responses of denial, anger, bargaining, depression and acceptance which inevitably forces one to choose a mode of being and responding to the illness which facilitates a way of coping. These responses involve the reworking and restoring of one's experience in such a way that a biographical reworking of one's self and the world is undertaken. However, this reworking of one's understanding of self often involves an initial disruption of typical psychosocial responses associated with one's stage of development (Busza, 2001:443).

2.6 LITERATURE REVIEW ON ECOSYSTEMS THEORY

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

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

2.6.1 The framework of ecological and systems theories

The word ecology comes from the Greek word *oikos* which means household. So, ecology is the study of how the earth household works. More precisely, it is the study of the relationships that interlink all members of the earth household (Bazzani & Feola, 2001:67). Therefore, being ecologically literate, or ecoliterate, means, in my view, understanding the basic principles of

ecology and being able to embody them in the daily life of human communities. In particular, principles of ecology should be the guiding principles for creating sustainable learning community and school organizations. In other words, ecoliteracy offers an ecological framework for the transformation of educational psychology practice in South Africa (Ludwig, Walker & Holling, 1997:67).

The ecological paradigm represents an integration of research and theory from developmental psychology and sociology, with experiential knowledge from social work, family support, early intervention and early childhood education. It represents a coalescing of what researchers are learning about the way different social environments and relationships influence human development. Because it is a developing model with many as yet unexplained elements, the ecological model is still in a state of flux (Castle, 2000:156). However, the basic tenets of the ecological model have been established for some time and can be stated as:

- human development is viewed from a person-in-environment perspective;
- the different environments individuals and families experience shape the course of development;
- every environment contains risk and protective factors that help and hinder development;
- influence flows between individuals and their different environments in a two-way exchange. These interactions form complex circular feedback loops; and
- individuals and families are constantly changing and developing. Stress, coping and adaptation are normal developmental processes (Epstein, 1992:43; Castle, 2001:48).

An ecological perspective focuses on dynamic developmental processes including the way stress, coping and adaptation contribute to development. A useful concept for understanding this view of development is the "goodness of fit"

the fit" model. This model suggests healthy development and effective functioning depend on the match between the needs and resources of a child or family and the demands, supports and resources offered by the surrounding environment. The developing individual responds to the "environmental fit" through developmental processes associated with stress management, coping and adaptation (Gunderson, 1995:15).

The "goodness of fit" model is useful for understanding how to support and strengthen families as well. Families develop too. They move through predictable developmental stages just as children do. Families must also respond to the demands and expectations from work, social groups, community institutions and the society as a whole. Stress builds when the resources and coping skills of a family are inadequate to meet the demands and expectations of the social environment. Family stress levels are a predictor of "rotten outcomes" for children. If stress increases beyond a certain point, for whatever reason, a family's ability to nurture its children decreases (Schwartz, Coatsworth, Pantin & Szapocznik, 2003:64).

A lack of fit or a mismatch can happen between children and their family or school environments or between a family and community environment. Problem behaviours in school may often be attributed to a mismatch between a child and the expectations of the school setting (Carpenter, Brock & Hanson, 1999:17). Mismatches also happen when the home culture and values are at odds with the dominant values of the school environment. This poses a threat to the linkages between family and school. The threat is lessened when both sides are carefully respectful and recognize the importance and value of each to the child. When a mismatch occurs and a child is disruptive or a family needs outside help, it may not be due to a deficiency in the child or family. The mismatch may come from a lack of resources or support from the social environment (Kirkman, 1997:376).

It can be inferred from the foregoing paragraph that environments help or hinder development. For example, a given environment may be bountiful and supportive of development or impoverished and threatening to development. Negative elements or the absence of opportunities in family, school or

community environments may compromise the healthy development of children or inhibit effective family functioning (Allen, Tainter & Hoekstra, 1999:405). Here are examples of different environments in a child and family's ecology and their impact:

- as children move out into the world, their growth is directly influenced by the expectations and challenges from peer groups, care-givers, schools, and all the other social settings they encounter (Loreau, Naeem, Incausti, Bengtsson, Grime, Hector, Hooper, Huston, Raffaelli, Schmid, Tilman & Wardle, 2001:804);
- the depth and quality of a family's social network is a predictor of healthy family functioning. During normal family transitions all families experience stress. Just having someone to talk to about the kids over a cup of coffee, swap child care, or offer help with projects, buffers a family from the stresses of normal family life (Taylor, 1999:198);
- strong linkages between families and community organizations such as schools, open channels that allow vital information and resources to flow in both directions, support families, schools, and communities (Shrader-Frechette, 2000:38); and
- the work environment, community attitudes and values, and large society shape child development indirectly, but powerfully, by affecting the way a family functions (Meyer, 1997:29).

So, when considering the ecology of a particular child, according to Kay (2000:137), one might assess the challenges and opportunities of different settings by asking:

- In settings where the child has face-to-face contact with significant others in the family, school, peer groups, or church:
 - Is the child regarded positively?
 - Is the child accepted?

- Is the child reinforced for competent behaviour?
- Is the child exposed to enough diversity in roles and relationships?
- Is the child given an active role in reciprocal relationships?
- When the different settings of a child's ecology such as home-school, home-church, school-neighbourhood interact:
 - Do settings respect each other?
 - Do settings present basic consistency in values?
 - Are there avenues for communication?
 - Is there openness to collaboration and partnership?
- In the parent's place of work, school governing body, local government, settings in which the child does not directly participate, but which have powerful impact on family functioning:
 - Are decisions made with the impact on families and children in mind?
 - Do these settings contain supports to help families balance the stresses that are often created by these settings?
- In the larger social setting where ideology, social policy, and the "social contract" are defined:
 - Are some groups valued at the expense of others (Is there sexism or racism)?
 - Is there an individual or a collectivist orientation?
 - Is violence a norm? (Gopalan, 2004:23)
- If a child with a genetic disability has supportive nurturing care-givers, the developmental impact of the disability is reduced (Cooper, 2001:482).

- A teen mother's strong social support network reduces risks to the mother-child relationship (Barnett & Whiteside, 2000b:18).
- If a child has one strong parent-child relationship, the risk associated with marital discord is reduced (Shrader-Frechette, 1997:17).

People are used to thinking about the environments children experience, but the environments families encounter also contribute to child development by their impact on family functioning. In a community there may, or may not, be the resources and relationships a family needs. Within its community setting, each family fabricates its own web of support from the formal and informal resources available. A family may forge many connections, a few strong connections, or no connections at all to the community resources. These connections link families to the tangible and intangible resources of the community (Crowfoot & Wondolleck, 1990:78).

Just as the child's environment offers challenges and opportunities, community settings offer challenges and opportunities for healthy family functioning. Generalizations about family-community interactions found in the literature include:

- Rural families have few employment opportunities, lower economic well being, fewer educational opportunities and less access to health care and social services. Urban families, on the other hand, have higher crime rates, more impersonal ties, higher density, and noisier living conditions (Shrader-Frechette & McCoy, 2000:15).
- Many parents have to cope with the threat of violent crime in their neighbourhood. A family's response to demands and challenges from a community environment may promote or hinder family functioning and child development. Withdrawing emotionally, keeping children inside, and restricting child activity are coping strategies parents use when faced with violence in their neighbourhood, but they may also impede normal development. (Bogenschneider, Small & Riley, 2000:17).

- Families are affected by how responsive community organizations are to family needs. Epstein (1995:705) identifies five strategies that make early childhood programmes more responsive to families. These include: increasing parent-programme communication; giving parents choices between different programmes; assessing family and child needs; re-defining staff roles and using community residents; and involving parents in decision-making.
- The relationship between families and their community changes and evolves over time. The needs and interests of family members change over the life span. Issues of responsiveness also change with aging and stage of development (Allen, Tainter & Hoekstra, 1999:405).
- "Community" may refer to relationships and social networks as well as a physical location. A family's informal social support network often provides services that are more accessible, culturally appropriate and acceptable than the services offered by formal support systems (McCormick, 1999:7).

A focus on the individual, isolated and independent, is deeply embedded in Western communities and schools' culture and values. In contrast, an ecological model emphasizes the interconnections of events and the bi-directionality of effects between organism and environment. An ecological perspective views human development from a person-in-environment context, emphasizing the principle that all growth and development take place within the context of relationships (Kay & Regier, 2000:122). Thus, a child must be studied in the context of the family environment and the family must be understood within the context of its community and the larger society. The language of the ecological model provides a sharp contrast to the image of the lone frontiersman pulling himself up by his bootstraps, the "paddle my own canoe" mentality upon which communities' legal, educational, and social service delivery system are often based. Perhaps, Western cultures can learn more from the African philosophy of Ubuntu/Botho whose ideals entail communalism and co-existence among Africans (Grumbine, 1997:44).

The most appropriate theoretical framework for ecology is the theory of living systems, hence the use of the concept ecosystems in the following paragraphs. This theory is only now fully emerging but has its roots in several scientific fields that were developed during the first half of the century such as organismic biology, gestalt psychology, general systems theory, and cybernetics (Coetzee & Streak, 2004:86). In all these scientific fields scientists explored living systems and this led to a new way of seeing the world and a new way of thinking, known as systems thinking, or systemic thinking, which means thinking in terms of relationships, connectedness, and context. This is a key aspect of systems thinking. It implies a shift of focus from objects to relationships. A vibrant community is aware of the multiple relationships among its members. Nourishing the community means nourishing these relationships (Forget & Lebel, 2001:33).

Now, understanding relationships is not easy for educators who were educated and trained only in a Western way, because it is something that goes counter to the traditional scientific enterprise in Western culture. In science, so we have been taught, we measure and weigh things. But relationships cannot be measured and weighed, they need to be mapped. You can draw a map of relationships, interconnecting different elements or different members of a community (Duraieppah, 2004:11). When one does that, s/he will discover certain configurations of relationships that appear again and again. This is what people call patterns. The study of relationships leads one to the study of patterns. Understanding ecosystems, then, leads us to understanding relationships and patterns of the way of life, philosophy of life, convictions, religion, language, values, norms *etc.* which form the core cultural virtues of communities and schools (Cooper, 1998:15).

So, how do ecosystems organize themselves? Well, the first thing that is recognized when an ecosystem is observed is that it is not just a collection of species but a community, which means that its members all depend on one another. They are all interconnected in a vast network of relationships, the web of life, that is, 'all living systems share a set of common properties and principles of organization' (Folke, 1992:37).

The application of ecological-systems framework to school, family and community interventions helps post-modern and social constructivist educators to view children through various social systems and to integrate techniques across diverse educational psychology practice perspectives. Such an application of theory to practice has been found to be a useful framework for developing integrative and empirically supported clinical interventions such as the Multisystemic Therapy (MST), for example (Gurney & Nisnet, 1998:7). The MST is a family and community-based treatment approach that is theoretically grounded in a social-ecological framework (Bronfenbrenner, 1979) and family systems (Epstein, 1995:707). Ecological-systems models like MST emphasize an empirically supported approach for using research knowledge to examine and explain the etiological and risk factors within learner systems that promote particular problems. Empirically supported and best practices are used to purposefully design effective interventions and systems of care within a community-based setting. The ecological-systems perspectives further emphasize the need for community development and maintenance strategies within the community systems network to assure that children continue to progress and change (Fiscus, 2002:24).

The ecological systems theory (Bronfenbrenner, 1979) looks at, in the context of this research, a child and adolescents' development within the context of the system of relationships that form his or her immediate environment. Bronfenbrenner's theory defines complex "layers" of environment, each having an effect on a child's development. This theory has recently been re-named *bio-ecological* systems theory to emphasize that a child's own biology is a primary environment fueling her/his development. The interaction between factors in the child's maturing biology, his immediate family/community environment, and the societal landscape fuels and steers his development. Changes or conflict in any one layer will ripple throughout other layers (Coatsworth, Maldonado-Molina, Pantin & Szapocznick, 2005:159). To study a child's development then, educators must look not only at the child and her immediate environment, but also at the interaction of the larger environment as well.

Bronfenbrenner's structure of environment is as follows:

- The *microsystem* – this is the layer closest to the child and contains the structures with which the child has direct contact. The microsystem encompasses the relationships and interactions a child has with her immediate surroundings. Structures in the microsystem include family, school, neighborhood, 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 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 (Grove & Burch, 1997:160).
- The *mesosystem* – this layer provides the connection between the structures of the child's microsystem (Berk, 2000:23). Examples: the connection between the child's teacher and his parents, between his church and his neighbourhood, and others.
- The *exosystem* – this layer defines the larger social system in which the child does not function directly. The structures in this layer impact the child's development by interacting with some structure in his/her microsystem (Berk, 2000:23). Parent workplace schedules or community-based family resources are examples. The child may not be directly involved at this level, but s/he does feel the positive or negative force involved with the interaction with his 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, 2000:27). 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 (Bazzani, Noronha & Sanchez, 2004:13).

- The *chronosystem* – this system encompasses the dimension of time as it relates to a child's environments. 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 aging of a child. As children get older, they may react differently to environmental changes and may be more able to determine more how that change will influence them (Keller & Golley, 2000:15).

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

2.6.2 The ecological systems theory's view of nature and nurture

More modern child development theories accept that both a child's biology and his/her environment play a role in change and growth. Bronfenbrenner's ecological systems theory focuses on the quality and context of the child's environment. He states that as a child develops, the interaction within his/her environments becomes more complex. This complexity can arise as the child's physical and cognitive structures grow and mature. This theory concurs well with Piaget and Erikson's theories on psycho-social development of human beings.

Bronfenbrenner (1986) sees the instability and unpredictability of family life societies all over the world have let their economies create as the most destructive force to a child's development. Children do not have the constant

mutual interaction with important adults that is necessary for development. According to the ecological theory, if the relationships in the immediate microsystem break down, the child will not have the tools to explore other parts of his environment. Children looking for the affirmations that should be present in the child/parent (or child/other important adult) relationship look for attention in inappropriate places like gangs and peer groups which leads to parents losing control of their children. These deficiencies show themselves especially in adolescence as anti-social behaviour, lack of self-discipline, and inability to provide self-direction (Duraiappah, 2004:45).

This theory has dire implications for the practice of educational psychology. It seems now that it is necessary for schools, teachers and educators to provide stable and long-term relationships with children and adolescents. Yet, Bronfenbrenner (1979) believes that the primary relationship needs to be with someone who can provide a sense of caring that is meant to last a life-time. This relationship must be fostered by a person or people within the immediate sphere of the child's influence. Schools, teachers and educators fulfil an important secondary role, but cannot provide the complexity of interaction that can be provided by primary adults, that is, parents. For the educational community to attempt a primary role is to help societies continue their denial of the real issue. The problems children and families face are caused by the conflict between the workplace and family life – not between families and schools. Schools, teachers and educators should work to support the primary relationship and to create an environment that welcomes and nurtures families. Educators can do this while they work to realize Bronfenbrenner's ideal of the creation of public policy that eases the work/family conflict (Ludwig *et al.*, 1997:66). It is in the best interest of all societies for educators to advocate and lobby for political and economic policies that support the importance of parent's roles in their children's development. Bronfenbrenner's theory fosters societal attitudes that value work done on behalf of children at all levels: parents, teachers, extended family, mentors, work supervisors, legislators (Forget & Lebel, 2001:3).

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

2.6.3 Family as a system

From an ecological perspective, the most logical model of a family is a system. While there are critics of this conceptualization, most researchers now approach the family from what could be loosely called a "systems perspective". A systems approach to human development considers the way relationships within the family and between the family and social environment influence individual development and family functioning (Castle, 2000:153).

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

- **Interdependence.** One part of the system cannot be understood in isolation from the other parts. Children cannot be understood outside the context of their families. Any description of a child has to consider the two-way patterns of interaction within that child's family and between the family and its social environment. Describing individual family members does not describe the family system. A family is more than the sum of its parts (Gopalan, 2004:64).
- **Sub-systems.** All systems are made up of sub-systems. Families' sub-systems include spousal sub-system, parent-child sub-systems and sibling sub-systems. A family's roles and functions are defined by its sub-systems (Kay, 2000:137).
- **Circularity.** Every member of a system influences every other member in a circular chain reaction. A family system is constantly changing as children develop; thus it is almost impossible to know for certain the causes of behaviour (Meyer, 1997:34).

- **Equifinality.** The same event leads to different outcomes and a given outcome may result from different events. What this suggests is that there are many paths to healthy development and there is no one-best-way to raise children (Schwartz *et al.*, 2003:11).
- **Communication.** All behaviour is viewed as interpersonal messages that contain both factual and relationship information (Barnett & Whiteside, 2000b:37).
- **Family Rules.** Rules operate as norms within a family and serve to organize family interactions (Shrader-Frechette, 2000:47).
- **Homeostasis.** A steady, stable state is maintained in the ongoing interaction system through the use of family norms and a mutually reinforcing feedback loop (Crowfoot & Wondolleck, 1990:15).
- **Morphogenesis.** Families also require flexibility to adapt to internal and external change. (Taylor, 1999:198).

A Family-Centred Approach borrows from family systems theory. Family systems theory gives us useful principles for studying children within the context of their family relationships. This framework requires us to stop operating as if children exist in isolation. Effective interventions understand and respect each family's system.

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

- **family.** The family performs many functions for its members essential to healthy development and mediates between the child and the other environments;
- **informal social network.** A family's social network grows out of interactions with people in different settings; extended family, social

groups, recreation, work. Ideally, this network of caring others shores up feelings of self-worth, mobilizes coping and adapting strategies and provides feedback and validation;

- **community professionals and organizations.** A community's formal support organizations provide families with resources related to professional expertise and/or technology; and
- **society.** Social policy, culture, the economy define elements of the larger ecology that impact the way a family functions (Carpenter *et al.*, 1999:22).

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

The children and adolescents that come to schools and educational psychology practices are largely a product of the family they are a part of. Educators need to be able to deal with a great variety of family systems in understanding their child and adolescent children (Loeue *et al.*, 2001:806). In today's society, the family is less frequently the archetypical combination of stay-at-home mother, working father, and sibling children. Single parent families, generation skipping families, and other non-traditional groupings are more common today than the traditional family. Another common force that has changed the family landscape in societies is divorce. Children of divorced parents often have a split family life such as at fathers for the weekend, at mothers during the week, or any number of other situations (Bronfenbrenner, 1977:515). Divorce is an excellent example of the type of interaction between systems that Bronfenbrenner writes about. The divorce arrangement can have a profound effect on the family and the development of the child, but it is often a product of society, decided by a judge, enforced by social services. In turn, the divorced family affects the community and society because by the proliferation of divorce social attitudes change and the social perception of

family is modified (Kirkman, 1997:377). The school is also affected by the changes in a divorced family. For example: Where does the report card go and who comes to parent-teacher conferences?

A number of other systems: community, religion, school, society, and cultural forces from within the mesosystem and the exosystem directly affect the family. Society and the culture of both the family and the neighbourhood have influence on the child's perception of the family's place in the community. The family can affect the community through its needs for services and its contribution as taxpayers and voters (Schrader-Flechette & McCoy, 2000:8).

The post-modern educator has to adopt a Family Centred Approach to working with families. A Family-Centred Approach is a process for delivering services to families that will fit many different "content areas," be it support for teen parents, family literacy or education for low-income children. It is not a set of particular practices but rather a "philosophy" in which families are recognized as having unique concerns, strengths and values (Kay & Regier, 2000:127). A Family-Centred Approach represents a paradigm shift away from deficit-based, medical models that discover, diagnose and treat "problems" in families to an ecological model. The ecological model views families from the perspective of "a half-full cup" rather than half empty. This approach builds and promotes the strengths that families already have (Grove & Burch, 1997:259). The key components of a Family-Centred Approach are:

- **creating partnerships and helping relationships** - Families are supported and child development is enhanced through helping and partnership relationships;
- **building the community environment** - Families gain information, resources and support through their connections to the community environment; and
- **linking families and community support** - Participation, two-way communication, and advocacy strengthen both the community support network and family functioning (Coetzee & Streak, 2004:84).

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

- all families need help at some time in their lives, but not all families need the same kind or intensity of support;
- a child's development is dependent upon the strength of the parent/child relationship, as well as the stability of the relationship among the adults who care for and are responsible for the child;
- most parents want to and are able to help their child grow into healthy, capable adults;
- parents do not have fixed capacities and needs; like their children, they are developing and changing and need support through difficult, transitional phases of life;
- parents are likely to become better parents if they feel competent in other important areas of their lives, such as jobs, in school, and in their other family and social relationships; and
- families are influenced by the cultural values, and societal pressures in their communities (Epstein, 1992:27).

These beliefs and assumptions about families guide the delivery of services by family support programmes. The service delivery principles of family support programmes are grounded in the practical experiences of serving families and are an important part of a Family-Centred Approach (Bazzani *et al.*, 2004:17).

When the family is examined from an ecological point of view, no one person or thing can be realistically identified as the 'cause' of a problem". Behaviour from an ecological perspective, is more complex than stimulus A causes predictable response B. The environmental demands and the reciprocal relationships between people interact with individual characteristics in complex chains of influence that define behaviour (Meyer, 1997:36). Although

parents have a profound influence on the ability of the child to develop in a healthy, competent manner, children also influence their parents' behaviour. When dealing with a child's acting out behaviour, or addressing a family's financial need, educators need to consider not only the individual but also contributing factors from the environment and interpersonal relationships (Fine, 1992:56).

The next section will now look into the school as an important system in the community. Schools are significant nurturing systems in communities.

2.6.4 Schools as systems

Traditionally, public schools have not had a strong emphasis on family involvement and support. Universities' Faculties of education have also typically offered little direct and practical training to aspirant educators in forming parent/teacher relationships. A 1987 University of Minnesota report on improving teacher education listed what researchers identified as the thirty-seven most important teaching skills, and learning how to work with parents was not among them. However, a number of factors have contributed to the current focus on parental involvement as a way to improve educational outcomes for all children, particularly children from low-income families (Kirkman, 1997:380).

During the last 20 years, vast economic and demographic changes have resulted in increased economic hardship and stress for many families and an accompanying pressure on schools to increase nations' competitiveness in a global economy. There is growing recognition that fostering "readiness" for kindergarten and for succeeding, educational environments will require addressing the strengths and needs of the whole child (Kay & Regier, 2000:123). The National Education Goals Panel endorsed a complex, multifaceted definition of readiness, which includes physical well-being and motor development, social competence, approaches toward learning, language and literacy, cognitive development, and general knowledge. This comprehensive definition requires a new approach to schooling, one which includes a shared responsibility for children's development and will likely

permanently alter the schools' relationships with families and communities (Castle, 2001:52).

Recognizing the vital role that parents play in their children's education, Title IV of the National Education Goals 2000: Education America Act encourages and promotes parents' involvement in their children's education, both at home and at school. Three decades of research have demonstrated strong linkages between parental involvement in education and school achievement (Loreau *et al.*, 2001:806). Family involvement is highest among middle and upper-class families. However, regardless of parents' education, parental involvement with children's schooling is associated with better attendance, higher achievement test scores, and stronger cognitive skills. In addition, when parents help elementary school children with their schoolwork, social class and education become far less important factors in predicting the children's academic success (Epstein, 1995).

Low-income, minority, and limited-English-proficient parents, however, may face numerous barriers when they attempt to collaborate with schools. These include: lack of time and energy; language barriers, feelings of insecurity and low self-esteem, lack of understanding about the structure of the school and accepted communication channels, cultural incongruity, race and class biases on the part of school personnel, and perceived lack of welcome by teachers and administrators (Keller & Golley, 2000:27).

Given these potential barriers, it is not surprising that research has demonstrated that successful parent involvement programmes must have a strong component of outreach to families. Studies show that school practices to encourage parents to participate in their children's education are more important than family characteristics, such as parent education, socio-economic and marital status (Epstein, 1995). A 1988 study of parental involvement in schools concluded that it wasn't parents who were hard for schools to reach, but schools that were hard for parents to reach (Carpenter *et al.*, 1999:27). If schools are to become places where families feel welcome and recognized for their strengths and potential (Riley, 1994), school personnel must not only embrace the concepts of partnership and parent

involvement, they must be given training and support to translate their beliefs into practice (Epstein, 1995).

While traditional forms of family involvement have focused on the supposed deficits of low-income and/or minority families, new models, congruent with the Family-Centred Approach, emphasize building on family strengths and developing partnerships with families, based on mutual responsibility. In these approaches, parents are involved as peers and collaborators, rather than children. Bazzani and Feoala (2001:23) have identified four tenets of programmes which have been shown to improve the educational outcomes for all children, particularly those of low-income and minority children:

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

The relationships a child develops in schools become critical to his or her positive development. Because of the amount of time children spend in school, the relationships fostered there carry real weight. Also, children may for the first time be developing relationships with adults outside their immediate family. These connections help a child develop cognitively and emotionally (Taylor, 1999:199).

This theory has dire implications for the practice of educational psychology. It seems now that it is necessary for schools, teachers and educators to provide support for stable, long-term relationships between children and parents, and also between children and mentors, and children and teachers. Schools,

teachers and educators should work to support the primary relationship and to create an environment that welcomes and nurtures families. Educators can do this while they work to realize Bronfenbrenner's ideal of the creation of public policy that eases the work/family conflict (Grumbine, 1997;44).

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

2.6.5 Religion or Spirituality

The relationship of religion to the developing child is usually seen as a source of moral and ethical values. In most communities, religion is an integral part of culture. Whether Irish-Catholic or Syrian-Baha'i, Shembe-African Umvelinqangi, Basotho-Badimo, Nguni-Amadlozi and others, a child's religion is usually based on the family's preference or heritage. There is a great variation in intensity of religious belief from family to family. Some have a very casual relation with a church, perhaps only observing major feasts or holidays, and some are very involved and their religion dictates everything from mode of dress to food preparation (Coatsworth *et al.*, 2005:160).

Educational policies sometimes conflict with religion, as in the evolution versus creation argument. In these cases, the effects of scientific theory that conflicts with religious dogma rather than any moral or ethical issues are seen. Few would dispute that the basic concepts of most established religions are similar in the areas of morals and ethics. Once the sectarian details are eliminated, the basic virtues of most religions are nearly the same, for example, love, respect, tolerance, and honour. These are certainly the same ideals communities wish to instill in children and adolescents, and a curriculum based on these would re-inforce the positive values received from church or family (Fiscus, 2002:19).

Educators of the twenty-first century have to empower children, adolescents and families to live by their highest values. Education is the key to transformation, but it must involve education which touches the human spirit. Educators should therefore adopt an approach which calls people to remembrance of the virtues, the qualities of character and the simple

elements of spirituality honoured by all cultures and sacred traditions (Berk, 2000:28). This approach has to be applied in a wide variety of ways which include: community development; healing projects after a traumatic experience such as terrorism, faction fighting *etc.*; programmes with street children and child-headed families; an enhancement of the religious life of “virtues congregations” of diverse faiths; in drug and alcohol rehabilitation programmes and prisons; restructuring the curriculum and culture of schools; enhancing unity in school organizations to counteract racism, racialism, sexism and monoculturalism; as a tool in day-care centres, palliative care programmes, personal development, and in parent education programmes (Carpenter *et al.*, 1999:16).

By being involved in community matters in this manner, educators will be serving humanity by having an empowering impact on the moral and spiritual development of peoples of all cultures, by helping them to remember who they really are and to live by their highest values. They will, also, be providing multi-cultural products and programmes of excellence and simplicity which can serve as tools for the cultivation of virtues in individuals, families, organizations and communities. In this way they will not be focused on the beliefs or practices of any particular religion but rather on the common thread that runs through all religions, the virtues. The virtues are the simple elements of spirituality, the universal values found in all cultures and sacred traditions (Waller, 2001:17).

All the systems mentioned in sections 2.4, 2.5 and 2.6 above are part of communities. It is therefore necessary to look into community as a system in the development of children and adolescents.

2.6.6 Community as a system

The involvement of the structures in a child's mesosystem is meant to provide the adult relationships required for positive development. The bio-ecological systems theory of Bronfenbrenner holds that these bi-directional relationships are the foundation for a child's cognitive and emotional growth. Structures of the exosystem, such as community, society, and culture, provide the support

for these relationships. They provide the values, material resources, and context within which these relationships operate (Kirkman, 1997:376).

Increasingly, however, societies have seen a breakdown in the structures of a child's mesosystem. For example, most children live with single parents. Further, the majority of children and adolescents live in households whose annual income falls below the poverty level. Increasing number of hours worked outside the home by both mothers and fathers means that they have less time to spend being involved in their child and adolescent's development. With this breakdown occurring on the mesosystemic level, the structures of Bronfenbrenner's exosystem must be called upon to shore up or provide primary relationships (Bogenschnider *et al.*, 2000:53).

Communities provide parents with access to people with similar concerns that can function as resources and emotional support. Communities also provide child care, parent employment, and programmes designed to encourage interaction among families. Partnerships between community agencies and business and industry will provide invaluable resources for families. The community has always been an important influence on children and youth, but even more assistance from the community is needed in order to ensure children and adolescents' success in academics as well as in life (Bazzani & Feola, 2001:20). Research by Cooper (1998:34), has shown that young people need and deserve five basics:

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

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

families needs. They create a series of referral touch points for families in need of health, financial, or crisis assistance. Co-ordination among these agencies, parents, and schools will help provide a safety net for families in crisis – and will provide a solid resource for strengthening all relationships within a child's mesosystem (Gunderson *et al.*, 1995:13).

Educating a child takes co-operation and involvement from educators, parents, families, and the community. Everyone has heard the saying "It takes a village to raise a child." Research has shown the greater the family and community involvement in schools, the greater the children' achievement (Allen *et al.*, 1999:403).

Parent involvement has an important influence on a child's school success, but today we are seeing an increasing number of children raised for some period of their childhood in less than ideal conditions. For example, in the South Africa at least one-fourth of children live with one parent and among Blacks this figure increases to more than 55% (Shrader-Frechette, 2000:15). At least one in five children in South Africa lives in a family with an income below poverty level and this rate doubles among Blacks. More and more mothers are working outside the home and that means that many parents cannot be as involved in their child's life as they should be (Spencer, Dupree & Hartmann, 1997:818).

With increased burden on families, communities are making a definite impact on children in a number of positive ways and community leaders continue to look for ways to impact schools and improve children and adolescent achievement. In this way, adults other than a child's parents are taking on significant child rearing roles. For example, a programme established in 1977 called Communities in Schools (Costanza, 1998:1) aims to provide mentors and volunteers that can provide support to schools. CIS' purpose is to connect needed community resources with schools to help young people learn, stay in school, and prepare for life. Their website (see bibliography) provides information about the programme and gives ways in which communities and schools can come together. This programme has reached over 500,000 young people and their families. According to Costanza (1998:2), the

programme exists in over 1,700 schools and “surrounds young people with “a community of tutors, mentors, health care providers, and career counselling – caring adults who can help...”

Mentoring programmes are one way community members can impact schools. A mentor is an adult who assumes “quasi-parental roles as advisors and role models for young people to whom they are unrelated”. The Big Brothers Big Sisters organization was one of the first mentoring programmes designed to provide children with a positive role model. Many school systems are currently starting up mentoring programmes with much success. This is a step towards each child having a personal relationship with an adult who they can confide in. Mentoring programmes should primarily concentrate on at-risk youths from single parent homes or an environment of poverty (Sterelny, 2001:438). One example of a successful programme is found in the Charlotte, North Carolina school system where more than 900 volunteers spend time each week with children and adults as mentors, tutors, and lunch buddies. Adults who serve as mentors benefit from these programmes by making a contribution to work with a single young person. It can give adults a chance to give back to their communities and increase their own sense of self-worth (Ulanowicz, 1997:28).

Adults who mentor may also inspire children to give their time to community service. An effective mentor should be committed, accepting, supportive, and a positive role model (Costanza, 1998:2). Adults can volunteer their time and resources in ways other than serving as a mentor such as:

- one-on-one tutoring,
- small group instruction,
- grading papers,
- career counselling,
- coaching,
- library assistance, and

- fundraising (Spencer *et al.*, 1997:56).

Limited financial resources in many school systems increase the value of volunteers who can assist in a variety of ways. Businesses are also forming partnerships with schools which benefits both parties involved. Businesses help ensure that their future workforce will be well trained and possess skills needed to succeed in the workplace. Companies can get involved in school through career talks, career fairs, tours, internships, job shadowing, apprenticeship programmes, and curriculum development. The business industry has complained for years that the schools were not teaching the right kinds of skills needed to succeed in the workplace. This gives business and industry the chance to get involved (Barnett & Whiteside, 2000b:29).

Much research has been conducted concerning how community involvement can contribute to achievement. The power of community involvement for improving learning can come from a number of different sources. According to Kay (2000:136), "beyond changes in curriculum or improvements in self-esteem, meaningful community involvement sets in motion a chain of events that transforms the culture of the school and often the community that the school serves." Alliances between schools and communities can be formed in countless ways including issues such as school safety, after school programmes, physical improvements, student health, literacy programmes, and many other ways (Gurney & Nisnet, 1998:7).

Subsequently, the big question is: How can educators get communities involved in school affairs? Careful proactive planning is an important component. Questionnaires and needs assessments given to teachers, parents, and community members may provide a starting point for determining where the needs are. How each educator may develop a plan is individual as each school and community has their own individual needs and priorities. Cooper (2001:489) has found that a community forum, consisting of school personnel and members of communities, of open discussion can provide a diversity of opinions and ideas.

The twenty-first century educator searches for ways to form alliances with schools and communities. Possibilities for alliances between educators, schools and communities are limitless. When communities bond together to assist schools, we see many benefits for schools and communities and most importantly a brighter future for South Africa's youth (Forget & Lebel, 2001:19).

Having looked into the community as a system in this section, it is now imperative that the application of ecological and systems theory to school and community should receive attention. The following section provides the core and crux of the section.

2.6.7 An application of an ecological and systems theory to school and community interventions

Knowledge of risks and protective factors is used in a post-modern interventions to promote the enhancement of nurturing environments for children in families, schools and communities. Ludwig *et al.* (1997:67) identifies the following four mediating mechanisms which act in ways which:

- reduce the impact of risks;
- reduce negative chain reactions;
- maintain self-esteem and self-efficacy through relationships and task achievement; and
- open opportunities for positive development.

Risk is a statistical concept used to predict the probability of negative outcomes. Resiliency and protective factors are the positive side of vulnerability and risk (Fiscus, 2002:90). Risk and protective factors are found both *within* the child (temperament, physical constitution, intelligence, education) and/or within a child's environment (caring adults, high expectations, good schools, high crime levels).

A child or family's developmental trajectory results from the negotiation of risks on one hand, and the exploitation of opportunities on the other. A way to conceptualize these interactions is to think of an ever changing equation containing plus and minus numbers. At any given time two or more numbers may combine to bolster development in a positive direction or push development toward negative outcomes. If the "solution" of the equation were graphed repeatedly, over time, it would represent the life trajectory of an individual (Bogenschneider. *et al.*, 2000:24) For example, perhaps biology contributes to a child's high intellectual potential. This should set the course of the child's development in a positive direction. This potential could be unrealized or move the child in a negative direction if a school setting failed to provide an appropriate educational experience leading the child to drop out of school. Various authors have highlighted the following statements about risk and protective factors, which are:

- the presence of a single risk factor typically does not threaten positive development. In situations where a child is vulnerable, the interaction of risk and protective factors determines the course of development;
- if multiple risk factors accumulate and are not offset by compensating protective factors, healthy development is compromised (Waller, 2001:178);
- poverty increases the likelihood that risk factors in the environment will not be off-set by protective factors (Fine, 1992:);
- when a child faces negative factors at home, at school, and in the neighbourhood the negative effect of these factors is multiplied rather than simply added together (Cotzee & Streak, 2004:84);
- resiliency studies explain why two children facing similar risks develop differently. A core of dispositions and sources of support, or protective factors, that can buttress development under adverse conditions have been identified (Gopalan, 2004:28);

- dispositions that act as protective factors include an active, problem-solving approach and a sense of self-esteem and self-efficacy. Resilient children are characterized by a belief in their power to shape and have an impact on their experience; and
- caring and support, high expectations, and opportunities for participation are protective factors for children found in families, schools and communities (Keller & Golley, 2000:26).

From the foregoing statements it is clear that protective factors reduce the effects of risk and promote healthy development. Protective factors influence the way a person responds to a risk situation. The protective factor is not a characteristic of the person or the situation, but a result of the interaction between the two in the presence of risk.

2.7 CONCLUSION

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

The next chapter presents the design of the empirical research.

CHAPTER THREE

RESEARCH DESIGN

3.1 INTRODUCTION

This chapter presents the research methods employed in this study. It includes an overview and justification of using qualitative research, research design and sampling. The use of interviews is taken as the most appropriate and practical technique in reaching the objectives of this study.

3.2 RESEARCH METHODOLOGY

In this section, aspects such as the research approach, design, population and sampling, measuring instruments and data analysis are explored.

3.2.1 Research approach

The qualitative research approach is deemed suitable for this research. Different scholars have provided various definitions and meanings of qualitative research. The term 'qualitative research' encompasses several approaches to research that have two things in common. First, they focus on phenomena that occur in natural settings – that is in the 'real world' and secondly, they involve studying those phenomena in all their complexity (Leedy & Ormrod, 2005:133). Qualitative research methodologies are methodologies dealing with data that are principally verbal (White, 2005:80). According to White (2005:81), qualitative research is more concerned with understanding social phenomena from the perspectives of the participants. This happens through the researcher's participation in the daily life activities of those involved in the research. Cresswell (2003:15) posits, that "...qualitative research is an inquiry process of understanding, based on distinct methodological traditions of inquiry that explore a social or human problem. In the process of a study, the researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting."

Among other reasons, qualitative research is more concerned with understanding social phenomena from the perspectives of the participants. In this research this was done through the researcher's participation in the participants' daily life activities.

Justification for this choice is, that firstly, it is a type of formative research that could offer specialized techniques for obtaining in-depth responses about what children of parents who are suffering from HIV/AIDS, their significant others, a health-worker and a teacher think about the plight of these children, how they feel about HIV, their needs and wants, as it is exploratory and interactive. Qualitative research enabled the researcher to gain insight into the plight of children whose parents suffer from HIV and their 'lived' experiences. Secondly, qualitative research provides a rich texture and context through which to learn about the infected person as an individual without losing the rich descriptions of his/her attitudes and feelings and the essence of his/her experiences.

This research is investigative and exploratory, and the interviews with parents infected by HIV/AIDS and their children, are designed to encourage them to tell their stories. According to Maddi (1999:64), this is consistent with the idea that people make sense of and communicate their experiences through stories. Lincoln and Guba (1999:42) explains, that the 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.

3.2.2 Research design

According to Miles and Huberman (1994:63), research design can be understood as the planning of any scientific research from the first to the last step. It can therefore, be regarded as a programme to guide the researcher in collecting, analyzing and interpreting observed facts. The following research designs were used in this research.

3.2.2.1 Phenomenology

Phenomenological research was conducted. This design is concerned with the essence or basic structure of a phenomenon. The term 'phenomenology' refers to a person's perception of the meaning of an event, as opposed to the event itself, as it exists external to a person (Leedy & Ormrod, 2005:139). This study attempts to understand the plight of children whose parents are suffering from HIV/AIDS, their perceptions, perspectives and understanding of their 'lived' experiences.

3.2.2.2 Case study

The term 'case' study pertains to the fact that a limited number of units of analysis such as an individual, is studied intensively. The researcher was directed to understand the uniqueness and idiosyncrasy of each case in all its complexity (Welman & Kruger, 2001:183). A case study is an intensive, holistic description and analysis of a single unit or bounded system. Case studies were used as the method of investigation of the plight of children whose parents suffer from HIV/AIDS and their experiences. A case study is a form of qualitative research, as well as a methodology. Patton (1990:12) describes case studies as 'an end-product of field-oriented research,' which means, the end report of a case investigation. It is in this context, that the case study method was selected for this research. A case study can be defined in terms of a process and can be used to carry out an investigation or inquiry of bounded systems or units of analysis selected for study.

Verbatim data from the transcripts were reviewed repeatedly through the case study formulation, compared to the audiotape, summarized and reported in a case study format. Careful and repeated review of the data was carried out in order to assure accuracy in the final case study report. Two case studies were generated. The case studies included in-depth and thorough explanation of the respondents' personal experiences as told by the respondent/interviewee. The case studies were presented as holistic and descriptive personal accounts of the different individual respondents. Unique experiences of each of the respondents are provided through direct quotes and details of influential

factors that played part in their psychological and physical well-being. Basic information on family background is contained in the case studies.

3.3 THE PURPOSE OF THIS STUDY

Through a qualitative design, this study examines and integrates the in-depth experiences of children whose parents suffer from HIV/AIDS. In-depth descriptions of their life experiences are provided through the inclusion of their case studies. Case studies were analyzed for common themes and patterns. A quantitative design was not chosen, because this process would require the use of standardized methods and would limit the extensive and varied experiences of the respondents by forcing a fit into predetermined categories (Patton, 2001:78).

The qualitative design included the following components which are.

- purposive sampling;
- case studies reporting so as to richly portray each of the credible 'stories'; and.
- inductive analyses of the themes or common patterns that tie the individual experiences of children whose parents suffer from HIV/AIDS together. This will allow for better understanding of these children's plight.

3.4 DATA COLLECTION

This section discusses the way the participants were selected, how the data were gathered and transcribed and how themes were deduced from the participants' responses.

3.4.1 Sampling

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

- record and understand the plight of children whose parents suffer from HIV/AIDS in their own terms;

- observe natural, ordinary 'lived' experiences of children whose parents suffer from HIV/AIDS; and
- generate detailed data about the children studied and also to provide contextual understanding (De Vos, 2001: 177).

There are different types of purposeful sampling; and network sampling is one of the types mentioned in Merriam (1998:137). The researcher decided to utilise network sampling. 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, and good interview subjects. In purposeful sampling, size and specific cases depend on the study purpose. The researcher used her network of friends who are managers of NGOs, social workers, members of the support groups for HIV-infected and – affected people and colleagues to conduct network sampling. The researcher decided to approach a social worker working with street, abandoned, orphaned and neglected children. The interviewer requested the social worker for assistance, as it was difficult to get this kind of information at schools. The social worker assisted the researcher with two case studies of children whose parents suffer from HIV/AIDS, who happened to stay in Edenville and Kroonstad in the Fezile Dabi District in the Free State. In these case studies, one educator, a health-worker, two children, four parents and a grandmother were interviewed (N=9). Educators do not know which children have parents who suffer from HIV and they have to depend on whether parents are prepared to disclose their status or not.

3.4.2 Research instrument

This section discusses the instrument which was used to elicit data from the participants who formed the sample of this research.

3.4.3 Interview procedure

Prior to the beginning of the interview, the participants were read the procedure the research was going to employ. This procedure specified, that confidentiality would be preserved during the documentation and reporting

process, and the identity of the respondent would remain confidential throughout the research project; the respondent was asked to select a pseudonym, which was used for the recorded interview, the transcription and the reporting process in this dissertation. It was stated, that the interview tapes and transcribed documents would be available only to the transcriber and the committee of the University of North-West (Vaal Campus).

Prior to the interview, the respondents were asked if they objected to the researcher taking handwritten notes. They were also told that they would receive a copy of the *verbatim* transcript. Respondents were asked to read the transcript and make the necessary corrections. They were also informed that they would receive their completed case studies. They were asked to correct it for any inaccuracies and to make sure that the case studies accurately portrayed the information they provided. The researcher requested the respondents to return their comments within one to two weeks after receiving their case studies.

3.4.4 Interview setting

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

3.4.5 Interview guide

In all four case studies the researcher opted for in-depth and semi-structured interviews which involved one-to-one interaction and were organized so to as encourage the respondent to express himself/herself freely about his/her plight of having parents who suffer from HIV/AIDS. In-depth interviewing focuses in considerable detail on the life experience and social behaviour of selected individual respondents. An open-ended interview was used to

explore each participant's thoughts and feelings about his/her plight of having parents who suffer from HIV/AIDS. In this open-ended interview, a group of questions was used to guide the interview.

According to Patton (2001:75), open-ended interviewing is considered to be an effective way to obtain individual perspectives. Open and non-threatening questions, such as the first question, "Would you tell me about yourself?" were included in order to help establish rapport and to allow the interviewee to respond freely. In addition to developing rapport, the open-ended interview dialogue was selected, because it assisted with enhancing the communication level between the respondent and the interviewer.

3.4.6 Transcriptions and analysis

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

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

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

3.5 ETHICAL CONSIDERATIONS

Due to the charged and emotive nature of the HIV/AIDS phenomenon, certain ethical considerations assumed particular importance. Shank (2002:230) notes, that the very nature of the aim of a phenomenological study, namely to access the individual's life-world, is obtrusive. In this study, this obtrusiveness will further be exacerbated by the sensitivity of the topic under investigation. First and foremost, the researcher will have a responsibility to respect the rights, needs, values and wishes of the participants (Gillham, 2000:112). In order to protect the participants' rights, the following safeguards as listed by Cresswell (2003:123), are employed.

- The research topic and objectives were expressed clearly in order to be well understood by the participants.
- Each participant's consent was requested to participate in the study.
- Transcriptions, interpretations and reports were made available to those participants who wished 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 in order to protect their anonymity. It was anticipated, that the discussion of the experience of meaning in individuals with HIV, could prove to be emotionally distressing for some participants. If necessary, the researcher would make recommendations for therapeutic interventions (Shank, 2002:67).

3.6 CONCLUSION

This chapter presents a research design employed in this study. The next chapter deals with results of the qualitative research.

CHAPTER FOUR

ANALYSIS AND INTERPRETATION OF RESULTS

4.1 INTRODUCTION

In this chapter the researcher presents results of interviews with children whose parents are HIV/AIDS-positive. The results are presented by means of themes. The family background of each case is presented first and the proceedings of the interviews follow.

The interviewer started her conversation with the participants, by first explaining that the purpose of the research was to gather information on the plight of children whose parents suffer from HIV/AIDS. The interviewer further requested the interviewees' permission to write down some of the revelations and also to electronically record the conversation so as not to forget what had been discussed.

4.2 TRANSCRIPTION OF THE INTERVIEWS

The following is a transcription of interviews with Makgeletsa's father, Makgiletsa's mother, Makgeletsa, the health-worker, the school principal, Fana, Fana's father, Fana's mother and Fana's aunt.

4.2.1 Case study 1: Makgeletsa

Here follows the family background of the family members who formed part of this research.

4.2.1.1 Family background

The father and mother of Makgiletsa (not her real name) were interviewed in this research. Both parents are HIV-positive. Makgiletsa is a 14-year-old girl who is now doing grade 8. She became aware of her parents' positive HIV status when they were invited to an HIV awareness function at her school. Her father was one of the speakers at this function.

Makgiletsa's parents are both unemployed and depend on her grandparents' pension grant.

4.2.1.2 Interview with Makgiletsa's father

QUESTION: ARE YOU WORKING?

'No, I'm not working. I am not well. I am always sick; but when I get to the clinic they tell me that I am fit to work. No company can hire me; I am frequently absent because of my ill health'.

QUESTION: WHY ARE YOU NOT WORKING?

'I have never worked all my life; I got tired of searching for jobs; I have been doing this for years, but to no avail. There are no jobs here; the only thing I get, is a piece-job'.

QUESTION: HOW MANY CHILDREN DO YOU HAVE?

'I have two children. The eldest, Makgiletsa, is 14 years old and the last-born is 5 years old. We had a third-born, but he died when he was six months old'.

QUESTION: WHAT IS THEIR STATUS?

'Fortunately, none of them have this dreadful virus. They got tested after we were tested. My wife got pregnant with our third child, but he died when he was six months old. That is when we were tested and were informed of our HIV-positive status.'

QUESTION: HOW DID YOU FIND OUT ABOUT YOUR POSITIVE HIV STATUS?

'I got very sick and could not even walk, I was frail and could not eat. My feet were swollen and my whole body ached. The nurse who attended to my case, suggested that I be tested. Although I did not want to be tested, I had no option. I was tested because I wanted them to give me something that could ease away the pain'.

'Because I underwent a rapid test, the nurse told me the results after a few minutes. That is after she counselled me. The results came out, 'positive.'

QUESTION: WHAT CAME TO YOUR MIND IMMEDIATELY THE POSITIVE TEST RESULTS WERE REVEALED TO YOU?

'I was devastated. I could not believe what I heard. I thought of my children and my family. When I was tested, I already knew that my wife was HIV-positive as she was tested first, but I never thought this could happen to me. I got tested in May 2004'.

QUESTION: WHO, DO YOU THINK, GOT INFECTED FIRST?

'My wife was taking care of my sister who died of HIV/AIDS. We were not aware that she was positive until she passed away. I think she got infected first and because we were not using protection, I got infected'.

QUESTION: WHOM DID YOU DISCLOSE TO AFTER YOUR POSITIVE HIV STATUS WAS REVEALED TO YOU?

'I went home to my mother and told her about my positive HIV status. That was the only person I felt free to talk to. It was not easy, but I needed her support. At first my mother could not believe what I said. I was in tears when I told her. She could also see that I was not well, as I was very thin and my feet were swollen'.

QUESTION: WHEN DID YOU TELL YOUR WIFE ABOUT YOUR POSITIVE HIV STATUS?

'It was after a week when I felt I was ready to tell her. I told her because she was always asking me about the results. That was the most difficult time of my life. She was diagnosed HIV-positive first. I never pushed her to tell me the results, but immediately after I tested, she pestered me to tell her the results'.

QUESTION: WHY WAS IT DIFFICULT FOR YOU TO DISCLOSE YOUR STATUS TO YOUR WIFE?

'My wife was tested first and diagnosed HIV-positive. When she told me about the results, I could not believe her: in fact, I blamed her for bringing this curse into our family. I was also worried about what people in our area were going to say about us. I was very angry with her for testing. I felt that she should have asked for my permission or we should have discussed this before she tested. I was totally not ready for these results. I did not want to tell her, because I was still very angry'.

'The other reason is, that she got infected first. She should have taken precautions when she was taking care of my sister. She had been very careless. It is all her fault that we are in this mess. I feel that she did this deliberately as she wanted to kill us'.

QUESTION: HOW DO YOU FEEL NOW ABOUT BEING HIV-POSITIVE?

'I think I have accepted the positive status. I mean there is nothing one can do. Because of the support group I attend, I have disclosed to most people in our area'.

QUESTION: HOW LONG DID IT TAKE YOU TO ACCEPT YOUR STATUS?

'I could not talk about being HIV-positive to anyone, except my mother, until up to the end of 2005. This whole time I was indoors. I could not get out as I did not want people to see me. It was as if people knew about my sickness. I was actually hiding. I got very sick towards the end of 2005 and had to be taken to the clinic. The doctor referred me to the hospital in Kroonstad. I was hospitalised for three months. We were all HIV-positive in the ward; we used to share our experiences and ordeals. This is when I started to open up and think positively'.

'I imagined my children without a father and I took a decision to live positively. After I had been discharged, I decided to attend a support group at the clinic. This is where I got the strength to disclose my status to other people'.

QUESTION: IT SEEMS THAT YOU LOVE YOUR CHILDREN DEARLY

'Actually they are the reason I am still alive. I love them so much, I cannot imagine my life without them. I also love my wife very dearly; it is only that living with HIV, does not allow me to show affection to them. If I was not in pain, I thought about what was going to happen to us'

QUESTION: HOW WAS LIFE AT YOUR HOUSE BEFORE YOU ACCEPTED YOUR POSITIVE HIV STATUS?

'During that time I could not see anything wrong, but now I can see how difficult life was for my wife and two children. We were always fighting with my wife; my mother even took the children as she said that she was afraid I was going to kill them. Yes, there were times when I thought of killing them, their mother and then commit suicide. I do not know what prevented me from doing that, because I continuously threatened my wife with this'.

'They were all living in fear. When I was not in the same room with them I could hear them talking, but when I entered the room, they would be very quite. If they wanted to talk about something, they would go to their mother, not me. There was no communication between us until after 2005; they were also afraid to be in the same room with me. They had no option in the afternoon; we had to be together, but immediately after supper they would sneak to their room; they avoided witnessing the fights. There were times when we fought in their presence and called each other names'.

QUESTION: INSTEAD OF FIGHTING LIKE THIS, WHY DIDN'T YOU SEEK ADVICE FROM YOUR MOTHER OR OTHER PEOPLE ON HOW TO HANDLE YOUR PROBLEM?

'I think I was enjoying the fights. It was a way of relieving my stress. It was easy to blame her for the problem and not to face my HIV-positive status. My wife asked some of our relatives, including my mother, to come and intervene. I threatened to kill them. I did not want any one talking about our problems; besides, they were not infected according to me so, what were they going to say about a matter they knew nothing about?'

QUESTION: HOW DO YOU THINK, YOUR CHILDREN FELT WHEN YOU WERE FIGHTING?

'I realise now that they felt very bad but then I just did not care. I wanted them to know the truth and that according to me, was that their mother was at fault. I wanted them to know that even if I would die, their mother would kill me. She was the reason we were always fighting and she is the reason we are living in poverty. They know that when I am healthy, even if I was did not work I would do, odd jobs and they would have new clothes, uniform and stationery, just like other kids. But now, because I am always sick, they cannot have these things. I think I wanted to win them to my side'.

QUESTION: DID YOU MANAGE TO WIN THEM TO YOUR SIDE?

'I am not sure, because they were always with their mother and they would ask her for things they needed and not me. But I think they got the message I wanted to convey, as sometimes they were cheeky and stubborn when she talked to them'.

QUESTION: NOW THAT YOU BEHAVE DIFFERENTLY THAN BEFORE, YOU ACCEPTED YOUR POSITIVE HIV STATUS; HOW DO YOU THINK, THEY FEEL?

'They are always happy; things are back to normal. In the evening we sit and chat as a family. They joke and laugh and they share jokes with us. Every evening we sit together and before we eat, they tell us about what they have been doing at school and we help them with homework. We are a happy family, although we have nothing'.

QUESTION: HOW DO THEY FEEL WHEN YOU ARE SICK?

'They feel bad. It is even worse with the eldest Makgiletsa; she understands what will happen to them if something should happen to me. She becomes so worried, it becomes difficult for her to go out and play. When I am sick, she comes straight home from school. Before she eats, she would come to the

bedroom and ask me how I am. Sometimes I pretend not to be in pain for her sake; she becomes so worried and the atmosphere becomes very tense'.

'The younger one does not seem to care that much, he also comes to my bedroom, but for a while and he goes out and plays. Makgiletsa never go out with friends when I am sick'.

QUESTION: DO YOU AS A FAMILY TALK ABOUT HOW SHE BEHAVES WHEN YOU ARE SICK?

'No, we do not. In fact, I do not want to talk about her worries. I understand that she is worried about what is going to happen to them if I die. I am also worried about that. Even if I was ready to talk about it, what would I say, I do not have a solution to the problem. My mother is not growing younger. I cannot say she can take care of them. I cannot think of anyone else. I sometimes stay awake the whole night thinking about this, I have realised that worry is not good for my health and I have decided that they will cross that bridge when they come to it'.

QUESTION: EXCEPT FROM YOUR MOTHER, DON'T YOU GET ANY SUPPORT IN THE FAMILY?

'No, we have not been very close with other family members. I have an older brother who stays in Kroonstad. He is working there; he does not want anything to do with us or my mother, for that matter'.

QUESTION: AROUND THE NGWATHE COMMUNITY, WHAT KIND SUPPORT DO YOU GET?

'I don't get anything from the community. There was a social worker from Kroonstad who gave us food parcels but used to come after every three months; but I no longer get those food parcels. I do not know what happened to the social worker; she does not visit us anymore'.

QUESTION: HOW DO YOUR FRIENDS SUPPORT YOU?

'I have friends who are also HIV-positive; they support me; they visit me, and sometimes we end up talking about this disease. I decided not to associate myself with the friends I had before I had been diagnosed HIV-positive. I thought they would not understand. In our area, when a person is HIV-positive, people do not want to associate with him or her in fear of their being regarded as infected themselves'.

QUESTION: WHAT KIND OF SUPPORT DO YOU GIVE EACH OTHER?

'Because we are all HIV-positive, we have to accept this disease; we sit and talk about this virus. We comfort each other and share our problems and experiences'.

QUESTION: ARE YOU AFRAID OF DEATH?

'No, at first I was afraid, but now I'm not afraid anymore. Revealing my HIV status to other people and attending the support group, has helped me to deal with my fears. I fear of what is to happen to my children after my death'.

QUESTION: ARE YOUR CHILDREN AWARE OF YOUR POSITIVE HIV STATUS?

'I did not have the guts to tell my children about my status. I just do not want them to be aware of this; it is my way of protecting them'.

'It was only when I was invited to an HIV-awareness function at school where Makgiletsa attends, that she became aware of this. I had to reveal my status to the children at this school, as I had to warn them about the dangers of sleeping around without a condom. I have not yet disclosed my status to my last-born; I am waiting for the right time when she is at least 10-12 years old'.

QUESTION: WHAT IF YOU WILL BE DEAD BY THEN?

'No, I hope I will still be around and healthy. I wish to see my children grow; I would like to protect and support them as their father. I am also hoping for a cure'.

4.2.1.3 Interview with Makgiletsa's mother

QUESTION: ARE YOU WORKING?

'No, I'm not working. I have never worked. I would like to work though but there is nowhere I can work. Very few people work in our area. It is even difficult to be a domestic worker. I also no longer have the strength'.

QUESTION: WHY ARE YOU SAYING THAT YOU DON'T HAVE THE STRENGTH?

'Because of this disease, I'm living, while my health has deteriorated. There are days when I feel strong; these are the days when I wish I could be working so that I can buy my children new clothes, school uniforms and stationery. At the moment they depend on hand-outs. I do not like this. We are still young to depend on hand-outs. Children whose parents are of the same age as us, do not lack basic needs but ours struggle to get food; this makes me very sad'.

'Although I never had a steady job, I used to get odd jobs for washing and cleaning other people's houses. I was not earning much, but I used to buy my children what they needed'.

QUESTION: HOW DO YOU THINK, THEY FEEL THAT YOU ARE NOT WORKING?

'Makgiletsa is a teenager; you know how teenagers are. She needs to have smart fashionable clothes like others have. She wears old torn clothes that are given to her by her friends. We cannot afford to buy them anything. We grow spinach and when it is ready, we sell to the teachers at school and our neighbours. The money we get from selling spinach, is enough only to buy other household necessities such as toiletry, electricity, etc'.

QUESTION: WHAT IS YOUR CHILDREN'S STATUS?

'They are both negative. The only one who was HIV-positive, was the last-born who died when she was six months old. They were tested in 2006. We felt that we should also know their status and put their mind's, especially

Makgiletsa's, at rest. People in our neighbourhood told her that she is HIV-positive; she cannot have parents who are HIV-positive and be negative is impossible. This happened after her father had disclosed his status to the children, parents and teachers at school'.

QUESTION: HOW WAS MAKGILETSA AFTER HER FATHER'S STATUS HAD BEEN REVEALED TO HER AT SCHOOL?

'Even though I was not at that function, one of the educators told me, that she was devastated and in shock. I could imagine, as this was the first time she learnt about her father's status in public and with other children. It was very unfair for her to learn about her father's status this way, but it seemed the only way'.

'The disclosure affected Makgiletsa so much, that she decided not to attend school for two weeks after that. We had to do something, as she was also starting to believe that she is HIV-positive. As they also did a rapid HIV-test, the results came out immediately. We were all thrilled to hear that they are both HIV-negative. It was a relief to Makgiletsa. She went back to school with confidence and told other children and their parents (who were teasing her about being HIV-positive), that she tested HIV-negative'.

QUESTION: HOW DID YOU DEAL WITH HER SITUATION?

'We thought of taking her to the clinic for an HIV-test to clear her name. That helped a lot as after the negative test results, she felt better. Concerning the embarrassment she suffered, we could not do much except to apologise. At first I could not face her; it took days before I could face her. I tried to convince her that even though we are HIV-positive, we are strong and healthy; it is only God who knows when we are going to die. I told her that it is not only people who suffered from this disease who die, but everybody is going to die but in different ways'.

QUESTION: DID YOU EXPLAIN TO HER WHY HER FATHER DISCLOSED HIS POSITIVE HIV STATUS TO THE WHOLE SCHOOL AND NOT TO HER FIRST?

'It was difficult for us to disclose our positive HIV status to her. We wanted to protect them. When my husband was invited to school to render a speech, we spoke about it and to us it seemed a solution to our inability to disclose to her at home. We saw this as an opportunity for the father to reveal his status to her. The reason I did not attend the function, was that I did not want her to learn about her father's and my status at the same time. We wanted her to deal with the news of her father's positive status first and after sometime, I would reveal mine. That was our plan'.

'This was not the first time that my husband revealed his status in our community, but in all the other instances it was in the absence of Makgiletsa. We could not hide this any longer as my husband is a good orator he is invited to many functions where HIV/AIDS days are celebrated. One of the community members would approach Makgiletsa one of these days'.

QUESTION: DO PEOPLE IN YOUR COMMUNITY STILL BOTHER MAKGILETSA ABOUT YOUR POSITIVE HIV STATUS?

'Yes, they still do. They do not bother her about her status, but they call her names because of our positive HIV status. There are people who understand, but there are those who do not want anything to do with us. She lost some of her friends after her father's disclosure, but others stood by her'.

QUESTION: HOW OFTEN DO YOU FALL SICK?

'A few times a month; when I fall sick, I stay in bed for a week or two; it depends. Sometimes it becomes difficult for me to get to the clinic. When I am sick, my husband takes care of me and I also do the same for him; that is, if I am not sick. The problem occurs when we both fall sick at the same time; Makgiletsa then has to take care of both of us'.

QUESTION: DOES SHE COPE TO DO THIS?

'I really cannot tell; she does not talk about whether she copes or not, but I think she doesn't. She is young; it is difficult for her to take care of both of us, see to it that her younger brother is ready for school and still do her school-work well'.

QUESTION: DO YOU EVER TALK TO HER ABOUT COPING IN TAKING CARE OF YOU AND YOUR HUSBAND?

'No, as the eldest, she knows that it is her duty to do so. A girl is expected to take care of the house. This would happen even if I was working; she would be the one who sees to it that everything is in order. The only difference is, that added to her household chores, she has to take care of us. If we talk about this, I would not know what to say if she feels that the responsibility is too much for her'.

'It is not that I do not feel that she is overburdened, but there is nothing we can do'.

QUESTION: WHY IS YOUR MOTHER-IN-LAW NOT TAKING CARE OF BOTH OF YOU WHEN YOU ARE SICK?

'She is not staying far from us; it is easy for her to come when she is healthy but she suffers from high blood pressure and diabetes, which makes it difficult for her to help us sometimes. We have to rely on Makgiletsa. Other close relatives cannot take care of us; they told us that they are afraid of people with AIDS. They advise us to get to the hospital when we are sick where there are qualified nurses to take care of us'.

QUESTION: WHAT MAKES YOU NOT TO GET TO THE HOSPITAL WHEN YOU ARE SICK?

'It is difficult to leave Makgiletsa and her younger brother alone in the house. We have to make arrangements with my mother-in-law to fetch and look after them while we are admitted to hospital; sometimes we do not even have time to do this. It becomes better for us to be at home. One other reason, is that

people are not always admitted to hospital; there are times when they treat you as an out-patient'.

QUESTION: HOW DO YOU FEEL ABOUT BEING HIV-POSITIVE?

'I sometimes feel like It is punishment from God for something I might have done wrong in the past. I feel really bad, because I do not understand how I became infected. Why are other people not HIV-positive; why me?'

QUESTION: HOW DID YOU REACT WHEN THE HIV-POSITIVE RESULT WAS REVEALED TO YOU?

'I felt numb and devastated. I was not expecting this. It took me time to get used to being HIV-positive. It was even worse at home, as I was not getting any support from my husband. Although I was afraid to disclose, I had to tell him. I needed someone who would understand what I was going through. He is the only person closest to me. I thought he would understand, but instead he accused me of sleeping around and being unfaithful to him'.

'Instead of things being better, they got worse. My husband turned into an animal. I regretted disclosing to him. For the whole year we fought like cat and dog. This affected the children more, as they did not understand what was happening. My health deteriorated because of stress. Life was difficult for all of us that whole year'.

QUESTION: WHO, DO YOU THINK, GOT INFECTED FIRST?

'I think I was infected first. I was taking care of my sister-in-law when we discovered after she had passed away that she was infected. It was only when we got her death certificate that one of the nurses in our neighbourhood explained the situation to us. I got sick a year after her death and was diagnosed HIV-positive'.

QUESTION: WHAT KIND OF SUPPORT DID YOU GET FROM YOUR FAMILIES?

'I get a lot of support from my mother in law; the only problem, is that she is old. She needs to be taken care of herself. I explained the situation to her and she understood. She is very supportive, she does everything that she is able to do for us even though she cannot afford anything; but she is trying hard to help'.

QUESTION: EXCEPT FOR THE SUPPORT YOU GET FROM YOUR MOTHER-IN-LAW, WHO ELSE IN THE FAMILY SUPPORTS YOU?

'No. Other members of the family do not want anything to do with us. Some of them are afraid that they will be infected if they help us. Others are blaming us for being careless. These members say that we are a disgrace to the entire family'.

QUESTION: WHAT KIND OF SUPPORT DO YOU GET FROM NGWATHE COMMUNITY?

'I don't get anything from the community. The only support they render us, is to buy our spinach. We once thought of selling fat-cakes, but we did not get any support. Instead, they told us that we are trying to infect them with the fat-cakes'.

'There was a social worker from Kroonstad who gave us food parcels, but comes only after three months'.

QUESTION: HOW DO YOUR FRIENDS SUPPORT YOU?

'I don't have friends; the only people I can talk to, are the ones I attend in support group with. They are very friendly and it is easy to talk to them about anything'.

QUESTION: WHAT KIND OF SUPPORT DO YOU GIVE EACH OTHER?

'Because we are both HIV-positive and have accepted this disease, we sit and talk about this virus and how it has affected our lives. We comfort each other

and share our problems. We are both on ARVs; we help each other to adhere to the medication by keeping track of each other's medication times'.

QUESTION: ARE YOU AFRAID THAT YOU MAY DIE?

'It happens all the time, even when I'm watching the programme that shows people who are very sick dying from this disease, I always think about myself. I am also worried about what will happen to my children should I die. Their grandmother is very old it will be impossible for her to raise them'.

QUESTION: HOW DID OTHER CHILDREN TREAT YOUR DAUGHTER AFTER THE DISCLOSURE?

'They treated her badly at first but after sometime there were those who understood her situation. She lost some of her friends and she was called all sorts of names. There were those who did not want to sit next to her in class. She was isolated and that is when she decided not to attend school for a period of two weeks. People in our community prevented their children from associating with Makgiletsa. She also started being aggressive; she would manhandle whoever mentioned that her parents are HIV-positive'.

'With time, she accepted the situation. I think she has adapted ways of dealing with the situation'.

QUESTION: WHEN ARE YOU GOING TO REVEAL YOUR STATUS TO YOUR SON?

'He is too young and I don't think he will understand till he is eight years old, but I already started talking about this disease and to encourage them to watch programs on Television, e.g. Soul City, Phamkate, etc., because these programs shown people who live with this disease. I also give them pamphlets illustrating all these diseases and encourage them to listen to the radio'.

'After her father disclosed his HIV-positive status in the presence of Makgiletsa, we decided to tell her everything. I also disclosed it to her. It was a very painful situation, but it had to be done'.

4.2.1.4 Interview with Makgiletsa

QUESTION: HOW IS THE SITUATION AT HOME?

'We are fine, although there are times when it is difficult. We do not always have food and other bare necessities. Life is difficult, especially when both my parents are sick'.

QUESTION: ARE YOU AWARE OF YOUR PARENT'S HIV POSITIVE STATUS?

'Yes. After my father disclosed at school, they told me about my mother's positive HIV status a week after'.

QUESTION: HOW DID YOU KNOW ABOUT THEIR CONDITION?

'My father disclosed at school where he was invited to give a speech. Then it was for the first time I heard about it; just like everyone who was there. Only my grandmother and my mother knew about it'.

QUESTION: HOW DID YOU TAKE IT FOR THE FIRST TIME YOU LEARNT ABOUT YOUR POSITIVE HIV STATUS?

'It was so painful and difficult; but through support from my friends, educators, children and my family, I managed to accept. It took me time though. I had to go for an HIV-test myself, as people and other children at school were accusing me of being HIV-positive. I had to fight with the others so as to stop them from talking badly about me. I had to be away from school for two weeks, just to recover from shock. In fact, I did not want to go back to school but after the negative test results, I had strength to confront my enemies. My parents also talked me into going back to school'.

QUESTION: WHAT HELPED YOU TO ACCEPT?

'The negative result helped a lot. I was relieved that I was not HIV-positive. My parents also helped by telling me the truth and no longer blamed them for being careless. My grandmother used to visit and comfort me. It was also good that I had few friends who supported me. The school-based support

team at school organised a psychologist for counselling. At first it was difficult for me to attend a session. I felt isolated, and disgraced. I felt lost or maybe punished for the sins of my parents’.

QUESTION: HOW DID YOU FIND OUT ABOUT YOUR PARENTS’ CONDITION?

‘My father disclosed his status at our school on Aids Awareness Day. When I arrived home, I asked if my mother knew about this and she kept quiet. I was so angry with both of them, I stayed in my room most of the time. It was after a week that they called me and told me about everything that had happened to them’.

QUESTION: WHAT DID YOU LEARN ABOUT THIS DISEASE?

‘We shouldn’t discriminate against people living with HIV/AIDS, but should at least try to understand how much pain they have. We should help them when they get sick and we must use gloves when they bleed, so that this disease doesn’t infect us. I know that there are people who are illiterate living nearby. It is my duty to teach them about this virus or ask knowledgeable person/s to come and advise and teach them’.

QUESTION: WHAT KIND OF SUPPORT DO YOU GIVE TO YOUR PARENTS?

‘I help them with taking care of everything when they are sick. I also take care of them. When they are sick, I have to go straight home to clean and cook. I have to wash my little brother’s school uniform for the next day. If it is only my father who is sick, I help my mother with the household chores, so that she can concentrate on him’.

QUESTION: DID YOUR MOTHER TELL YOU HOW SHE GOT INFECTED?

‘Yes, she told me that she used to take care of my aunt who happened to have AIDS. She is afraid that I would also be infected if I take care of them. She makes sure that I bring them food and take the necessary precautions when I am taking care of them’.

QUESTION: UNTIL SO FAR, HOW DO YOU COPE?

'I cannot say I cope. I do a lot of work; by the time I get to bed I am dead tired. It becomes difficult to do homework. My school work is also affected, but I try to do my best'.

QUESTION: HOW DOES IT FEEL LIKE WHEN ARE THEY SICK?

'I get scared when they are very sick; I sometimes think they are going to die. I think of what would happen to us when they are gone. It would be difficult for my granny to raise us; she is very old'.

QUESTION: AFTER YOUR FRIENDS FOUND OUT ABOUT YOUR PARENTS' STATUS, HOW DID THEY SUPPORT YOU?

'Some of my friends rejected me, but there were a few who stood by me. I have learnt that I should not rely on friends as they can turn against you anytime. The ones I am left with, help me with my necessities.'

4.2.1.5 Interview with the health worker

QUESTION: DO YOU ENCOURAGE PEOPLE TO TEST?

'Yes, we do encourage people to test if they are HIV-positive, to test; if they are not willing to do so, we can't force them. We usually tell them about the advantages of testing, which include access to medical care, support from the NGOs. Knowing one's status, helps as one can live positively. Others, because of these advantages, decide to test; we then counsel them and encourage them to join a support group.'

QUESTION: WHY DO YOU ENCOURAGE THEM TO TEST?

'It is difficult to offer any help to them if we do not know their status. We can only offer full support, if they disclose their HIV-positive status. Sometimes they come to the clinic very sick; sometimes we can see the signs and symptoms such as shingles, boils, severe weight loss and maybe one has Kaposi Sarcoma, diarrhoea, etc. This is recognised after the patient has been treated several times for the same problem.'

QUESTION: HOW DID YOU MEET THIS FAMILY?

'I met this family at the clinic while I was giving them a pre-post counselling. After that session we started building a relation so that they were able to visit me whenever they encountered problems concerning their well-being. I have known them for four years now'.

QUESTION: HOW DID YOU ENCOURAGE THEM TO TEST?

'I told them about the advantages and disadvantages of not knowing one's status. I also told them that they can't get the support and treatment they deserve'.

QUESTION: HOW DO YOU SUPPORT THIS FAMILY?

'Sometimes I pay a visit to see how they are coping and give them some advice. If they have social problems, I refer them to the Department of Social Development'.

QUESTION: DOES THE COMMUNITY SUPPORT THIS FAMILY?

'I think things are getting better now; at first when their HIV-positive status was revealed to the majority of the people in our area, they distanced themselves from them. They were the first people in Edenville whose positive HIV status was revealed to community members. Before that, talking about HIV/AIDS was taboo. There are other people now who reveal their positive HIV status to the public'.

'The community of Edenville is still afraid of people with HIV. People with HIV/AIDS are still discriminated against they are not invited in family gatherings and functions. People do not want to associate with them'.

'At the clinic, all people who have been diagnosed HIV positive, who cannot get a social grant because their viral load is high, even if their CD4 count is low, are supplied with seeds. This is to encourage them to cultivate food gardens for fresh vegetables. When their vegetables are ripe, they sell them

to community members. That is the only way they get support from the community’.

QUESTION: DO YOU THINK THE MOKOENA FAMILY IS DISCRIMINATED AGAINST BECAUSE OF BEING INFECTED WITH HIV/AIDS?

‘Yes, but it depends on the situation, because there are those people who understand this situation; others attended workshops and health talks at the clinic. There are people who still think that by talking to people who are HIV-positive can infect them.’

‘Because Edenville is a very small area, if a person is diagnosed HIV-positive today, tomorrow everybody knows. So, people gossip. What I think, is that people discriminate or stigmatise because of fear, insecurity, lack of knowledge and ignorance.’

QUESTION: DO YOU THINK THIS DISCRIMINATION AFFECTS CHILDREN OF PARENTS WHO ARE HIV-POSITIVE?

‘Yes, I think they are affected. Most of the children whose parents are HIV-positive, are also regarded as infected. Other children do not want to play with them for fear of being infected. These children end-up being isolated.’

QUESTION: WHAT SUPPORT DO YOU GIVE TO THE CHILDREN OF THIS FAMILY?

‘We only offer support to people who are HIV-positive and not to their children. There is nothing we can help them with, unlike adults who can be helped with food parcels and a soup kitchen. We offer meals to orphans only. They come during break for midday meals and after school. Children who still have parents, even if they are HIV-infected and also live in poverty, are not catered for.’

4.2.2 Case study 2: Fana's case

4.2.2.1 Family background

This is a family of six, consisting of two parents and four children, namely Siphe, Fana, Zodwa and Fikile. The former, Siphe, is the father's child from a previous marriage, whilst Fikile was adopted from the aunt who passed away as a result of HIV/AIDS. Only two of these kids belong to the current marriage.

The entire family is infected with HIV/AIDS, except for Siphe, who is from the father's first marriage. Added to this ordeal, both parents are not employed and depend entirely on the social grant they receive every month, while they are living in a two-roomed shack.

Fana and Zodwa are still attending school and educators are aware of the family's HIV-positive status. Siphe is an eighteen-year-old boy who dropped out of school when he was in Grade 9.

The social interaction is good at Fana's home. They enjoy support from the neighbours who are aware of their status. Among the supportive activities the family enjoys, is the support around family business, where the selling of liquor and cigarettes reach certain heights. Selling liquor does not bother this family, as their privacy is not invaded; the father is known to be a disciplinarian and a comedian by nature. The family has accepted their status support of each other; interacting well with the neighbours, responding well to the medication and coping with different situations.

4.2.2.2 Interview with Fana

QUESTION: HOW DID YOU DISCOVER THAT YOU ARE HIV-POSITIVE?

'I was tested at Boitumelo hospital when I was five years old and the results were positive. My HIV-positive status only revealed to me was three years ago when I was nine years old. My parents took me to hospital, because my younger sister Zodwa was very sick. The doctors could not detect what was wrong until such time that she was tested for HIV. The doctor suggested, that

we should all be tested, as my both parents are HIV-positive. The results were positive for all three of us: that is myself, Zodwa and Fikile.'

QUESTION: DO YOUR TEACHERS KNOW THAT YOU ARE HIV-POSITIVE?

'My parents told the teachers that Zodwa and I are HIV-positive. The school is not far from where I stay. I am in grade six. Teachers are aware that I am HIV-positive. My parents were unable to pay the school-fees. They were called in by the principal. The principal could see that both my parents are very sick. She advised them to go to the social worker who would assist them with grants so that they could be able to pay school-fees.'

QUESTION: DID YOUR PARENTS GO TO THE SOCIAL WORKER?

'Yes, they did go, because today they get eight hundred and twenty rand each for ill health. They both have tuberculosis. They are now able to pay for Themba and me.'

QUESTION: DO YOUR FRIENDS KNOW THAT YOU ARE HIV-POSITIVE?

'I no longer have friends; they left me after they learnt about my parents' HIV-positive status. They told me that their parents told them not play with me anymore as I would infect them. They do not want to play and eat with me.'

QUESTION: WHAT WAS YOUR REACTION AFTER HEARING THAT YOU ARE HIV-POSITIVE?

'It was late in the evening when my parents called me to their bedroom. I immediately realised that something was wrong. The only person who is usually called to the bedroom, is my older brother Sihle, who is always in trouble. Everytime when he had done something wrong, they would call him to the bedroom to scold and reprimand. They reminded the time when we were tested and told me that the results came out positive. They also told me that they decided to tell me this, because they do not want me to hear about it from people in the streets. I felt so bad. I had a lump on my chest. They were in and out of the hospital because they were HIV-positive. They told us about

their HIV-positive status two years before. I thought of what other children would say at school. They were already isolating me because of my parents' positive HIV status. I wondered what was going to happen to me. It was as if the whole world had come to a stand-still. I asked them about the status of my other siblings. They told me that Zodwa and Fikile were also HIV-positive, but they are still too young to be told. They also told me that Siphe was not infected.'

QUESTION: HOW LONG HAS YOUR POSITIVE HIV STATUS BEEN REVEALED TO YOU?

'It has been three years now. I was doing Grade three when my positive-HIV status was revealed to me.'

QUESTION: HOW DO YOU FEEL NOW ABOUT BEING HIV-POSITIVE?

'Life is difficult. I do not have a future. My parents' health is deteriorating. My two younger sisters are also HIV-positive. Our eldest brother does not want anything to do with us. He tells us that after the death of our father we would never see him again. I do not know what would happen to us then; it is tough for us now!'

QUESTION: HOW IS THE SITUATION AT HOME?

'Everything seems okay; we carry on as if everything is fine. Life is much better though, because of the grant we get every month and the profit my father is getting from selling liquor and cigarettes. We have food. The problem is, that my father's customers cause trouble sometimes when they are drunk. They would fight but I have noticed that my father has a special way of handling them. There is a special room where they sit and drink liquor. When they make noise and drink the whole night, especially during week-ends, it becomes difficult for us to sleep or do homework.'

QUESTION: WHO ELSE KNOWS THAT YOU ARE HIV-POSITIVE?

'All my relatives know that we are HIV-positive, except for Sihle. Some of them are supportive; but others do not like my father; they blame him for my

mother's HIV-positive status. Those who have accepted us, sometimes bring food and vegetables. They love, hug and kiss me and this makes me feel accepted and happy. We no longer visit the members of the family who are not supportive; they do not want us to visit their homes, they say we will bring them bad luck.'

QUESTION: DO YOU EVER GET SICK?

'Yes, sometimes headache and flu are the main problems. I usually go to Boitumelo hospital at Kroonstad when I am sick. They give me Bactrim syrup, of which I must take 10ml once a day. I have to go to the hospital once a month for a check-up.'

QUESTION: WHAT SUPPORT DO YOU GET FROM YOUR PARENTS?

'They support me in everything I do, but this depends on whether they are sick or not. As one or both of them are always sick, it becomes difficult for them to assist us with homework. During these days we wash our own school uniforms. Zodwa helps my mother with the cleaning of the house and cooks, sometimes.'

QUESTION: ARE YOU TAUGHT ABOUT HIV/AIDS ISSUES AT SCHOOL?

'Yes, we learn about HIV/AIDS at school, especially during the periods of Life-Orientation. Sometimes we watch TV programmes of HIV/AIDS at school. Sometimes we have plays where children would act being HIV-positive.'

QUESTION: HAVE YOU EVER PLAYED HIV-POSITIVE AT SCHOOL?

'I have never played HIV-positive in our plays. In fact, I do not want to be part of HIV/AIDS day celebrations. I do not attend the functions. I watch other children when they are rehearsing. They are just acting. It is different from being HIV-positive or having parents who are HIV-positive.'

'I am ridiculed and laughed at because my parents are HIV-positive. They call me names. I feel that I am less than other children who are of the same age. I feel that even if were not HIV-positive, the mere fact that my parents are,

would be a disadvantage. I am only in Grade six. If anything happens to them, I do not think I will be able to continue attending school and I think Sihle would also chase us out of the house.'

QUESTION: DO YOUR TEACHERS AT SCHOOL INVITE MOTIVATIONAL SPEAKERS FROM OTHER SCHOOLS OR ORGANISATIONS OR DISTRICTS?

'Yes, occasionally motivational speakers are invited. I do listen to them. I take their advice to live positively but it is difficult. If I were HIV-positive and my parents were not, I think it would be better, as they would support me fully but it is different; they have their own problems to solve. They are really struggling and taking care of us, is an added burden.'

QUESTION: DO YOU EVER TALK ABOUT HIV/AIDS WITH OTHER CHILDREN?

'No, it is only when they call me names, because of my HIV-positive parents. They call me 'rake', as they see me as too thin. They say that they will never eat at my house as the very food we eat, is infected. Sometimes I talk back but other times I just keep quiet when they go on and on about how my parents are. They say they have enough viruses to infect the whole community. I do not like this, but there is nothing I can do about it.'

QUESTION: HOW DO YOU THINK, YOU CONTRACTED HIV?

'I contracted it from my parents; that is what they said when they revealed my HIV-positive results to me. I am sometimes angry with them, because they should have taken precautions, but sometimes I accept that I am HIV-positive; there is nothing I can do to.'

QUESTION: DOES YOUR BROTHER SUPPORT YOU AND THE REST OF THE FAMILY; HE IS THE ONLY WHO IS HIV-NEGATIVE?

'No, he doesn't. He tells us that we must not go around telling people that we are his siblings. He does not want anything to do with us. He is afraid that I

would infect him; he is sometimes frustrated to have a half-brother that is HIV-positive. This makes our relationship not to be good.'

QUESTION: HOW IS YOUR PERFORMANCE AT SCHOOL?

'My performance is not good at all. Although my parents help me sometimes, I do not always concentrate in class. I sometimes think of my family and especially my two younger sisters. Zodwa is trying her best at school, although she is also not doing well.'

'When we are doing group activities, other children do not want me to be in the same group with them. Sometimes the teacher intervenes by allocating me to one of the groups even if they do not want me. When this happens, the group members do not accept my contribution, as they say I know nothing. After the activity they will tell the teacher that I did not contribute and I would be allocated lower marks than the others, but sometimes the teacher does not listen to them and just allocates the same mark for all of us.'

'I no longer enjoy school. I have too many problems to deal with. This makes concentration in class difficult sometimes. There are days and weeks when I do not attend school, because I am ill. The same applies to Zodwa, but her rate of absenteeism is even worse than mine, as sometimes she has to be home with her my mother with the household chores. This happens when my father is ill and my mother has to be in the tuck-shop. Zodwa has to clean and cook for the whole family.'

QUESTION: WHICH CAREER DO YOU WANT TO FOLLOW WHEN YOU GROW UP?

'I have not thought about that. If my parents were not HIV-positive and I was also negative, I would study to be an educator but I do not think that will ever happen. Who would pay for my fees when my parents have died?'

QUESTION: HOW DO YOU SUPPORT YOUR SISTERS?

'I love both my sisters. I know that Fikile is not my sister; she is my cousin, but our parents encourage us to love and care for her as our own sister. We do

not call her cousin, but 'little sis'. We play together. These are the people I am free to play with. Although Zodwa is three years younger than I am, we talk sometimes about our fears. We would sit together and console each other. I help them with other children who give her a hard time. I try to be a big brother to them; after all, I will have to take care of them when our parents have gone.'

4.2.2.3 Interview with Fana's father

QUESTION: WHEN DID YOU KNOW THAT YOU ARE HIV-POSITIVE?

'I knew a long time ago before I got married to my second wife. I got tested at a clinic and the HIV-positive results were revealed to me. I did not take it serious as I had no signs of AIDS. I went to the clinic because I was coughing a lot. I was not even bothered about being HIV-positive, as what I wanted then, was to get a medicine to relieve the cough.'

QUESTION: AT THE MOMENT, DO YOU SHOW SIGNS OF BEING HIV-POSITIVE?

'Yes, I have pneumonia, backache, and skin problems; my skin colour has changed to a darker colour, although I am of light in complexion, and I cannot work more than four hours; my chest and bones are painful and I become weak and tired.'

QUESTION: DOES YOUR WIFE KNOW THAT YOU ARE HIV-POSITIVE?

'Yes, she knows now. I could not tell her that when we met before we got married. I did not think that was necessary and besides I did not believe that I was HIV-positive. I was fresh and fit, just like other people. I told my wife after she gave birth to her second child Zodwa. Zodwa's ill-health led to all of them being tested. I did not test for the second time. I told her and the nurse that I had tested four years before I met her and the results were positive. It was then that I see that this HIV 'thing' is real and serious.'

QUESTION: HOW DID YOUR WIFE REACT TO THE DISCLOSURE OF YOUR HIV-POSITIVE STATUS?

'She felt bad. She was depressed for quite some time. She did not want to talk to me for a long time. I think she was blaming me, although she did not say so. We started communicating after we attended counselling sessions. At the moment she is okay. She accepts our status and she is supportive. She does not have any signs; she sometimes suffers from arthritis and flu.'

QUESTION: DO YOU FEEL THAT SHE IS RIGHT BY BLAMING YOU?

'I think she is right. I am at fault. I should have told her when we met, but I think she would then not have agreed to marry me. I did not take the positive-HIV results serious. I am not sure why, but now I realise that I have ruined their lives.'

QUESTION: HOW DID THIS AFFECT YOUR CHILDREN?

'Sihle did not care because, he is not on good terms with his step-mother. He took my side, as he wanted us to separate. It really affected Fana, especially after he knew that he was HIV-positive. I can say it divided the family. There was a time when I could see that Fana was taking her mother's side. During this time we could not concentrate on their problems; the only thing we had time for, was to solve this problem. My in-laws were also involved; they still do not visit us, even now. They do not understand why she forgave me after how I had betrayed her.'

QUESTION: DO YOUR CUSTOMERS KNOW ABOUT YOUR STATUS?

'Yes, they all know about my status. When customers first learnt about our HIV-positive status, they were divided. There were those who did not care and continued buying our stuff, but we lost some of the customers. Although they never said anything, I suspect that they did not want to buy from people who are HIV-positive. The customers who still buy from us, enjoy buying at my place, because I make jokes and we laugh. Sometimes we even talk about HIV/AIDS.'

'Although I wash the glasses well, there are others who do not want to come and drink at my shebeen in fear of their being infected. They say they cannot use glasses that have been used by people with HIV/AIDS. I do not get enough from selling liquor, but it is much better than having a grant only. It helps, as I also drink with my customers in order to relieve my stress.'

QUESTION: ARE YOUR RELATIVES SUPPORTIVE?

'Some of them are very supportive, but other relatives do not want anything to do with us. When I am sick, they remind me of taking treatment, eating enough food and getting enough sleep. My neighbour also knows about my status and some community members and all people who buy liquor at my place. I told them and they thought I was joking; as I usually make jokes, they do not believe it, even now. I told them, because I wanted to be free in my conscience and I wanted to live a positive life. They help me if I need something. They give us vegetables, fruit and money. They help to call the ambulance if I am ill or unable to walk; they even use their cars if the need arises.'

QUESTION: ARE YOU ABLE TO SUPPORT YOUR CHILDREN AND WIFE WITH THE PROFITS YOU MAKE FROM LIQUOR?

'The profit I make, is not enough to feed and clothe my family, but it is better than relying entirely on the social grant. We use it mostly to buy herbs from Nature's Health. These herbs are very expensive, but we have to buy them for our health. We then use the grant for groceries and household necessities.'

QUESTION: DO YOU EVER TALK ABOUT HIV/AIDS WITH YOUR WIFE?

'No, we just support each other. I do not feel comfortable to talk to her about my HIV-positive status or hers, for that matter. I do not know what is going to happen to my family after my death. I cannot imagine the life I will live if she dies first. We do not talk about those things. I do not want her to be worried.'

QUESTION: DO YOU ASSIST FANA WITH HIS SCHOOLWORK?

'Sometimes; most of the time I am selling liquor, that is when I am not sick. I am at home when I am sick but during these days I do not want to be disturbed.'

QUESTION: DO YOU EVER CHAT WITH FANA OR ZODWA?

'No, it is not that I do not want to chat with her, but there is no time to do that. If I am not at the tuck-shop, I sleep because of pains.'

QUESTION: DO YOU THINK THAT NOT HAVING TIME TO CHAT WITH YOUR CHILDREN AFFECTS THEM?

'I think it does. I think they also have questions to ask me, or maybe they just want to talk about their fears. There is no time to just sit and talk to them; we have to work; in the evenings we are all tired.'

QUESTION: IS IT ONLY BECAUSE THERE IS NO TIME TO CHAT?

'I also think that I am not ready to talk to them about HIV/AIDS. We do not talk, because I really do not know what to say to them. I cannot say just say I am sorry they are infected or I am the cause of their plight. It is difficult as a parent to talk about these things to your children.'

QUESTION: DON'T YOU THINK IT IS BETTER TO TALK ABOUT IT THAN TO KEEP QUIET?

'Yes it is, but I really neither have the guts nor the energy to talk about our situation to the children. I just hope that they will forgive me and I hope that they will live longer; maybe in few years there will be a cure. The only chance they have for a better life, is when they could be adopted by a person who can love and care for them.'

QUESTION: WHO CAN TAKE CARE OF YOUR CHILDREN AMONG THE FAMILY MEMBERS?

'I cannot think of any one who can take care of my children after my death. I stay with my sister. She has three children to raise. She is not working. I do not think she will be able to take care of my children; it would be too much for her.'

QUESTION: HAVE YOU EVER THOUGHT OF DEATH?

'Yes, when I am sick, I am worried about leaving my children with my wife; that would be a bad thing. I do not talk to them about death. I am afraid to do so. I do not even talk to my wife about death. Each family in our street contribute R20 if one of the neighbours has passed away. There is a burial society, which we have joined through Standard Bank at Kroonstad. We contributes R52 for each family, and this caters for all funeral arrangements.'

QUESTION: DO YOU DRINK ALCOHOL?

'Yes, I must have a way of forgetting my problems. I also started smoking after I was diagnosed HIV-positive. It is easy to be drunk; especially weekends some of my friends get their salaries and have enough money to buy liquor. It is also very difficult to sell liquor to people if you do not drink.'

4.2.2.4 Interview with Fana's mother

QUESTION: WHEN YOU MET YOUR HUSBAND FOR THE FIRST TIME, DID YOU KNOW THAT HE WAS SICK?

'No, I didn't know because he never told me or he was not aware of his status until such time that I delivered our second child after we were married.'

QUESTION: HOW DID YOU FEEL ABOUT THE RESULTS?

'I felt sad; devastated; I wanted to kill myself; I cried the whole week. We fought a lot as I felt that he robbed me of my health. I never thought that I could be infected with HIV/AIDS. I was very angry with him. I really did not

want to see him. I thought he did this deliberately and that he did this, because he hated me. It took me time to get used to the diagnosis.'

QUESTION: ARE YOU STILL ANGRY WITH HIM?

'No, not really. I felt after sometime that there is no point in being angry with him we are both HIV-positive. There is nothing that can be done. My relatives suggested that I should live with him. I thought of that but what about my children? I would have to take them along. How would I feed them? I am not working. It was a difficult decision to make but I decided to stay with him.'

QUESTION: WERE YOUR CHILDREN AFFECTED BY YOUR FIGHTS?

'Yes, they were. We would not talk to each other for days. It would be tense in the house and it would be difficult for them to tell us the problems they encounter at school.'

QUESTION: HOW DO YOU SUPPORT THESE KIDS THROUGHOUT THEIR DAILY LIVES?

'I support them by giving them their treatment daily; cooking for them; helping them with their homework when I am able to do so.'

QUESTION: WHO DOES ALL THESE THINGS WHEN YOU ARE SICK?

'I have trained Zodwa to make sure that all three of them have taken their medication. She also ensures that they have eaten in the morning before they get to school. She cleans the house in the afternoon before she can go out to play.'

QUESTION: HOW OLD IS ZODWA?

'She is nine years old. She is in Grade three. She is still young to do all the household chores but there is nothing I can do, we have no one to help us. She cleans and cooks well, you would not say she is nine years old.'

QUESTION: DOES THIS NOT AFFECT HER AT SCHOOL?

'I am not sure whether she is affected by the situation at home or not. She is not doing well at school. When we are both sick she does not have time to do her homework, same with Fana. I think that they are also affected by the fact we are HIV-positive. They do not only worry about us but also about their own lives. I wish there was something I could do to relieve them of the stress and worry.'

QUESTION: HOW DO YOU COPE WITH ALL THIS STRESS?

'It is difficult I think it would have been better to deal with only one member of the family who is HIV-positive than almost all members. As I say it is even worse with them dealing with their own positive HIV-status and ours. It is as if we are cursed. I do not blame people in our community who say that our family is cursed. I do not think I cope. There are days when I feel that I am strong I am going to make sure that everything goes well. There are days when I feel so down that I do not want to go out of the house.'

QUESTION: DO YOU TALK TO YOUR HUSBAND WHEN YOU ARE STRESSED?

'We are not used to talking to each other about our emotions, let alone HIV/AIDS. It is better for me to talk to my mother about my fears but also not about HIV/AIDS.'

QUESTION: IF YOU CANNOT TALK TO YOUR HUSBAND ABOUT HIV ARE YOUR CHILDREN ABLE TO TALK TO YOU ABOUT THEIR?

'They do not talk to us about HIV or their emotions and fears. We are encouraged at the clinic to allow children to talk to us about their fears. The problem with me is that I do not know what to say. It is difficult to say things are going to be better because I know they won't. All of us are worried about what will happen after our death. Who is going to take care of them? Will they be able to attend school and further their education? I am not able to put their minds at ease concerning these challenges. What is the point then in talking?'

QUESTION: DO YOU WATCH TV PROGRAMMES WITH YOUR CHILDREN WHERE THEY TALK ABOUT HIV/AIDS?

'Yes, we do. I hope that they will get some of the information from these programmes. I cannot tell them about using protection, I have failed to do so as a parent. They better get this information from other people.'

QUESTION: HOW DO YOUR PARENTS SUPPORT YOU?

'They do not support us. They are angry with me for choosing to stay with Fana's father. They feel that I should have taken him to court. They do not want anything to do with us. I am worried about this as I was hoping that after so many years they would have forgotten about this or forgiven me. I was also hoping that they will take care of my children if I can die.'

QUESTION: DO YOU HAVE FRIENDS?

'No, I do not have friends. I had friends before I was diagnosed HIV-positive. After the news of our positive status were revealed I lost all my friends. People do not want to associate with others who are HIV-positive.'

4.2.2.5 Interview with Fana's grandmother

QUESTION: DO YOU KNOW THAT YOUR DAUGHTER AND YOUR SON-IN-LAW ARE HIV-POSITIVE?

'Yes, I know that they are HIV-positive. My son in-law was once admitted at Sterkfontein (he was mentally ill); it is where his status was diagnosed and he did not hide his positive status when he came back from hospital.'

QUESTION: HOW DID THEY TELL YOU?

'They asked me to visit them and we sat around the table together and they told me. When my daughter told me she was very sad and she was crying. The situation was very tense. I felt very angry. I was angry at my son-in-law, I still am.'

QUESTION: DO YOU THINK YOU WILL EVER FORGIVE THEM FOR THE SAKE OF YOUR GRANDCHILDREN?

'No, I do not think so. It is more than eight years now that I have known about their positive-HIV status. After all those years I still feel the same way. I am sorry about that their children are HIV-positive but there is nothing I can do. I cannot change just because he is sick.'

QUESTION: WHAT WILL YOU DO IF THEY CAN ASK YOU TO TAKE CARE OF THEIR CHILDREN?

'I can take care of them but I do not want them to rely in me. I do not want to be part of this as other family members also do not associate with them. It is even worse if the children also are HIV positive. How am I going to take care of them? It is easy with their parents because they are also HIV-positive, I am not.'

QUESTION: HAVE YOU THOUGHT OF WHAT WOULD HAPPEN IF YOUR DAUGHTER CAN DIE FIRST?

'I will bury my daughter but I will not take the children from his husband. I do not care what people will say. He will have to pay for killing my daughter. He is the one who brought this curse he must reap the consequences.'

QUESTION: DO YOU EVER VISIT THEM?

'No, I used to visit them before I their HIV-positive status was revealed to me. After they told me I vowed never to visit them ever again. I told my daughter I would visit if she can come back home to me with her children. You see, I am prepared to take care of my daughter and her children even if they are HIV-positive but not my son-in-law. He deserves to die alone without anyone helping him.'

QUESTION: ARE YOUR GRAND-CHILDREN AWARE THAT YOU WILL NEVER FORGIVE THEIR FATHER?

'They are still too young especially Zodwa and Fikile. Siphe and Fana knows. I always tell them when we meet that I will never set my foot in their house as long as their father is alive.'

QUESTION: HOW DO YOU THINK THEY FEEL ABOUT?

'I think they feel bad especially Fana, he always worry about what is to happen to him and his younger sisters. I think it affects him. I am not the cause of this friction his father is. If he wants to blame someone he should blame his father.'

4.2.2.6 Interview with Fana' aunt

QUESTION: DO YOU KNOW THAT YOUR BROTHER AND SISTER-IN-LAW ARE HIV-POSITIVE?

'Yes I know, they told me. When they told me I felt pity for them. I am now strong for their sake. I feel pity for their children who are also HIV-positive.'

QUESTION: HOW DO YOU SUPPORT THEM?

'I usually help sometimes by cleaning the house when they are both sick. This is rear because I also do odd jobs to support my three children. I do visit them when I have time but once in three months.'

QUESTION: HOW DO YOU FEEL THAT YOUR BROTHER IS HIV-POSITIVE?

'I feel pity, terrible and bad; I wish I could take their pain and bear it with them. Their children would cry out for them especially Fikile, waiting to be picked up hugged and loved. I realised that these children feel very bad when one or both their parents are sick.'

QUESTION: WHAT DO YOU THINK IS GOING TO HAPPEN TO THESE CHILDREN WHEN THEIR PARENTS HAVE PASSED AWAY?

'That is going to be a real problem. I do not want to think about this. My mother does not want anything to do with them or their children for that matter. She is the one who should take care of them. I cannot, I am raising my three children I cannot afford to add another three. I do odd jobs as I said the money I make is not enough for us if I can add other people we would not have food for days. I do not have a solution to this problem I really cannot tell what they should do.'

QUESTION: DO YOUR CHILDREN VISIT THEM?

'No, I am afraid of what my mother would say. It is better that I visit not them. My mother still believes in that they can be infected by playing together.'

QUESTION: ARE YOU WORRIED ABOUT YOUR BROTHER'S POSITIVE STATUS?

'Yes, I am worried about his health. Although my brother and his family are positive about their status I am worried about their children. They do not get any support from both families. I am afraid these children will not be supported even after their death.'

4.2.2.7 Interview with the principal of the school where Fana and Zodwa attends

The interview session with the principal of the school where Fana and Zodwa attend follows. His responses to the questions of the interviewer are presented *verbatim*.

QUESTION: HOW LONG HAVE YOU KNOWN FANA AND ZODWA?

'I have known the Fana for four years now, and I met the Zodwa when her parents came to school two years ago.'

QUESTION: IN WHAT GRADES ARE THEY?

'The boy is in Grade six and his sister should be doing Grade two this year, but she was retained in Grade one, she should be doing Grade three this year.'

QUESTION: HOW DO THEY BOTH PERFORM AT SCHOOL?

'Well, one suspects that there might be underlying factors that affect their performance, because they are both not performing as expected, and they are not slow children. Another factor that has been of concern to us as is that they are always late for morning classes and they are frequently absent from school. They do not stay far from school they do not have transport problems like others. Most of the time we get reports that they are either sick or have gone to the clinic for treatment.'

QUESTION: HOW DO YOU HELP THEM TO CATCH-UP?

'There is not clear strategy to help these children catch-up. Sometimes they do not attend school for days or months. We have substantial number of such children in each class. The problem is that educators have to finish learning programmes at specified periods. It becomes difficult for educators to drag or re-do the learning activities in order to accommodate children who are frequently absent from school due to sickness or their parents.'

'We usually discuss such matters in our meetings we have strategies to address the problems that these children encounter in our learning area policies. These strategies are never implemented as the catch-up classes are after school when everybody is tired and ready to go home.'

QUESTION: DO YOU SEND SCHOOL-WORK HOME WHEN CHILDREN ARE ABSENT FOR LONGER PERIODS?

'We do not send work to these children, this is difficult to do. We are aware that we should be doing it but it is not practically possible. Some activities need to be explained to children and others assistance by the educator.'

'Some of the children in question arrive late for school, and have to live early because they stay far. It becomes impossible for principals to organise either morning or afternoon classes for them, they cannot even participate in extra-curricular activities which are conducted in the afternoon. As a school we really do not know what to do.'

QUESTION: HAVE YOU AS A SCHOOL TRIED TO ADDRESS THE PROBLEM BY TALKING TO THE PARENTS OR THE CHILDREN THEMSELVES?

'Parents in this school do not fully attend parents' meetings. Concerning children, perhaps it is high time that each school is afforded a psychologist by the Department of Education that will follow up cases such as these, so as to address the underlying factors that affect their performance.'

QUESTION: HOW WOULD YOU COMPARE THEM WITH OTHER CHILDREN?

'Both of them are withdrawn in class, especially the boy in Grade six, they never raise their hands to give answers, they do not participate fully in groups, but when they are directly pointed for a response they usually give correct answers. They do not have a full school uniform, it is even worse in winter when others are wearing track suits and blazers, they come with torn light jerseys. They also look very needy. These children also miss out on educational excursions as they are unable to pay. Even when the school allows them to go without paying, then they lack basic things such as provision.'

QUESTION: WHAT DOES THE SCHOOL DO TO HELP THESE NEEDY CHILDREN?

'We do have a school nutrition programme, they are both part of the programme. There is nothing we can do about their uniform, some educators ask for donations from children whose parents are well-off. They do not always get a positive response.'

QUESTION: WHAT MEASURES DO YOU HAVE IN PLACE FOR CHILDREN WHO CANNOT AFFORD TO PAY SCHOOL FEES?

'According to the South African Schools Act, these children should be partially or fully exempted from paying school fees. Our school is Quintine 1 so children are expected to pay except for those who have been partially or fully exempted. We encounter problems in this regard as we do not know which children to exempt, parents do not come forward.'

4.3 THEMES EMERGING FROM THE INTERVIEWS

4.3.1 Theme 1: Parents who are HIV-positive are unemployable because of their ill-health, a situation which makes their families to leave in dire poverty

'I'm not working No company can hire me I would be frequently absent because of my ill health It is even difficult to be a domestic worker. I also no longer have strength. We cannot afford to buy them anything We do not always have food and other bare necessities. Life is difficult especially when both my parents are sick. We cannot afford to buy them anything', 'There are days when I feel strong these are the days when I wish I could be working so that I can buy my children new clothes, school uniform and stationary', 'We do not always have food and other bare necessities', '...both parents depend are not employed and depend on the social grants.'

4.3.2 Theme 2: Children of parents who suffer from HIV/AIDS are affected when their parents fight over their positive-HIV status

'They were living in fear', 'There was no communication between us', '...they were afraid to be in the same room with me', '...they avoided witnessing the fights' , 'There were times when we fought in their presence and call each other names', 'This affected the children more as they did not understand what was happening.'

4.3.3 Theme 3: Children of parents who suffer from HIV/AIDS are discriminated against and stigmatised by other children, friends and people from their communities

'In our area when a person is HIV positive people do not want to associate with him or her in fear of being regarded as infected themselves', 'I decided not to associate myself with the friends I had before I was diagnosed HIV positive', 'There were those who did not want to sit next to her in class', 'She was isolated', 'People in our community prevented their children from associating with Makgiletsa', 'People in our community prevented their children from associating with Makgiletsa', 'they do not want us to visit their homes', 'they say we will bring them bad luck', 'They told me that their parents told them not play with me anymore as I would infect them', 'They do not want to play and eat with me', 'They were already isolating me because of my parents' positive HIV status', 'What I think is that people discriminate or stigmatise because of fear, insecurity, lack of knowledge and ignorance', 'People do not want to associate with them', 'People with HIV/AIDS are still discriminated against they are not invited in family gatherings and functions', 'These children end-up being isolated', 'Other children do not want to play with them in fear of being infected', 'Although they never said anything I suspect that they did not want to buy from people who are HIV-positive', 'Although I rinse the glasses well, there are others who do not want to come and drink at my shebeen in fear of being infected', 'They say they cannot use glasses that have been used by people with HIV/AIDS', 'My mother still believes in that they can be infected by playing together.'

4.3.4 Theme 4: The condition of parents who are HIV-positive affects their children both psychologically and emotionally

'The disclosure affected Makgeletsa so much that she decided not to attend school for two weeks after that, I understand that she is worried about what is going to happen to them after I die I understand that she is worried about what is going to happen to them after I die,

Makgeletsa never go out with friends when I am sick, Sometimes I pretend not to be in pain for her sake, she becomes so worried and the atmosphere becomes very tense, She becomes so worried in that it becomes difficult for her to go out and play. Concerning the embarrassment she suffered we could not do much except to apologise, 'We wanted her to deal with the news of her father's positive status first and after sometime I would reveal mine', 'I was so angry with both of them, I stayed in my room most of the time', 'I had to be away from school for two weeks just to recover from shock', 'I had to fight with the others so as to stop them from talking badly about me', 'I felt so bad. I had a lump on my chest', 'It was as if the whole world has come to a stand-still', 'I realised that these children feel very bad when one or both their parents are sick', 'he always worry about what is to happen to him and his younger sisters. I think it affects him.'

4.3.5 Theme 5: Parents who suffer from HIV blame each other for the HIV-positive status sometimes as a way of relieving stress

'I blamed her for bringing this curse into our family', '...she should have taken precautions when she was taking care of my sister', '...she had been very careless', 'It was easy to blame her for the problem than to face my HIV positive status', 'It was a way of relieving my stress', 'For the whole year we fought like a cat and a dog', 'I thought he did this deliberately and that he did this, because he hated me', 'We fought a lot as I felt that he robbed me of my health'.

4.3.6 Theme 6: When these parents blame each other for their HIV-positive status their children are caught in the cross-fire

'I think I wanted to win them on my side, I wanted them to know the truth and that according to me was that their mother was at fault, She was the reason we were always fighting and she is the reason we are living in poverty', 'We would not talk to each other for days. It would be tense in the house and it would be difficult for them to tell us the problems they encounter at school.'

4.3.7 Theme 7: Children of parents who suffer from HIV/AIDS assume adult responsibilities at a very tender age

'I help my mother with the household chores so that she can concentrate on him', 'I have to wash my little brother's school uniform for the next day', 'I help them with taking care of everything when they are sick', 'I also take care of them. When they are sick I have to go straight home to clean and cook', 'We have to rely on Makgiletsa', 'Zodwa has to clean and cook for the whole family', 'she has to be home to her my mother with the household chores', 'She is still young to do all the household chores but there is nothing I can do', 'I have trained Zodwa to make sure that all three of them have taken their medication. She also ensures that they have eaten in the morning before they get to school. She cleans the house in the afternoon before she can go out to play', '

4.3.8 Theme 8: These children usually lack basic needs such as food, clothing, school uniform, school necessities etc.

'She wears old torn clothes that are given to her by her friends, new clothes, uniform and stationary just like other kids, but now because I am always sick they cannot have those things'

4.3.9 Theme 9: The scholastic performance of children of parents who suffer from HIV/AIDS gets negatively affected, they lack concentration, do not have enough time to do homework and are frequently absent from school a situation which lead them to drop out

'It becomes difficult to do homework', 'My school work is also affected but I try to do my best', '...sometimes I do not always concentrate in class', 'There are days and weeks when I do not attend school because I am ill, same applies to Zodwa, but her rate of absenteeism is even worse than mine', 'My performance is not good at all', 'This makes concentration in class difficult sometimes', 'I no longer enjoy school', 'Zodwa is trying her best at school although she is also not

doing well', 'She is not doing well at school', 'When we are both sick she does not have time to do her homework, same with Fana',

4.3.10 Theme 10: Children of parents who suffer from HIV/AIDS become vulnerable to verbal, emotional and physical abuse

'They treated her badly at first', 'She lost some of her friends and she was called all sorts of names', 'When we are doing group activities other children do not want me to be in the same group with them', 'They say they have enough viruses to infect the whole community', 'They say they have enough viruses to infect the whole community', 'They say that they will never eat at my house as the very food we eat is infected', 'I am ridiculed and laughed at because my parents are HIV-positive', 'I am ridiculed and laughed at because my parents are HIV-positive,' 'They call me names I feel that I am less than other children who are of the same age,'

4.3.11 Theme 11: Children of parents who suffer from HIV/AIDS do not get the necessary support they need from their family members, community, government institutions such the Department of Health and in schools where they attend

'I no longer get those food parcels, we have not been very close with other family members, he does not want anything to do with us or my mother for that matter, 'I don't get anything from the community', 'Other members of the family do not want anything to do with us', 'Some of them are afraid that they will be infected if they help us', 'Some of them are afraid that they will be infected if they help us', 'I was not getting any support from my husband', 'Other close relatives cannot take care of us, they told us that they are afraid of people with AIDS', 'There is nothing we can help them with', 'We only offer support to people who are HIV-positive and not their children', 'Children who still have parents even if they are HIV-infected and also live in poverty are not catered for', 'Our eldest brother does not want anything to do with us', 'We no longer visit the members of the family

who are not supportive', 'My in-laws were also involved they still do not visit us even now', 'but other relatives do not want anything to do with us', 'I do not want to be part of this as other family members also do not associate with them', 'I will never set my foot in their house as long as their father is alive.'

4.3.12 Theme 12: Children and parents who suffer from HIV/AIDS do not seem to be coping with the circumstances they find themselves in especially if they are also HIV-positive

'Life is difficult especially when both my parents are sick', 'I cannot say I cope. I do a lot of work by the time I get to bed I am dead tired', 'They are really struggling and taking care of us is an added burden', 'They do not only worry about us but also about their own lives', 'As I say it is even worse with them dealing with their own positive HIV-status and ours', 'I must have a way of forgetting my problems',

4.3.13 Theme 13: There is no communication between children of parents who suffer from HIV/AIDS and their parents concerning their experiences about the disease, how they feel and the future expectations

'it is not that I do not want to chat with her, but there is no time to do that', 'There is no time to just sit and talk to them', 'We do not talk because I really do not know what to say to them', 'The problem with me is that I do not know what to say', 'They do not talk to us about HIV or their emotions and fears', 'We are not used to talking to each other about our emotions, let alone HIV/AIDS', 'I am not able to put their minds at ease concerning these challenges. What is the point then in talking', 'I really neither have the guts nor the energy to talk about our situation to the children',

4.3.14 Theme 14: There is no clear plan on what should children of parents who suffer from HIV/AIDS do in the case of their death

'...they will cross that bridge when they come to it', 'I do not know what will happen to us then, it is tough for us now', 'if anything can happen to them I do not think I will be able to continue attending school and I think Sihle would also chase us out of the house', 'Who would pay for my fees when my parents have died?', 'All of us are worried about what will happen after our death', 'I cannot think of any one who can take care of my children after my death', 'The only chance they have of a better life is when they can be adopted by a person who can love and care for them'.

4.3.15 Theme 15: There are no clear strategies to assist children whose parents suffer from HIV/AIDS to catch-up with their school work after a long absence

'There is not clear strategy to help these children catch-up', 'It becomes difficult for educators to drag or re-do the learning activities in order to accommodate children who are frequently absent from school due to sickness or their parents. These strategies are never implemented as the catch-up classes are after school.'

4.3.16 Theme 16: Children whose parents suffer from HIV/AIDS do not receive any work from school while they are at home sick or recuperating from illness as per the National Policy on HIV/AIDS (27/1996)

'We are aware that we should be doing it but it is not practically possible We do not send work to these children, this is difficult to do'

4.4 CONCLUSION

This chapter presented the verbatim provision of the responses of the children whose parents are suffering from HIV/AIDS, their significant others and a

health worker, who formed the sample of this research. The themes which emerged from their responses were also presented.

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

CHAPTER FIVE

SUMMARIES AND RECOMMENDATIONS

5.1 INTRODUCTION

In this section summaries of both the literature review and the empirical research are discussed. A proposed ecosystemic based on the empirical research findings is presented.

5.2 SUMMARIES

5.2.1 Summary of the literature proceeding

The findings of the literature review indicated that:

- part of the burden that learners whose parents suffer from HIV/AIDS comes in the form of mental stress and experiences caused by, merely staying with a sick loved one whose condition deteriorates where hope of improvement was expected, prolonged sickness of a loved one; and witnessing the slow painful death of a loved one especially at home (see 1.1);
- people living in deprived communities where death through violence or disease is commonplace tend to become fatalistic: the incentive to protect oneself against infection is low when HIV is only one of many threats to health and life. Poverty may also breed low levels of respect for self and others, and thus a lack of incentive to value and protect lives (see 2.4.4);
- living with sick parents, caregivers, or others who are sick of HIV/AIDS can be stressing to children. The times during which parents and caregivers are ill are often times of increased stress and difficulty for children. For example, children often take on additional domestic tasks or care for sick relatives or younger siblings. Children's school attendance can be compromised during this time (see 2.4); and

- knowledge of risks and protective factors is can be used in interventions to promote the enhancement of nurturing environments for children in families, schools and communities. The mediating mechanisms act in ways which reduce the impact of risks, reduce negative chain reactions, maintain self-esteem and self-efficacy through relationships and task achievement and open opportunities for positive development (see 2.6.7).

Findings from the empirical research indicated that:

- parents who are HIV-positive are unemployable because of their ill-health, a situation which makes their families to leave in dire poverty;
- children of parents who suffer from HIV/AIDS are affected when their parents fight over their positive-HIV status;
- children of parents who suffer from HIV/AIDS are discriminated against and stigmatised by other children, friends and people from their communities;
- the condition of parents who are HIV-positive affects their children both psychologically and emotionally;
- parents who suffer from HIV blame each other for the HIV-positive status sometimes as a way of relieving stress;
- when these parents blame each other for their HIV-positive status their children are caught in the cross-fire;
- children of parents who suffer from HIV/AIDS assume adult responsibilities at a very tender age;
- these children usually lack basic needs such as food, clothing, school uniform, school necessities etc.;
- the scholastic performance of children of parents who suffer from HIV/AIDS gets negatively affected, they lack concentration, do not have

enough time to do homework and are frequently absent from school a situation which lead them to drop out;

- children of parents who suffer from HIV/AIDS become vulnerable to verbal, emotional and physical abuse;
- children of parents who suffer from HIV/AIDS do not get the necessary support they need from their family members, community, government institutions such the Department of Health and in schools where they attend;
- children and parents who suffer from HIV/AIDS do not seem to be coping with the circumstances they find themselves in especially if they are also HIV-positive;
- there is no communication between children of parents who suffer from HIV/AIDS and their parents concerning their experiences about the disease, how they feel and the future expectations;
- there is no clear plan on what should children of parents who suffer from HIV/AIDS do in the case of their death;
- there are no clear strategies to assist children whose parents suffer from HIV/AIDS to catch-up with their school work after a long absence; and
- children whose parents suffer from HIV/AIDS do not receive any work from school while they are at home sick or recuperating from illness as per the National Policy on HIV/AIDS (27/1996).

5.3 RECOMMENDATIONS

Bronfenbrenner sees the instability and unpredictability of modern family life as the most destructive force to a child's development. This destructive force may spill over into the school setting. Some children do not have the constant mutual interaction with important adults that is necessary for development. According to the ecological theory, if the relationships in the immediate family break down, the child will not have the tools to explore other parts of his/her

mesosystem. Children looking for the affirmations that should be present in the child/parent (or child/other important adult) relationship look for attention in inappropriate places such as gangs and peers. These deficiencies show themselves especially in schools as anti-social behaviour, lack of self-discipline, and inability to provide self-direction.

Bronfenbrenner highlights the importance of bi-directional interactions with caring adults in the child's life. He outlines the following five propositions that describe how relationships developed at home and at school work and together for positive development: These five propositions have implications for practice in schools today. Based on the above the following programme is proposed:

- **Proposition 1** - The child should have on-going, long-term mutual interaction with an adult (or adults) who have a stake in the development of the child. These interactions should be accompanied by a strong tie to the child that ideally is meant to last a life time. It is important for this attachment to be one of unconditional love and support. This person must believe the child is "the best," and the child must know that the adult has this belief.
- **Proposition 2** - This strong tie and the pattern of interpersonal interaction it provides will help the child relate to features of his or her mesosystem. The skills and confidence encouraged by the initial relationships will increase the child's ability to effectively explore and grow from outside activities.
- **Proposition 3** - Attachments and interactions with other adults will help the child progress to more complex relationships with his or her primary adults. The child will gain affirmation from a third party relationship, and will bring those new skills to the primary relationship. Also, these secondary adults will give support to the primary adults, and help the child see the importance of the primary role.

- **Proposition 4** - The relationships between the child and his primary adults will progress only with repeated two-way interchanges and mutual compromise. Children need these interchanges at home and at school or child-care parents need these interchanges in their neighbourhoods and workplaces.
- **Proposition 5** - The relationships between the child and adults in his or her life require also a public attitude of support and affirmation of the importance of these roles. Public policies must enable time and resources for these relationships to be nurtured, and a culture-wide value must be placed on the people doing this work. This includes the work of parents and teachers, but also the efforts of extended family, friends, co-workers, and neighbours.

The presence of protective factors helps to change a developmental trajectory from a negative direction to one with a greater chance of positive outcome.

A word needs to be said here about emphasizing “prevention” or “promotion” approaches. Much of educators’ thinking about how to work with communities and schools has been dominated by a treatment, prevention and promotion continuum. The continuum ranges from:

- **treatment** - eliminate or reduce existing dysfunction (a deficit-based approach) to;
- **pevention** - protect against or avoid possible dysfunction (a weakness-based approach) to; and
- **promotion** - optimize mastery and efficacy (a strength-based approach).

A post-modern approach rejects the treatment model in favour of a blending of prevention and promotion models. It uses strength-based, non-deficit strategies to strengthen and support family, school and community functioning. A strength-based approach is recommended in this research as it helps school managers to develop programmes that operationalize the

ecological and systems perspective in their planning and implementation. The key components of a strength-based approach are:

- creating helping and partnership relationships; and
- building the community environment and linking community resources.

The applications of the ecological perspective in school and community intervention programmes result in:

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

The foregoing paragraph recommends that the post-modern educators' school and community interventions incorporate:

- a comprehensive approach to child development that combines health, education and social services;
- a strong emphasis on parent participation in the programme services and programme administration; and
- a re-definition of professional roles toward greater collaboration and partnership with parents.

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

- programmes work with whole families rather than individual family members;
- programmes provide services, training and support that increase a family's capacity to manage family functions;

- programmes provide services, training and support that increase the ability of families to nurture their children;
- the basic relationship between programme and family is one of equality and respect; the programme's first priority is to establish and maintain this relationship as the vehicle through which growth and change can occur;
- parents are a vital resource; programmes facilitate parents' ability to serve as resources to each other, to participants in programme decisions and governance, and to advocate for themselves in the broader community;
- programmes are community-based, culturally and socially relevant to the families they serve; programmes are often a bridge between families and other services outside the scope of the programme
- parent education, information about human development, and skill building for parents are essential elements of every programme; and
- programs are voluntary; seeking support and information is viewed as a sign of family strength rather than as an indication of difficulty

Interventions involving the family are more effective than those working with the child alone, early intervention programmes re-define the relationship between families and professionals.

Key lessons learned from early intervention programmes are the important role family values and family strengths play in efforts to nurture children with special needs. Parents are no longer treated as children to be schooled by experts who know what is best for their child, but as partners with different kinds of expertise. Early intervention programmes have distilled guidelines for how to build strong parent-professional partnerships. These guidelines include:

- recognizing the knowledge and expertise parents have about their child and that child needs;

- empowering parents, as a way to provide help and information and to increase a parent's ability to nurture children; and
- negotiating a match between the family's values, needs and goals and the professional's approaches, priorities and services.

5.4 CONCLUSION

This research comprises a literature review on the plight of children whose parents suffer from HIV/AIDS. An empirical research on their plight was undertaken. On the basis of both the literature review and empirical research methods, a programme founded on the ecosystems theory was proposed.

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ADDENDUM A

ADDENDUM A: INTERVIEW SCHEDULE

CASE STUDY 1: MAKGELETSA

Interview with Makgiletsa's father

Are you working?

Why are you not working? How many children do you have?

What is their status?

How did you find out about your positive HIV status?

What came to your mind immediately the positive test results were revealed to you?

Who, do you think, got infected first? Whom did you disclose to after your positive HIV status was revealed to you?

When did you tell your wife about your positive HIV status?

Why was it difficult for you to disclose your status to your wife?

How do you feel now about being HIV-positive?

How long did it take you to accept your status?

It seems that you love your children dearly

How was life at your house before you accepted your positive HIV-status?

Instead of fighting like this, why didn't you seek advice from your mother or other people on how to handle your problem?

How do you think, your children felt when you were fighting?

Did you manage to win them to your side?

Now that you behave differently than before, you accepted your positive HIV-status; how do you think, they feel?

How do they feel when you are sick?

Do you as a family talk about how she behaves when you are sick?

Except from your mother, don't you get any support in the family?

Around the Ngwathe community, what kind support do you get?

How do your friends support you?

What kind of support do you give each other?

Are you afraid of death?

Are your children aware of your positive hiv status?

What if you will be dead by then?

Interview with Makgiletsa's mother

Are you working? Why are you saying that you don't have the strength?

How do you think, they feel that you are not working?

What is your children's status?

How was Makgiletsa after her father's status had been revealed to her at school?

How did you deal with her situation?

Did you explain to her why her father disclosed his positive HIV status to the whole school and not to her first?

Do people in your community still bother Makgiletsa about your positive HIV status?

How often do you fall sick?

Does she cope to do this?

Do you ever talk to her about coping in taking care of you and your husband?

Why is your mother-in-law not taking care of both of you when you are sick?

What makes you not to get to the hospital when you are sick?

How do you feel about being HIV-positive?

How did you react when the HIV-positive result was revealed to you?

Who, do you think, got infected first?

What kind of support did you get from your families?

Except for the support you get from your mother-in-law, who else in the family supports you?

What kind of support do you get from Ngwathe community?

How do your friends support you?

What kind of support do you give each other?

Are you afraid that you may die?

How did other children treat your daughter after the disclosure?

When are you going to reveal your status to your son?

Interview with Makgiletsa

How is the situation at home?

Are you aware of your parent's HIV-positive status?

How did you know about their condition?

How did you take it for the first time you learnt about your positive HIV-status?

What helped you to accept?

How did you find out about your parents' condition?

What did you learn about this disease?

What kind of support do you give to your parents?

Did your mother tell you how she got infected?

Until so far, how do you cope? How does it feel like when are they sick?

After your friends found out about your parents' status, how did they support you?

Interview with the health worker

Do you encourage people to test?

Why do you encourage them to test?

How did you meet this family?

How did you encourage them to test?

How do you support this family?

Does the community support this family?

Do you think the Mokoena family is discriminated against because of being infected with HIV/AIDS?

Do you think this discrimination affects children of parents who are HIV-positive?

What support do you give to the children of this family?

CASE STUDY 2: FANA'S CASE

Interview with Fana

How did you discover that you are HIV-positive?

Do your teachers know that you are HIV-positive?

Did your parents go to the social worker?

Do your friends know that you are HIV-positive? What was your reaction after hearing that you are HIV-positive?

How long has your positive HIV status been revealed to you?

How do you feel now about being HIV-positive? How is the situation at home?
Who else knows that you are HIV-positive?

Do you ever get sick?

What support do you get from your parents?

Are you taught about HIV/AIDS issues at school?

Have you ever played HIV-positive at school?

Do your teachers at school invite motivational speakers from other schools or organisations or districts?

Do you ever talk about HIV/AIDS with other children?

How do you think, you contracted HIV?

Does your brother support you and the rest of the family; he is the only one who is HIV-negative?

How is your performance at school?

Which career do you want to follow when you grow up?

How do you support your sisters?

Interview with Fana's father

At the moment, do you show signs of being HIV-positive?

Does your wife know that you are HIV-positive?

How did your wife react to the disclosure of your HIV-positive status?

Do you feel that she is right by blaming you? How did this affect your children?

Do your customers know about your status?

Are your relatives supportive?

Are you able to support your children and wife with the profits you make from liquor?

Do you ever talk about HIV/AIDS with your wife?

Do you assist Fana with his schoolwork?

Do you ever chat with Fana or Zodwa?

Do you think that not having time to chat with your children affects them?

Is it only because there is no time to chat?

Don't you think it is better to talk about it than to keep quiet?

Who can take care of your children among the family members?

Have you ever thought of death?

Do you drink alcohol?

Interview with Fana's mother

When you met your husband for the first time, did you know that he was sick?

How did you feel about the results?

Are you still angry with him?

Were your children affected by your fights?

How do you support these kids throughout their daily lives?

Who does all these things when you are sick?

How old is Zodwa?

Does this not affect her at school?

How do you cope with all this stress?

Do you talk to your husband when you are stressed?

If you cannot talk to your husband about HIV are your children able to talk to you about their?

Do you watch TV programmes with your children where they talk about HIV/AIDS?

How do your parents support you? Do you have friends?

Interview with Fana's grandmother

Do you know that your daughter and your son-in-law are HIV-positive?

How did they tell you?

Do you think you will ever forgive them for the sake of your grandchildren?

What will you do if they can ask you to take care of their children?

Have you thought of what would happen if your daughter can die first?

Do you ever visit them?

Are your grand-children aware that you will never forgive their father?

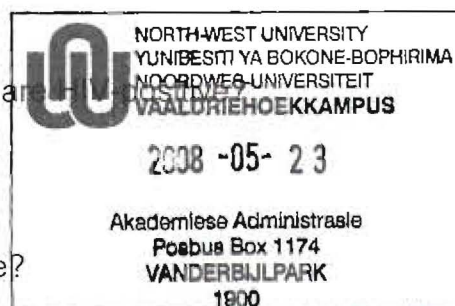
How do you think they feel about?

Interview with Fana' aunt

Do you know that your brother and sister-in-law are HIV-positive?

How do you support them?

How do you feel that your brother is HIV-positive?



What do you think is going to happen to these children when their parents have passed away?

Do your children visit them?

Are you worried about your brother's positive status?

Interview with the principal of the school where Fana and Zodwa attends

How long have you known Fana and Zodwa?

In what grades are they?

How do they both perform at school?

How do you help them to catch-up?

Do you send school-work home when children are absent for longer periods?

Have you as a school tried to address the problem by talking to the parents or the children themselves?

How would you compare them with other children?

What does the school do to help these needy children?

What measures do you have in place for children who cannot afford to pay school fees?