THE PSYCHOLOGICAL WELL BEING OF LEARNERS AFFECTED BY HIV/AIDS

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SUMMARY

The aims of this research were to investigate the condition of the psychological well being of learners affected or orphaned by HIV/AIDS; investigate the way in which these learners perform at schools, investigate the nature and extent of social support these learners get from their families, community and society; investigate the condition of the physical well being of these learners; and make recommendations for their psychosocial support in order to enhance and strengthen their psychological well being.

Findings from the literature review revealed that when HIV infected parents fall ill and die as a result of AIDS, usually a child or adolescent's life also often falls apart. This is an indication that with HIV and AIDS effects, the hardships hit well before children and adolescents are orphaned. This is to say, first a parent or breadwinner becomes ill with HIV or AIDS, and is unable to work. Then the entire family feels the economic impact – for example, children especially girls, must often drop out of school to go to work so that they can provide food for the family, care for their ill parents and look after their siblings. Such a phenomenon leads to the following psycho social problems in the lives of these children and adolescents:

- experience of grief and bereavement among children and adolescents affected by HIV/AIDS;

- introduction of major social change which may involve moving from a middle or upper-class urban home to a poor rural relative's home. It may involve separation from siblings, which is often done arbitrarily when orphaned children are divided among relatives without due considerations of their needs;

- increase in new labour responsibilities and instances of labour and work responsibility being given to children as young as five. Responsibilities and work in the household also include domestic chores, subsistence agriculture and provision of care giving to very

young, old and ill members of the household. Work outside of the home may involve a variety of formal and informal labour, including farm work and begging for food and supplies in both community and beyond;

- a phenomenon of irregular school attendance and absconding from school;

- suffering from malnutrition and may not have access to available health services;

- vulnerability to HIV infection. Their risk for infection arises from the early onset of sexual activity, commercial sex and sexual abuse, all of which may me precipitated by economic need, peer pressure, lack of supervision, exploitation and rape;

- likelihood that as the ratio of the dependent children increases as a result of the HIV/AIDS epidemic, so will the chances of children being lured into trafficking and sexual exploitation; and

- manifestations of negative emotional responses such as fear, anger, depression, anxiety, feelings of dependency and so on.

Findings from the empirical research revealed that learners who formed the population sample of this research are unhappy and sad to see their family members, that is, their parents and breadwinners, being ill, and as a result their health is also psycho socially affected; they do not have and cannot afford school uniform and there are no people or relatives who can help them with money to buy school uniform; and their mental health is not in good condition and that they had been ill, suffering from stress in the last six months.

Recommendations with psycho-educational implications were made in the last chapter.

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CHAPTER 1

ORIENTATION

1.1 INTRODUCTION AND STATEMENT OF THE PROBLEM

HIV/AIDS is fast becoming one of the greatest humanitarian and developmental challenges the world has ever seen. In the hardest hit regions of the world, the epidemic is increasing poverty and inequality and reversing decades of improvements in health, education, and life-expectancy (Barnett & Whiteside, 2002:18; Benatar, 2002:168). World wide, it is estimated that about twenty-two million people have died of AIDS; 36 million are currently infected with HIV and approximately seventy percent of this number live in sub-Saharan Africa. AIDS is also leaving millions of children orphaned and living in situations of acute vulnerability, resulting in unique social and economic consequences (WHO, 2003:19; Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002:16).

According to Busza (2001:449), one of the worst consequences of AIDS deaths is an increase in the number of children affected by this disease. Children and adolescents affected by HIV/AIDS in the context of this research are children and adolescents of up to age 18 years whose parents or breadwinners in their families are infected with HIV/AIDS or have lost the mother or both parents or breadwinners due to AIDS (WHO & JOINT UN PROGRAMME, 2004:11). With this definition, the number of children and adolescents affected by HIV/AIDS had increased to 1.5 million by December 2005 in South Africa.

The literature review reveals that HIV/AIDS has had a profound impact on South Africa and other African countries. The African extended family system that could have absorbed children orphaned by AIDS is unable to do so due to the rising levels of poverty (Adeyi, Hecht, Njobvu & Soucat, 2001:34). Poverty has eroded the capacity of South African and other African families to take up additional children and responsibilities. Prior to the AIDS epidemic, approximately 6% of the

children under the age of 18 years in South Africa were orphans. These orphans were cared for by the extended family members, and when the need arose, community members came together to assist (Barnett & Whiteside, 2002:18). However, the explosive spread of AIDS over the past two decades has contributed to a doubling in number of orphans which has made it practically impossible even for extended family members to assist children and adolescents who have been orphaned by AIDS (Carr, Lamptey & Wiggley, 2002:18).

The figure of 13 milllion AIDS orphans at the end of 2005 under-estimates the true scale of the problem. UNAIDS defines an orphan as a child under 15 years of age who has lost their mother (maternal orphan) or both parents (double orphan) to AIDS. Based on this definition, the figure of 13 million is projected to rise to 24.3 million in 2010 and to reach 40 million by 2020. The definitions used by UNAIDS, however, excludes the following categories of orphans and other children affected by AIDS:

- paternal orphans;
- orphans aged 15 to 18;
- non-AIDS and 'social' orphans – i.e. children orphaned or abandoned as a result of other causes (WHO, 2003:15; World Bank, 2002:19).

Recent research into the orphan situation in one district in Uganda (Monk 2000a: 34) found that the children in these three categories are often as severely affected, according to basic welfare criteria, as orphans that fitted the UNAIDS definition. Indeed, paternal orphans were often more severely affected than maternal orphans. Moreover, the experience of orphanhood often increases the age at which adolescents become independent, due to factors such as disrupted school attendance (Monk, 2000b:23). Hence, the researcher of this dissertation believes that 18 years is a more appropriate upper age limit, and is consistent with the United Nation's Convention on the Rights of the Child. Research has also shown that children who are not themselves orphans but who shared households with fostered orphans, experienced increased poverty as a result

(Williams, 2000:275). Differentiation about how a child becomes an orphan can lead to stigmatisation and discrimination even amongst this already 'under priviledged group' group of children (Whiteside & Sunter, 2000:15).

A broad definition of AIDS-affected children including all the categories described above, i.e., maternal, paternal and double orphans from all causes under the age of 18, plus co-residents, when applied to the study district in Uganda yielded a total that was *nine times higher* than the one based on the UNAIDS definition of AIDS orphans (Carr, Larnptey & Wigley, 2002:57). If other research yielded similar findings this would give rise to even more alarming estimates and projections than those produced by UNAIDS, that is, 218.7 million by 2010 and 360 million by 2020.

Since the UNAIDS definition is limited, the following tables of orphan estimates give estimates for other definitions as well as those provided by UNAIDS. The definitions used are as follows:

- **UNAIDS estimated number of orphans (under 15)**: Estimated number of children who have lost their mother (maternal orphans) or both parents (double orphans) to AIDS and were alive and under 15 at the end of 1999 (Sidley, 2000:104).
- **USAID estimated number of orphans (under 15)**: Estimated number of children who have lost their mother (maternal orphans), their father (paternal orphans), or both parents (double orphans) due to all causes (i.e., not only due to AIDS), alive and under 15 in 2000 (Hunter & Williamson, 1997:35).
- **Estimated number of orphans under 18 – all causes**: Estimated number of children who have lost their mother (maternal orphans), their father (paternal orphans), or both parents (double orphans) due to all causes, alive and under 18 at the end of 1999 (Monk, 2000a:45). These estimates were derived using the ratio between the total yielded by the UNAIDS definition of orphans in the study area in Uganda (Monk,

2000b:27), and the total after three additional categories were added – i.e., paternal orphans, children between 15 and 17, and children whose parents were recorded as having died of causes other than AIDS. The figures for the Uganda study derived from adding the three additional categories were 4.7 times higher than the UNAIDS definition. The UNAIDS estimates for the different countries were then multiplied by 4.7 to arrive at the new estimates incorporating the additional categories. These estimates are shown to give an idea of the potential scale of the current orphan situation, although it is acknowledged that similar research would be needed in other countries to verify their accuracy (Butler, 2005:24; Carr *et al*, 2002:3.

The impact of HIV/AIDS has also had diverse effects on the psychological well being of children and adolescents. The following are just a few of the problems children affected by AIDS and their families may experience:

- **Psychological distress** - The stress of losing a parent, and sometimes being separated from brothers and sisters can reduce the ability to cope. The orphaned child may lose hope in his/her future (Bergren, Carlsson, Hakeberg & Hagglin. 2002:19).
- **Anxiety about safety** - Children living in families affected by HIV/AIDS worry about the future. This elevated degree of anxiety may trigger behaviour problems such as aggression or emotional withdrawal (Donahau, 2000:34).
- **Lack of parental nurturing** - Denial, fear and stigma compound the stress within families dealing with AIDS. Parents may not be able to deal with their children's physical and emotional needs. Children may be unable to express their mixed feelings of grief, anger and fear (Foster & Germann, 2000:35).
- **Problems with basic needs** - Children affected by HIV/AIDS may experience nutritional insecurity, shortage of clothing and inability to pay

for medical care. Their caregivers will need additional income (Foster, 2002:16).

- **Problems with inheritance** - Orphans may lose their parent's property owing to "grabbing" by extended relatives or other people (Cohen, 1999b:28).
- **Problems with safety and children protection** - Households affected by HIV/AIDS are depleted of economic resources, and the child may need to generate cash. Working for a wage exposes a child to economic and sexual risks. Girls orphaned by AIDS may be married at an early age to relieve their families of a financial burden (Reynolds & Alorizo, 1998:29);
- **Less education** - The chance of children affected by HIV/AIDS going to school is reduced, and those who go, spend less time in school. This is attributed to the lack of money to pay school fees, as well as time spent taking care and sick parents and younger sibling (Roudy, Nkurikiye & Niyongabo, 2001:21)
- **Stigma and Discrimination** - Fear of people living with HIV/AIDS is widespread, and communities react by isolating and discriminating against people with AIDS and their children. Fear of people known to be having HIV/AIDS, is a powerful deterrent for people seeking voluntary testing and counseling, disclosing HIV positive status to family members/friends and others. Parents often fear informing their children of being HIV positive which tends to increase children's anxiety and fear of not knowing what is happening to their parents and how to prepare for their passing away. (UNAIDS, UNICEF & USAID, 2004:39; Campbell & Rader, 2000:4).

In light of the foregoing paragraphs, the following questions come to mind:

- What is the psychological well being of learners affected by HIV/AIDS in the Vaal Triangle townships in Gauteng?
- What is the scholastic performance of these learners?

- What is the nature and extent of social support these learners get from their families, communities and societies?
- What is the physical well being of these learners?
- How can the psycho-social support of these learners be enhanced to strengthen their psychological well-being?

The foregoing questions are converted into research aims (see 1.2).

1.2 **AIMS OF THIS RESEARCH**

The aims of this research were to:

- investigate the condition of the psychological well being of learners affected or orphaned by HIV/AIDS;
- investigate the way in which these learners perform at schools;
- investigate the nature and extent of social support these learners get from their families, community and society;
- investigate the condition of the physical well being of these learners ; and
- make recommendations for psycho-social support of these learners in order to enhance and strengthen their psychological well-being.

In order to attain these aims, a certain methodology had to be selected (see 1.3).

1.3 **METHODOLOGY**

The methodology to generate data for this research entailed the following components.

1.3.1 **Literature study**

A literature study was done to acquire understanding of the main concepts under study such as HIV/AIDS, AIDS orphans, children and adolescents affected by

HIV/AIDS, psychological well being, psychological wellness, mental health, and health in the post-modern era. To achieve this, all available data bases (both national and international) were consulted during the study, for example, the NEXUS-SABINET On-line, the EBSCO Host web and various other web-based sources as well as a DIALOG search were conducted to gather recent information on the subject. The above mentioned main concepts which formed the core and basis of this research were used in the search.

1.3.2 **Empirical research**

Focus group interviews were utilized to obtain empirical data for this research. Creswell (2003:93) describes the focus group interview as a purposive discussion of a specific topic or related topics taking place between four to twelve individuals with a similar background and common interests. The focus group interview is essentially a qualitative data gathering technique that finds the interviewer/moderator directing the interaction and inquiry in a very structured or unstructured manner, depending on the interview's purpose (Gillham, 2000:35). Interviews are an important part of any action research project as they provide the opportunity for the researcher to investigate further, to solve problems and to gather data which could not have been obtained in other ways (Creswell, 2003:41). Berg (2003:135) suggests that the focused interview with a group of people yields a more diversified array of responses and affords a more extended basis both for designing systematic research on the situation in hand.

Focus group interviews as part of qualitative research concentrate on words and observations to express reality and attempts to describe people in their natural situations. The key element here is the involvement of people where their disclosures are encouraged in a nurturing environment. It taps into human tendencies where attitudes and perceptions are developed through interaction with other people. During a group discussion, individuals may shift due to the influence of other comments. Alternately, opinions may be held with certainty.

DeMarrais and Lapan (2004:26) suggest that the purpose is to obtain information of a qualitative nature from a pre-determined and limited number of people.

In this research, semi-structured focus group qualitative interviews based on the self-designed interview schedule (see Appendix A for the interview schedule) were conducted in the form of an open-ended format - asking the same set of questions in the same sequence and wording to the group of interviewees who were affected or orphaned by HIV/AIDS.

1.3.2.1 **Sampling**

The study planned two focus group interviews of which only one materialised. The plan was to hold one focus group interview in the Sebokeng township and the other in the Sharpeville township of the Vaal Triangle area of Gauteng province. Each focus group interview was to consist of six interviewees. Only one focus group of interviewees materialised, which make it a total number of six persons (n=6). The other group did not attend in fear of being discriminated. Of the six interviewed interviewees, one adolescent is an HIV/AIDS double orphan by virtue of having bereaved of both parents due to HIV/AIDS, two adolescents had lost either a mother or a father through death caused by HIV/AIDS, and the other three adolescents' parents were infected with HIV/AIDS and were very ill.

1.3.2.2 **Data analysis**

Before the collected data were analysed, they were first transcribed. Audio-taped interviews were listened to and typed in order to produce written text. The next step was to code the transcribed data into relevant categories and to consider the frequency of occurrence with the purpose of producing themes (Denzin & Lincoln, 2005:7). Thereafter proper analysis, which is the process of searching for patterns and forming connections about what the AIDS orphans were saying and the effects thereof, began.

1.4 ETHICAL ISSUES

In order to facilitate the participants giving their fully informed consent, all the necessary information pertaining to the research including the nature, purpose and usefulness, procedures, confidentiality and the protection of anonymity as well as the voluntary nature of participation in the research were given. This exercise was carried out with the participants rather than only effecting what Maxwell (2004:23) refer to as "gatekeepers".

1.5 SIGNIFICANCE OF THE RESEARCH

This research should contribute to the theory and practice of socially and cognitively contextualized individual and family counselling of victims of HIV/AIDS or AIDS orphans, and has the potential to reveal the unique social realities of AIDS orphans' families.

The new role of the school in the ecology and psychology of families is highlighted. The ecology and psychology of school-going AIDS orphans fall within the scope of practice of schools, families, community agencies that are oriented towards HIV/AIDS issues and societal agencies such as the Departments of Social Development and Health because of their being the social systems within which the children and adolescents develop.

1.6 PREVIEW OF CHAPTERS

Chapter one contains an orientation to the study, which entailed introduction and statement of the problem, aims of the research, as well as methodology.

In chapter two, both national and international literature was reviewed in order to provide the theoretical framework of this research and to present information about HIV/AIDS, children and adolescents affected or orphaned by HIV/AIDS, as

well as on the impact of HIV/AIDS on the psychological well being of school-going children and adolescents.

In chapter three, the methodology, which was employed for this research is described in detail. Explanation for the actions taken towards answering the research questions of the study was given. Other aspects covered in this chapter include: description and construction of the interview schedule, aims of the research design, *modus operandi* of the focus group interviews, decoding of data, validity and reliability and the interpretation of data.

Chapter four presents the data collected through focus group interviews with children and adolescents affected by HIV/AIDS. It also presents the interpretation of the data towards achieving the set aims of the study.

Chapter five deals with conclusions and recommendations made in view of the findings from both the literature review and empirical research.

1.7 **CONCLUSION**

This chapter presented an orientation to the study, which entailed introduction and statement of the problem, aims of the research, methodology and a preview of the chapters of this research.

The next chapter presents literature review.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In light of the revelations in 1.1 above, there is no doubt that the HIV/AIDS epidemic has, and will, predicate enormous suffering for countless children, families and communities. Unknown numbers of children will go hungry, starve and suffer stunted physical and mental development. Similarly, many children will endure enormous anguish as they potentially find themselves alone and socially unsupported, the butt of cruel commentary and behaviour, excluded, exploited, beaten, raped and forced into labour (Benatar, 2002:47; Monasch & Boerma, 2004:36). Many children will have to make their own way in the world, sleeping rough, doing opportunistic work, begging and soliciting patronage and protection from street groups. None of this will leave anyone in South Africa or in the Sub Saharan region untouched (Kelly, 2002:18).

This chapter reviews literature on psychological well being of children and adolescents affected by HIV/AIDS; clarifies the concepts and theories which form the basis of this research; outlines determinants of psychological and social disorders; and the effects of HIV/AIDS on the children and adolescents' psychological well being.

2.2 CONCEPTUAL AND THEORETICAL FRAMEWORK

This section clarifies both the concepts and theories that form the core and basis of this research.

2.2.1 Conceptual framework

The concepts wellness, resilience, hardiness, stamina, fortigenesis and psychological well-being are clarified in the context of their use in this research

which is about the psychological well being of children and adolescents who are affected by the HIV/AIDS epidemic.

2.2.1.1 **Wellness**

Wellness on the individual level is described in terms of positive traits such as the capacity for agency, a sense of coherence, emotional intelligence, optimism, resilience, courage, interpersonal skills, aesthetic sensibility, creativity, perseverance, initiative, forgiveness, spirituality, faith, future mindedness, hope, honesty, self-efficacy, mastery orientation, emotional self-regulation, a positive affect balance, physical toughness, capacity for flow, and the capacity for love and vocation (Chen, 1995:76).

On a group level, wellness is about responsibility, nurturance, altruism, civility, moderation, tolerance, about the promotion of communion reflecting virtues such as beneficience, practical wisdom, creative improvisation, forgiveness, and justice (Ryff & Singer, 1996:29).

Subsequently, being emotionally well, means possessing the ability to feel and express human emotions such as happiness, sadness and anger (Aspinwall & Staudinger, 2003:249).

Wellness also implies having the ability to love and be loved and achieve a sense of fulfilment in life. Being able to identify the barriers and obstacles in the way of achieving emotional wellness and taking appropriate steps to cope with such problems, is also important. Emotional wellness in this research will mean being optimistic about the future and having success in life, possessing a high self-esteem and positive self-acceptance, as well as the ability to share feelings with significant others (Wissing, 2000:59).

Another critical element of emotional wellness is the ability to manage stress. Stress can occur when external and/or internal resources exceed the resources of the person. Stress is defined as the physical and emotional responses that

accompany any stimulus that disrupts an individual's normal life (Angst, 1999:38).

Physical responses to stress may include an accelerated heart rate, an elevated blood pressure, increased perspiration to cool your skin, headaches, and various muscle aches (Grabe, Spitzer & Freyberger, 2001:37).

Responses to stress caused by the effects of HIV/AIDS pandemic in the world vary from person to person and may include acceptance, assertiveness in talking about the plight they are psychologically going through. Inappropriate behavioural responses to the effects of HIV/AIDS pandemic include the use of drugs or alcohol and violence. People affected by HIV/AIDS who manage stress well and have a high level of emotional wellness, have more time to enjoy life (Hoglend & Perry, 1998:28).

2.2.1.2 **Resilience**

Resilience has been conceived as a buffering process, one that may not eliminate risks or adverse conditions, but does help individuals deal with them effectively (Aldwin, Sutton & Lachman, 1996:26). However, as Aspinwall and Staudinger (2003:21) suggested, resilience may also reflect the concept of 'reserve capacity.' That is, a resilient mindset helps people who are infected and affected by HIV/AIDS pandemic to prepare for future adversity and enables the potential for change and continued personal growth throughout their lives.

2.2.1.3 **Hardiness**

Aspinwall and Staudinger (2003:17) used the concept of hardiness to describe those people who underwent stressful life events, but did not succumb to illness. Pelzer (2000:32) proposed the hardy personality style as a source of positive resistance. Hardiness, as a construct, evolved out of the stress and coping literature to explain individual differences in stress resiliency (Kaufman, Cook, Arny, Jones & Pittinsky, 1994:14). The concept of hardiness is considered a

personality style consisting of three interrelated factors, namely an experience of a sense of commitment, control and challenge in the face of difficult situations (Larson, 2000:18). The commitment disposition is expressed as a tendency to involve oneself in (rather than experience alienation from) whatever one is doing or encounters. Committed individuals' relationships to themselves and to the environment can be described as involving actions and approach rather than being passive and avoidant (Amrhein, 2004:71). The control disposition is expressed as a tendency to feel and act as if they can influence the events shaping their lives. The challenge disposition is expressed as the belief that change rather than stability is normal in life, and that the anticipation of changes are interesting incentives to growth rather than threats to security. Individuals high on the challenge disposition, therefore consider change not only as a threat, but also as an opportunity for development (Layman, 1996:38; Kobasa, 2005:18).

According to Lyubomirsky (2001:26), hardy individuals who are infected and affected by HIV/AIDS have a general sense of purpose, meaning and commitment. In general, there is extensive evidence suggesting that hardiness is positively related to physical and mental health, and that it mitigates negative health outcomes of stress emanating from their experiencing of the effects of HIV/AIDS such as grief and bereavement (O'Conor & Shimizu, 2002:29). The Personal Views Survey as a measure of hardiness as well as the three interrelated factors of control, commitment and challenge, has been used substantively both internationally and locally. According to Reivich and Shatte, (2002:19), previous theorizing and construct-validational research suggest that hardiness expresses physiological vitality and enhanced performance.

Sinclaire and Tertric (2000:29) investigated the relationship between hardiness and the clinically relevant scales of the Minnesota Multiphasic Personality Inventory, using a sample of undergraduate students. Results of the study suggest that hardiness is a general measure of mental health and that it is not an artifact of negative affectivity, which was controlled for in the study. With regard to research on coping, Taylor and Armor (1996:38) aimed to identify whether

intra-personal support variables (strengths already within the individual) might serve to protect the person from the effects of stress, using a sample of students registered for their Masters of Business Administration Degree. Results of the study showed that hardiness significantly moderated the relationship between work-related stress and the emotional exhaustion dimension of burnout, measured by the Maslach Burnout Inventory (Warr, 1999:27).

2.2.1.4 **Stamina**

Strümpfer (1995:46) and Wissing and Van Eeden (1994:37) are the authors that used the concept of 'stamina' in a salutogenic context. Strümpfer (1990:41) defined stamina, using a dictionary definition of the word, as "the physical and moral strength to resist or withstand disease, fatigue or hardships and endurance." According to her, human beings are born with "different potentialities and susceptibilities, which life experiences may mold into a protective shield undergirding future health (Strümpfer, 1990:272). In trying to explain what qualities distinguish older persons who demonstrate emotional resilience despite age-related losses and life changes, Viviers and Cilliers (1999:46) assessed stamina in terms of capacity for growth, personal insight, life perspective, likelihood of functional breakdown and general competence. Strümpfer (1990:29) notes that one of Colerick's summary statements is strongly reminiscent of statements by Antonovsky of sense of coherence and by Kobasa on hardiness: "Elderly with high stamina for managing change have learned through the years that change is inevitable, challenging and manageable ... triumph perceptions in later life flow from years of success in acting on the environment.

Individuals affected by HIV/AIDS who have the necessary physical and moral strength to resist or withstand effects of the pandemic such as grief, bereavement, depression, anxiety and so on look beyond the pandemic for new ways to use their life energy in increasing their understanding for the value of life and ways to develop their life aspirations and expectations in order to achieve their life goals.

2.2.1.5 **Fortigenesis**

Some researchers believe that the pathogenic view and salutogenesis can be described in terms of a "health disease/ease continuum," implying that the individual will function between the two poles of terminal illness and total wellness (Strümpfer, 1990:37). It could be proposed that the criteria for psychological well-being and the criteria for psychopathology are to a great extent independent and that well-being and pathology are not just the endpoints of the same continuum. The absence of psychopathology such as HIV/AIDS infection does not necessarily indicate psycho-physical well-being or the presence of psychological strengths in withstanding the effects of HIV/AIDS. In the same sense, low scores on measures of well-being or psychological strengths on the effects of HIV/AIDS epidemic on the mind, spirit and body of the person do not necessarily indicate pathology (Wissing & Van Eeden, 1998:27).

2.2.1.6 **Psychological well-being**

Psychological well being is a subjective term that means different things to different people. The term is used throughout the health industry as kind a of a catch-all phrase meaning contentment, satisfaction with all elements of life, self-actualization (a feeling of having achieved something with one's life), peace, and happiness. Other researchers refer to a person with "psychological well-being" as a happy, satisfied person (Wissing, 2000:18).

For the purposes of this research, it refers to a happy and satisfied person who has been orphaned or affected by HIV/AIDS epidemic.

2.2.2 **Theoretical framework guiding this study**

Because of this study's focus on the psychological well being of children and adolescents affected by HIV/AIDS epidemic, this research is founded on the theory of psychofortology. Wissing and Van Eeden (1998:16) postulate that the

theory of psychofortology is premised on origins of psychological strengths, as implied by the names salutogenesis and fortigenesis, and on the nature, dynamics and enhancement of psychological well-being. Wissing (2000:18) suggests that the term psychofortology (the science of psychological strengths) be used for the domain of psychology in which psychological well-being is studied.

Within the theory of psychofortology, a better understanding of psychological strengths will point to new directions for capacity building, the prevention and enhancement of the quality of life of children and adolescents who are affected by the HIV/AIDS epidemic, both in their private as well as academic and scholastic lives. Many constructs have been proposed to conceptualize aspects of psychological wellbeing, including processes involved in the coping of individuals and the enhancement of wellness. Strümpfer (1995:18) identified the following six constructs, which supposedly describe the core of salutogenic and fortigenic functioning of human beings, including children and adolescents affected by HIV/AIDS epidemic.

2.2.2.1 **Fortitude**

In investigating the health-sustaining and stress-reducing effects of a range of individual and environmental factors, Castlebury and Durham (1997:16) proposed the construct of fortitude as the answer to the fundamental question of the fortigenic paradigm: Where does strength come from? Factor analyses of variables included in this study (namely, self-esteem, self-denigration, self-worth, personal competence, personal efficacy, belief about support from others, perception of problem-solving skills, perceived number and availability of support, support from friends, support from family and family environment) identified three meaningful factors, which were labelled:

- self-appraisal;
- support appraisals; and

- family appraisals (Clarke, 1996:49).

A particular theory of fortitude was therefore suggested by the results, in which it is hypothesized that an individual with fortitude, that is, one who copes successfully with stress and experiences low levels of depression, has positive appraisals of the:

- self;
- family, and
- support from others.

Diener, Sur, Lucas and Smith (1999:23) see fortitude as the strength to manage stress and stay well and this strength derives from a positive appraisal of the:

- self;
- family; and
- support from others.

Epstein and Feist (1998:28) contend that fortitude is based within a theory of appraisal and is premised by the notion that people's evaluations of themselves, their abilities, their support resources and their family and environment influence their emotions and behaviour during transactions with the environment, and that people who perceive these negatively will have serious doubts about their ability to deal with a stressful encounter and consequently succumb to the effects of such a stressor. On the other hand, a positive appraisal of these by the individual, will result in a greater belief in his/her ability to manage a stressful encounter (Benatar, 2002:166).

Fortitude, in the context of this study, can thus be regarded as a construct that could explain how children and adolescents who are affected by HIV/AIDS manage to maintain psychological well-being (or cope) in the face of adversity or stress caused by the epidemic. The Fortitude Questionnaire (Kobasa, 2005:17), as a measure of fortitude and its interrelated factors of self-appraisal, family-

appraisal and support-appraisal has been used substantively in a number of studies in South Africa. All these studies, however, point in the direction that fortitude is associated with coping and positive psychological well-being. In a study by Monsen and Havik (2001:28), investigating differences in academic achievement in children of divorced parents, with a sample of 110 participants in grades five through to seven, a negative relationship was indicated between depression (measured by the Children's Depression Inventory) and stress-resistance (measured by the FORQ). In another study by Ryff and Singer (1996:17), focusing on the relationship between psychofortigenic factors and psychological burnout amongst a sample of 226 nurses from twenty one institutions caring for patients with Alzheimer's disease (among other conditions), significant negative correlations between burnout and psychofortigenic factors (Fortitude and Sense of Coherence) were indicated. Kossuth (1998:18) investigated the influence of gender and fortitude on the types of problems students were presented with at the Institute for Counselling at the University of the Western Cape, using a non-probability sample of 70 participants. Significant negative correlations were indicated between total functioning (as indicated by the 'Checklist of Problems and Concerns' used at the Institute for Counselling) and the FORQ overall (fortitude) scale as well as the three (self-appraisal, family-appraisal and support-appraisal) sub-scales (Vailant, 2000:18). It was suggested that participants measuring high on fortitude would present with less problems, thus supporting the premise that fortitude is associated with less stress and less presenting problems. In a study investigating gender differences with regard to aspects of psychological well-being, using a multicultural availability sample consisting of 378 participants, Wissing (2000:43) found that men scored significantly higher than females on fortitude and other psychological well-being constructs such as:

- physical self-concept;
- positive automatic thoughts;
- constructive thinking;
- cognitive flexibility; and

- total self-concept.

These results suggest gender–related differences in perceptions of psychological well-being.

According to Wissing and Van Eeden (1998:18), other constructs that conceptually resemble the constructs defined above and which relate to the maintenance and enhancement of psychological wellness include:

- self-actualization;
- toughness;
- social support;
- satisfaction with life;
- dispositional optimism; and
- self-efficacy.

Viviers and Cilliers (1999:18) assert that different theoretical traditions and empirical observations inspired these constructs and their consequent operationalisation, and further note that, although these constructs are operationalised, it has not been empirically determined to what degree these constructs refer to the same or different aspects of psychological well-being. They also note that it is furthermore unclear to what extent there is an overlap between these specific indices of psychological well-being and more general indices of well-being (Wagner, Ferrando & Rabkin, 2000:29).

The foregoing findings from the literature review's findings indicate that psychological fortitude, that is, strengths are significant for children and adolescents affected by HIV/AIDS to enjoy optimum quality of life.

2.2.2.2 **Locus of control**

The concept of 'locus of control' refers to the relationship between the environment and the individual's assessment of his or her ability to deal with it and to adjust behaviour accordingly. Locus of control has two dimensions - the

external and internal (Boyden, 2003:11). The external locus of control assumes that a person's life is controlled by external factors, such as:

- luck;
- fate; and
- nature.

Externally oriented individuals ('externals') do not see themselves as responsible for what happens to their lives but merely accept what happens. From this perspective, a person is helpless and is at the mercy of the environment (Davis, Nolen-Hoeks & Larson, 1998:36).

The internal locus of control assumes the ability to predict environmental events and be able to respond appropriately. Internally oriented individuals, that is, internals, feel they have the ability to control events and the resultant behaviour. Therefore, they are in control of their own fate. It is this perception of the ability "to do something" that gives rise to the concept of perceived control (Brissette, *et al,* 2002:102).

From the foregoing definition of the concept of locus of control, it is clear that it describes the extent to which individuals believe that their behaviour has a direct impact on events that follow. Rotter (1966) described individuals who believe that they can control what happens to them as having an internal locus of control, that is, internals. Those who tend to think about what happens to them as a function of luck, fate, or powerful others, have an external locus of control, that is, externals. Several measures for this construct are used in research, of which the Internal–External Control Scale (Warr, 1999:28; Western, Stimson, Mullins, Memmott, Baum, Johnston & Van Gellicum, 2002:65) is probably the most well known. However, the Locus of Control Questionnaire (Schepers, 1995) is used more frequently in South African research because of its favourable psychometric qualities. The Locus of Control Questionnaire consists of three scales, namely:

- external control;

- internal control; and
- autonomy.

It is important to note that, where the scale of Rotter viewed internal and external locus of control as dependant variables on a continuum, Wissing, Wissing, Du Toit and Temane (2002:16) postulate that internal and external control are not bipolar opposites but independent variables instead. It is therefore possible for an individual to achieve a high score on external as well as internal control on this questionnaire.

This construct is significant to be taken cognisance of if schools, families and communities are to succeed in strengthening the ability of children and adolescents affected by HIV/AIDS to have control over their lives and the environments in which they find themselves.

2.2.2.3 **Hardiness**

The construct of hardiness evolved out of the stress and coping literature to explain individual differences in stress resiliency (Kobasa, 2005:120). The concept of hardiness is considered a personality style consisting of three interrelated factors, namely:

- commitment, that is, individuals who involve themselves in whatever they are doing;
- control, that is, individuals who believe and act as if they can influence the events shaping their lives; and
- challenge, that is, individuals who consider change not only as a threat but also as an opportunity for development (Sack, Kunsebeck & Lamprecht, 1997:34).

This construct is significant to be taken cognisance of if schools, families and communities are to succeed in developing the cognitive, affective, somatic and spiritual resiliency of children and adolescents affected by HIV/AIDS to have

some measure of control over their lives and the environments in which they find themselves.

2.2.2.4 **Potency**

In a situation where the resources at the disposal of a person are inadequate for meeting certain demands and this causes tension, that is, a disturbance in homeostasis, potency will enable the individual to restore this homeostasis and thus prevent the tension from turning into lasting stress. Potency refers to a person's enduring confidence in his/her own capacities - resulting from successful coping experiences in the past - as well as confidence in and commitment to the social environment, which is perceived as basically ordered, predictable and meaningful (Aspinwall & Staudinger, 2003:17). This construct emphasizes that coping has to be considered as a product of interaction between the person and the environment. Potency as described above, can be measured effectively by the Potency Scale (Smith & Rapkin, 1996:38), which contains 19 items measuring:

- self-confidence;
- mastery;
- commitment to society; as well as
- the perceived meaningfulness and orderliness of society.

This construct is significant to be taken cognisance of if schools, families and communities are to succeed in unravelling the innate and latent human potentialities of children and adolescents affected by HIV/AIDS to have control over their lives and the environmental circumstances and conditions in which they find themselves.

2.2.2.5 **Learned resourcefulness**

Learned resourcefulness refers to a set of well-learned behaviours and skills by which individuals self-regulate or control their behaviour. It is seen as a personality repertoire that includes mainly three functions - for example,

- regressive self-control;
- reformative self-control; and
- experiential self-control (Barnard, 1994:18; Brissette, Scheier & Carver, 2002:108).

Regressive self-control can help children and adolescents affected by HIV/AIDS epidemic to regulate their internal responses to the effects of the epidemic, such as pain, emotions, and cognition that interfere with the smooth execution of an on-going task. Reformative self-control enables children and adolescents affected by HIV/AIDS epidemic to change their current behaviour caused by the effects of HIV/AIDS epidemic in the hope of achieving a greater reward in the future by using:

- planning skills;
- problem-solving strategies; and
- the delay of immediate gratification (Brissette, Scheier & Carver, 2002:19).

Experiential self-control enables children and adolescents affected by HIV/AIDS epidemic to experience and enjoy unknown and pleasurable activities to the fullest. Learned resourcefulness can be measured by the Self-Control Schedule, consisting of 36 items that covers:

- the use of cognition and self-instruction to cope with emotional and physiological responses;
- application of problem-solving strategies;
- ability to delay immediate gratification; and

- a general belief in a person's ability to self-regulate internal events (Chang, 1996:34; Chen, 1995:168).

Other constructs relating to the maintenance and enhancement of psychological wellness are constructive:

- thinking;
- satisfaction with life;
- emotional intelligence;
- reality orientation;
- self-actualization;
- resilience;
- toughness;
- coping;
- social support;
- dispositional optimism;
- personal causation;
- self-directedness;
- social interest; and
- sense of humour (Diener, 2000:28; Epsteeinn & Feist, 1998:312).

All of these show some kind of conceptual resemblance to the above defined constructs.

This construct is significant to be taken cognisance of if schools, families and communities are to succeed in developing proactive psycho-social development skills, emotional intelligence and metacognitive academic and scholastic skills of children and adolescents affected by HIV/AIDS to have control over their lives and the environmental circumstances and conditions in which they find themselves.

2.2.2.6 **Self-efficacy**

Self-efficacy refers to individuals' belief that they can successfully perform the behaviour required for a specific task. It is a relatively enduring set of beliefs that a person can cope effectively in a broad range of situations (Bandura, 1997:17). Self-efficacy expectations determine:

- what activities people engage in;
- how much effort they will expend; and
- how long they will persevere in the face of adversity.

Well known measuring instruments for self-efficacy are the:

- Self-Efficacy Scale (Bernard, Hutchison, Lavin & Pennington, 1996:28) indicating generalized self-efficacy beliefs; and
- Eight-Item Self-Efficacy Scale developed by Murdock (2000:17), measuring self-efficacy beliefs regarding a specific task or situation, such as participation in self-managing work teams.

Perceived self-efficacy is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how:

- people feel;
- think;
- motivate themselves; and
- behave.

Such beliefs produce these diverse effects through four major processes, which include cognitive, motivational, affective and selection processes (Miller & Delaney, 2005:21; Bundy, 2004:16).

A strong sense of efficacy enhances human accomplishment and personal well-being in many ways. People with high assurance in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided (Bandura, 1997:23). Such an efficacious outlook can foster children and adolescents affected by HIV/AIDS epidemic's intrinsic interest and deep engrossment in general life and learning activities, that is to say, they can:

- set themselves challenging psycho-social and learning goals and maintain strong commitment to them;
- heighten and sustain their learning efforts in the face of failure as a result of the effects of HIV/AIDS epidemic;
- quickly recover their sense of self-efficacy after failures or setbacks as a result of the effects of the HIV/AIDS epidemic (George, Thornton, Touyz, Waller & Beumont, 2004:17);
- attribute failure as a result of the effects of HIV/AIDS epidemic to insufficient effort or deficient knowledge and skills which are acquirable; and
- approach threatening situations such as the pending death of parent(s), brothers, sisters, uncles, aunts and so on as a result of the HIV/AIDS epidemic with assurance that they can exercise control over them (Badcock-Walters, 2001:80).

Such an efficacious outlook can help children and adolescents affected by the HIV/AIDS epidemic to produce personal life and academic accomplishments, which have the potential to reduce their stress related to the effects of HIV/AIDS and lower vulnerability to depression as a result of the effects of the HIV/AIDS epidemic..

Children and adolescents affected by the HIV/AIDS epidemic who doubt their capabilities:

- shy away from difficult tasks which they view as personal threats;

- have low aspirations and weak commitment to the goals they choose to pursue;
- when faced with difficult tasks, they dwell on :
    - their personal deficiencies;
    - the obstacles they will encounter; and
    - all kinds of adverse outcomes rather than concentrate on how to perform successfully (England & Artinian, 1996:56).
- slacken their efforts and give up quickly in the face of difficulties;
- are slow to recover their sense of efficacy following failure or setbacks. Because they view insufficient performance as deficient aptitude it does not require much failure for them to lose faith in their capabilities; and
- fall easy victim to stress and depression (Rosenbaum, 1990:29).

Children and adolescents affected by the HIV/AIDS epidemic's beliefs about their efficacy can be developed by the following four main sources of influence:

- The most effective way of creating a strong sense of efficacy is through mastery experiences. Successes build a robust belief in your personal efficacy. Failures undermine it, especially if failures occur before a sense of efficacy is firmly established (Fournier, De Ridder & Bensing, 2002:36). If people experience only easy successes they come to expect quick results and are easily discouraged by failure. A resilient sense of efficacy requires experience in overcoming obstacles through perseverant effort. Some setbacks and difficulties in human pursuits serve a useful purpose in teaching that success usually requires sustained effort (Thoms, Moore & Scott, 1996:27). After people become convinced they have what it takes to succeed, they persevere in the face of adversity and quickly rebound from setbacks. By contending with difficult times, they emerge stronger from adversity.
- The second way of creating and strengthening self-beliefs of efficacy is through the vicarious experiences provided by social models. Seeing

people similar to yourself succeed by sustained effort raises observers' beliefs that they too possess the capabilities master comparable activities to succeed (Viviers & Cilliers, 1999:27). By the same token, observing others fail despite high effort, lowers observers' judgments of their own efficacy and undermines their efforts. The impact of modelling on perceived self-efficacy is strongly influenced by perceived similarity to the models. The greater the assumed similarity the more persuasive are the models' successes and failures (Wissing & Van Eeden, 1994:27). If people see the models as very different from themselves, their perceived self-efficacy is not greatly influenced by the models' behaviour and the results the perceived self-efficacy produces. Modelling influences do more than provide a social standard against which to judge a person's own capabilities. People seek proficient models who possess the competencies to which they aspire. Through their behaviour and expressed ways of thinking, competent models transmit knowledge and teach observers effective skills and strategies for managing environmental demands. Acquisition of better means raises perceived self-efficacy (Bandura, 1997:26).

- Social persuasion is a third way of strengthening people's beliefs that they have what it takes to succeed. People who are persuaded verbally that they possess the capabilities to master given activities are likely to mobilize greater effort and sustain it than whether they harbour self-doubts and dwell on personal deficiencies when problems arise (Helgeson, 1994:53). To the extent that persuasive boosts in perceived self-efficacy lead people to try hard enough to succeed, they promote development of skills and a sense of personal efficacy. It is more difficult to instil high beliefs of personal efficacy by social persuasion alone than to undermine it. Unrealistic boosts in efficacy are quickly disconfirmed by disappointing results of a person's efforts. Instead, people who have been persuaded that they lack capabilities tend to avoid challenging activities that cultivate potentialities and give up quickly in the face of difficulties. By constricting

activities and undermining motivation, disbelief in a person's capabilities creates its own behavioural validation (Bausmeister, Campbell, Kreuger & Vohs, 2003:17). According to Castlebury and Duham (1997:27), successful efficacy builders do more than convey positive appraisals. In addition to raising people's beliefs in their capabilities, they structure situations for themselves in ways that bring success and avoid placing people in situations prematurely where they are likely to fail often. They measure success in terms of self-improvement rather than by triumphs over others. People also rely partly on their somatic and emotional states in judging their capabilities. They interpret their stress reactions and tension as signs of vulnerability to poor performance (Chen, 1995:26). In activities involving strength and stamina, people judge their fatigue, aches and pains as signs of physical debility. Mood also affects people's judgments of their personal efficacy. A positive mood enhances perceived self-efficacy, a despondent mood diminishes it.

- The fourth way of modifying self-beliefs of efficacy is to reduce people's stress reactions and alter their negative emotional predispositions and its interpretations of their physical states (Diener, Suh, Lucas & Smith, 1999:28). It is not the sheer intensity of emotional and physical reactions that is important, but rather the way in which they are perceived and interpreted. People who have a high sense of efficacy are likely to view their state of affective arousal as an energizing facilitator of performance, whereas those who are beset by self- doubts regard their arousal as a debilitator (Lightsey, 1996:26). Physiological indicators of efficacy play an especially influential role in health functioning and in athletic and other physical activities.

Much research has been conducted on the four major psychological processes through which self-beliefs of efficacy affect human functioning, including those of children and adolescents affected by HIV/AIDS:

(a) **Cognitive Processes**

The effects of self-efficacy beliefs on cognitive processes take a variety of forms. Much human behaviour, being purposive, is regulated by forethought embodying valued goals. Personal goal setting is influenced by self-appraisal of capabilities. The stronger the perceived self-efficacy, the higher the goal challenges people set for themselves and the firmer their commitment is to themselves (Ochsner & Lieberman, 2001:28).

Most courses of action are initially organized in thought. People's beliefs in their efficacy shape the types of anticipatory scenarios they construct and rehearse. Those who have a high sense of efficacy, visualize success scenarios that provide positive guides and supports for performance. Those who doubt their efficacy, visualize failure scenarios and dwell on the many things that can go wrong (Lyubomirsky, 2001:26). It is difficult to achieve much while fighting self-doubt. A major function of thought is to enable people to predict events and to develop ways to control those that affect their lives. Such skills require effective cognitive processing of information that contains many ambiguities and uncertainties. In learning predictive and regulative rules people must draw on their knowledge to:

- construct options;
- weight and integrate predictive factors;
- test and revise their judgments against the immediate and distal results of their actions; and
- remember which factors they had tested and how well they had worked (Reinecke, Dattilio & Freeman, 2002:32).

It requires a strong sense of efficacy to remain task oriented in the face of pressing situational demands, failures and setbacks that have significant repercussions such as HIV/AIDS infections and effects. Indeed, when people are faced with the tasks of managing difficult environmental demands such as

families affected by HIV/AIDS epidemic under taxing depressive and stressful circumstances, those who are beset by self-doubts about their efficacy become more and more erratic in their analytic thinking, lower their aspirations and the quality of their performance deteriorates (Tanaka-Matsumi, Higginbotham & Chang, 2002:27). In contrast, those who maintain a resilient sense of efficacy set themselves challenging goals and use good analytic thinking which pays off in performance accomplishments.

(b) **Motivational Processes**

Self-beliefs of efficacy play a key role in the self-regulation of motivation. Most human motivation is cognitively generated. People motivate themselves and guide their actions anticipatorily by the exercise of forethought. They form beliefs about what they can do. They anticipate likely outcomes of prospective actions. They set goals for themselves and plan courses of action designed to realize valued futures (Ryff & Singer, 1996:38).

There are three different forms of cognitive motivators around which different theories have been built. They include:

- causal attributions;
- outcome expectancies; and
- cognized goals.

The corresponding theories are:

- attribution theory;
- expectancy-value theory; and
- goal theory, respectively.

Self-efficacy beliefs operate in each of these types of cognitive motivation. Self-efficacy beliefs influence causal attributions (Sack, Kunsebeck & Lamprecht, 1997:25). Children and adolescents affected the HIV/AIDS epidemic who regard

themselves as highly efficacious attribute their failures as a result it to insufficient effort, and those who regard themselves as inefficacious attribute their failures as a result it to low ability. Causal attributions affect motivation, performance and affective reactions mainly through beliefs of self-efficacy (Thoms *et al*, 1996:16).

In expectancy-value theory, motivation is regulated by the expectation that a given course of behaviour will produce certain outcomes and the value of those outcomes. People act on their beliefs about what they can do, as well as on their beliefs about the likely outcomes of performance, thus motivating influence of outcome expectancies is thus partly governed by self-beliefs of efficacy (Kossuth, 1998:27). There are countless attractive options people do not pursue because they judge themselves to lack the specified capabilities. The predictiveness of expectancy-value theory is enhanced by including the influence of perceived self efficacy.

The capacity to exercise self-influence by goal challenges and evaluative reaction to a person's own attainments provides a major cognitive mechanism of motivation. A large body of evidence shows that explicit, challenging goals enhance and sustain motivation. Goals operate largely through self-influence processes rather than regulate motivation and action directly (Strümpfer, 1995:23). Motivation based on goal setting involves a cognitive comparison process. By making self-satisfaction conditional on matching adopted goals, people give direction to their behaviour and create incentives to persist in their efforts until they fulfil their goals. They seek self-satisfaction from fulfilling valued goals and are prompted to intensify their efforts by discontent with substandard performances (McMillen & Fisher, 1998:28).

Motivation based on goals or personal standards is governed by three types of self influences, which include:

- self-satisfying and self-dissatisfying reactions to a person's performance;

- perceived self-efficacy for goal attainment; and
- re-adjustment of personal goals based on a person's progress.

Self-efficacy beliefs contribute to motivation in the following several ways (Norem, 2001:56):

- They determine the goals people set for themselves, how much effort they expend, how long they persevere in the face of difficulties; and their resilience to failures.
- When faced with obstacles and failures, people who harbour self-doubts about their capabilities slacken their efforts or give up abruptly. Those who have a strong belief in their capabilities, exert greater effort when they fail to master the challenge.
- Strong perseverance contributes to performance accomplishments (Peterson, 2000:25).

(c) **Affective Processes**

Children and adolescents affected by the HIV/AIDS epidemic's beliefs in their coping capabilities affect how much stress and depression they experience in threatening or difficult situations such as the death of parent(s) or any other beloved member of the family, as well as their level of motivation. Perceived self-efficacy to exercise control over stressors caused by the effects of the HIV/AIDS epidemic plays a central role in anxiety arousal (Pretorius, 1997:27). Children and adolescents affected by the HIV/AIDS epidemic who believe they can exercise control over threats do not conjure up disturbing thought patterns. But those who believe they cannot manage threats, experience high anxiety arousal (Bernad, Hutchison, Lavin & Pennington, 1996:125). They dwell on their coping deficiencies. They view many aspects of their environment as fraught with danger. They magnify the severity of possible threats and worry about things that rarely happen (Pretzer & Walsh, 2001:28). Through such inefficacious thinking, they distress themselves and

> impair their level of functioning. Perceived coping self-efficacy regulates avoidance behaviour as well as anxiety arousal. The stronger the sense of self-efficacy, the bolder children and adolescents affected by the HIV/AIDS epidemic are in taking on taxing and threatening life and academic activities (Reivich & Shatte, 2002:17).

Anxiety arousal is affected not only by perceived coping efficacy but by perceived efficacy to control disturbing thoughts. The exercise of control over a person's own consciousness is summed up well in the proverb: "You cannot prevent the birds of worry and care from flying over your head. But you can stop them from building a nest in your head" (Riskind, Sarampote & Mercier, 1996:26). Perceived self-efficacy to control thought processes is a key factor in regulating thought produced stress and depression. It is not the sheer frequency of disturbing thoughts but the perceived inability to turn them off that is the major source of distress. Both perceived coping self-efficacy and thought control efficacy operate jointly to reduce anxiety and avoidant behaviour (Roysamb & Strype, 2002:18).

Social cognitive theory prescribes mastery experiences as the principal means of personality change. Guided mastery is a powerful vehicle for instilling a robust sense of coping efficacy in people whose functioning is seriously impaired by intense apprehension and phobic self-protective reactions (Watts, 2003:19). Mastery experiences are structured in ways to build coping skills and instil beliefs that people can exercise control over potential threats. Intractable phobics, of course, are not about to do what they dread. People must, therefore, create an environment so that incapacitated phobics can perform successfully despite themselves (Amrhein, 2004:27). This is achieved by enlisting a variety of performance mastery aids. Feared activities are first modelled to show people the way to cope with threats and to disconfirm their worst fears. Coping tasks are broken down into subtasks of easily mastered steps. Performing feared activities together with the therapist further enables phobics to do things they would resist doing by themselves (Aldwin, Sutton & Lachman, 1996:34). Another way of

overcoming resistance is to use graduated time. Phobics will refuse threatening tasks if they will have to endure stress for a long time. But they will risk them for a short period. As their coping efficacy increases the time they perform the activity is extended. Protective aids and dosing the severity of threats also help to restore and develop a sense of coping efficacy (Aspinwall & Staudinger, 2003:12).

After functioning is fully restored, the mastery aids are withdrawn to verify that coping successes stem from personal efficacy rather than from mastery aids. Self-directed mastery experiences, designed to provide varied confirmatory tests of coping capabilities, are then arranged to strengthen and generalize the sense of coping efficacy. Once people develop a resilient sense of efficacy they can withstand difficulties and adversities without adverse effects (Brissette, Scheier & Carver, 2002:15).

Guided mastery treatment achieves widespread psychological changes in a relatively short time. It elirminates phobic behaviour and anxiety and biological stress reactions, creates positive attitudes and eradicates phobic ruminations and nightmares (Cilliers, Viviers & Marais, 1998:34). Evidence that achievement of coping efficacy profoundly affects dream activity is a particularly striking generalized impact.

A low sense of efficacy to exercise control produces depression as well as anxiety. It does so in several different ways. One route to depression is through unfulfilled aspiration. People who impose on themselves standards of self-worth they judge they cannot attain drive themselves to bouts of depression (Feldt, 1997:16). A second efficacy route to depression is through a low sense of social efficacy. People who judge themselves to be socially efficacious seek out and cultivate social relationships that provide models on how to manage difficult situations, cushion the adverse effects of chronic stressors and bring satisfaction to people's lives (Diener, 2000:12; Boyden, 2003:24). Perceived social inefficacy to develop satisfying and supportive relationships increases vulnerability to

depression through social isolation. Much human depression is cognitively generated by dejecting ruminative thought. A low sense of efficacy to exercise control over ruminative thought also contributes to the occurrence, duration and recurrence of depressive episodes (Larson, 2000:19).

Other efficacy-activated processes in the affective domain concern the impact of perceived coping self-efficacy on biological systems that affect health functioning. Stress has been implicated as an important contributing factor to many physical dysfunctions. Controllability appears to be a key organizing principle regarding the nature of these stress effects (O'Conor & Shimizu, 2002:39). It is not stressful life conditions *per se*, but the perceived inability to manage them - that is debilitating. Thus, exposure to stressors with ability to control them has no adverse biological effects. But exposure to the same stressors without the ability to control them, impairs the immune system. The impairment of the immune function, increases susceptibility to infection, contributes to the development of physical disorders and accelerates the progression of disease (Pretorius, 1997:18).

Aldwin, Sutton and Lachman (1996:56) opine that biological systems are highly interdependent. A weak sense of efficacy to exercise control over stressors activates autonomic reactions, catecholamine secretion and release of endogenous opioids. These biological systems are involved in the regulation of the immune system (Roysamb & Strype, 2002:39). Stress activated in the process of acquiring coping capabilities may have different effects than stress experienced in aversive situations with no prospect in sight of ever gaining any self-protective efficacy. There are substantial evolutionary benefits to experiencing enhanced immune function during development of coping capabilities vital for effective adaptation (Ryan & Frederick, 1997:16). It would not be evolutionarily advantageous if acute stressors invariably impaired immune function, because of their prevalence in everyday life. If this were the case, people would experience high vulnerability to infective agents that would quickly infect them. There is some evidence that providing people with effective means

for managing stressors may have a positive effect on immune function (Ryff & Singer, 2000:18). Moreover, stress aroused while gaining coping mastery over stressors, can enhance different components of the immune system.

There are other ways in which perceived self-efficacy serves to promote health. Lifestyle habits can enhance or impair health. This enables people to exert behavioural influence over their vitality and quality of health (Salovey, Rothman, Detweiler & Steward, 2000:110). Perceived self-efficacy affects every phase of personal change - whether people even consider changing their health habits, whether they enlist the motivation and perseverance needed to succeed should they choose to do so, and how well they maintain the habit changes they have achieved (Schmutte & Ryff, 1997:49). The stronger the perceived self-regulatory efficacy the more successful people are in reducing health-impairing habits and adopting and integrating health-promoting habits into their regular lifestyle. Comprehensive community programs designed to prevent cardiovascular disease by altering risk-related habits, reduce the rate of morbidity and mortality (Siebert, 1996:18).

2.2.2.7 **Selection Processes**

The discussion so far has centred on efficacy-activated processes that enable people, including children and adolescents affected by the HIV/AIDS epidemic, to create beneficial environments and to exercise some control over those they encounter day in and day out. People are partly the product of their environment (Spreitzer, 1995:17). Therefore, beliefs of personal efficacy can shape the course lives take by influencing the types of activities and environments people choose. People avoid activities and situations they believe exceed their coping capabilities, but they readily undertake challenging activities and select situations they judge themselves capable of handling (Taylor & Armor, 1996:28). By the choices they make, people cultivate different competencies, interests and social networks that determine life courses. Any factor that influences choice behaviour can profoundly affect the direction of personal development. This is because the

social influences operating in selected environments continue to promote certain competencies, values, and interests long after the efficacy decisional determinant has rendered its inaugurating effect (Thoms *et al,* 1996:87).

2.3 DETERMINANTS OF PSYCHOLOGICAL AND SOCIAL DISORDERS

According to Vailant (2000:89), determinants of psychological and social disorders in children tend to be non-specific, that is, no particular interpersonal or environmental determining condition is associated with a specific psychosocial manifestation. For example, although parental divorce is associated with psychosocial trauma in children, children whose parents get divorced do not all become depressed, wet their beds or suffer discernible signs of maladjustment. In fact, only a minority of children show ill effects when exposed to adverse conditions (Wagner, 2000:18). Rather, children's response to high levels of stress is determined to a large degree by personality and temperament, learned coping style, age of exposure, the availability of caring adults and social supports in their environment and, critically, opportunities for recovery afforded by achievements, new relationships, changing circumstances and the like. About a third of children exposed to extremely disadvantaging conditions thrive, achieve high intellectual standards and are well adjusted (Aspinwall & Staudinger, 2003:56). Less than a third of such children are affected in negative ways. The basis of so-called resilience is to be found largely in children's ongoing relationships with caring others, and their continued membership of social networks and social institutions (Barnard, 1994:16). This is one reason why strong cultural effects are found in children's response to disasters; for example, children in cultural groups that have strong social connections through extended kin are less affected by events in the nuclear family than are children who have fewer and less intense blood relationship networks beyond the household (Brissette *et al,* 2002:102).

The likelihood of maladjustment is increased when adverse conditions endure over time, when stresses are cumulative and when children are given limited

opportunities for support and hope. Thus, long-term maladjustment is dependent on the availability of conditions for recovery as much as, or more than, the form or severity of precipitating stresses (Chang, 1996:38).

It is thus necessary to prevent the social conditions and poverty of families made especially vulnerable by HIV/AIDS from deteriorating to the degree that large numbers of children find themselves in these extremely difficult situations. It also means that the widespread institutionalization of children in residential settings, which is almost invariably associated with abuse and delay, must be averted (Cilliers *et al,* 1998:35).

On a very broad level, there are three main categories of 'determinants' of poor adjustment that are likely to occur in the context of the HIV/AIDS epidemic, given prevailing conditions:

- **Poverty** - As discussed, the HIV/AIDS epidemic is inextricably bound up with poverty. In general and without considering associated confounding effects such as substance abuse in the home or residential instability and displacement poverty is associated with deprivation syndromes in children. Deprivation syndromes include poor growth and health, decreased motivation, increased passivity, impoverished experience and frames of reference and lower cognitive performance (Haacker, 2001:39; Berggren, Carlsson, Hakeberg & Hagglin, 2002:185).

- **Loss, separation and bereavement** - Many children in the Southern African region are going to be separated from and lose their parents, caregivers and the breadwinners on whom they depend. Again, without considering associated confounding effects such as residential and school change and worsening socio-economic conditions, the loss of parents and loved ones is associated with internalising psychological conditions including anxiety, rumination, depression, social isolation, survivor's guilt and low self-esteem (Halperine, 2001:39; Baylies, 2000:79).

- **Cruel and impersonal child care** - Children affected by HIV/AIDS may be subjected to impersonal and abusive child care through exploitative family and community care; poorly chosen and supervised foster care; and long-term institution-based rearing. In general, and without considering associated effects such as pre-existing home conditions, separation and bereavement, impersonal and abusive care is associated with a range of psychological disorders, including a reduced capacity for affection and compassion, acting out and more aggressive coping styles (Petersen & Swartz, 2002:10).

At this stage its unclear how many children are exposed to unmitigated poverty, multiple loss and bereavement, and/or cruel and impersonal care. Of those children who are exposed to these conditions, it is not known what proportion will succumb to the effects of the associated stresses and begin to show disturbed behaviour or diminished capacity (Boyden, 2003:33).

2.4 THE IMPACT OF HIV/AIDS ON CHILDREN AND ADOLESCENTS

This section provides literature review's revelations on the impact of HIV/AIDS on children and adolescents.

2.4.1 The impact of HIV/AIDS on children's rights

According to (Brown & Sittitrai, 1996:19) HIV/AIDS has many direct and indirect impacts on children's rights, ranging from the consequences of the psychological impact of losing one or both parents, to reduced access to quality education and health services. The mere mention of the concept of children's rights means that the following principles need to underpin any societal policies and regulations regarding learners affected and infected by HIV/AIDS:

- the right to survival, development and protection from abuse and neglect;
- the right to have a voice and be listened to;

- that the best interests of the child should be of primary consideration; and
- the right to freedom from discrimination (Barnett & Whiteside, 2002:24; Webb, 2001:21).

However, for many children who have been infected or affected by HIV/AIDS, these rights are being compromised. Children who are themselves living with HIV/AIDS, or have lost one or both parents to HIV/AIDS, often experience discrimination and exclusion from the community as a result of stigma (Whisson, 2002:4). The growing number of child-headed households also affects the rights of children to:

- education;
- rest and leisure;
- survival and development;
- protection from sexual and economic exploitation; and
- protection from abuse and neglect (Tarantola & Gruskin, 1998:129; UNAIDS, 2001a:16).

The deaths of parents and worsening poverty as a result of HIV/AIDS are contributing to the growing number of children working in hazardous and exploitative conditions (Rajkumar, 2000:54).

For many children who are infected or affected by HIV/AIDS, some of the above-mentioned fundamental principles, especially the rights to non-discrimination, survival and development, are most often compromised (Phiri, Foster & Nzima, 2001:29). This results from the communities' fear of HIV/AIDS and a lack of understanding of the ways in which HIV is transmitted. For infected children, their supposed impending death is at the root of most discrimination they face (Piot, 2001:42). Misconceptions regarding HIV/AIDS result in many children, whose parents are living with HIV, being stigmatised, whether or not they themselves are infected. This stigmatisation is made worse by the fact that it comes from

every section of the community including other children, guardians, teachers and even parents themselves (especially widows and stepmothers) (Alidri, 2001:67).

In Malawi orphans of AIDS tend to form their own informal peer groups as a result of this stigma and process of peer exclusion (Cook, 1999:35). Teachers often refuse to allow these children into schools. The tragic case of Nkosi Johnson in South Africa was brought to the world's attention. This young boy living with HIV was denied his rights to education and freedom from discrimination (Piot, 2001:51). Other, equally significant, reasons for reduced access to education for children, especially girls, affected by HIV/AIDS include loss of earnings or the need to re-direct household spending towards medical treatment denying the funds to send children to school. In addition, children whose parents become ill often have to leave school to care for them (Mendel, 2002:33).

In Uganda, in one study, around half of affected children reported that attendance and grades had been adversely affected by parental illness (Gilborn, 2000:29).

2.4.2 **The ways in which children's rights to survival and development are impacted and affected by the HIV/AIDS epidemic**

Grainger, Webb and Elliott (2001:11) opine that HIV/AIDS also affects the survival and development of children through its impacts on health, family livelihoods, social welfare and protection. The impact of HIV/AIDS on the health of children relates not only to the growing number of children being infected with HIV, but also to the effects HIV/AIDS has on access to health-care for children who are HIV-negative (O'Connor, 2001:29). As with access to education, stigmatisation and discrimination also threaten access to health services. The reduction and re-orientation of the family's income to cover the costs of HIV-related treatments has significant impacts on the health of children. For example,

families with one or more members living with HIV/AIDS will spend a much higher proportion of their income on HIV-related treatments, thereby reducing the income available for general health-care, including immunization (Haacker, 2001:38). Also, the parent's level of illness may make it very difficult for them to provide adequate child-care and food or to travel to health centres with their children. Higher rates of stunting and wasting have been reported in orphaned children as well as higher rates of severe or moderate malnutrition (Human Rights Watch, 2001:129).

The most significant effect of HIV/AIDS on the social welfare and protection of children is the disintegration of traditional support structures and 'social safety nets.' As the number of affected children increases, the capacity of the community to support these children is being stretched significantly (Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda, 2001:26). There is a growing number of child-headed households, especially in sub-Saharan African countries. As parents' livelihoods are increasingly threatened, children are forced to take on a premature adult role. The death of one or both parents and the resulting increased household expenditure on health, place more economic responsibilities on children. Many are forced to drop out of school and take up work to contribute to family incomes (Chakraborty, Christtie & Zomingthanga, 2000:54). In Burundi, children in AIDS affected households begin work for income at younger ages compared to unaffected households, becoming involved in petty trading and running errands at the ages of six or seven (Roudy *et al.*, 2001:27). Some children end up working in highly hazardous conditions, for example, in the informal mining industry where they risk severe injury. A UNICEF study on HIV/AIDS and child labour concluded that AIDS was responsible for pushing a significant percentage of the millions of working children onto the labour market (UNICEF – ESARO, 2001:187).

Growing household poverty and the increase in 'demand' for uninfected younger sexual partners has also increased the numbers of children who are sexually

abused and paid as sex workers (Desmond & Gow, 2001:29). This inevitably puts children, especially girls, at extreme risk of contracting HIV. Once out of school, these young people may find it very difficult to gain access to HIV prevention messages and sexual health services as they become 'out of reach'. In South and south-east Asia, children who are orphaned may be at greater risk of being trafficked and sexually exploited. In seriously affected communities the whole nature of childhood is changing fundamentally (Kelly, 2000:15; Kinoti & Taufik, 2002:21).

2.5 THE EFFECTS OF HIV/AIDS ON THE PSYCHOLOGICAL AND SOCIAL WELL BEING OF SCHOOL-GOING CHILDREN AND ADOLESCENTS

When HIV infected parents fall ill and die of AIDS, usually a child's life also often falls apart. This is an indication that with HIV and AIDS, the hardship hits well before children are orphaned. This is to say, first, a parent or breadwinner becomes ill with HIV or AIDS, and is unable to work (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002:18). Then the entire family feels the economic impact – for example, children, especially girls, must often drop out of school to go to work so that they can provide food for the family, care for their ill parents and look after their siblings. Such a phenomenon leads to the following psychosocial problems in the lives of these children and adolescents (Carr, Lamptey & Wigley, 2002:18).

2.5.1 Manifestations of emotional problems among orphans

However, in spite of these efforts, many of the orphaned children continue to experience emotional problems and little is being done in this area of emotional support. There are several reasons. First, there is a lack of adequate information on the nature and magnitude of the problem; secondly, there is a cultural belief that children do not have emotional problems and therefore there is a lack of attention from adults (Desmond, Barnett & Whiteside, 2000:22). Thirdly, since

psychological problems are not always obvious, many adults in charge of orphans are not able to identify them. However, even where the problem may have been identified, there is a lack of knowledge of how to handle it appropriately (Joseph, 2002:39). In many cases children are punished for showing their negative emotions, thereby adding to their pain. In schools, there is an obvious lack of appropriate training of teachers in identifying psychological and social problems and therefore offering individual or group attention (Kiragu, 2001:73).

2.5.2 **Expirience of grief and bereavement among children and adolescents affected by HIV/AIDS**

Like adults, children are grieved by the loss of their parents. However, unlike adults, children often do not feel the full impact of the loss simply because they may not immediately understand the finality of death. This prevents them from going through the grieving process which is necessary to recover from the loss (Mendel, 2002:63). Children therefore are at risk of growing up with unresolved negative emotions which are often expressed with anger and depression. Adults may also experience negative emotions in times of bereavement, but, unlike children, adults have the intellectual ability, life experience and emotional support that enables them to control their anger and depression (Mohlala, 2002:31).

Unfortunately, adults do not seem to appreciate that children are also adversely affected by bereavement, even though they may not have an adult's understanding of death (O'Connor, 2001:88). Little attention is therefore given to children's emotions. Children are not given the required support and encouragement to express their emotions nor are they guided to deal with them. For example, children are not always talked to, nor listened to, and therefore their emotions are not understood. When they have no appetite for food or when they have no strength for house chores, or lack the strength to attend school, or when they become inattentive in class, they are simply punished (Piot, 2001:39).

2.5.3 **Introduction of major social change in the lives of children and adolescents affected by HIV/AIDS**

Death of parents introduces a major change in the life of a vulnerable child. This change may involve moving from a middle or upper-class urban home to a poor rural relative's home. It may involve separation from siblings, which is often done arbitrarily when orphaned children are divided among relatives without due considerations of their needs (Whisson, 2002:17). It may mean the end of a child's opportunity for education, because of lack of school fees. Those children who choose not to move or who may not have any other relative to go to may be forced to live on their own, constituting child-headed families (Barnett & Whiteside, 2002:37). All these changes can easily affect not only the physical, but also the psychological well-being of a vulnerable child. These changes can be very stressful as they pose new demands and constraints to children's life.

It is feared that many children may find it difficult to adapt to the new changes. Beresford (2002:16) makes it clear that it is not the social change itself that may cause psychological problems, rather it is the failure of the individual to adapt to social change. Like bereavement, social change and the resultant need to adapt to it, creates stress. According to Piot (2001:10), this stress may be shown in symptoms of confusion, anxiety, depression, and behavioural disorders such as disobedience. The same symptoms may cause learning problems. Children who are frustrated, fearful, and depressed, may fail to concentrate in class and therefore perform badly. Failure by the school and the home systems to recognize these symptoms and address them will aggravate the child's psychological problems (Bennell, Hyde & Swainson, 2002:39).

2.5.4 **Risk of being confronted by adverse circumstances and lack of locus of control among children and adolescents affected by HIV/AIDS**

As noted above (see paragraph 2.5.3), most orphans are at risk of being confronted by powerful cumulative and often negative social changes in their lives over which they have no personal control. Experiences in continuously adverse circumstances do not make life appear to be subject to control through a person's own efforts (Cilliers, 1998:28). Perceived lack of control produces a feeling of helplessness and loss of hope, and diminishes an individual's will power (Cooper, 2004:39).

Death of parents makes children vulnerable and predisposes them to physical and psychological risks over which they have no control. The feeling of helplessness is very costly in terms of psychological well-being and may be reflected in lack of concern, involvement and vitality in social and school activities. Emotionally, it is indicated by sadness and depression. The effects of death and bereavement are not always negative (Diener *et al,* 1999:267). Positive effects are possible as when a child moves from a poor family to an economically better-off one. Children who are fostered may be motivated to use all their power to prove their worth to their new families and to win their support. Children who are forced to live on their own, may behave more responsibly and more maturely as a result of the sheer need to survive (Halperin, 2001:12; Monasch & Boerma, 2004:56).

Locus of control is important for effective coping behaviour in the case of stress. When faced with stress, internals tend to adopt a problem-solving strategy while the externals tend to react emotionally, for example by being angry (Jacoby, 2003:26). Consequently, internals are able to leave their disappointments behind them and live happily. Externals, on the other hand, continue to carry their burdens into their future and hence are often depressed (Larson, 2000:170). The theoretical expectation is that depression is positively correlated with external

locus of control and negatively correlated with internal locus of control. This means that those who scored high on the depression scale also scored high on the locus of control scale (Lightsey, 1997:65). Likewise, those who scored low on depression, also scored low on the locus of control scale.

2.5.5 Increase in new responsibilities and instances of premature labour commitments for children and adolescents affected by HIV/AIDS

Several studies have shown that responsibilities and work, both within and outside of the household, increase dramatically when parents or caregivers become ill or die. In such circumstances, instances of labour and work responsibility being given to children as young as five, have been observed (Maddi, 1999:29). Responsibilities and work in the household include domestic chores, subsistence agriculture and provision of care-giving to very young, old and ill members of the household. Work outside of the home may involve a variety of formal and informal labour, including farm work and begging for food and supplies in both the community and beyond (Masten, 2001:227; Fleischman, 2003:11).

2.5.6 A phenomenon of irregular school attendance and absconding from school by children and adolescents affected by HIV/AIDS

In households affected by HIV/AIDS, the school attendance of children declines because their labour is required for subsistence activities and, in the face of reduced income and increased expenditure, the money earmarked for school expenses is used for basic necessities, medication and health services. Even where children are not withdrawn from school, education often begins to compete with the many other duties that affected children have to assume (Whisson, 2002:28; Pawinski & Laloo, 2001:48).

According to the 1999 South African October Household Survey, as many as 35% of rural African children between the ages of six and 17 years do not attend school. In the sub-Saharan region, an estimated 44 million children, more girls than boys, are not attending school (WHO, 1999:27). Absconding from school is likely to increase as families become unable to afford the costs of schooling and as children's contribution to care and work is required at home. Experience suggests that the most vulnerable orphans are those in their school years, aged ten years and older (Bateman, 2001:36; Opiyo, 2001:29). Thus, despite all their shortcomings, schools have significant potential to play a critical role in obviating the worst effects of the HIV/AIDS epidemic on children. Apart from the accrued personal and social benefits of education for work and national development, schooling provides stability, institutional affiliation and the normalization of experience for children. It also places children in an environment where adults and older children are potentially available to provide social support (Beresford, 2002:18).

Adeyi, Hecht, Njobvu and Soucat (2001:62) assert that absconding from school, child labour and sexual exploitation, present real dangers to children as well as to society. It reduces individual and national developmental potential, marginalise and dehumanise children and separate them from available sources of help and support, engender widespread disregard for children, and has close associations with crime (Carr *et al,* 2002:18). Without schooling, both individual potential and social capital is lost, leaving affected individuals vulnerable to unemployment, menial working conditions and poverty. Similarly, child labour is often physically damaging, psychologically stunting and demeaning to the dignity of children whose labour is exploited (Clinton, 2003:46). Together with sexual exploitation and the trafficking of children, absconding from school and child labour, indicate the disintegration of the social institutions that serve to protect and develop children and, by their existence, they further undermine fragile families and communities. In addition, child labour and sexual exploitation fuel crime as children become traded for profit (Cohen, 2000:23).

Busza (2001:441) asserts that stigmatisation may prompt affected children to stay away from school, rather than endure exclusion or ridicule by teachers and peers. A study in Zambia, for example, showed that 75% of non-orphaned children in urban areas were enrolled in school compared to 68% of orphaned children (Butler, 2005:25). At a national level, a World Bank study in Tanzania suggested that HIV/AIDS may reduce the number of primary school children by as much as 22% and secondary school children by 14% as a result of increased child mortality, and decreased attendance and dropping out (Clinton, 2003:18).

2.5.7 **Suffer from ill-health and malnutrition**

Children affected by HIV/AIDS may receive poorer care and supervision at home, may suffer from malnutrition and may not have access to available health services, although no studies have yet demonstrated increased morbidity and mortality among broadly affected children compared to unaffected control groups (Bennell *et al.*,2002:32). In this regard, it has been suggested that the safety nets of families and communities are still sufficiently intact to protect the majority of children from the most extreme effects of the epidemic - or alternatively, that orphans may not be worse off than peers living in extreme poverty (Beresford, 2002:19). Indeed, with high levels of ambient poverty in most high-prevalence communities, it is difficult to ascertain which effects on children's health are attributable specifically to HIV/AIDS.

2.5.8 **Experience of a variety of psycho-social problems**

Affected and orphaned children are often traumatised and suffer a variety of psychological reactions to parental illness and death. In addition, they endure exhaustion and stress from work and worry, as well as insecurity and stigmatisation as it is either assumed that they too are infected with HIV or that their family has been disgraced by the virus (Clinton, 2003:25). Loss of home, absconding from school, separation from siblings and friends, increased

workload and social isolation may all impact negatively on current and future mental health (Desmond *et al.,* 2000:28). Existing studies of children's reactions suggest that they tend to show internalising rather than externalising symptoms in response to such impacts - depression, anxiety and withdrawal - as opposed to aggression and other forms of antisocial behaviour (Foster, 2002:18).

2.5.9 Vulnerability to infection

Apart from other impacts, children affected by HIV/AIDS are themselves often highly vulnerable to HIV infection. Their risk for infection arises from the early onset of sexual activity, commercial sex and sexual abuse, all of which may be precipitated by economic need, peer pressure, lack of supervision, exploitation and rape (Haacker, 2001:25). Some studies of street children, for example, show that vulnerable children do little to protect themselves from HIV infection because the pressures for basic survival such as finding food - far outweigh the future orientation required to avoid infection (Halperin, 2001:12).

2.5.10 Chances of being sexually exploited and subjected to child trafficking

There is limited hard data available on the extent and nature of human trafficking in either the region or beyond and much of what is available is based on relatively small-scale research. According to the International Organization for Migration (IOM), however, the trafficking of women and children is the third most lucrative type of organized crime in the Southern African region, following the sale of arms and drugs (Joseph, 2002:15). A recent report released by the IOM suggests that considerable numbers of women and children are trafficked annually in the Southern African region. Trafficking in children occurs for the purposes of child prostitution, illegal and false marriage, illegal adoption and child labour (Mendel, 2002:24). An unknown number of children are trafficked for body parts. In the Southern African Development Community (SADC) region, children are trafficked primarily as bonded labour and for the purpose of sexual

exploitation. The IOM report highlights, as examples of trafficking in the region, a European-led child sex tourism industry in Malawi and the trafficking of Mozambican children into prostitution in Johannesburg (Piot, 2001:23; Bennell, Hyde & Swainson, 2002:41).

It is likely that as the ratio of dependent children increases as a result of the HIV/AIDS epidemic, so will the chances of children being lured into trafficking and sexual exploitation. Once imprisoned, or left without the means of escape, children are at their most vulnerable (UNAIDS, UNICEF & USAID 2004:28).

2.5.11 **Suffer long-term psychological effects of emotional deprivation**

Children who grow up without the love and care of adults devoted to their wellbeing are at higher risk of developing psychological problems. A lack of positive emotional care is associated with a subsequent lack of empathy with others and such children may develop antisocial behaviours (Whisson, 2002:19). Not all children are, however, affected or affected to the same degree. Protective factors in the form of compensating care from other people, including teachers, as well as personality predisposition may lessen the impact on children of reduced care in the home environment (WHO, 1999:29).

2.5.12 **Increase in child labour**

Many children in South and Southern Africa already work hard. The Survey of Activities of Young People (SAYP) commissioned in 1999 by the South African Department of Labour found that more than half a million children between five and 14 years of age work for long hours, mainly collecting wood or water. Close to 400,000 children do night work; 183,000 do three or more hours a week of paid domestic work and 137,000 work with or close to dangerous machinery or tools (Bateman, 2001:65; Kelly, 2002:11). About 19,000 children (0.1%) beg for money or food in public for three or more hours a week. More than 70% of children work to help their families, either willingly or unwillingly. About 30% of children's work is in contravention of the law. The International Labour

Organisation (ILO) estimates that worldwide approximately 120 million children in the five to 14 year age group work on a full-time basis, and this figure rises to around 200 million when those for whom work is a secondary activity are included (Benatar, 2002:163; UNAIDS, 2001b:39). Other surveys conducted by the ILO have found that, over a 12-month period, the proportion of economically active children in the five to 14 year age group could rise to as high as 40% in developing countries. Such studies conclude that children's labour contributions are an important component of household income, in some cases amounting to as much as one-third of household income (Carr *et al,* 2002:14).

While not all child labour is necessarily injurious - a moderate amount of responsibility can have a positive influence illegal child labour can be damaging to children's physical and mental health, may prevent children from attending school and may be cruel and dehumanising (Badcock-Walters, 2001:17). Child labour is likely to increase as economic conditions of children in families affected by HIV/AIDS deteriorate. Instruments dealing with child labour infringements such as the Convention on the Rights of the Child and, in South Africa, the constitution and multiple laws do not in their current form lead to financial assistance for the child or the family to ameliorate the economic conditions leading to child work (Cohen, 2000:21).

2.5.13 **Manifestations of negative emotional responses**

Learners affected by HIV/AIDS experience the following emotions. These emotional responses include fear, loss, grief, anger, depression, feelings of dependency and hope (Cross, 2001:19).

2.5.13.1 **Fear**

Fear and shame may prevent PWHIV from confiding in others and gaining support; they may also be reluctant to seek help from AIDS organizations and the rehabilitation system. Fear can arise in the infected person from the

unpredictable nature of the disease. Fear can aggravate depression symptoms and lead to feelings of hopelessness, frustration and being overwhelmed (Halperin, 2001:12). Fear can also arise in others, with repercussions for the person with HIV/AIDS. Friends and co-workers may shy away because of irrational fears of contagion or fears of a person's death, therefore leaving the person with HIV with a deep sense of isolation and loss (Dorkenoo, 2001:38).

2.5.13.2 **Loss**

HIV has been called a disease of losses. Sadness is one outcome of experiencing repeated losses. People with HIV/AIDS may have to grieve the loss of deceased lovers, children and friends while at the same time mourning the loss of their own future. With many successive losses, it can take the form of "chronic, unrelenting loss". Other losses can include loss of partner, family, friends, co-workers, mobility, strength, weight, appetite, and physical attractiveness, locus of control, social role, income, employment, housing to name a few (Fleischman, 2003:27; Meyer, 2003:44).

2.5.13.3 **Grief**

Three stages of grieving can be identified:

- How did the person die? This entails the cause of death and the manner.
- What did the person mean to you? This includes if this was a friend, partner, co-worker, parent, child.
- How will you learn to live without the person? Including what a person will need to do to go on living. It is believed that anticipatory grief (i.e., grief about possible future losses) and bereavement often result in anger and depression (Keeton, 2002:17; Kinoti & Tawfik, 2002:29).

2.5.13.4 **Anger**

Anger may be directed at several targets simultaneously. The person with HIV disease may blame the following - themselves for getting infected and the resulting physical and mental loss, at family not being able to do anything, at a person's support system for lack of understanding, empathy or compassion; at society for their rejection; and the medical establishment, for failing to find a cure (Lovelife, 2001:26; Mkandawire, 2001:18). The fluctuating nature of HIV disease and the interface with the health care delivery system can cause frustration and anger. The need to stay in control can sometimes produce behaviour such as quarrelling, arguing, complaining, or being demanding (Meyer, 2003:17).

2.5.13.5 **Depression**

Feelings of depression can be expected and surface as feelings of discouragement, dejection, or helplessness. Signals that depression is being experienced include disturbance in sleep, appetite changes, withdrawal from all activity, failure to find pleasure in favourite activities, or difficulty in concentration. If depression is unresolved, a maladaptive coping strategy is substance abuse or attempted suicide (Mkandawire, 2001:33; Pawinski & Laloo, 2001:28). Psychological causes can include the anticipation of dying and death; the loss of friends, lovers, parents, or children; the possibility of becoming disabled; and the discomfort of becoming increasingly dependent on others (Whiteside & Sunter, 2000:28).

2.5.13.6 **Feelings of dependency**

Feelings of dependency can be experienced by people with disabilities arising from a loss of functional capacity in both physical and emotional areas. Being dependent on others brings on threats to autonomy, privacy, control, and independence and feelings of helplessness and vulnerability that are often

intolerable. This can have the effect of being unwilling to ask for accommodation because of change in identity, feelings of shame, not wanting to feel different or pitied (Williams, 2000:274; Mulugeta & Atnafou, 2000:56).

2.5.13.7 **Hope**

Not all emotional responses to HIV/AIDS are negative. For people with HIV/AIDS, maintaining hope is not merely a virtue, but a primary task. It appears that people actually live longer when they can hope for and plan future activities, achievements and relationships (Sidley, 2000:18). Hope sustains them through the inevitable "bad days" and increases the capacity to appreciate periods of good health. Feelings of hope fluctuate daily, and sources of hope differ from person to person (World Bank, 2002:28). Hope can be engendered by developing or maintaining spiritual practices such as organized religion, twelve-step programs and meditation. Hope is sustained by maintaining employment and relationships with co-workers - becoming involved in activist groups - cultivating social and family ties, and finding meaning in new roles or new experiences (Watson & Tharp, 2002:26). The most important factor in maintaining hope is active participation in decision-making. Any intervention that enables a person with HIV/AIDS to feel in greater control of their health care and activities strengthens their feelings of hope (Cohen, 2000:28).

2.6 CONCLUSION

This chapter provided the conceptual and theoretical framework which forms the basis of this research. Such a framework was necessary to guide the researcher's arguments on the constructs of psychological well being, and to also understand which psychological human dimensions of children and adolescents are in most instances affected by the HIV/AIDS epidemic. This chapter also highlighted the significance of environmental control for children and adolescents who are affected by HIV/AIDS. Without the personal control of the environmental

circumstances in which they find themselves, children and adolescents affected by the HIV/AIDS epidemic are devoid of the necessary self-efficacy belief that enables them to deal in an assertive and exerting manner with the effects of HIV/AIDS.

The next chapter presents programmes for helping children and adolescents affected by HIV/AIDS cope with its effects.

CHAPTER THREE

PROGRAMMES FOR HELPING CHILDREN AND ADOLESCENTS COPE WITH HIV/AIDS EFFECTS

3.1 INTRODUCTION

This chapter presents literature review findings on programmes and policy challenges necessary for designing or facilitating responses to the effects of the HIV/AIDS epidemic on children and adolescents affected by it. The literature suggestions highlight that there is no one size fits all (Mutangadura, Mukurazita & Jackson, 1999:28). Different communities depending on their specific needs and prevailing national and local contexts may require or call for a set of specific responses. This means that there is no widely accepted model of response, but principles of responses are being agreed upon. These must evolve further to better define the vulnerabilities of affected children within communities and the meanings of rights based approaches through their application in different contexts (Olenja, 1999:189). Policy priorities relate to resources primarily, and the balance between community mobilised resources and external financing and intervention. This balance will vary from place to place and current operational research can provide an understanding of economic realities to be combined with the emerging ethical and principle based ethos of programmers (National AIDS Authority of Cambodia, 2001:11).

Addressing the psychosocial well-being elements of orphans and children in affected communities through effective and relevant programmes is now a matter of urgency. The cycle of infection will be exacerbated by children and adolescents growing up in contexts where mental ill- health is rife, combined with feelings of isolation, despair and social disenfranchisement (Poulter, 1997:29). The responses required are in themselves not complex, but are needed at such

an unprecedented scale that we are only starting to comprehend the implications. While constraints remain in the form of chronic and deepening poverty, capacity limitations and political indifference at all levels, the challenges facing themselves have never been greater (Rugalema, 1999:44).

The next section provides programmes which the researcher gleaned through literature review.

3.2 CHILD-FOCUSED AND RIGHTS BASED PROGRAMMING

According to Schietinger (1998:55), rights based programming implies holism in approach and dealing with aspects of prevention, care, protection and the impact mitigation of HIV/AIDS. These responses must involve not only young adolescents, but also, where appropriate, children under the age of 15. A rights based response also aims to promote the participation of children and adolescents in HIV/AIDS programmes (Raynolds & Alonzo, 1998:257). This is being achieved through the work of key global institutions working for the rights of children through developing a set of principles to guide programming for orphans and other vulnerable children. These principles aim to provide a framework for a much broader response to children and adolescents affected by HIV/AIDS (Ayieko, 1998:54). The main aspects of these principles are to:

- foster links between HIV/AIDS prevention activities, home-based care, and efforts to support orphans and other vulnerable children (Phiri *et al*, 2001:33);
- target the most vulnerable children and communities;
- give particular attention to the gender-specific needs of boys and girls;
- involve children and adolescents as part of the solution (Bennell *et al*, 2002:29);
- strengthen the role of schools and education systems;
- reduce stigma and discrimination;

- strengthen the caring capacities of families through community-based mechanisms;
- · strengthen the economic coping capacities of families and communities (Busza, 2001:451);
- enhance the capacity of families and communities to respond to the psycho-social needs of orphans and vulnerable children, and their caregivers;
- find sustainable ways to remove children from hazardous and exploitative work (Cohen, 1999a:15);
- accelerate learning and information exchange;
- strengthen partnerships at all levels and build coalitions among key stakeholders; and
- ensure that external support does not undermine community initiative and motivation (Collins & Rau, 2000:23).

The foregoing programming principles are fundamental to effective care and support and to the development of the coping capacities of affected households and communities, with child participation at the centre of the response. Looking at the entire array of the child's needs and the situation from the child's perspective, but without including the child's participation is being 'child-centred' (Bradshaw *et al*, 2002:16). On the other hand looking at all their needs and including their participation in the decisions being made about their lives is being 'child focused.' Most programmes aimed at helping children fail as far as ensuring full child participation in their:

- design;
- implementation; and
- evaluation (Campbell, 2000:55).

Children's participation is critical and it is one of the enduring challenges facing all stakeholders.

As these principles enjoy increasing rhetorical dominance, there remains the issue of translation of principles into activities. Such programming implies the move away from pre-determined categories of vulnerability towards local and context specific definitions (Reid, 1998:26). While rights conceptually remain universal, responses must be grounded in local realities, necessitating a needs assessment and social mobilisation process far removed from more traditional welfare responses (Bateman, 2001:68). This itself is cost and time intensive, creating a crisis of capacity, for when the emphasis becomes prioritising local conditions, the identification of 'good' and 'best' practices becomes itself more difficult (Berggren *et al*, 2002:186).

3.3 DEFINING AND SCALING UP OF GOOD PRACTICES

A critical challenge is the identification of what constitutes or defines 'good practices' and how these can be scaled out to impact upon more children. The use of the term 'best practice' is problematic and remains valid at a conceptual level only (Webb, 2001:43). There is a wide range of approaches being practiced by different organisations, governments and communities in the care of orphans and children affected by AIDS. Given the rising number of orphans in Africa for example, responses are far smaller than the scale commensurate with the nature and extent of the problem (Webb & Paquette, 2000:94). Approaches that could go to scale have to be:

- simple;
- owned and managed in the community;
- cost efficient; and
- easy to replicate (Phiri *et al.*, 2001:2; Foster 2001a:29; Haacker, 2001:41).

Scaling up is threatened by:

- lack of political support or political interference;
- corruption;

- inadequate information dissemination about government policies and funding;
- reluctance to modify child protection legislation; and
- under funding of state service delivery and coordination of child care systems (Verhoef, 2001:52; Miller, 2005:208)

Difficulties in scaling up are primarily grounded in the political economy of the response. Governments have to be convinced of the validity of support models, which may complement or intrinsically criticise government responses by addressing key support gaps (Whiteside & Sunter, 2000:18). Non-Governmental Organizations will have differing agendas and governments, acting through the mediation of district and provincial officialdom, opt to disengage with the non-state actors due to the perceived threat of interaction of plain disinterest (Western, Stimson, Mullins, Memmott, Baum, Johnston & Van Gellecum, 2002:34). This challenge is considerable in parts of south and south-east Asia where rigid corruption structures tend to scupper local government adoption of Non-Governmental Organization responses, pushed often by bilateral funding. This factor is considerable in India, China, Cambodia and Vietnam where local governments are only starting to consider the impending orphan crisis (Benatar, 2002:165).

Political constraints not withstanding, at the implementation level there is a basic set of prerequisite questions before scaling up can begin. These include what the existing coping strategies are, what structures frame these responses, what could be described or agreed upon as the basic minimum package for an effective response and how it can be delivered or helped to emerge without eroding community capacity (Williams, 2000:275). Assessing models of care involves key questions such as:

- if and how the model responds to the needs of orphans – physical, material, educational, psychosocial, cultural and spiritual;

- the number and types/categories of needs addressed;
- numbers of children reached;
- the degree of 'child focus';
- transparency in targeting;
- nature of community ownership;
- sustainability; and
- influence on policy at local and national level (FAO, 2002:12; Phiri, 2001:23; Loewenson & Whiteside, 2001:14).

Underpinning these assessment criteria is the search for 'good practices'.

3.4 GOOD PRACTICES IN RESPONDING TO CHILDREN AFFECTED BY HIV/AIDS

Community based or community managed responses are centred around 'informal' fostering where community members assume responsibility for caring for orphans. This is the norm in a number of countries in sub-Saharan Africa and Asian developing nations and has been observed in rural or semi-urban areas where there is little access to services. Religiousity, compassion, community solidarity, reciprocal altruism, concern for society's well being and blood ties are all key factors (Williamson 2001:23; Phiri *et al.*, 2001:87).

3.5 COMMUNITY BASED CARE VERSUS INSTITUTIONAL CARE

While the discussions surrounding scaling up are usually related to community based responses, externally imposed 'solutions' take on a more welfare character. As the impacts of AIDS become manifest, there are increasing numbers of institutions such as both unregistered and registered children's homes and orphanages. In Thailand, numbers of HIV positive children placed in institutions has increased ten-fold between 1992 and 1997 (Hennessy, 2001:45). Statutory foster care processes vary, according to whether there is a court or officially appointed figure given the authority to identify, monitor and supervise

the foster placement of a child. Guidelines and standards of care act as criteria to determine where to place a child and the failure or success of placement, but their use is inconsistent (Hickey, 2000:23).

Alternative care options differ from country to country. Typical of South Africa are community family models where up to six children are placed with a foster mother in a home which is purchased and furnished by an external organisation/individual (Loening-Voysey & Wilson, 2001:372). The foster mother is paid an allowance and receives foster grants for the children, with periodical assistance from a 'relief mother'. Siblings are kept together where possible. Community leadership structures are involved in the process of monitoring, and cluster foster homes are typically run by volunteer women or couples who keep up to six children each and receive foster care grants, material and child care support as well as health services and income generation activities (Levine & Foster, 2000:23). Less common is collective foster care, where religious groups of women or couples collectively agree to act as surrogate mothers for children who remain in their own deceased parents' houses (McKerrow, 1996:21; Loening-Voysey & Wilson, 2001:374).

3.6 INSTITUTIONAL CARE

Institutions for children have a long history; early examples being established and maintained by religious or missionary groups. For the most part, the growth of institutionalisation can be seen as an expedient social policy response to the growing numbers of children in need of care and protection (Hunter, 2000:29). It is seen as an easy option for social or child care workers to place children in these institutions, and a growing number of families also 'place' their children in orphanages. In many countries there is no principle of the State as parent and no legal requirements governing whom a child can be placed with by the parents during their life or on death (Lovelife, 2001:14).

One factor that makes orphanages an attraction is the perception among some members of impoverished communities that they will provide the food, education, health and other services that the caregivers are unable to provide to the children (Halperine, 2001:13). A survey by the International Rescue Committee in Rwanda has shown that economic pressure was one of the prime reasons that children were living in institutions (Williamson, 2000:23; Williamson, *et al*, 2001:56). Yet this can lead to subtle forms of 'abuse' as the *raison d'etre* of the institution is compromised. For example a study in Zimbabwe showed that 75 per cent of the children in institutions had contactable relatives (Powell 1999:34); similar to an earlier study in Uganda in 1991 where it was found that half of the children in institutions had both parents alive and one quarter had one parent alive (Williamson *et al.,* 2001:64). In India's Mizoram State, 47 per cent of the children were placed in orphanages after the divorce of their parents. Another 15 per cent were placed there because they had been born out of wedlock (Chakraborty *et al.*, 2000:26). It is clear that these types of arrangements would significantly contribute to the undermining of more 'traditional' community coping processes.

While they may provide some of the 'nurture', typical institutions do not provide the holistic care that children are entitled to for all round development. Research has shown that children in institutions:

- lack basic and traditionally accepted social and cultural skills to function in their societies;
- they have lower levels of educational attainment;
- have problems adjusting to independence after leaving the orphanage, lack basic living skills;
- have more difficulties with relationships;
- lack parental skills; and
- some of them, often have a misplaced sense of entitlement without a parallel sense of responsibility (Powell, 1999:36; Wright, 199913; Verhoef,

2001:25; Rajkumar, 2000:37; Grainger *et al.*, 2001:120; Williamson *et al.*, 2001:66).

Children in institutions have tenuous cultural, spiritual and kinship ties with families, clans and communities. These ties are especially critical in Africa and Asia as they are the basis for people's sense of:

- connectedness;
- belonging; and
- continuity (Lorey & Sussman, 2001:47; Webb, 1996:25).

They are the basis upon which life skills as well as social and cultural skills are attained. Children raised in institutions struggle to be accepted or fit into traditional rituals and ceremonies as well as contracts and alliance arrangements. The feelings of ostracism these situations engender further adversely affect psychological and emotional well being. It may also be the case that children raised in institutions may likely look down upon their own communities as being inferior after getting used to the trappings of an institution – especially the kind that provides a materially high western standard of care (Powell, 1999:116; Ntozi, 1997:126).

A separate critical issue with institutions is cost. In most countries with mature epidemics and an unprecedented growth in the numbers of orphans, it is impossible to accommodate any significant number to make an impact. The cost of keeping a child in a centre in Rwanda, for example, is approximately US$540, plus the cost of donated food, per child, per year (Williamson *et al.*, 2001). In Eritrea the cost per orphan in an institution was estimated at US$1,350 per year, while in Tanzania it cost US$649 per child per year in 1990 and US$689 per child per year in Burundi (Cohen, 2000:44; Lusk, Huffman & O'Gara, 2000:36). In South Africa statutory residential care was estimated to cost as high as R2590 or R3525 per child per month with palliative care costs. A 1995 survey in Zimbabwe revealed that the average monthly cost of maintaining a child in an institution in

the country was Z$1,058 at that time in the most expensive facility and Z$341 in the least expensive. Rapid inflation would have pushed these figures to Z$3,000 and Z$1,000 respectively. The latter figure approximates to the average monthly salary of a typical family in the country (Schietinger, 1998:54).

The capital costs of setting up institutions also need to be considered. In Zimbabwe, where between a fifth and one third of children are orphans, one institution was estimated to cost Z$25 million. In contrast, a traditional type family unit for orphans cost Z$500,000 and the running costs for the family type unit was Z$131 per child per month (Lugalla, 1999:16). It is therefore estimated that the institutions are 14 times more expensive than the traditional arrangements (Powell, 1999:35). Just based on capacity, it is evident that this option is illogical. In Zimbabwe there are only 41 institutions accommodating less than 3,000 orphans (Lugalla, 2003:29).

Institutions should be the last resort after family, foster or community care in the absence of other models of care being available (Masten, 2001:227). It has been recognised, however, that for a small number of children, residential care will be necessary and that other alternatives may not be feasible, for example:

- the abused children;
- children abandoned soon after birth;
- those whose families refuse to take them in for various reasons, including the fear of evil spirits;
- street children who need night shelters;
- those that might be in need of temporary care who later return to their communities;
- some of the unaccompanied minors in war times, even those that have been sold as labour or slaves across borders (Brown & Sittitrai, 1996:43; Wright, 1999:19; Subbarao, Mattimore & Plangemann, 2001:34; Grainger *et al.*, 2001:36; Williamson *et al.*, 2001:21).

Correctly managed institutions can provide emergency temporary care particularly to protect orphans at risk of abuse. They can help with behaviour and emotional difficulties. However, they are an expensive resource, with an inherent danger of institutionalization, and placements for children should only be used when it is in the child's best interest. Uganda, during the 1990s provides a model for inspecting and monitoring the use of residential care facilities (Smart, 2001:45). The process involved collecting information on institutions and the children in them, followed by legal regulation and policy guidelines, staff training through open distance learning materials, an implemented policy of re-unifying children able to return to families plus inspection and monitoring by the government (Snetro, Zoumana & Yacouba, 2001:34).

3.7 EVOLVING MODELS OF COMMUNITY BASED CARE

Precisely to respond to these problems with institutions, a number of countries have developed alternative models of care. The Civil Affairs Departments of Anhui Province and Guangde County in China, for example, has been working in partnership with Save the Children (UK) embarking on a programme to shift from large scale institutions to smaller groups of family type homes. Many of these homes are integrated into communities and they have begun promoting more foster care (Kiragu, 2001:23). The changes from large institutions to smaller units will take sometime, in an initial model the smaller units were on the same premises and the care units were subject to overall rules of the total establishment. Another problem encountered was how to avoid staffing the units on a permanent basis with young single women, inexperienced as mothers, and how to integrate children with disabilities (Lovelife, 2001:23).

Where children are unable to live with their families, they should be afforded as near as possible environments that approximate to those of families and thus:

- family style units have been established;

- children attend nurseries and schools in the community just like other children; and
- girls and boys live in the same unit as siblings and disabled children are not segregated (Mendel, 2002:15).

Communities are thus participating in the raising of these children who are not isolated and learn social, cultural skills and self-reliance. Some lessons of this programme highlighted what needed to be changed in policies regarding children in need of special protection in China. Subsequently, there was a change in the guidelines and standards for admission, placement and care (Save the Children, 1999:37). The new guidelines for foster care influenced policy and legislation. For instance, in 1998 the law changed in that the minimum age at which a person would be allowed to foster went down to 30 years (Rugalema, 1999:38). It is important for institutions to have well developed, stringent admission criteria so that they do not become dumping grounds for unwanted children, or that they do not act as magnets for families that feel children will be better off in the institutions. Criteria and guidelines will ensure that the children that absolutely need this service have access and opportunities to receive them while at the same time ensure that community coping mechanisms are not undermined (Segu & Wolde-Yohannes, 2000:46).

Aggressively working to prevent families breaking down in the first place through supportive interventions obviates the need for alternative care (Wright, 1999:34), and equally interventions can focus on getting children out of institutions. In Ethiopia, the SKIP project and the Jerusalem Association for Children's Homes both worked to de-institutionalise children by first enabling them to travel to their birth-places during school holidays to look for their kin (Sidley, 2000:106). Older adolescents were helped to become independent through their own development of business plans for which they were given small grants, having apprenticeships organised where they received skills and mentoring, and were given opportunities to attend higher education. As a result of children being re-

integrated into their communities one home was closed (Gebru & Atnafou, 2000:45). SKIP promoted the concept of family type units where children lived in the same style of housing as other community children, had same standards of clothing and nutrition, went to the same schools, worshipped in the same religious structures and engaged in the same mode of agriculture as their peers in the communities. SKIP re-integrated 98 per cent of all the children back into their communities after eight years (Richter & Swart-Kruger, 1995:31).

Temple boy systems and community care centres have been suggested as other alternative models of care especially where there is a strong Buddhist tradition. In Thailand and Cambodia, for example, it is traditional for boys to be placed in a temple where they receive an education (Riskind, Sarampote & Mercier, 1996:42). This has been suggested as an option for male children orphaned by AIDS if the religious community would be encouraged to extend the system to target orphans and actively destigmatise AIDS related orphanhood (Brown & Sittitrai, 1996). This may be a critical model in Cambodia, where the genocide of 1975-1979 (killing between one and three million people) has removed many potential grand-parent care-givers for the estimated 60,000 orphans at the end of 2001 (NAA, 2001:63). In Cambodia, without a concerted a widespread response, rates of child abandonment will be unusually for AIDS affected populations. In addition, other faiths through their own structures and through faith-based organisations could be encouraged in the up-take or adaptation of the system to fit their faiths. This system if developed would need to recognise the situation of girl orphans and monitor the children's welfare in the long-term (Foster, 2002:15).

Given the scale of the current and impending orphan crisis and realising that fostering arrangements will be one of the responses that will be promoted in most developing countries, it is important to note that most of these countries still retain legislation, criteria, guidelines and administrative procedures based on western models (Foster & Williamson, 2001b:30). For example, in South Africa in 1998, the government introduced child support grants for under sevens living in

impoverished households with the intent that within five years up to three million children would have had access to the grant. After the first year, however, less than 30,000 or a meagre one per cent had been able to receive the grant. This was because of stringent information requirements. For example, not everyone in rural and impoverished areas had birth certificates that the department was demanding (Loening-Voysey & Wilson, 2001:27; Haber, 1998:28).

Models of fostering and adoption services developed in the west are by no means universally useful. Adoption requires rigorous legal oversight and assessment procedures and may not be applicable in societies where extended family considers themselves to have responsibilities for a relative's child, and of course this is being re-inforced in high prevalence areas (Joseph, 2002:28). Fostering also provides definitional problems as it is necessary to be clear as to exactly which parental responsibilities are being transferred to the foster parent and in the case of formal fostering what responsibilities are being held by government social workers and the state (Jacoby, 2003:24). Fostering schemes started in countries in transition, intended as alternatives to institutions have rarely reduced numbers of children in residential care but have emerged as a parallel system requiring both fostering allowances and supervision on a long-term basis (Hennesy, 2001:26). Foster relatives have in most cases refused to care for children when allowances were not forthcoming. Formal fostering on a long-term basis raises many rights issues and may not be the *panacea(*Human Rights Watch, 2001:64).

In most cases, developing and transition countries have not ensured that their social policy keeps pace with their economic reform. In those countries where the context facilitates the choice of institutions as the first policy choice for care, state revenues have dwindled to levels where institutions can no longer be supported adequately (Hunter, 2001:31). The impending huge numbers of orphans will make the situation even more unmanageable if no alternative models of care are developed. In addition, the minimum standards set for formal foster care and

adoption are often too high for the many poor but willing community members (Richter & Swart-Kruger, 1995:35). The concept of 'good enough' standards appropriate to the local context, norms and traditions of the community in which the child will grow up should be seriously considered in these countries where the numbers of orphans are numbing (Phiri *et al.*, 2001:18).

3.8 COMPARING COST EFFECTIVENESS AND QUALITY OF CARE

Research in South Africa has examined both the quality of care as well as cost effectiveness of six models of care for orphans and vulnerable children (Loening-Voysey & Wilson, 2001:17; Desmond & Gow, 2001:28). 'Cost effectiveness' was defined as the cost of care per month per child and the cost of providing a minimum standard of care per month in each of the six models which included:

- statutory residential care;
- statutory adoption and foster care;
- unregistered residential care, home based care and support types; and
- community based support structures and informal fostering or non-statutory foster care (Roysamb & Strype, 2002:17; Clinton, 2003:43).

The authors argued that it was imperative to develop a framework for evaluating the quality of service as well as assessing the feasibility of each approach. 'Quality of care' was defined as 'care which meets the needs of children in a culturally relevant and acceptable manner and at the same time, enables them to realise their rights' (Loening-Voysey & Wilson, 2001:37). The analysis concluded that institutional care was the most expensive and least cost effective of the models and that community based care and informal fostering was cheaper and more cost effective. However, the study also pointed out that the quality of care in family or informal fostering was increasingly being compromised by a distinct lack of, as well as access to, resources (FAO, 2002:62). As such the needs of

orphans in this care were not being responded and children's rights were not being recognised.

Costings exercises are hampered by the fact that there are some aspects of care that are extremely difficult to measure or cost – for example affection or love of the carer. It can also be argued that it would be difficult to cost or measure local advocacy or even community parenting' where significant others in the community contribute to the parenting of orphans (Foster, 2000:59). There is also the clear discrepancy between the availability of resources in a given context and the realisation of children's rights. As discussed above, a lack of awareness of the rights of children as enshrined in the United Nation's Convention on the Rights of the Child, as well as difficulties involved in the application of rights based approaches to policy and programming, remain a serious challenge (Ryan & Frederick, 1997:29). The difficulties involved in such a costings review are many and relate to the following:

- the variation in intervention types;
- the tendency to cost specific sub components of programmes such as food or education costs;
- varying definitions of target groups and vulnerabilities;
- the absence of capacity inventories for different community contexts;
- varying values of resources in different contexts: of land, population density, leadership strength, human resource availability;
- subjective nature of costing human resources and other aspects of 'social capital';
- how to quantify and measure quality of support given; and
- how to conceptualise, and cost the strengthening of health and social service systems (Arlington International HIV/AIDS Alliance, 2001:18; Roudy *et al*, 2001:56).

The aim of defining an equation of external resources mobilising internal capacity and 'social capital' in order to supporting OVC to an agreed standard is simplistic

but presents the nature of the challenge. Where internal resources have been mobilised these have been measured when connected to micro-credit programmes and material outputs such as foodstuffs and sometimes money itself (Ainsworth & Semali, 2000:68). Within the COPE Programme in Malawi by July 2000 the DACCs and CACs had raised around US$20,000, compared to the US$1.6m needed to keep COPE going through to 2001. Although the time frames may be different, in this case it is looked at internal financial mobilisation of around 1.25 per cent of the total amount needed for the programme (Williamson & Donahue, 2001:65). This raises the question of the potential for sustainability when considering financial stability, as well as the need to better define non-financial resources, as finances are only one component of social capital generated by the programme structures (Ali, 1998:62).

These and other issues are major constraints on reaching universal consensus on costings, and the way forward may be to firstly to define support packages per capita/family, and have estimates according to each, using methods employed in health systems management models, or those developed to cost home care structures (Angst, 1999:46).

3.9 ORPHAN SUPPORT AS COMMUNITY DEVELOPMENT IN EASTERN AND SOUTHERN AFRICA

Despite the uncertainties, scaling up efforts are on-going. The Uganda Women's Efforts to Save Orphans (UWESO) has used the model of children's villages to organise cluster and community foster care arrangements. The organisation gives school and medical costs, and assists with food and clothing provision and organises training in community-based child-care and livelihood support families with orphans (Barnard, 1994:135). UWESO uses an approach that enables communities themselves to care for orphans, where orphans live in their own communities and are assisted using traditional structures, thus engendering ownership and facilitating sustainability. Communities are responsible for

identifying the most needy, prioritising using their own index of vulnerability. Thus far the project has had an impact on over 10,000 orphans, raising income at households levels, increasing the nutritional status of orphans as well as improving the quality of shelter in the community. Costs for primary schooling have been reported as being US$35 per child per year and US$75 per year for secondary school students (Subbarao, 2001:63). A further example is provided by the FOCUS project in Zimbabwe. This is a programme of Family AIDS Caring Trust (FACT), an AIDS service organisation established in 1987 (Conference on Access to HIV/AIDS Care and Support, 2001:10).

Research on orphan enumeration and community coping mechanisms has been conducted by FACT since 1991. In 1993, the FOCUS programme was started by recruiting 25 women from 18 villages and several churches throughout the communal farming programme area, approximately 200 square kilometers with a population of 10,611 people in 2,089 households (Beresford, 2002:18). Traditional leaders in adjoining areas asked for the programme to expand to cover their villages so more volunteers were recruited. In addition, more volunteers were recruited as more vulnerable children were identified. This enabled the visiting caseload of volunteers to be reduced to around 10 families per volunteer (Alidri, 2001:31). By 2000, the FOCUS programme in this area had expanded to involve 40 volunteers and covered 22 villages.

The programme emphasised identification and monitoring of vulnerable children through:

- regular household visits;
- community ownership;
- keeping children in school;
- income generating activities; and
- volunteer training and motivation (Blum & Rinehart, 2000:28).

The programme was established and maintained in close liaison with community leaders. The community and church leaders nominated volunteers as respected and credible people of good standing (Brissette *et al*, 2002:107).

Most volunteers were widows or women already caring for orphans themselves with experience in caring for vulnerable children. Volunteers were initially trained by FACT staff and ongoing training, supervision and monitoring was provided by the Programme Co-ordinator during monthly volunteer meetings in the community (Adeyi *et al*, 2000:63). Volunteers were responsible for identifying and visiting orphan households within a two-kilometer radius of their homes. Those considered more vulnerable are allocated priority status on a register and are visited at least twice per month (Mkandawire, 2001:23). Volunteers identify unmet basic needs of the households and provide essential material support including maize seed, fertilizer, food, clothing, blankets, school fees (US$2-4 per annum) and so on. Visits provide emotional and spiritual support and, in addition, volunteers may offer to bathe children, sweep the house, fetch firewood or cook. Visits enable the children's situation to be observed and children who are out-of-school, in emotional distress or being abused are identified and appropriate action can then be taken. The likelihood of abuse, exploitation and maltreatment of orphans lessens in communities where frequent visiting is occurring (Mohlala, 2002:10).

Visits also enable spiritual activities such as prayer, scripture reading and praise songs to be shared. Psychosocial support is provided through weekly craft, cultural and sporting activities. Volunteers are also involved in advocacy and awareness raising on orphan issues (Phiri *et al.*, 2001:28). Small volunteer incentives were provided, in the form of uniforms, shoes and training and meeting expenses, as well as an annual Christmas bonus of US$10. Some volunteers visit other programmes through an exchange visit scheme (Benell *et al*, 2002:51). Volunteers who look after orphans in their own homes may receive

small amounts of material support (average US$11 per annum). Incentives help to keep volunteer drop-out levels very low (Foster, 2000:58).

By 2000 programme replication meant that there were nine sites, which had 2,764 orphan households on their priority registers; and 178 volunteers were active in the programmes, 97 per cent of whom were female (Feldt, 1997:145). This lack of male voluntarism in the programme is an obvious issue of concern and is part of a wider reluctance of males to take on caring roles. Indeed, of the five active males, four were site supervisors, mostly pastors paid small monthly allowances by FACT (Brown *et al*, 1996:23). During 1999, 142 volunteers at seven FOCUS sites reported making 93,000 visits to 2,170 households containing some 6,500 orphans and vulnerable children; 992 children had their school levies paid and as a result were attending primary school (Layman, 1996:70). Income generating projects initiated by volunteers included gardening, crocheting, green-house horticulture involving mushroom growing, goat keeping, poultry rearing, sewing and knitting (Loening-Voysey & Wilson, 2001:78).

According to Meijer (2002:22), during the period 1996-99, the number of households visited increased from 798 to 2,170 and volunteers from 81 to 142; total programme costs stayed fairly constant at between US$20-30,000 per annum, and approximately 50 per cent of programme expenditure was at community level in the form of material support, volunteer incentives and meeting costs (Miller & Delaney, 2005:17). The cost per family was approximately US$10 and per vulnerable child US$3 per year. The cost per visit was US$0.11 while the cost per volunteer was US$68. Now the programme is expanding and strengthening its approach. The visits include activities and routines to include interaction with the orphans themselves not just the adult care-givers (Siamwiza, 1998:34). This is meant to ensure that the orphan point of view is included in planning responses, and more psychosocial activities have been introduced. The further development of nutrition gardens is assisted by the fact that some of the gardens have been set aside by chiefs – through the tradition of Zunde

raMambo, which means the 'chief's garden.' This is what the government has been advocating as community resource mobilization and advocacy to respond to the needs of orphans (Phiri *et al.*, 2001:45).

3.10 MULTI SECTORAL RESPONSES: THE COPING PROGRAMME OF MALAWI

The Community-based Options for Protection and Empowerment of Save the Children (US) in Malawi has developed multi-pronged strategies of assisting communities to respond to the needs of children, families and communities affected by HIV/AIDS. It works through existing structures or organisations at district, community and village level (Savenstedt, Savenstedt & Haggstrom, 2000:54). The structures or organisations can include community based religious organisations. For the most part COPE revitalised a structure set up by the National AIDS Control Programme with the help of UNICEF and other donors in 1992. The structure through which the programme works comprises the District AIDS Co-ordinating Committee (DACCs) (a multi-sectoral, multi-stakeholder structure at the district level), the Community AIDS Committee (CACs), usually defined by a health catchment area or traditional authority, comprising as many as 100 villages, and the Village AIDS Committees (VACs) (Foster, 2002:29). COPE resuscitates the DACCs, which in turn work to establish or strengthen existing CACs. The CACs are then responsible for catalysing the communities. After defining broad based community based and community managed care coalitions, the programme also develops their leadership and organizational capacities to undertake activities intended to respond to the diverse needs of affected children and families. At the CAC and VAC level, coalitions typically include traditional leaders, religious leaders, teachers, community based government workers including social workers, community development workers, agricultural extension workers, health surveillance assistants, nurses, etc. They also include businesspersons, widows, married and unmarried women, single and married men, and youth (Gilborn, 2000:59).

There are four technical sub-committees that are tasked with the different areas of response, namely:

- orphans;
- youth;
- home based care; and
- prevention (Kalemba, 1998:13; Ryffe & Singer, 2000:38).

The coalitions also are trained to raise resources internally and externally. Each community decides on what activities it will implement. All communities include in their activities identification, monitoring, assistance and protection of orphans. Other activities include:

- home based care activities for the terminally and chronically ill;
- youth and anti-AIDS club formation (both for prevention, peer education activities as well as support and care activities for other orphans and other vulnerable families) (Jessor, Turbin & Costa, 1998:199);
- community gardens;
- structured recreational activities to respond to the psychosocial needs of the children;
- community managed child care-centres to provide community care (Keeton, 2002:31);
- stimulation and psychosocial activities for under sixes, that is, for both orphans and others; and
- vocational skills and life skills training (Hunter, 2001:23).

Teachers and other workers that interact with children are also trained on the psychosocial needs of children. The programme also links communities with other economic activities, opportunities and programmes in the district or beyond. In this respect activities have included links with micro-finance institutions, and the World Bank Funded Social Action Fund which has assisted with the establishment of community child-care centres, school fees assistance and other

activities defined by the communities themselves (Bayles, 2000:84). The programme planned to link closely its plans and partner with the National Safety Net Program and the poverty reduction activities at national level which proposes support through nutrition programmes and direct transfers to transient poor as well as the core poor (including orphans, vulnerable children, the elderly). The district assemblies of which the DACCs and CACs are a part are expected to play a key role in targeting, coordination and resource mobilisation (Hunter, 2001:46).

A 2001 review by Hunter (2001:48) concluded that COPE mobilisation has created a demand in other communities, some actually starting their own activities or requesting assistance to initiate a response. It also created an increase in the demand for:

- basic services in health;
- education; and
- access to water, sanitation and agricultural services.

The potential for sustainability is enhanced through:

- the fostering of ownership and the flexibility of services; and
- the deliberate involvement and empowerment of the youth and that the training and capacity development which has added subsidiary value, so often unrecognised in traditional cost analysis (Fleischman, 2003:37) .

COPE has and continues to have major influence on the national policies and programmes affecting orphans.

The COPE programme has scaled up from one district in 1995 to four districts and currently serves upwards of 12 per cent of the population in Malawi. In its third phase COPE plans to scale up to cover the whole country through three principle strategies (Save the Children, 1999:11). One is through strategic partnership with other International Non-Governmental Organizations, local Non-Governmental Organizations, and the government who would then replicate the

programme in other areas to reach at least 75 per cent of the country and 100 per cent of all districts by the end of 2006 (Ryff & Singer, 2000:38). This is the first proposed partnership programme in sub-Saharan Africa to take up the challenge of going to national scale to meet the various needs of children affected by HIV/AIDS. Evidently the partnership will itself have a powerful influence on national policy and practice. The second strategy is through co-ordination of capacity building at the local and national level (Blum & Rinehart, 2000:36).

3.11 GOOD PRACTICE LEARNING AND DISSEMINATION

Capacity building also provides for international learning. The basic concept is that of the 'living university'. This is an ongoing resource and technical assistance centre for local, national as well as international visitors (Levin & Foster, 2000:28). Save the Children (US) has successfully piloted this concept in Vietnam and Egypt. FACT has also successfully developed and implemented the concept in Zimbabwe where it has resulted in replication of its model orphan visiting and assistance programme within Zimbabwe as well as four other countries in Africa. The living university is an ongoing social laboratory where an implemented project can be observed and discussed at various stages of implementation (Lovelife, 2001:19; Sidley, 2000:104).

Its 'campus' is the key locales of the programme and the 'faculty' comprises the key staff members who have been trained as trainers as well as the community members who are implementing the activities. The curriculum is largely the training manuals, constantly evolving and adaptive developed and being developed during the course of the implementation of the project. The living university also provides critical technical assistance and quality control and framework for monitoring and evaluation to local partners (Hunter, 2001:65; Bateman, 2001:79). It is a critical element in influencing policy and practice as well as scaling up responses.

At the local level the living university locales are principally centres of learning where community to community learning through visiting and collaborative review can also take place (Phiri *et al.* 2001:24; Berggren *et al*, 2002:186). Save the Children (US) will also continue implementing through mobilisation in some districts without or with partners. At the regional level there are plans to use the principles, guidelines and lessons learned to start up COPE like programmes in Mozambique and Ethiopia and later to other countries in the region and beyond.

3.12 ADDRESSING THE NON-MATERIAL NEEDS OF ORPHANS

Psychosocial needs of children affected by AIDS, especially orphans, are most often neglected in programme design. Most organisations, governments, and donors have felt that the material, economic, nutritional and other physical needs are the most critical, requiring immediate response (Hickey, 2000:24). However intangible, psychosocial needs of children are critical – as they have a direct bearing on all the development aspects of a child growing in any context. Psychological wounds might be manifest in different guises including, but not limited to:

- depression;
- isolation;
- aggression;
- listlessness;
- attention deficits;
- nightmares;
- unresolved guilt; and
- eating disorders (Barnard, 1994:138).

As parents become sick, children worry about them and about their own future. Children usually do not verbalise these feelings, making it difficult to assess

whether the child has reached closure about the terminal illness or death of their parent. Children may instead become withdrawn, aggressive, play truant, engage in antisocial behavior and are prone to depressive disorders in adult life (Poulter, 1997:46). The children do not just lose parents, they also suffer a loss of parenting – which entails a loss connectedness, a bond, a sense of trust and continuity. Sibling separation also exacerbates feelings of isolation. In a Uganda study two thirds of older children in affected households are separated from at least some of their siblings (Gilborn, 2000:44; Amrhein, 2004:72). Children's needs for security from all aspects of economic want (based on their families' capacities and context) cannot be separated from their psychosocial needs. Some commentators and researchers have termed these as 'psycho-economic needs.'

Children begin to be affected well before the parents die. Denial of education and involvement in informal sector labour can lead to reduced play opportunities and socialisation is adversely affected, impeding self-esteem development (Helgeson, 19994:29). Orphans often are deprived of education as foster parents (often mistakenly) assume the child is HIV positive and consider the opportunity costs of education as too high. Infected children are sometimes denied school-fees from caregivers due to impending funeral costs (Alidri, 2001:56). For those remaining in school, performance deteriorates due to worry, depression and other physiological manifestations of anxiety. Often children are also not told about the progression of the parent's disease or the cause of the parent's death, overtly to protect the child from the trauma, pain and to conform to cultural norms regarding discussion of death (Hoglend & Perry, 1998:41).

Some experts feel that it is important to disclose the status of the parent's illness to children aged seven and over as they are mature enough to understand the finality of death and are aware of HIV/AIDS because of what they hear, learn at school and in the community (Jacoby, 2003:44). It is argued that having this information may help to protect children from contracting the disease since they

are sometimes caring from the parents. Others argue that disclosing the information only makes life harder for children. Yet the decision should rest with the parents (Aldwin *et al*, 1996:69). Because of the strong and deep emotions involved, the deep-rooted traditional sensitivities, HIV positive parents find it very difficult to disclose their status to their children. Children do sense what is going on around them even if it is not discussed with them or expressly articulated (Ryan & Frederick, 1997:55). Others have argued that this makes the children more anxious and stressed. Research in the Kagera region in Tanzania concluded that children whose parents had talked to them about dying appreciated the opportunity to share time and listen to parental advice about how to do things when their parents die (UNAIDS 2001:47). Similarly in Uganda, where 69 per cent of a sample of affected children whose parents had discussed their HIV status with them thought that parent's openness about their status was positive (Gilborn 2000:30; Gilborn *et al*, 2001:22).

The National Association of Women Living With AIDS in Uganda is a project addressing these needs. The project had adapted the Memory Book approach, originally developed in the UK by Barnados (Hoglend & Perry, 1998:39). The book is a journal of facts and memories for children who face imminent loss or separation from a parent. It is an attempt to keep the memories, milestones in the child's and family's life alive and create a sense of enduring belonging and connection (Roysamb & Strype, 2002:14) . It connects the past, the present and the future of the child helping them keep a sense of continuity and belonging and rootedness. It may include descriptions of the favorite memories of the mother or father, family traditions, special events, health and education and a family tree. The parents can complete it and then take the child through the steps or the child can be part of the process of completing it (Lorey & Sussman, 2001:54). The Memory Book provides opportunity to talk about HIV and may facilitate disclosure of parental (or even child) serostatus. Future challenges relate to helping caregivers disclose the HIV status of children and their parents, sometimes with the direct help of counsellors (Alidri, 2001:33).

The issue of succession planning is integrated in the activities. Parents or guardians discuss with the participation of the child the person who will be their caregiver or parent after the death of the parent. This is most often an uncle or aunt of the children, in around 40 per cent of cases (Gilborn, 2000:67). Mothers are now discussing not just surrogate parenting but also other options, by identifying one who is considered primary care giver and at the same time identifying others who might play certain other significant roles in the child's life. This mirrors reality, where the child is parented not just by the one biological mother and father but by other relatives, neighbours and other significant adults (Miller, 2005:8).

A cadre of facilitators continue to undergo training sessions to enable them to train mothers in communication skills with children, child and community counseling, the writing of memory books, home visits, facilitating psychosocial activities for children, basic will preparation, literacy for mothers and identification of supportive future care takers (Sampa-Kamwendo, Syamujaye & Brakarsh, 1998:17). One of the critical lessons learned is that in order for infected and affected children living in rural areas to receive quality care and support, external agents should integrate programmes for these children into existing community based structures and services (Sack, Kunsebeck & Lamprecht, 1997:151). A child focused home care handbook is also being prepared for community health workers by Save the Children UK, in consultation with National Association of Women Living With AIDS in Uganda. The Memory Project will also initiate children and mothers' legal projects to address children and widows' inheritance rights and other legal issues (Ryff & Singer, 2000:27).

The experience of the Humuliza project in Tanzania show that schools and teachers are critical to the development of children affected by AIDS, especially in the wake of the loss of parents and parenting (UNAIDS 2001:29). Teacher training that responds to the psychosocial needs of affected children has become

a critical policy and programme response. Teachers are expected to become sensitive to children playing truant, being disruptive and withdrawn in class. For example, as part of the Humuliza project in Tanzania teachers were sensitised to identifying the needs of children and communicating with them (Hoglend & Perry, 1998:42). The teachers in turn are sensitising and advocating with politicians and traditional leaders to respond to the needs of thee children. Most importantly the teachers themselves have created a fund for orphaned children in their schools or communities, which helps to buy essential school supplies. The teachers contribute 200 TZ shillings (US$0.26) every month from their own salaries (UNAIDS 2001:34). The critical first step in building a school based response is acknowledging that teachers are also in need of counselling, as a significant proportion of them are living with HIV, are battling with terminal and debilitating illnesses, and themselves losing loved ones (Kosuth, 1998:21).

In Uganda, schools are spontaneously responding to needs of affected children (Alidri, 2001:47), although teachers are in need of further sensitisation and counselling training. Affected children are reported by teachers to be late for school more often, have irregular attendance, have poor concentration due to hunger and sickness and suffer stigma from fellow students (such as deliberate avoidance or sitting apart from them) (O'Conor & Shimizu, 2002:178). When parents take the initiative to disclose to the school the serostatus of their child, the schools do consider action such as exemption from strenuous activity, preferential seating at the front of class, fewer disciplinary measures and exemption from some school related costs (Parry, 1998:28).

At a broader level it is clear that schools are critical in responding to the needs of children orphaned by AIDS. Governments affected by the epidemic must be assisted in the development of country-level strategic and implementation plans for HIV/AIDS prevention and impact management in education systems which aim to:

- assess, manage and mitigate the impacts of HIV/AIDS on education systems;
- improve the capacity of the education system to reduce vulnerability to HIV/AIDS and promote factors and environments that are inclusive, healthy and protective for individuals, communities and societies; and
- strengthen capacities of education systems, especially schools, to implement wellresourced, full-scale HIV/AIDS prevention (and care) programmes that specifically address risk behaviours and situations (O'Reilly, 2000:51; Murdock, 2000:58).

A working definition of psychosocial programming should be embedded in the psychological and social dimensions of a specific culture. Generally the main aim of psychosocial programming is to protect children from the accumulation of stressful events; to enhance the capacities of families and communities to respond to the psychosocial needs of children as well as to enable children's participation in their own re-building of a sense of normalcy and continuity (Kelly, 2000:29). The goals should be to ideally implement programmes that support outcomes that include the enabling of secure attachments with caregivers, the establishment of meaningful peer relationships, social and cultural ties and connections, the development of self esteem, trust and key competencies; access to economic opportunities and a sense of hope for the future (Duncan *et al.* 2001:46).

To help programming there is a need to start from strengths of the community (Cook, 1998:35) not to focus so much on the negative aspects. Critical to this is the identification of protective factors, that is, features of the external and internal environment that facilitates resiliency in the children and their community. The importance of a consistent connection to a primary care giver (in particular the biological father), has been well documented in the United States as being a prime determinant of risk outcomes in adolescents (Roudy *et al*, 2001:38). Children without such a connection are prone to early sexual debut, violence,

greater involvement in risk activities and a negative social outlook (Kirby, 1999:46; Resnick *et al.*, 1997:12; Blum & Reinhart, 2000:64; Jessor *et al.*, 1998:34). As parent dies due to AIDS this connection is increasingly under threat, as well connections to other members of ones own cultural group or routines, community resources and educational opportunities. The implications of this psychological deficit are not yet manifested but researchers point to increased levels of violence, deviancy and adult depressive disorders (Badcock-Walters, 2001:8).

Psychosocial support is implicit in support programmes. Micro-credit programmes for women, youth skills training and employment creation is critical to economic needs but also fundamental to psychosocial health. These programmes may help to reduce stress related to worry about the future economic status, and in the case of adolescents the programmes increase their self esteem, provide opportunities for peer relationships and social skills (Duncan *et al.*, 2001:63). Structure, predictability, and stimulation contribute to a strong sense of connection for children, and rites of passage, ritualised routines, recreational activities, traditional games, stories, legends, myths, song, dance, movement, sports, all contribute to this end (Kiragu, 2001:51).

3.13 AIDS IN THE CONTEXT OF POVERTY

It has been suggested that HIV/AIDS will be the main obstacle to reaching national poverty reduction targets and the United Nation's Millenium Development Goals. Hitherto most policy responses internationally have been focused on prevention, control and treatment. There has been little on mitigation, even less specifically on orphans (Loewenson & Whiteside, 2001:31). Yet AIDS and impacts cause and deepen poverty. HIV/AIDS is directly and indirectly linked to a host of negative outcomes that include:

- reduced social sector spending, giving rise to a lack of access to affordable health care and prevention services;
- lower education status;
- falling household per capita income, and increased spending on medicines and funerals;
- lost productivity, disrupted farming cycles and systems;
- increased dependency ratios, worse gender inequalities, and increased number of orphans, street children, crime, and commercial sex work (Kinoti, 2002:15; Kirby, 1999:29; Sebert, 1996:12).

These outcomes inevitably and unavoidably give rise to perverse household risk management strategies including sell of land and assets (Cohen, 1998:46; Hunter, 2000:18; Loewenson & Whiteside, 2001:89; Adeyi *et al.,* 2001:41).

In response to the challenge, in Zimbabwe, in 2001 the World Bank's Enhanced Social Protection Programme aims to reach vulnerable children. One component of the programme is the Basic Education Assistance Module (BEAM). The programme, which is expected to begin operations in twelve districts, is a targeted school fees, examination fees and levy waiver aimed at reducing the number of needy children dropping out of school due to economic constraints (Aspinwall & Staudinger, 2003:248). Broad based and inclusive School Selection Committees comprising members with knowledge of the socio-economic situations of the communities in which they live are responsible for identifying the children most in need of assistance. The funds for fees and levies go directly to the accounts of the schools each semester whereas the stipend element flow to the local post office savings banks where eligible children are permitted to withdraw one part of the stipend at the beginning of the school year to cover expenses for uniforms, travel and other school supplies (Mulugeta & Atnafou, 2000:64). They are allowed to withdraw the remainder if they satisfy some minimum attendance criteria. A system of monitoring and evaluation with periodic participatory assessments has been established. The programme is expected to

reach approximately 426,00 children at both primary and secondary schools throughout the country and will cost US$6.8 million or an annual cost of US$16 per child (Subbarao, 2001). It would be ideal if the guidelines in question are developed with active input from the communities using their own criteria or index for vulnerability (Phiri *et al.*, 2001:60).

Another component of the programme is the Children in Extremely Difficult Circumstances whose objective is to intensify various forms of assistance to Children in Extremely Difficult Circumstances through strengthening the communities' capacities to respond to their needs (Riskind, Sarampote & Mercier, 1996:110). Child Welfare fora have been established in the country to assist communities with training and grants to Non-Governmental Organizations working with CEDCs and their families. Two other components are the public works, which will supplement incomes of poor households through temporary employment and the social protection strategy for capacity building for planning, implementation and monitoring of the institutions (World Bank, 2000:18).

Similarly in Zambia, the Social Investment Fund has developed a Children In Difficult Circumstances module that is offered to each community as part of the outreach process. Grants are now being made available in tandem with technical assistance, monitoring and evaluation support (Mkandawire, 2001:49). These are grants for communities to respond to the needs of orphans and other vulnerable children. Malawi too has a similar initiative underway. There is a need, however, for these programmes to demonstrate credibility. The programmes need to ensure effective targeting of the vulnerable, have adequate implementation capacity, and allow genuine participation by communities and children. Questions of sustainability are also paramount (Mohlala, 2002:9).

Given the interrelationship of poverty and HIV/AIDS, it has been suggested that the Highly Indebted Poor Countries Debt Initiative provides an opportunity for an unprecedented and significant mobilisation of resources (O'Reilley, 2000:24).

These are the resources to mitigate the impacts of HIV/AIDS; provide an opportunity for a multi-partner and multi-sector co-ordination and collaboration as well as an opportunity to scale out and scale up the best practices in the response to the pandemic. Indeed a critical challenge for country teams working on Poverty Reduction Strategy Papers is to include HIV/AIDS as a central part of the overall poverty reduction effort. Adeyi *et al.* (2001:38) suggest that as part of the HIPC monitorable conditions, the budgetary savings from the debt relief could be earmarked and allocated to the AIDS programmes through Poverty Action Funds, national development funds or micro projects to reach local public and community institutions. In high prevalence countries it is estimated that a minimum of US$1.50-2.00 per capita is needed for a solid programme (Parry, 1998:62). The savings would constitute an important financial and political investment by the government and thus also prove its political commitment and will. It is imperative that the relationship between poverty and HIV/AIDS should be flagged and the analysis should be used as an advocacy tool to make the case for HIV/AIDS within the strategic plan. Only a few countries to date, however, have seized the opportunity in a thorough manner (Adeyi *et al.*, 2001:65). This is a missed opportunity, sad but indicative of the gaps in strategic planning, policy formulation, implementation, management and programming (Olenja, 1999:189).

The establishment of a Global Fund for AIDS, tuberculosis and Malaria in late 2001, of a requested US$7–10 billion a year, could be a crucial access point for governments seeking resources to tackle the impacts of AIDS. One of the key objectives of the Fund is the protection of those made most vulnerable by the epidemic, especially orphans. Underfunding of this initiative ($1.5 billion by December 2001) hints that commitment to fighting the impacts of AIDS is still woefully lacking (Kelly, 2002:46).

3.14 **CHANNELING RESOURCES TO THE FRONTLINE OF THE RESPONSE**

It is evident that households, community members and families are the ones that are caring for orphans, visiting and supporting them in various ways, raising whatever they need to pay the various educational and health costs. Various grassroots organizations and faith-based initiatives are also helping in the effort (Roudy *et al*, 2001:29). However given the fact that most of the communities, carers and grassroots organisations do not have the economic means to manage adequately, given the pervasive poverty in these communities and the increasing numbers of orphans it is important that internal and external resources are mobilised to assist. The challenge however is to ensure those external resources trickle right down to the communities (Kirby, 1999:54). In the past international organisations efforts to get resources to the communities have been beset by problems of poor targeting, insignificant impact and extremely low levels of resources in proportionate terms actually reaching the targets (Williamson et al. 2001). At the same time we have to be careful that organisations, as well meaning as they may be, do not undermine communities' ownership of responses by overwhelming them with resources right at the beginning of the mobilisation process, thus creating the impression and expectation that this is a problem that will be solved by the external agency providing the money (Human Rights Watch, 2001:129). More often than not that agency, at any rate, will only be there for two or three years. Community action cannot be mobilised as well as sustained by providing resources as a carrot for motivation. Funding should come in tandem with capacity building geared to the establishment of structures to strengthen absorption, accountability and democratic principles (Phiri *et al.*, 2001:27).

Williamson *et al.* (2001:36) suggest the following mechanisms that can be utilised, adapted singly, or in parallel. They caution that these are not the only options and they are not mutually exclusive and they all may have advantages as well as limitations in given contexts.

3.14.1 **Networks or Umbrella Organisations Working with Children.**

The membership of these organisations may include Non-Government Organizations, and government departments. They may assist with writing proposals, monitoring and accountability. Examples are Children in Need Network in Zambia, UCOBAC in Uganda, and Network for OVC in Ethiopia (Hunter & Williamson, 1997:29).

3.14.2 **Multilayer Committee Structures**

Examples are the AIDS Committee structures in Malawi, the AIDS committees in Kenya, the Orphans and Vulnerable Children Committees in Zambia and the Child Welfare Forums in Zimbabwe. These structures reach the grassroots, incorporate various stakeholders including government departments and personnel, thus enhancing accountability and promoting multi-partner co-ordination (Halperine, 2001:12).

Some of them may not have legal status or operational capacity to absorb funds and may rely on one of the members to do this.

3.14.3 **Capacity building Non-Government Organizations**

Most of these have strong management, fiscal accountability systems and training capacity. They focus on building the capacity of local organizations and provide technical assistance, which enables local organisations to in turn mobilize communities to respond to the needs of orphans and other children affected by HIV/AIDS (Kiragu, 2001:69). For example, the International HIV/AIDS Alliance provides capacity building to local organisations in Africa, Asia and elsewhere. So too does Private Agencies Cooperating Together (PACT) in Ethiopia and Zimbabwe. Family AIDS Caring Trust (FACT) in Zimbabwe is now providing technical assistance and capacity building to over 200 organisations

with a vision to scale up and scale out (Kirby, 1999:29). The limitations may include the fact most of these organisations are grant funded and will only be there for a while. The other is that they may focus on capacity building to deliver services rather than to the catalytic role of mobilising action in comminutes (Rugalema, 1999:62).

3.14.4 **National Funds**

This category may include Social Action Funds, independent foundations, trusts or such legal entities. These can receive external funds and sub-grant to local organisations, play advocacy roles, monitor as well as build capacities. Examples include the Nelson Mandela Children's Foundation in South Africa, The Kenneth Kaunda Foundation in Zambia, the Tanzania Social Action Trust Fund, the Malawi Social Action Fund and the Zimbabwe Enhanced Social Protection Fund (Miller, 2005:9). All are assisting orphans and other vulnerable children through various programmes and mechanisms. Sometimes these funds are wholly donor funded while others are supported by the private sector. A case in the latter category is the Tanzania Social Action Trust Fund. It uses interest earned from loans and investments in the private sector to make grants to local Non-Government Organizations to assist orphans (Mcmillan & Fisher, 1998:179). Fifty per cent of its earnings are ploughed back into investments and loans to ensure sustainability of the program of assistance. SATF has expanded grants from 100 million Tanzania shillings (US$112,000) covering eight regions in 1999 to 195 million shillings (US$218,000) covering Non-Government Organizations in twelve regions (Mohlala, 2002:5).

Other mechanisms include international funding structures whose advantage is that they can raise more money faster and effectively. Examples are the Global Initiative on AIDS in Africa, Communities Organized to Respond to HIV/AIDS Epidemic (CORE) and the Hope for African Children Initiative which all provide grants and technical assistance to local Non-Government Organizations. They

have strong management capacity but on the other hand are too far to make consistently right decisions or to be able to include other stakeholder in the process of identifying the recipients (Sengendo & Nambi, 1997:105).

The role of faith based organizations needs to be highlighted also. Faith based organizations are significantly involved in the education, health, agriculture and basic community development sectors. Religious women's guilds in the Christian churches and the Dawa sisters in some of the Muslim faithful communities in Malawi are both examples of women groups that help, support the needs of widows and orphans by visits, with spiritual, moral and other resource support. (Phiri *et al.*, 2001:45). It has been suggested that the facilitation of local family and neighborhood spiritual connectedness is one of the key foundations for an effective response (Campbell & Rader, 2000:67), and it is known that religiosity is a significant protective factor for young people regarding risk behaviours. How faith based organizations are to be brought in to wider coalition based, programme responses is still a relatively unexplored area. To date there is no documented organisation of sets of partners with an explicit strategy to work or partner with faith based organizations to mitigate the impacts of AIDS on orphans. Indeed structured dialogue between donors, International Non-Government Organizations and faith based organizations is limited (Kinoti & Tawfik, 2002:18).

3.14.5 **Mobilising political will and the creation of frameworks for policy and programme implementation**

Most affected countries have been charged with a lack of political will and commitment. There have been concerted calls for the mobilisation of high level leadership as one of the critical elements in an expanded and effective response to the needs of orphans and children affected by AIDS. Concerted, active, high visibility advocacy in all arenas of involvement including the local, district, national and international is critical. Yet this commitment is sorely lacking. For

example in Malawi the AIDS Coordinating Committee Structure has been neglected by central government, even though the model is held up as a regional standard (Williamson & Donahue, 2001:38). At the International Conference on AIDS and Sexually Transmitted Diseases in Africa held in Lusaka in 1999, not one head of state attended.

The United Nation's Declaration of Commitment on HIV/AIDS of June 2001 acknowledges that while prevention of HIV infection must be central to responses to the epidemic, for these to be effective they must also address the care and support of people living with HIV (Bennell *et al*, 2002:61).

These responses also need to have a strong focus on children infected and affected by HIV/AIDS, especially those *indirectly* affected – as all too often the needs of these children are forgotten. The governments of the world have signed this commitment and are now accountable to its implementation. And we know what to do (Webb, 1996:128). There are a number of specific laws, policies and practices that are likely to contribute significantly to improving the lives of affected children. These include:

- policies and Laws to uphold the property rights of orphans and widows in case of the death of their husband and father;
- free primary school education including the waiver of school fees for orphans and other vulnerable children. This should include subsidising other school costs;
- recognition of community schools and related financial and technical support provision for their establishment and development;
- gender sensitive policies including the waiver of school uniforms for girls and the revision of policies that expel pregnant girls from school;
- elimination of violence against women (inheritance property grabbing has also been defined as violence against women);
- support and endorsement to community based care for orphans rather than institutions;

- promoting and supporting good governance within decentralization;
- provision of clean water, sanitation as well as more water points availability to reduce time spent by women collecting water;
- development of female economic empowerment programmes (credit and other micro-finance programmes);
- female literacy programmes;
- food security programmes;
- inter-cropping practices to reduce weeding time and the promotion of high yielding drought resistant crops that are less labour intensive;
- the promoting of natural pest management thus reducing expenses;
- the improvement of access to land, capital, draught power;
- well targeted health insurance, for example, pre-payment schemes for health services such as letting people pay in-kind after they harvest;
- the development of efficient stoves to reduce time women spend collecting firewood; and
- preventive health care to reduce morbidity and mortality (Mutagandura *et al.*, 1998:56; Hunter & Williamson, 2000:38; Phiri, 2001:19; WLSA, Malawi, 2001:29; Foster, 2001a:65; Loewenson & Whiteside, 2001:38).

Decentralisation is the dominant political process within which the response to orphans and children affected by AIDS is evolving. This could facilitate resource flow to the frontline as well as community empowerment. Full and prolonged 'engagement' is a necessary step. "(Engagement) blends good governance, participation, consensus building and indeed, stewardship" (Van Sant, 2000:127). Decentralisation is not enough when local officials are not accountable to the citizenry. Decentralisation should go beyond administrative and financial measures to include political power sharing, accountability, transparency and full-fledged participation by the citizenry and civil society. At the same time, autonomous local control will achieve more benefits than the mere assignment of figurative responsibility to local government while substantive programme and resource control remains with central government (Van Sant, 2000:28). Local

government is closer to the communities and will be better placed to work there, along with Non-Government Organizations (Nampanya-Serpell, 1998:65).

Communities will also have easier access to the decision and policy-making processes if they come closer to them. Strengthened local (district) government departments can coordinate activities of local organisations by monitoring and evaluating responses to support orphans (Nyambedha, Wandibba & Aagaard-Hansen, 2001:88). There is also the role of providing technical assistance, engaging in advocacy, implementing targeted income transfers, facilitating local economic growth, and leading poverty reduction programmes. Local government must involve the local citizenry in the design, implementation and evaluation of the responses to AIDS, ensuring that these are implemented by local organisations and that they are transparent and accountable (Webb & Paquette, 2000:94).

The primary constraint remains the disconnection between policies and the laws on the one hand and community participation, awareness and mobilisation on the other. There is also disconnection between policies and legal instruments and the perceptions, practices, knowledge, capacities, capabilities and resources of the population. This is one area that external change agents need to address urgently (Smart, 2000:67).

3.15 CONCLUSION

This chapter presented literature review findings on programmes and policy challenges necessary for designing or facilitating responses to the effects of the HIV/AIDS epidemic on children and adolescents affected by it. The literature review findings in this chapter highlighted that addressing the psychosocial well-being elements of HIV/AIDS orphans and children in HIV/AIDS affected communities through effective and related ecological and systemic programmes is now a matter of urgency. The cycle of infection and effects will always be

exacerbated by children and adolescents growing up in social contexts where mental ill-health as a result of HIV/AIDS is rife, combined with feelings of isolation, despair and social disenfranchisement. The social programmes required in response to the effects of HIV/AIDS on children and adolescents are not complex, but are needed at such an unprecedented social scale that communities are only starting to comprehend the implications. While constraints remain in the form of chronic and deepening poverty in communities, capacity limitations and political indifference at all levels, the challenges facing schools, families and communities have never been greater.

This chapter will form the basis of the recommendations that this research suggest in chapter six. The next chapter deals with the empirical research design which guided the qualitative research method that the researcher used in investigating the psychological well being of children and adolescents who formed the population sample of this study.

CHAPTER FOUR

RESEARCH DESIGN

4.1 INTRODUCTION

The purpose of chapter three is to outline the methodology that is applied to obtain and utilise information/data from both primary and secondary sources towards attainment of the aims (see 1.3) of the study.

This chapter therefore presents the reality about methodological aspects and procedures, which prevailed during the course of the study. Furthermore, the chapter covers the following aspects, the research design, which includes instrument, population and sample as well as the interpretation of data.

4.2 AIMS OF THE RESEARCH

The aim of any research design is to select or choose and utilise the methods and techniques that the researcher considers imperative to yield a better attainment of the aims and objectives of the study being conducted. There are numerous research methods in literature, which researchers employ for specific nature and kind of research to be undertaken (Bogdan & Bicklen, 1998:28). It is difficult to find one single research method being suitable for every type of research problem at all times. There are clusters of other factors that implicate the choice of research methods for any given research problem such as, the nature and dynamics of the problem being researched, costs and time (Creswell, 2003:28) to mention only a few. As such, it is mandatory that a specific research problem be solved through relevant research methodology (Denzin & Lincoln, 2005:27). For these reasons researchers have to consciously and purposefully select and utilise only those research methods that would permit better, convenient and successful attainment of specific research aims (Creswell,

2003:28). This study is not an exception and therefore the research method and techniques considered by the researchers to be relevant are utilised as presented in 3.3 to 3.7.

4.3 **QUALITATIVE RESEARCH**

The qualitative research that will be discussed below entails the aims of qualitative research and the focus group interviews.

4.3.1 **Aims of qualitative research**

Berg (2003:10), Creswell (2003:3) and Flick (1998:23) indicate that qualitative research is multi-method or mixed-method in nature and focus. It involves an interpretative naturalistic approach to its subject matter. By this statement it implies that qualitative researchers study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. This study therefore seeks primary data from learners who are directly involved with the subject matter in focus. The primary sources of data used in this study as stated in section 3.6 were learners affected by HIV/AIDS.

The six HIV/AIDS affected learners (see section 3.6) were interviewed in their natural settings and the data collected was described and interpreted with the following aims that this study endeavours to investigate, which are:

- the condition of the psychological well being of these learners;
- the scholastic performance of these learners;
- the nature and extent of support these learners get from their families, community and society;
- the condition of physical well being of these learners ; and
- the manner in which psychosocial support of these learners can be enhanced to strengthen their psychological well-being.

The research instruments utilised for the collection of data was the interview, which includes one focus group interview.

4.3.2 **Focus group interviews**

This research used the focus group interview method to empirically collect data from the participants.

4.3.2.1 **Purpose of the interviews**

According to Patton (2001:31), the term focus group interview is a qualitative technique, using discussion among a group of 4 – 12 people, in a comfortable, non-threatening environment, to explore topics, or obtain perceptions about a given problem or topic of interest. The technique makes use of group interaction, to provide insight and data, which is not accessible without the stimulus of the group discussion. Such an interview is conducted with the limited group of persons who have been brought together for the same and specific purpose.

The use of focus group interview (FGI) technique or method of research is suggested in literature by Edmunds (1999:34), Gillham (2000:25), Maxwell (2004:306). From these studies, the aims/purpose with focus group interviews are hereby formulated as follows:

- To collect data within limited time.
- To supplement data that was collected by means of questionnaires.
- Ideas, views and perceptions of participants are verified and synthesised through the discussions.
- Focus groups provide insights into the attitudes, perceptions and opinions of participants.
- To confine the role of the interviewer to that of initiating discussion rather than playing the directive role. In this way participants take major

responsibility for stating their views and drawing out the views of others in the group.

- The interactions among the participants stimulate them to state feelings, perceptions and beliefs that they would probably not express if interviewed individually (Denzin & Lincoln, 2005:18).

It was with the above in mind that the qualitative interview method of focus groups was opted for in this study.

4.3.2.2 **Aims of the interview**

The use of interviews in research has been recommended by different authorities in the field of qualitative empirical research, including in the works of Patton (2001:15) and DeMarrais and Lapan (2004:15).

The aim of the interviews was to obtain primary information from the subjects who were selected (see section 3.6 for discussion of the sampled population) to participate in the study. Due to the nature of the study, the researcher wanted to:

- ask numerous open-ended questions (Bogdan & Bicklen, 1998:24), or open-ended probes.
- record verbatim the answers given by the participants.
- accord participants opportunities to say what they think and to do so with great richness and spontaneity.
- generate or attain an improved response rate by interviewees and by so doing enhance the quality of the study. These aspects concur with the advantages of interview schedule stated by Kvale (1996:26).

Furthermore, the researcher wanted to gain first-hand-in-depth information from the participants on the items of the interview schedule (see Appendix A). Not only was the researcher interested in what the participants had to say, but also in how and why they said it. Such depth of involvement and observation was required to enable the researcher to form a holistic view/picture on the feelings

and desires of the participants, which were critical regarding the items of the interview schedule.

4.4 CONSTRUCTION AND DESCRIPTION OF THE INTERVIEW SCHEDULE

The instrument used in this study is an interview schedule (see Appendix A).
As stated in section (1.3), semi-structured interviews were conducted. To that effect the interview schedule was constructed as described below.

The interview schedule consisted of eight key questions (see Appendix A). The first question endeavoured to gather demographic information about the participants. The other seven questions were formulated strategically and specifically to address the five research questions posed in 1.1 leading to the attainment of the aims of the study stated in 1.2.

Table 4.1: **Interview items related to the first four aims (see 1.2) of this study**

Research aims	**Items in the interview schedule addressing each aim**
Research aim 1: To determine the condition of the psychological well being of learners affected by HIV/AIDS.	Interview items 5 & 6
Research aim 2: To determine how the scholastic performance of these learners is.	Interview item 2
Research aim 3: To investigate the nature and extent of support these learners get from their families,	Interview 3

community and society.	
Research aim 4: To investigate the condition of the physical well being of these learners is; and	Interview 4

All the interview items had structured followed-up questions. The interview items in the interview schedule were formulated from the literature review with a view to reach the aims of the research.

4.5 **POPULATION SAMPLE**

As stated in section 1.3.2.1, the study planned two focus group interviews of which only one materialised, that is, that of Sebokeng Township in the Vaal Triangle area of the Gauteng Province of South Africa. The other group, that is, that of Sharpeville Township in the same area and province did not attend in fear of being discriminated. The plan was to hold one focus group interview in the Sebokeng township and the other in the Sharpeville township of the Vaal Triangle area of Gauteng province. Each focus group interview was to consist of six interviewees. Only one focus group of interviewees materialised, which make it a total number of six persons (n=6). Of the six interviewed interviewees, one adolescent is an HIV/AIDS double orphan (who lost both parents), two adolescents had lost either a mother or a father through death caused by HIV/AIDS, and the other three adolescents' parents were infected with HIV/AIDS and were very ill.

The selection of the sample was based on the fact that the participants are directly psychologically and socially affected by HIV/AIDS in the sense that their biological parent/s or breadwinners are infected with HIV/AIDS, or one or both parents have died of this disease. Because of the sensitive nature of this research topic, the researcher had to work collaborately with the Social workers

who work with children and adolescents that are affected by HIV/AIDS. The Social worker gave the interviewer a list of names of children and adolescents affected or orphaned by HIV/AIDS in Sebokeng and Sharpeville townships of the Vaal Triangle area in the Gauteng Province. The researcher requested the Social worker to rank these children according to the intensity of their being affected, that is, those who are affected in the sense that they had parents who were suffering from HIV/AIDS or had parent (s) who died of AIDS. Two lists with names of children and adolescents from both Sebokeng and Sharpeville were given to the researcher. There was a list of twelve children and adolescents who are affected by HIV/AIDS in the sense that they had parents who were suffering from the disease and the other list had twelve children and adolescents whose parent (s) died of AIDS.

The purposive non-probability sample technique was used to select the first six names of children and adolescents affected and/or orphaned by HIV/AIDS from both Sebokeng and Sharpeville lists. Purposive sampling can be very useful for situations where the researcher needs to reach a targeted sample quickly and where sampling for proportionality is not the primary concern. With a purposive sample, the researcher is likely to get the opinions of his/her target population, but s/he is also likely to overweight subgroups his/her population that are more readily accessible (Marshall & Rossman, 1999:18).

The decision to use the purposive non-probability sample technique in this research was motivated by the nature of the study which required learners who have experienced intense effects of HIV/AIDS such as learners whose parents were gravely sick due to HIV/AIDS or had parent (s) who died of AIDS. The researcher felt that such a decision would add value to the quality and outcomes of the research.

4.6 **DATA ANALYSIS AND INTERPRETATION**

Data analysis consisted of three phases. Phase one included reading through transcripts to confirm their accuracy and listening to audio-taped interviews in order to (re)familiarise the researcher with the conversation with the participants. Phase two involved a process of identifying the meanings hidden within the discourse. Patton (2001:13) states that there are two contexts to quotations, namely:

- the interview from which it is taken; and
- the "pool of meanings" that arise from the discourse.

Merriam (1998:9) explains that the analysis phase of a research involves a process of comparison of data and the identification of patterns between instances and individuals that describe meaningful categories. In addition, interpretation of quotations throughout the analysis phase was based on the context of experience. Thus, quotations were highlighted from interview transcripts and discourse was interpreted within the scope of the meanings expressed by each participant across an entire interview.

The focus group interview was held simultaneously, the data was captured and presented *verbatim*. As such, data collected were therefore analysed and interpreted simultaneously. Discussion of the data was made by way of quoting *verbatim* the information given by the participants as presented in chapter 4.

Furthermore, data was organised questions by questions according to the question sequence on the interview schedule. For every question on the interview, the experiences of all six learners affected by HIV/AIDS were transcribed and audio-taped for the purpose of analysis and interpretation of data.

4.7 **CONCLUSION**

In this chapter, the design for the empirical research of this study was presented. The population sample, the qualitative research method which is in the form of both a focus group interview and individual interview, and methods of data analyses and interpretations were described. The next chapter presents data analyses and interpretation of the qualitative research method's responses of the participants who formed sample of this research.

CHAPTER 5

ANALYSES AND INTERPRETATION

5.1 INTRODUCTION

This chapter provides analyses and interpretation of the responses of the interviewees to the interview questions. All nine interviewees who participated in this research are directly affected by HIV/AIDS and are learners. Their personal experiences were investigated through the following aims:

- the condition of the psychological well being of these learners;
- into the scholastic performance of these learners;
- the nature and extent of support these learners get from their families, communities and societies;
- the physical well being of these learners is; and
- psychosocial support of these learners can be enhanced to strengthen their psychological well-being.

The *verbatim* transcripts of the interviews are placed first, followed by the analysis and interpretation of each item on the interview schedule (see 3.5).

5.2 PRESENTATION OF THE RESPONSES OF THE INTERVIEWEES

Focus group interviews were conducted as said in Chapter three and the responses to each question are grouped per item. The names used in this research are not their real names.

5.2.1 Interviews with Phindile, Ben, Ntshepise, Thato, Elizabeth and Len.

All interview responses for all items follow.

5.2.1.1 **Interview questions:** Scholastic performance

Interviewer	:	Are you enrolled in a school?
Phindile	:	Yes
Ben	:	Yes
Ntshepise	:	Yes
Thato	:	Yes
Elizabeth	:	Yes
Len	:	Yes

Interviewer	:	**In which grade are you?**
Phindile	:	In grade five
Ben	:	In grade eight
Ntshepise	:	In grade four
Thato	:	In grade seven
Elizabeth	:	In grade six
Len	:	In grade eight

Interviewer	:	**Do you have a school uniform?**
Phindile	:	No, I do not have black shoes, I wear brown ones. I also do not have a school jersey, my brother cannot afford to buy me one.
Ben	:	Yes.
Ntshepise	:	Yes.
Thato	:	No, I only have a white shirt, I wear it from Monday to Friday. It becomes difficult when we do not have powdered soap. I have to wear a dirty shirt.
Elizabeth	:	No, I borrow shirts and shoes from my friend. My friend's mother bought me a tunic and socks.
Len	:	No, I do not have a pair of black shoes, I have managed to

buy a shirt and a pair of grey trousers.

Interviewer : **Who provided you with a school uniform?**

Phindile : No one did.

Ben : I bought them with the profit I make.

Ntshepise : My aunt bought them.

Thato : No one has provided these things for me.

Elizabeth : No one did.

Len : No one.

Interviewer : **Do you have writing material at school?**

Phindile : Yes, they were provided by the school

Ben : Yes, they were provided by the school

Ntshepise : Yes, they were provided by the school

Thato : Yes, they were provided by the school

Elizabeth : Yes, they were provided by the school

Len : Yes, they were provided by the school

Interviewer : **Have you paid the school fees?**

Phindile : No, we do not have money, my mother is not employed.

Ben : No, My aunt promised to pay when she gets her bonus, but she had other problems that needed money and could therefore not pay.

Ntshepise : No, I do not pay school fund because I have been exempted from paying.

Thato : No, I do not have money to pay.

Elizabeth : No, I have been exempted from paying the school fund.

Len : No, I do not have money to pay for school fees.

Interviewer : **Do you attend regularly?**

Phindile : No, my attendance is irregular.

Ben : No, my attendance is irregular.

Ntshepise : No, my attendance is irregular.

Thato : No, my attendance is irregular.

Elizabeth : No, my attendance is irregular.

Len : No, my attendance is irregular.

Interviewer : **What has affected your attendance?**

Phindile : The health of my mother has affected my attendance.

Ben : The health of my father has affected my attendance.

Ntshepise : The health of mother has affected my attendance.

Thato : The health of stepmother and stepsister has affected my attendance.

Elizabeth ; My health has affected my attendance.

Len : My mother's health has affected my attendance.

Interviewer : **How has the health of your family member affected your attendance?**

Phindile : I have to be at home constantly because my mother is ill and there is no one who will take care of her. I sometimes have to accompany her to the hospital when she is weak. Sometimes I stay away from school to care for my little brother who is sick.

Ben : I have to take care of my father when he is very ill. My aunt is working so I have to take care of him.

Ntshepise : I sometimes stay at home so I can prepare food for her.

Thato : I have to cook, clean the house and accompany my sick stepmother or my sister to the hospital to get their treatment.

Elizabeth : My attendance is not affected by the health of other people because I do not care for anybody. I only care for myself because I am infected. My attendance is affected because I have to get to the hospital to get my

treatment. Sometimes I become very sick and can not attend on those days that I am sick.

Len : My attendance is affected by accompanying my mother to the hospital to get her treatment.

Interviewer : **When you miss school for any reason how do you spend your day?**

Phindile : I clean the house, cook and care for my mother and brother.

Ben : I sometimes go to the market to buy the stuff I have to sell.

Ntshepise : I cook and clean the house and read.

Thato : I clean, cook and study.

Elizabeth : I clean, cook and visit my friends who are not attending school or spend the day with my boyfriend.

Len : I help my mother with cleaning and cooking when she does not feel well.

Interviewer : **Have your marks changed since you/your parent was confronted by health problems.**

Phindile : Yes, my performance has dropped.

Ben : Yes, my performance has dropped.

Ntshepise : Yes, my performance has dropped.

Thato : Yes, my performance has dropped.

Elizabeth : Yes, my performance has dropped.

Len : Yes, my performance has dropped.

Interviewer : **What exactly has caused your marks to be low?**

Phindile : Poor school attendance, worries and lack of Concentration and my health.

Ben : Poor school attendance, worries and lack of concentration.

Ntshepise : Poor school attendance, worries

Thato : Poor school attendance, worries and lack of concentration.

Elizabeth	:	Poor school attendance, worries and lack of concentration.
Len	:	Poor school attendance, worries

Interviewer	**:**	**Has your attendance changed since you/your parent confronted serious health problems?**
Phindile	:	Yes, it has changed, It is worse.
Ben	:	Yes, it has changed, It is worse.
Ntshepise	:	Yes, it has changed, It is worse.
Thato	:	Yes, it has changed, It is worse.
Elizabeth	:	Yes, it has changed, It is worse.
Len	:	Yes, it has changed, It is worse.

Interviewer	**:**	**What kind of work do you do often at home?**
Phindile	:	Cooking and cleaning
Ben	:	Selling fruits
Ntshepise	:	Cooking.
Thato	:	Cooking and cleaning
Elizabeth	:	Cleaning and cooking as well as laundry,
Len	:	Doing laundry.

5.2.1.2 **Interview questions: Material wellbeing**

Interviewer	**:**	**Do you work for wages?**
Phindile	:	No, I do not work for wages.
Ben	:	I do not get paid, as the business is mine.
Ntshepise	:	No.
Thato	:	No.
Elizabeth	:	No.
Len	:	No, I sell vegetables I do not get paid I use profit to buy food at home.

Interviewer	:	**Do you sleep on a bed and a mattress?**
Phindile	:	No, I sleep on a mat on the floor.
Ben	:	Yes.
Ntshepise	:	Yes.
Thato	:	Yes.
Elizabeth	:	Yes.
Len	:	No, I sleep on an old sofa.

Interviewer	:	**What type of a mattress is it?**
Phindile	:	I sleep on the floor.
Ben	:	Foam mattress.
Ntshepise	:	sponge
Thato	:	Foam mattress.
Elizabeth	:	Foam mattress..
Len	:	I sleep on an old sofa.

Interviewer	:	**Do you sleep with a blanket.**
Phindile	:	Yes, I have two blankets.
Ben	:	Yes, I bought myself a blanket.
Ntshepise	:	Yes, we have blankets at home.
Thato	:	Yes, when my father was still working he bought us blankets.
Elizabeth	:	Yes, my friend's mother gave me two blankets to sleep with.
Len	;	Yes, I have two old blankets, I got them from my grandmother.

Interviewer	;	**Do you have a pair of shoes?**
Phindile	:	Yes.
Ben	:	Yes
Ntshepise	:	Yes
Thato	:	Yes

Elizabeth : Yes

Len : No

Interviewer : Who provided the shoes for you? :

Phindile : They are a gift from one of our neighbours.

Ben : I bought them with the profit I make.

Ntshepise : They were provided by my aunt.

Thato : My grandmother.

Elizabeth : My friend.

Len : No one.

Interviewer : Do you have clothes for church or visits?

Phindile : No, I do not have clothes for church or visits.

Ben : Yes, I have clothes for church or visits.

Ntshepise : Yes, I have clothes for church or visits.

Thato : No, I do not have clothes for church or visits.

Elizabeth : No, I do not have clothes for church or visits.

Len : No, I do not have clothes for church or visits.

Interviewer : Who provided you with the clothes?

Phindile : No one

Ben : I bought them with profit I make from selling.

Ntshepise : My aunt provided them.

Thato : No one provided.

Elizabeth : No one

Len : No one

5.2.1.3 Interview questions: Health and nutrition

Interviewer : In general how is your health?

Phindile : Good.

Ben	:	Good
Ntshepise	:	Not good, I have a boil in my armpits. I went to the clinic two months ago but I still feel the pain.
Thato	:	Not good, I always have headaches.
Elizabeth	:	Poor, I am always sick, I have headaches most of the time and I often cough.
Len	:	Good.

Interviewer	**:**	**Have you been sick in the last six months?**
Phindile	:	Yes, I had been sick.
Ben	:	Yes, I had been sick.
Ntshepise	:	Yes, I had been sick.
Thato	:	Yes, I had been sick.
Elizabeth	:	Yes, I had been sick.
Len	:	Yes, I had been sick.

Interviewer	**:**	**What were you suffering from?**
Phindile	:	I was suffering from headaches.
Ben	:	Stress.
Ntshepise	:	measles, cold and I had some sores.
Thato	:	I had flue that lasted for three weeks. I could not go to school for two weeks.
Elizabeth	:	I had diarrhoea and I sweated a lot.
Len	:	Stress.

Interviewer	**:**	**When you are sick where do you go for treatment?**
Phindile	:	Government hospital.
Ben	:	Local clinic.
Ntshepise	:	Government hospital or clinic.
Thato	:	Local clinic
Elizabeth	:	Government hospital.

Len : Government hospital.

Interviewer : Who provide meals for you?

Phindile : My brother who works temporarily and is at school and our neighbours sometimes provides.

Ben : My aunt, sometimes I do.

Ntshepise : We receive food parcels from the support group.

Thato : My paternal grandmother.

Elizabeth : My friend's mother.

Len : I provide for the family no one does.

Interviewer : What do you eat every day?

Phindile : Porridge and vegetables.

Ben : Porridge and vegetables.

Ntshepise : Porridge and vegetables.

Thato : Porridge and vegetables.

Elizabeth : Porridge and vegetables.

Len ; Porridge and vegetables.

Interviewer : Which meals do you afford to eat everyday?

Phindile : Supper

Ben : Lunch and supper.

Ntshepise : Breakfast, lunch and supper.

Thato : Supper.

Elizabeth : Supper.

Len : Supper.

Interviewer : Are you given food like fruits or tea or snacks in between meals

Phindile : No.

Ben : No.

Ntshepise : Yes.
Thato : No.
Elizabeth : No.
Len : No.

Interviewer : What common foods do you eat everyday?
Phindile : Porridge and vegetables or tea.
Ben : Porridge and vegetables
Ntshepise : Porridge and vegetables.
Thato : Porridge and vegetables
Elizabeth : Porridge and vegetables.
Len ; Porridge and vegetables.

Interviewer : Do you always have lunch on school days
Phindile : No
Ben : Yes.
Ntshepise : Yes.
Thato : No
Elizabeth : No
Len : No.

Interview : Do you share your plate?
Phindile : Yes
Ben : No
Ntshepise : No
Thato : No
Elizabeth : No
Len : No.

Interviewer : How often do you eat meat?

Phindile	:	A few times a month.
Ben	:	A few times a month.
Ntshepise	:	A few times a week.
Thato	:	A few times a month.
Elizabeth	:	A few times a month.
Len	:	A few times a month.

Interviewer	:	**Who prepares food for you?**
Phindile	:	I prepare them myself.
Ben	:	My aunt prepares them.
Ntshepise	:	I prepare them myself.
Thato	:	I prepare them myself.
Elizabeth	:	My friend and her mother.
Len	:	My mother sometimes prepares them, when she is sick I prepare them myself

Interviewer	:	**How often do you drink milk?**
Phindile	:	Seldom.
Ben	:	about thrice a week.
Ntshepise	:	A few times a week.
Thato	:	Seldom.
Elizabeth	:	A few times a month.
Len	:	Seldom.

Interviewer	:	**Are there days when you do not have enough to eat?**
Phindile	:	Yes
Ben	:	Yes
Ntshepise	:	Yes
Thato	:	Yes
Elizabeth	:	Yes
Len	:	Yes

Interviewer : **Are there special reasons why you do not have enough food to eat?**

Phindile : Financial problems.

Ben : Financial problems.

Ntshepise : Financial problems and usually when the food parcels were not delivered on time..

Thato : Financial problems.

Elizabeth : Financial problems.

Len : Financial problems.

Interviewer : **May I see your vaccination card?**

Phindile : I do not have one.

The other five produced their cards and they had the correct updated information.

5.2.1.4 **Interview questions: Psychological issues**

Interviewer : **How happy are you, compared to other children?**

Phindile : Very unhappy, sometimes I am sad or depressed.

Ben : Very unhappy

Ntshepise : Very unhappy

Thato : : Very unhappy

Elizabeth : Very unhappy

Len : Unhappy.

Interviewer : **What will or can make you happy?**

Phindile : If my family members can recover.

Ben : Health recovery of my sick family member.

Ntshepise : Health recovery of my sick family member.

Thato : Health recovery of my sick family member.

Elizabeth : If I can regain my health.

Len : If I can get a job and the improvement of my mother's health.

Interviewer : What do you do for fun?

Phindile : Watching television.

Ben : Playing football.

Ntshepise : Reading.

Thato : Reading.

Elizabeth : Watching television and reading.

Len : Playing chess.

Interviewer : What makes you sad?

Phindile : Seeing my mother so sick.

Ben : Seeing my father so sick.

Ntshepise : when I am ill or my mother is.

Thato : Seeing my family members so sick.

Elizabeth : The fact that I am now HIV- positive but I was not misbehaving.

Interviewer : With whom do you spend most of your time?

Phindile : I spend most of my time with my family.

Ben : My aunt.

Ntshepise : My mother.

Thato : My grandmother.

Elizabeth : My friend.

Len : My father.

Interviewer : Who do you talk to when you have a problem?

Phindile : I try to talk to my mother when I have a problem but it doesn't help as there is nothing she can do. There is no point in talking to her.

Ben : My aunt, I stay with her, it is easy for me to tell her whatever bothers me.

Ntshepise : I do not tell anyone about my problems. My mother is always sick and I think she has her own problems to think about.

Thato : I only share my problems with my grandmother when she visits us. Most of the time I keep them to myself.

Elizabeth : My friend, I think I am lucky to have a friend who supports and understand me. I am able to tell her everything.

Len : I do not share my problems with anyone.

Interviewer : Do you like going to school?

Phindile : No, I do not like going to school.

Ben : Yes.

Nthepise : Yes.

Thato : Yes.

Elizabeth ; Yes.

Len : Yes.

Interviewer : How do you get along with other children?

Phindile : Somehow well.

Ben : Well.

Ntshepise : I get well with other children.

Thato : Well.

Elizabeth : Well.

Len : Well.

Interviewer : How do you get along with your sibling?

Phindile : Well.

Ben : Well.

Ntshepise : Well.

Thato : Well.

Elizabeth : Well.

Len : Well.

Interviewer : How has the health of your family member affected your emotions?

Phindile : I become easily angered.

Ben : I feel frustrated.

Nthepise : I feel frustrated and worried.

Thato : I am sad more often that I used to in the past.

Elizabeth : I am angry mot of the time.

Len : I prefer to be alone as I am frustrated most of the time.

Interviewer : How has the health of your sick family member affected your personality.

Phindile : I am quieter than I used to be.

Ben : I prefer to be alone more than before.

Ntshepise : I no longer play as much as I used to.

Thato : I am not as happy as I was before.

Elizabeth ; I am withdrawn.

Len : I now prefer my own company more than before.

5.2.1.5 **Interview questions: Emotional well being**

Interviewer : Do you cry a lot over small things or over nothing during the course of the day?

Phindile : Yes, I sometimes cry a lot over small things and over nothing.

Ben : Yes, I sometimes do.

Ntshepise : Yes, a lot.

Thato : I often do.

Elizabeth : most often I cry over nothing.

Len	;	No. I do not.

Interviewer:	**What exactly makes you to cry?**
Phindile:	If I do not get what I want I cry, it makes me feel better.
Ben:	I just cry whenever I feel sad.
Ntshepiseng:	When I cry people start taking me serious.
Thato:	I cry to get what I want
Elizabeth:	Most of the time it is frustration, when things do not go my way I become frustrated and cry.

Interviewer	:	**Do you have scary dreams and nightmares?**
.Phindile	:	Yes.
Ben	:	No.
Ntshepiseng	:	Yes.
Thato	:	Yes.
Elizabeth	:	Yes.
Len	:	No.

Interviewer	:	**How often do you have scary dreams or nightmares?**
Phindile	:	Often.
Ben	:	I do not have scary dreams or nightmares.
Ntshepise	:	Often.
Thato	:	Often.
Elizabeth	:	Often.
Len	:	I do not have scary dreams or nightmares.

Interviewer	:	**How frequently are you sad?**
Phindile	:	Often.
Ben	:	Often.
Ntshepise	:	Sometimes.
Thato	:	Often.

Elizabeth : Often.

Len : Often.

Interviewer : **Why do you become sad?**

Phindile : When I think about my mother, I do not know what would happen to me if something can happen to her.

Ben : It is difficult for me, I do not have time to play with other children at home, my father is very sick, I have to take care of him. If something can happen to him I will only be left with my aunt.

Ntshepise : I only become sad when I think about my mother who at the moment is very sick.

Thato : The health of my stepmother and my stepsister affects me, we do not have time to think about anything else except for their health. There is never a time where we just sit and chat like a family, if it not my stepsister it is my stepmother who is very sick.

Elizabeth : The life I live makes me sad. I am infected with HIV/AIDS, I have to be absent from school more oftenly when I am sick. I have seen how people who are infected with HIV/AIDS are especially in the late stages of the disease. I become sad when I think about my own health and my future.

Len : I cannot enjoy life like other kids, my mother is sick. I am worried about her, if only I had an elder brother or sister things would have been different. It is like I am carrying this burden, I feel sadder when I cannot help my mother just to ease the pain. She is in so much pain sometimes that I stay awake the whole night just to make sure she doesn't die.

Interviewer : **Do you fight with other children?**

Phindile : On rare occasions, it only happens when I get tired of them

teasing me about my torn school uniform. I become angry and fight with them.

Ben : No, this is because I do not play with them oftenly.

Ntshepise : No, it's better to let them tease me; I do not want to fight.

Thato : No, they sometimes start up a fight but I just keep quite, there is nothing I can do they are stronger than I am.

Elizabeth : Yes, I can't handle it when they start talking behind my back about me. No one is going to fight for me I must protect myself. I do not respond sometimes when I feel weak because I know they will take advantage of that.

Len : No, there is no point they are stronger they usually overpower me, so I decide to keep quite and let it go.

Interviewer : **Do you maybe prefer to play alone?**

Phindile : Yes, I do, it is difficult to play with people who will always mock you because of your torn clothes. There is nothing I can do to have a full school uniform; things maybe will be better if my mother can recover.

Ben : Yes, sometimes. I just feel I am not like other learners at school. They are always laughing, joking and seem to be enjoying life. It is difficult for me, sometimes I do not even feel like playing. If maybe there were kids that are experiencing the same problems as I do, I would play with them. They would understand me better.

Ntshepise : Yes, kids at my school are not very friendly. They always talk about how hungry I am, and that they do not want to play with people whose parents are dying of HIV/AIDS. They say that I also have AIDS and if they play with me they will contract it.

Thato : Yes, often. I just do not like playing with other kids. I play

alone at school and at home. They always boast about what their parents have bought them. I will never have those things, so instead of listening to them brag about these things I just play alone.

Elizabeth : What's the point of playing with other children who do not want to play with you? If I come nearer them to play they move to another spot, so instead of following them around I just play alone.

Len : I do not feel free playing with other kids in our school, they always tell me that I am poor, I want to play with them because I want their food. They also like asking me what I am going to do when my mother dies.

Interviewer : **Do you at times refuse to go to school?**

Phindile : Yes, I sometimes do, I am absent from school most of the time, I therefore get used to it.

Ben : No.

Ntshepise : No.

Thato : No.

Elizabeth : Yes, sometimes, there is no point I am always sick. I do not think I will attend school for long. I sometimes become tired in class and lack concentration, a situation which makes my performance to be below average.

Len : No.

Interviewer : **Are you stubborn or disobedient at school?**

Phindile : I am never stubborn or disobedient at school.

Ben : I am never stubborn or disobedient at school.

Ntshepise : I am never stubborn or disobedient at school.

Thato : I am never stubborn or disobedient at school.

Elizabeth : I am never stubborn or disobedient at school.

Len : I am never stubborn or disobedient at school.

Interviewer : **Are you disobedient or stubborn at home?**
Phindile : I am never stubborn or disobedient at home.
Ben : I am never stubborn or disobedient at home.
Ntshepise : I am never stubborn or disobedient at home.
Thato : I am never stubborn or disobedient at home.
Elizabeth : I am never stubborn or disobedient at home.
Len : I am never stubborn or disobedient at home.

Interviewer : **Do you bully or attack other children?**
Phindile : I never bully or attack other children.
Ben : I never bully or attack other children.
Ntshepise : I never bully or attack other children.
Thato : I never bully or attack other children.
Elizabeth : I never bully or attack other children.
Len : I never bully or attack other children.

Interviewer : **Do you worry?**
Phindile : Yes, I often worry about what would become of me when my mother dies.
Ben : Yes, I often do, after matric I am not sure if I am going to be able to pay for my fees. My future guardian is a domestic worker she cannot afford to pay for my tertiary education.
Ntshepise : Yes, although my aunt promised to take care of me, I do not want to lose my mother. I wish she could recover. I become worried when she becomes very sick.
Thato : Yes, I often do, sometimes both my stepsister and stepmother would be very sick at the same time. These are the most difficult tirnes for me. At school I always think of how they will be when I reach home.

Elizabeth : Yes, most of the time. I worry about my health and my future. I do not stay with my parents, I stay at my friend's place. I was raped by my uncle and then became infected with HIV/AIDS. My parents never asked my uncle why he raped me. They do not care about me. I cannot go back and stay with them. I feel like I am a burden to my friend and her mother.

Len : Yes, I often do, my father passed away. I am worried what will become of me if something can happen to my mother. It is difficult for me as we can only have food when I have sold vegetables. I have to make sure that I sell, if I haven't sold anything that day we sleep without food. This worries me as my mother will die of hunger.

Interviewer : Do you refuse to eat at meal time?

Phindile : Never.

Ben : Yes, but seldom. This only happens when I am worried.

Ntshepise : No.

Thato : Yes, but seldom, I refuse to eat when I am tired of having the same meal everyday.

Elizabeth : Yes, often. I usually do not have appetite this makes it difficult for me to eat.

Len : No.

Interviewer : How often do you refuse to eat?

Phindile : Never.

Ben : Seldom.

Ntshepise : Seldom.

Thato : Seldom.

Elizabeth : Often.

Len : Seldom.

Interviewer : **Do you become afraid of new situations or changes?**

Phindile : Sometimes, I become afraid of situations and change.

Ben : Sometimes, I do not know if we are going to get along with my aunt and cousins after my father has passed away.

Ntshepise : Yes, but not often, although I know my aunt and cousins very well, I am not sure how things are going to be when I have to stay with them. I will have to attend school nearer to their place.

Thato : I seldom do, if anything can happen to both my stepsister and stepmother I have to stay with my grandmother. This means staying with my uncle and aunt and their children. At home it's only the three of us while at my grandmother's house there are about ten people staying under the same roof.

Elizabeth : Yes, I often do, I wish I could stay at my friend's place forever, I have been moving from one place to the other. I want to just settle down. I do not think I can be able to stay with my parents. Their way of life is totally different from my friend's and her mom's.

Len : Sometimes, I have four siblings I have to move with to my grandmother's place. I feel I still have to take care of them there. Things are going to be different. I am used to taking decisions on how things should be as I am the eldest; I do not know if my granny is going to allow me to do so.

Interviewer : **Do you become very angry?**

Phindile : I often become angry when other children talk badly about my mother's health. They sometimes tell me that I am not supposed to play with them as they will become infected with HIV/AIDS.

Ben ; Yes, at times, I am still very angry at my mother. I cannot

understand why she decided to commit suicide living us with a lot of problems.

Ntshepise ; No.

Thato : No.

Elizabeth : Yes, I often do, I would not have been HIV/AIDS positive if my uncle didn't rape me. I am not only angry at him for raping me but also at my parents for not reporting the case to the police.

Len : No.

Interviewer : Do you have trouble falling asleep?

Phindile : Yes, I often have trouble falling asleep, I am worried about my mother's health, I always think about her.

Ben : Yes, I have trouble falling asleep, I always think about my future.

Ntshepise : Yes, I often have trouble falling asleep; I have to wake up at night for my mother's medication. She sometimes snores, and then I become worried as to what is happening.

Thato : Yes, I often have trouble falling asleep, I wake up more often during the night to check if either my stepmother or stepsister is still alive.

Elizabeth : Yes, I often have trouble falling asleep, especially when I am sick. I sometimes think that if I sleep I will die on my sleep.

Len : Yes, I often have trouble falling asleep, I am always worried about my family. I feel I should be doing more for them, but what can I do?

Interviewer : Do you have problems making friends?

Phindile : Sometimes, I feel that I am not like them, they have everything, school uniform and nice clothes. If I can make friends with them what am I going to wear?

Ben ; I feel I will not be accepted by other learners, so I do not bother making friends with them.

Ntshepise : Sometimes, I feel that other learners know about my life, if I make friends with them, they will visit my place and I would feel embarrassed.

Thato : Sometimes, I do not want other kids to know how we live, if I make friends with them they will visit.

Elizabeth : Often, other children just look at me and move away, even if I want to make friends with them it becomes difficult. I cannot be able to tell them that I am HIV/AIDS positive although they seem to suspect it. It is better to keep the only friend I have, she accepts me as I am maybe others won't.

Len : Sometimes, I won't have time to hang around with friends, I have to sell after school and on weekends.

Interviewer : Do you wet the bed?

Phindile : No.

Ben : No.

Ntshepise : No.

Thato : No.

Elizabeth : No.

Len : No.

Interviewer : Have you ever run away from home?

Phindile : Never.

Ben : Never.

Ntshepise : Never.

Thato : Never.

Elizabeth : Never.

Len : Never.

5.2.1.6 **Interview questions: Plans for the future**

Interviewer	:	**Is there someone who will care for you in future?**
Phindile	:	Yes, my brother
Ben	:	Yes, my aunt
Ntshepise	:	Yes, my aunt
Thato	:	Yes, my grandmother
Elizabeth	:	Yes, my friend's mother
Len	:	Yes, my grandmother

Interviewer	:	**How often do you see your future guardian?**
Phindile	:	I see him everyday, we stay together.
Ben	:	I see her everyday, I stay with her and my cousins.
Ntshepise	:	I see her on weekends and month-ends. She visits us especially when my mother is very sick. She cannot visit us every week because she is working and has children.
Thato	:	I see my grandmother every weekend, she makes it a point that she visits us. She brings us food especially month-end.
Elizabeth	:	I see her everyday as I stay with her.
Len	:	I rarely see my grandmother as I am always busy selling. Even when my grandmother has visited us I see her late in the evening.

Interviewee	:	**How long have you known this person, who is your future guardian?**
Phindile	:	I have known my brother since birth, I can say I know him very well.
Ben	;	Since birth, I know her very well.
Ntshepise	:	Since birth, I know her very well.
Thato	:	Since birth, I know her very well.
Elizabeth	;	This is the second year that I have known her. I do not know

her well.

Len : Since birth, I know her very well.

Interviewer : How well do you like him/her?

Phindile : I like him very much.

Ben : I like her somehow.

Ntshepise : I like her very well.

Thato : I like her very much.

Elizabeth : I like her very well.

Len : I like her very well.

Interviewer : Has this person promised to care for you in future?

Phindile : No, he hasn't, I know he will because he is the one who is taking care of us.

Ben : Yes, my aunt always comforts me telling me that everything will be fine. She tells me that she is going to take care of me.

Ntshepise : Yes, she has, she told me this when my mother was very ill.

Thato : Yes, my grandmother she assured us all that she will take care of us after the burial of my father.

Elizabeth : No, but I hope that she will take care of me. She treats me very well, far better than my biological parents.

Len : Yes, my grandmother assured my mother that she should not worry, she will take care of us.

Interviewer : How did you respond when s/he told you that s/he will take care of you?

Phindile : He has not as yet informed me.

Ben : I felt slightly relieved.

Ntshepise : I felt very happy.

Thato : Relieved.

Elizabeth : She has not told me.

Len : I felt relieved.

Interviewer : Would you feel comfortable to discuss your problems with your future guardian?

Phindile : Yes, we are very close with my brother.

Ben : Yes, I think so.

Ntshepise : Yes.

Thato : Yes.

Elizabeth : Yes, we usually talk about a lot of things, I trust.

Len : Somehow, yes.

5.2.1.6 **Interview questions: Stigma and discrimination**

Interviewer : Have you been treated badly or differently because of the health of your sick family member?

Phindile : Yes, I had been treated differently. Other children like to tease me about my mother's health. They even go to an extent of saying the whole family is infected.

Ben : No.

Ntshepise : Yes, our neighbours are not very friendly, they do not want me to play with their children. I can't even share food with them, as they were told not to accept any food from me.

Thato : Yes, other relatives never pay us a visit, they say they do not want to be associated with people who are dying of AIDS.

Elizabeth : Yes, by my parents, after I was raped they didn't want anything to do with me. I was staying with them but living like an outcast. It was as if I deserved to be raped.

Len : No.

Interviewer : Have you ever been sexually abused

Phindile : No, but rape was attempted.

Ben : No.

Ntshepise : No.

Thato : No.

Elizabeth ; Yes, I was raped by my uncle.

Len : No.

Interviewer : Have you ever been emotionally abused?

Phindile : Yes.

Ben : Yes.

Ntshepiseng : No.

Thato : Yes.

Elizabeth : Yes.

Len : No.

Interviewer : Have you ever been verbally abused?

Phindile : Yes.

Ben : Yes.

Ntshepise : No.

Thato : Yes.

Elizabeth ; Yes.

Len ; No.

Interviewer : Who verbally or emotionally abused you?

Phindile : Other children.

Ben : My aunt's child.

Ntshepise : No one.

Thato : Our neighbour' child.

Elizabeth : My paternal grandmother.

Len : No one. :

Interviewer ; Have you ever been physically abused? :

Phindile	:	No.
Ben	:	No.
Ntshepise	:	No.
Thato	:	No.
Elizabeth	:	Yes.
Len	:	No.

The interviewer thanked all the learners who participated in the interview for both their time and revealing their experiences. These responses will be analysed and interpreted below.

5.3 **INDIVIDUAL INTERVIEWS**

The interviewer conducted individual interviews with three learners who are affected with HIV/AIDS. The *verbatim* interviews of the three participants which are Thuli, Kagiso and Meropa follow below.

5.3.1 **Interview with Thuli, Kagiso and Meropa**

Interviewer	:	How old are you?
Thuli	:	I am fourteen years old. Kagiso is twelve years old.
Interviewer	:	What grade are you both doing at school?
Thuli	:	I am in grade eight and Kagiso is in grade six.
Interviewer	:	I know you lost both of your parents. Do you know what caused their death?
Thuli	:	Yes, we knew before they actually died that they were dying from HIV/AIDS disease.
Interviewer	:	How did you find out? Did your parents tell you?
Thuli	:	No, our parents kept on saying that they were suffering

from Tuberculoses (TB) as they were both coughing. It is our grandmother who told us that they were infected.

Interviewer : How did your grandmother know?

Thuli : We have no idea

Interviewer : Did you ask your parents after finding out about their sickness?

Thuli : No, we could not ask my parents that, we were afraid, they would say we know too much.

Interviewer : Did you know anything about HIV/AIDS?

Thuli : That is why I say we were scared because we knew the lessons that we received from school that, if HIV/AIDS is not handled well, infected people can die.

Interviewer : Is it your educator who taught you about the HIV/AIDS pandemic?

Thuli : Much knowledge we received from the school is from nurses who visited our school as well as from a group called Khanya/Lesedi, which also educates us about HIV/AIDS infected people who end up being alone because people are scared of them.

Interviewer : What is the most important lesson you learnt from the group in the play?

Thuli : It was about loving the infected people and treating them normally, because HIV/AIDS can be spread through sex and by coming into contact with blood on an open wound and not by otherwise like hugging, kissing or using the same toilet or utensils.

Interviewer : How did you feel after knowing that your parents were HIV/AIDS infected?

Thuli : I was hurt, bitter and shocked at the same time. I always had people talking about HIV/AIDS, I never thought a member of my family could suffer from it.

Interviewer : Did you also feel isolated by other children in the neighbourhood?

Thuli : Yes, we began to understand the people around us, their actions, and their coldness. We immediately felt alone, and we cried most of the time. If we go out to play with other children they would move away to another spot. Fortunately this was not the case with learners at school as they did not know our situation.

Interviewer : What did your parents say when they noticed that obviously you must know something?

Thuli : I do not think that they noticed us as having some knowledge about their status because; our eldest sister, Meropa, encouraged us to pretend that we do not know. Even if they were suspecting that we should know they kept quiet.

Interviewer : How did you manage not to show your grievance or depression to your parents?

Thuli : It was very hard and our mother seemed to feel our sorrow as she kept on saying we should keep together as a family and respect our elder sister, things will be fine.

Interviewer : Which of your parents died first?

Thuli : My father, although he was stronger than our mother, died first, and at the time my mother was bedridden at Sebokeng Hospital.

Interviewer : When this happened, were you at home and with whom?

Thuli : We were all by ourselves, my sister was trying to feed him, but he coughed terribly and vomited.

Interviewer : What did you then do?

Thuli : My sister asked us to call our neighbour, aunt Lerato, while she was trying to pick up our father who had fallen off the bed.

Interviewer : Did Aunt Lerato come, and what happened?

Thuli : Yes, she came and asked us to go and sleep at her house while she first asked our sister Meropa to call a few neighbours and we sensed that our father was no more. We cried quietly.

Interviewer : How did you feel during this period, your father dying and your mother seriously ill in hospital?

Thuli : It was the most depressing moment of our lives. We could not attend school regularly as we had to be there for funeral arrangements. Even when we had to go to school it was difficult to concentrate as we were worried about our mother. We always asked each other what was going to happen to us if she dies.

Interviewer : Was your mother able to attend the funeral?

Thuli : No, she was frail and could not attend the funeral, she died as well a month later – she died in Sebokeng Hospital.

Interviewer : Kagiso, you have been quiet can you tell me who catered for your needs as children after the funeral?

Kagiso : It was very tough, our relatives could not stay with us. They told us to go to Tshepiso.

Interviewer : Why?

Kagiso : They said they could not afford to support us.

Interviewer : Why were you sent to Tshepiso?

Thuli : Before dying, our parents had acquired one of these Reconstruction Developmental Programmes (RDP) houses.

Interviewer : You say your relatives chased you out to go to Tshepiso, whom are you referring to?

Kagiso : Our grandparents, aunts and uncles, and our cousins were also indifferent to us.

Interviewer : In this situation - who provided you with food?

Kagiso : At Moedi Primary school where the three of us were learners, before Meropa and Thuli went to the secondary school where Thuli is now, we were put on the school nutrition programme. We at least could have a meal, and if there were left-overs they would give them to us.

Interviewer : How did the educators know of your plight?

Kagiso : Apparently, before our mother was seriously ill, she had informed the school of our situation so that we could be exempted from paying the school fees as there was no one working. She did not tell them about their status but just about the fact that they are very ill, they are both not working and they cannot afford to pay school fees or buy us uniforms.

Interviewer : So you had some food at Moedi Primary school, and who helped you with dinner and breakfast?

Kagiso : Educators gave us some bread to take home, but it was difficult during weekends at times, we could not eat for the whole day.

Interviewer : Is there no one who tried to give you emotional and financial support during this period?

Kagiso : There was no one to talk to and as a result my sister Meropa had to drop- out of school to go and seek piece jobs like ironing for the white employers in suburbs such as Vanderbijlpark, Vereeniging and Three rivers .

Interviewer : How old were you Meropa, when you dropped out of school?

Meropa : I am the eldest in the family, I was only 14 years of age when I decided to drop out of school. It was difficult, we had nothing to eat and my younger brother Kagiso was very ill, I could not afford to take him to a doctor and at the clinic they are out of medicine most of the time. We could not rely on food left-overs from school forever. When I asked the neighbours for food they

would tell me that they have only enough for their children, I must go and work.

Interviewer : Are you still doing piece jobs to support your brother and sister?

Meropa : No, I found myself a boyfriend that now supports us financially. In fact this is what girls in our neighbourhood do, you cannot just work, but you have to have someone to support me. It was the happiest time of my life, having someone who loves and supports me. We were all happy to have Tshepo working for us. At least we could have food on the table every evening like all the other households in our neighbourhood.

Interviewer : At what age did you get the boyfriend?

Meropa : If we had means I would have just celebrated my fifteenth birthday. I would be still at school doing grade ten.

Interviewer : How old is the boyfriend? Is he of the same age maybe?

Meropa : No, Tshepo is older than me. He was 26 years old when we first met. This did not bother me at all as we needed some one older to protect us as well. I also liked the fact that he was matured, he knew a lot of things I did not know. It was as if he was our father.

Interviewer : Is Tshepo, your boyfriend still working?

Meropa : Yes, he has a good job, his mother also helps us with clothes sometimes.

Interviewer	:	Kagiso, after all this development, do you still regard yourselves as people who are in poverty?
Kagiso	:	Much as Tshepo and his mother are helping, there are also dark days.
Interviewer	:	What do you mean?
Kagiso	:	We would like to be like other children, have birthdays, eat what we like, have a fridge and have ordinary cold water in summer.
Interviewer	:	Thuli, tell me about the government social support grant, did you apply for it?
Thuli	:	Our sister, Meropa has been trying to apply for it for sometime now, but in vain, maybe they do not take her seriously because she is a child herself.
Interviewer	:	Meropa, how old are you now?
Meropa	:	I am 21 years old now.
Interviewer	:	Is there no one who has helped you with the application of the government grant?
Meropa	:	No one. We hear people talking about social workers but we do not know where their offices are. I do not have an ID document - my boyfriend promised to help me apply for it but he has not done that yet.
Interviewer	:	What about your relatives?
Thuli	:	No one is interested to know how we survive.
Interviewer	:	Do they visit you to give you social support?

Thuli : They never visit us, but we visit them sometimes. We are still angry at them. We feel that they should have accommodated us until we were older and able to stay on our own.

Interviewer : What do you think is the reason for this neglect?

Thuli : Kagiso has been sickly even before our parents died. So we think that they fear he might be HIV/AIDS positive as well. People do not want to live with those that are infected. They think they might also be infected.

Interviewer : Why do you think like that?

Thuli : When we visit them, they treat him very coldly. They isolate him. Even their children do not want to play with him.

Interviewer : Kagiso, let me refer this question directly to you. How do you feel about this kind of treatment that you receive from your relatives?

Kagiso : It used to depress me more than I can say. They called me names because of my body. They called me "*Mokoto*".

Interviewer : Do you know the meaning of that name "*Mokoto*", what does it mean?

Kagiso : That is usually a name given to a very thin dying dog.

Interviewer : How is this affecting you now?

Kagiso : I have learnt to accept things as they are, I cannot change them, only I am grateful for the two sisters that I have, they are very supportive.

Interviewer : Now, about your health. Are you seeing any doctor or visiting the clinic?

Kagiso : I am not HIV/AIDS infected, I tested negative last month. If it was this disease I would be long dead. But because people see that I am underweight they think that I have AIDS. I know I am thinner and shorter than children of my age, this is due to the fact that I am under-nourished. That is what was said at the clinic. My parents could not afford to buy us vegetables we were satisfied to have only mealie-meal porridge as a meal.

Interviewer : Did the doctor tell you what the problem with your health is?

Kagiso : The simple explanation is that when I was very young I could not get nutritious food, because my parents were not working. I did not have warm clothes like other children. So, I was forever coughing and had diarrhoea because there was no proper healthy food for me.

Interviewer : How is your health presently?

Kagiso : I have improved, but in winter I still cough a lot.

Interviewer : How do you find your neighbours here in Tshepiso?

Thuli : When we first arrived in Tshepiso the neighbours were very cold towards us. Other children would not play with us.

Interviewer : Is the situation better now, or is it still the same?

Thuli : I think the situation has improved. One day I had to fight with one boy who kept on nicknaming Kagiso, '*Mokoto*'. That is why I have this scar. Since that day, we seemed to have gained some form of respect.

Interviewer : Are you saying the way they used to treat you changed?

Thuli : Yes, it is not like before. At times even their parents are helpful when we are open to danger. One day heavy rain flooded our house and they helped us with dry blankets and treated us well.

Interviewer : Now, let us talk about school. How are you coping? Is there any learning support?

Thuli : I think we are not doing well at all. I am still doing Grade eight. Children of my age are doing Grade nine. I am a year behind as I failed Grade eight. We are not coping at all, we are derided in class. Whenever I try to participate in a group activity, other learners just laugh at what I say. I feel we are not like the rest of the learners as we cannot afford to have a proper school uniform. No one knows of our situation, because we are staying in a house on our own. One other problem is that we stay too far from school, which makes it difficult for us to arrive early for classes. We always

miss out on the first two periods every day. Meropa cannot afford to give us money for a taxi.

Kagiso : What worries me is that we cannot even participate in extracurricular activities because of the distance we have to walk back home. I love soccer, but I cannot play it at school. I cannot afford to buy soccer boots.

Interviewer : Where do you get the courage to keep up a pleasant face?

Thuli : Our sister Meropa motivates us to be serious about school and at least to pass Grade 12. So we do not want to disappoint her.

Interviewer : Why?

Thuli : Meropa, has been the only person that has been taking care of us during our darkest days. She left school to find work for us.

Interviewer : Meropa, as a child herself is trying to play a parental role. Do you respect her for that?

Thuli : Yes, we respect her, but like any other family, we do fight with her, and that does not mean that we do not respect her.

Kagiso : But Meropa at times, she is too strict, when I come back home late like other boys, she reprimands me, as if she is my mother.

Interviewer : In conclusion of our discussion, what else would you like to talk about, something that depresses you maybe?

Kagiso : I am very bitter about the way our relatives treated us, how they chased us out of Sharpeville where we were born and bred. Now on winter days we have to travel on foot to Sharpeville where our school is. We cannot afford a taxi like other children. The taxi costs R6.00 return per day for each one of us, and we cannot afford that.

Thuli : Well as a teenager and being a girl, I have specific needs, the girls stuff like toiletry. My heart aches to think of what I have to use to meet nature, whilst the girls of my age have their own budget to cater for being a girl who has reached womanhood.

Interviewer : Meropa thank you for allowing me to talk to all of you. You have been very wonderful. I just want to ask you a few more questions as well. You were only 14 years old when you became a full time care giver to your siblings. How did you feel about this?

Meropa : I was scared, very bitter and depressed. I did not think. What ever I did, it just happened automatically. I would go to the shop and literally ask for bread, though I did not have money. At times they would give me bread that has expired, and we ate it, maybe that is why Kagiso had unstoppable diarrhoea.

Interviewer : What did you do when Kagiso was very sick?

Meropa : I took him to the clinic where we would sometimes spend the whole day in a queue and end up being told that the medicine was finished.

Interviewer : How did you cope with a sick sibling and at the same time you had to find food for them?

Meropa : On several occasions I thought of committing suicide and leave all the grief behind me. I cried mostly at night when my sister and brother were asleep so that they could not see that I was depressed. I had to be strong for them.

Interviewer : Do you still feel like committing suicide?

Meropa : Things are better now, Tshepo helps us with financial support though it is not enough, but the little bit that he gives me, I am able to buy the basics, like a bag of mealie meal, salt, soap, no fancy food like eggs. Meat is not our commodity.

Interviewer : How did you meet Tshepo, your boyfriend?

Meropa : He came to our house selling clothes and he was unaware of our situation. He was very friendly, funny enough we started talking and I explained that we are orphaned. He was very sympathetic. He came the following day with meat and soft drinks and we had a feast of our lifetime. This happened more often, until it just happened that we fell in love. He was my social supporter. Eleven months ago I gave birth to his child.

Interviewer : Does he still visit you regularly and also bring you meat?

Meropa : He now only gives us money for the basic needs at home. He has to buy food and clothes for our baby as

well. I appreciate the financial support that he gives no matter how little it is.

Interviewer : All of you, thank you so much for talking to me.

5.4 ANALYSES AND INTERPRETATION

Each item of the responses of the participants will be analysed and interpreted below. The scholastic performance of the learners will be analysed interpreted first.

5.4.1 Item one: Scholastic performance

The responses of the participants concerning scholastic performance will be analysed and interpreted.

- **Analysis**

From the answers to the interview questions it was clear that all/ the majority of the learners agreed on the following issues.

All learner participants are enrolled in schools, the majority does not possess a school uniform, they do not have people who can provide uniform for them. All of the participants have writing material, which they get their writing material such as stationery from the school.

Very few learner participants have been exempted from paying school fees, those who have not been exempted are not paying due to the fact that they do not have money to pay.

All learner participants do not attend regularly, those who still have parents indicated that their attendance is affected by their parent's ill health and that they take care of their ill parents. Others indicated that they stay very far from school.

All learner participants are not performing well, their performance has dropped. Their performance has dropped because of poor attendance, lack of concentration and worrying. Those who still have parents indicated that their attendance became poor since their parents confronted serious health problems and that they often cook and clean at home instead of concentrating on schoolwork. Some of these participants indicated being derided in class. This is what one of them said:

> "Whenever I try to participate in a group activity, other learners just laugh at what I say. I feel we are not like the rest of the learners as we cannot afford to have a proper school uniform."

Some of these learners cannot even participate in extracurricular activities because of the distance they have to walk back home after school.

- **Interpretation**

It is worrisome that the majority of these learners indicate that they do not have school uniform. This could lead to a situation where these learners drop out of school. These learners though do have writing material provided by the school, which is in line with the Constitution of South Africa, which contends that all learners have a right to education. The schools where these learners attend seem not to exempt learners who are affected and are not able to pay school fees. The South African Schools Act (84/1996) recommends that these learners should be exempted from paying school fees if the combined salary of parent/s or guardian/s is below a certain amount.

Learner participants do not attend school regularly as they are also caregivers to their sick parents. This poor attendance can adversely affect their general performance at school. It is worrying that these learners have to take on an adult's role at a very tender age and added to their chores, they have to cook and clean and do laundry as the parents are sometimes too ill, to do it. It seems that there is no one who can help these learners to improve their performance at school, which is aggravated by their high rate of absenteeism, lack of concentration and worrying. This finding indicates that these learners are not supported by the community, their relatives and educators at school to improve their performance. In the literature review it is stated that parents should take the initiative to disclose to the school their serostatus, so that schools can consider actions such as exemption from strenuous activity, preferential seating at the front of class, fewer disciplinary measures and exemption from school related costs (see 3.12).

5.4.2 **Item two: Material well being**

The responses of the participants concerning their material well being is analysed and interpreted below

- **Analysis**

From the answers to the interview questions it was clear that all/ the majority of the learners agreed on the following issues.

The majority of learner participants do not work for wages except for one. Most of them sleep in beds with foam mattresses. They all sleep with blankets. The majority have school shoes, which they got from their relatives and significant others, they do not have clothes to wear for visits and church.

Some of the learner participants indicated that they like other children would like to have birthdays, eat what they like, have a fridge and have ordinary cold water in summer. They indicated not having an ID document as a problem as they cannot get a support grant from the Department of Social Development. This is what they said about the application for a support grant:

> "Our sister, Meropa has been trying to apply for it for sometime now, but in vain, maybe they do not take her seriously because she is a child herself."

One of the respondents indicated that being a girl and not having toiletry is a problem. This is what she said:

> "I have specific needs, the girls stuff like toiletry. My heart aches to think of what I have to use to meet nature"

- **Interpretation**

The participants seem to be having the bare necessities as they indicated that they only possessed blankets, beds or mattresses and shoes. However, it is impressive that other learners seem to be helped by significant others with school shoes. These learners indicated having no decent clothes to wear when they are just visiting or going to church, if these learners do not have nice clothes like all the others they could develop a low self-esteem. It is a concern that girls especially do not have toiletry (including sanitary pads). It is the responsibility of the school to identify the needy learners and devise some means of partnering with community agencies to help them. The literature review's findings highlighted that schools are critical in responding to the needs of orphans and those affected by HIV/AIDS (see 3.12).

5.4.3. **Item three: Health and nutrition**

The responses of the participants concerning scholastic performance is analysed and interpreted.

- **Analysis**

From the answers to the interview questions it was clear that all/ the majority of the learners agreed on the following issues.
The majority of the learner participants indicated that their health is not good and that they had been sick in the last six months, they have suffered from stress, headaches, measles, diarrhoea and flue. They are all treated at the Government hospitals or at their local health clinics when they are ill. The majority of the respondents get their food from the significant others and others are working to provide for their families. Respondents eat porridge and vegetables everyday and had also indicated that it is their common food, they only afford to eat supper. Learner participants:

- are not given food like, fruit, tea or snacks in between meals;
- do not have lunch on school days;
- do not share their plate with anyone;
- eat meat few times a month;
- prepare the food themselves;
- they seldom drink milk; and
- they do not have enough food to eat in other days.

One of the learner respondents indicated that malnutrition had an effect on her appearance and her weight. This is what he said about being underweight:

> "The simple explanation is that when I was very young I could not get nutritious food. But because people see that I am underweight

they think that I have AIDS. I know I am thinner and shorter than children of my age, this is due to the fact that I am under-nourished. My parents could not afford to buy us vegetables we were satisfied to have only mealie-meal porridge as a meal."

All respondents indicated financial problems as the main reason for them not having enough to eat.

- **Interpretation**

The interviewees' health seems not to be good as it is affected by poor nutrition. The respondents' diet seems to lack a lot of vitamins and nutrients that are needed by their bodies to grow well. It is commendable that these learners are able to seek medical care from the Government hospitals, this is an indication that the Department of Health is committed to delivering services to the poorest of the poor. Learners who do not get proper nutrition lack concentration in class and cannot performance. These learners should be identified and be made part of JAM (Joint Aid Management), which complements School Nutrition Programme by providing breakfast. These learners would benefit more from these programmes if they can be given food to take home.

5.4.4 **Item four: Psychological and emotional issues**

The responses of the participants concerning their material well-being will be analysed and interpreted.

- **Analysis**

From the answers to the interview questions it was clear that all/ the majority of the learners agreed on the following issues.

All learner participants are unhappy compared to other children. Those who still have sick parents/members indicated that recovery of their ill family member/s would make them happy. They are made sad by seeing their family members ill. These learners spend most of their time with family members as most of them are caregivers.

The majority of these learners do not have anyone to share their problems with. This is what they said about this:

> "I try to talk to my mother when I have a problem but it doesn't help as there is nothing she can do. There is no point in talking to her."

> "I do not tell anyone about my problems. My mother is always sick and I think she has her own problems to think about."

> "I only share my problems with my grandmother when she visits us. Most of the time I keep them to myself."

> "There was no one to talk to and as a result my sister Meropa had to drop- out of school to go and seek piece jobs."

All participants get well with other learners, and their siblings although they are now are more worried, easily angered and frustrated than before because the health of their family members affect their emotions and they are now much quieter and prefer their own company as their personality is also affected.

Learner participants who lost their parents indicated psychological distress. This is what they said about how they felt after the death of their parents:

"On several occasions I thought of committing suicide and leave all the grief behind me. I cried mostly at night when my sister and brother were asleep so that they could not see that I was depressed."

"I was scared, very bitter and depressed."

"It was the most depressing moment of our lives"

Respondents indicated that they often cry over small things or over nothing, have scary dreams more often are sad frequently. These learners do not fight with other children but prefer to play alone. They do not refuse to go to school, are never stubborn or disobedient both at school and at home, do not bully or attack other children at school.

The majority of these learners sometimes become frustrated when things do not go their way or when those things seem not to work, become scared of new situations, are having trouble falling asleep, sometimes have problems in making new friends.

- **Interpretation**

The emotional well being of these learners is affected as they sometimes become frustrated when things do not go their way. These learners show indications of not having skills to deal with difficult or unfamiliar situations. Their indication of having problems to fall asleep could be a sign of anxiety. These learners do not have a clear support structure, as they say they have no one to share their problems with. A lack of positive emotional care is associated with a subsequent lack of empathy with other and such children may develop antisocial behaviours (see 2.5.11). These learners seem to lack skills to communicate with people as they indicate inability in making new friends. This lack of

communication could deprive these learners a chance to ask for help or support in future.

The interviewees' psychological well being seem to be affected by their parent's ill health. The ill health of their family members affect their emotions and their personality, these learners could go to an extent of being aggressive. These learners seem to be showing signs of depression. According to literature review, if depression is unresolved, a maladaptive coping strategy is substance abuse or attempted suicide (see 2.5.13).

5.4.5 **Item five: Plans for the future**

The responses of the participants concerning scholastic performance will be analysed and interpreted.

- **Analysis**

From the answers to the interview questions it was clear that all/ the majority of the learners agreed on the following issues.

Learner respondents indicate that they have someone who will take care of them in future relatives will take care of them, they see these future guardians everyday, they have known these people since birth, they know them very well and they like them a lot, they feel comfortable to discuss their problems with their future guardians.

This is what some of the respondents said about being prepared for the future:

> "Our sister Meropa motivates us to be serious about school and at least to pass Grade 12."

- **Interpretation**

It is commendable that these learners' future concerning having future guardians who will take care of them should anything happen seem to be intact. These learners seem to be in safe hands as these future guardians seem to be people they know and trust. Although their present situation seems not to be good but their future could be secure. This could help these learners to look forward to the future instead of lamenting about the present state of affairs.

It is commendable that these learners still have zeal to study further up until they get a grade 12 certificate. It is however, worrisome that their limit is low. The future of these learners after grade 12 seems to be bleak at a time when there is so much competition for jobs and tertiary education.

5.4.6 **Item six: Stigma and discrimination**

- **Analysis**

From the answers to the interview questions it was clear that all/ the majority of the learners agreed on the following issues.
Learner participants indicated that they are verbally or emotionally abused by other children, their relatives as well as their neighbours. They all had never been physically abused. This is what they revealed about stigma and discrimination:

> "Other children like to tease me about my mother's health. They even go to an extent of saying the whole family is infected."
>
> "our neighbours are not very friendly, they do not want
> me to play with their children. I can't even share food with them, as they were told not to accept any food from me."

"relatives never pay us a visit, they say they do not want to be associated with people who are dying of AIDS."

"my parents, after I was raped they didn't want anything to do with me. I was staying with them but living like an outcast. It was as if I deserved to be raped."

"we began to understand the people around us, their actions, and their coldness. We immediately felt alone, and we cried most of the time. If we go out to play with other children they would move away to another spot."

"When we visit them, they treat him very coldly. They isolate him. Even their children do not want to play with him."

One of the respondents revealed that his relatives even went to an extent of calling him names, this is what he said:

"They called me names because of my body. They called me "*Mokoto*"

- **Interpretation**

It is worrying that these learners seem to be treated badly especially by their peers who should be supporting them. This is an indication that these learners are subjected to stigma and discrimination, within their families, communities and at school. This could be an indication of isolation. These learners seem to be ridiculed and teased at school and at their homes. Stigma and discrimination seem to have negative effect on these learners as they reveal that it becomes difficult for them to participate in class. Literature supports this notion when it says, stigmatisation may prompt affected children to stay away from school,

rather than endure exclusion or ridicule by teachers and peers. Social stigmas are a source of chronic stress for learners affected by HIV/AIDS (see 2.5.6)

5.5 **CONCLUSION**

This chapter analysed and interpreted data collected through focus group and individual interviews used in this study.

The next chapter deals with conclusions, findings and recommendations.

CHAPTER 6

SUMMARIES OF FINDINGS AND RECOMMENDATIONS

6.1 INTRODUCTION

In this chapter, summaries of findings from the literature review and empirical research and recommendations are presented.

6.2 SUMMARY OF THE FINDINGS FROM THE LITERATURE STUDY

In the literature review it was found that the effects and impact of HIV/AIDS lead to psychological distress, anxiety about social security and the future, lack of parental nurturing, problems with basic social needs, problems with inheritance from parents' estate, poor education, stigmatization and discrimination in their communities among children and adolescents whose parents are sick or died of HIV/AIDS (see 1.1 and 2.4).

This was a clear confirmation from the available literature that HIV/AIDS impacts on the psychological well being of children and adolescents.

6.3 SUMMARY FROM THE EMPIRICAL RESEARCH

The findings of the empirical research led to the achievement of the aims (see 1.2) that this research set for itself, as follows:

- In investigating the condition of the psychological well being of learners affected by HIV/AIDS, the study revealed that they are unhappy compared to other children and that they are sad to see their family members, that is, their parents and breadwinners, being ill. The health of their family members affect their emotions in that they now are more worried and

easily angered as well as frustrated than before, they often cry over small things or over nothing and that recovery of their sick family member would make them happy. This has also affected their personality in that they are now much quieter and prefer their own company and as a result, they prefer to play alone. They sometimes become frustrated when things do not go their way or when those things seem not to work. They become scared of new situations, they have trouble falling asleep and scary dreams, occur more often. They sometimes have problems in making new friends, but they do not wet their beds and they had never considered running away from home.

- In investigating the way in which these learners perform scholastically, this study revealed that they do not have and cannot afford school uniform and there are no people or relatives who can help them with money to buy school uniform. All of the participants have writing material - they get their writing material from the school. All of the participants have not paid school fees, and only a few of these learners have been exempted from paying the school fees. All of the participants do not attend school regularly, the learners' attendance is affected by their parent's ill health, they indicated taking care of their ill parents as their reason for poor attendance at schools, and that their attendance of school became poor since their parents were confronted by serious health problems. All the participants help with the house work when they have not attended school, and that they often cook and clean at home and all the participants' scholastic performance has dropped because of poor attendance, lack of concentration and worrying.

- In investigating the nature and extent of social support these learners get from their families, communities and societies, the study revealed that all participants have school shoes which they got from their relatives and significant others. They do not have clothes to wear when they go out or

attend church services; and they do have significant others who will take care of them in future after the death of their parents or breadwinners. The participants stated that when they are ill they are treated at the Government hospitals or at their local health clinics.

- In investigating on the condition of their physical well being, the study revealed that their health is not in good condition and that they had been ill, suffering from stress in the last six months. The empirical research also revealed that the physical growth of the children and adolescents affected by HIV/AIDS could be affected by inadequate nutrient intake and sickness spells they experience, which could affect their school attendance. School attendance is important as it, enhances children's learning and cognitive development.

6.4 RECOMMENDATIONS

This study recommends the following in order to help school going children and adolescents who are affected by HIV/AIDS:

The South African government, together with international social agencies oriented towards HIV/AIDS issues such as, the United Nations and non-governmental organisations (NGOs), faith-based organisations (FBOs) and community-based organisations (CBO's), should make use of a range of child-centred approaches to support children who are affected or orphaned by HIV/AIDS. These organizations which form social systems for the effective holistic development of children and adolescents should engage with children to find ways to meet their practical needs and/or to provide other forms of psychological and social support. Effective ecosystemic and child-centred approaches are underpinned by a set of principles that view the child as a whole person, rather than as a set of separately defined needs. Effective ecosystemic and child-centred social interventions seek to listen to children and their families.

They work to strengthen the capacities of children, families and communities to respond effectively.

Child - centred approaches to HIV/AIDS include:

- listening to children and adolescents to learn about the situation from their perspective, to understand their needs, and to find out about their coping strategies and their aspirations;
- supporting children to help themselves and others, so that children and adolescents' potential is recognized and they become active participants in community activities, in an environment where they feel safe and supported;
- supporting extended families and communities to care for children and adolescents, rather than placing them in institutions. This includes providing material support and economic opportunities, where appropriate, at family and community level. Grandparents, in particular, often need support to cope with adopting their orphaned grandchildren, and with meeting their practical and emotional needs;
- responding to the psychological needs of children and adolescents by helping parents/guardians and other community members to understand and respond to children and adolescents' needs. This can help to prevent long-term emotional, social, and psychological problems, including reducing children and adolescents' own vulnerability to HIV infection;
- reducing children's vulnerability to HIV infection through effective prevention programmer, including life-skills-based education, open access to health services, alternative income-raising activities, voluntary and confidential counselling, and HIV/AIDS testing;
- providing children and adolescents with opportunities for education such as programmes that enable vulnerable children to continue to attend school or the provision of non-formal education alternatives,

with flexible timing for children who are unable to attend full-time education;

- providing children and adolescents with opportunities for vocational training, income generation, and access to savings and loan schemes. Non Governmental Organizations and community based organizations should identify technical support to help them to plan these economic interventions, since it is a specialized area;
- strengthening community-based responses and local networks such as groups of people infected and affected by HIV/AIDS, women's groups and faith-based groups. These groups are central to identifying vulnerable children and adolescents and are central to enabling effective, sustained social support, rather than one-off handouts to orphans and vulnerable children;
- promoting co-operation between different social systems at community level who are involved with supporting children. It is therefore important to link the activities of schools, health centres, CBOs, faith-based organisations and other groups, so that the needs of children are met holistically. Ideally, a committee could be brought together at community level to co-ordinate work with children and adolescents. This committee should include child and adolescent participants. Similar multi-systemic co-operation should also exist at district and national levels;
- creating links between different interventions for children in health, education, social services and others. It is also important to establish links between interventions that address different aspects of the HIV/AIDS pandemic, such as HIV prevention, support to orphans and vulnerable children, and health care for children and adults living with HIV; using outside support to reinforce – not undermine – community initiatives and motivation, recognising that external programmes should avoid creating dependency. Communities may need support, for example, in accessing

resources and using them in a way that is effective and transparent to the whole community;

- ensuring continuous monitoring and evaluation of the changing impact of HIV/AIDS on communities and of the effectiveness of ongoing interventions. Children can actively participate in this research; and
- promoting the experience of affected children and adolescents through advocacy on policy reform at national and international level to ensure that governments protect the rights of their child citizens and provide essential support and services, including access to anti-retroviral drugs to enable parents to survive their children's childhood and adolescence.
- schools should render Psychological Services to the children and adolescents affected by HIV/AIDS in order to ensure that their psychological wellness and well being is enhanced and strengthened. Psychological services should cater for the counselling of children and adolescents affected or orphaned by HIV/AIDS so that they can be in the position of managing or coping with the social plight they find themselves in because of being affected or orphaned by HIV/AIDS. It is now high time that the Department of Education employ the services of Educational Psychologist for each school if South Africa is to succeed in concertedly dealing with the psycho-social problems that children and adolescents affected or orphaned by HIV/AIDS undergo. Children and adolescents affected or orphaned by HIV/AIDS need bereavement counseling to psychologically support them on the loss of their loved ones and to help them proactively consider their future.

Both intra and extra-curricular activities at schools should infuse knowledge and skills of dealing with being stigmatized, labeled and

discriminated on the basis of being both infected and affected by HIV/AIDS. Such knowledge and skills can be embedded in the Life Skills learning area.

It is recommended that the government provides incentives for families affected by HIV/AIDS so that they can be able to keep their children in schools. Such families could be assisted through free or the reduction of school related expenses, for example, school fees and the costs of school uniform and learning material.

The government through its Department of Social Development needs to provide family and community caregivers to HIV/AIDS patients who choose to be at home. Such caregivers can be trained by health workers to effectively provide the prescribed medications and other physical and psychological support that may be needed by parents or breadwinners of children and adolescents affected or orphaned by HIV/AIDS. Such a provision can help HIV/AIDS affected children and adolescents to regularly attend schools instead of caring for their sick parents during the time when they are supposed to be at school.

6.5 **LIMITATIONS OF THIS RESEARCH**

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

The interviews with the educators and next of kin of the children and adolescents affected or orphaned by HIV/AIDS would have given more comprehensive

understanding of the psychological well being of these children and adolescents from scholastic and familial perspective. There is, therefore, a need for a comprehensive study which should involve focus group interviews or individual interviews with educators, school governing body members, Department of Education officials, government officials especially those of the Departments of Social Development and Health and next-of-kin of school going children and adolescents affected or orphaned by HIV/AIDS. Such a holistic study will help in gaining a holistic and comprehensive understanding of the psychological well being of children and adolescents affected or orphaned by HIV/AIDS.

6.6 **CONCLUSION**

In this research, the psychological well being of school-going children and adolescents affected or orphaned by HIV/AIDS were investigated by means of both the literature review and empirical research. The results of the empirical research were analysed and interpreted. On the basis of both the findings of literature review and empirical research, this study was able to make recommendations with educational and psychological implications for schools, families, communities and societies to assist school-going children and adolescents affected or orphaned by HIV/AIDS.

The researcher hopes and prays that schools, families, communities and societies will pay attention to what this research exposed and start developing educational and psychological programmes, which can help all learners affected or orphaned by HIV/AIDS develop wholly and holistically.

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APPENDIX A

Interviews questions with Phindile, Ben, Ntshepise, Thato, Elizabeth and Len.

Interview questions under item one: Scholastic performance

Are you enrolled in a school?
In which grade are you?
Do you have school uniform?
Who provided you with school uniform?
Do you have writing material at school?
Who provided you with writing material?
Have you paid the school fees?
Why have you not paid the school fees?
Do you attend regularly?
What has affected your attendance?
How has the health of your family member affected your attendance?
When you miss school for any reason how do you spend your day?
Has your marks changed since you/your parent was confronted by health problems.
What exactly has caused your marks to be low?
Has your attendance changed since you/your parent confronted serious health problems?
What kind of work do you do often at home?

Interview questions under item two: Material wellbeing

Do you work for wages?
Do you sleep on a mattress?
Do you sleep on a bed?
What type of a mattress is it?
Do you sleep with a blanket.
Do you have a pair of shoes?
Who provided the shoes for you?
Do you have clothes for church or visits?
Who provided you with the clothes?

Interview questions under item one: Health and nutrition

In general how is your health?
have you been sick in the last six months?
What were you suffering from?
When you are sick where do you go for treatment?
Who provide meals for you?
What do you eat every day?
Which meals do you afford to eat everyday?
Are you given food like fruits or tea or snacks in between meals
What common foods do you eat everyday?
Do you always have lunch on school days
Do you share your plate?
How often do you eat meat?
Who prepares food for you?
Who provide meals for you?
What do you eat every day?
Which meals do you afford to eat everyday?
Are you given food like fruits or tea or snacks in between meals?

What common foods do you eat everyday?

Do you always have lunch on school days

Do you share your plate?

How often do you eat meat?

Who prepares food for you?

How often do you drink milk?

Are there special reasons why you do not have enough food to eat?

May I see your vaccination card?

Interview questions under item four: Psychological issues

How happy are you, compared to other children?

What do you do for fun?

What makes you sad?

With whom do you spend most of your time?

Who do you talk to when you have a problem?

Do you like going to school?

How do you get along with other children?

How do you get along with your sibling?

How has the health of your family member affected your emotions?

How has the health of your sick family member affected your personality.

Interview questions under item five: Emotional well being

Do you cry a lot over small things or over nothing during the course of the day?

Do you have scary dreams and nightmares?

How often do you have scary dreams or nightmares?

How frequently sad are you?

Do you fight with other children?

Do you maybe prefer to play alone?

Do you at times refuse to go to school?

Are you stubborn or disobedient at school?

Are you disobedient or stubborn at home?

Do you bully or attack other children?

Do you worry?

How often do you refuse to eat?

Do you become frustrated when things do not go your way or when Those things seem not to work?

Do you become afraid of new situations or changes?

Do you become very angry?

Do you have trouble falling asleep?

Do you have problems making friends?

Do you wet the bed?

Have you ever run away from home?

Interview questions under item six: Plans for the future

Is there someone who will care for you in future?

Who is that?

How often do you see your future guardian?

How long have you known this person, who is your future guardian?

How well do you know this person?

Has this person promised to care for you in future?

How did you respond when s/he told you that s/he will take care of you?

Would you feel comfortable to discuss your problems with your future guardian?

Interview questions under item seven: Stigma and discrimination

Have you been treated differently because of the health of your sick family member?

Have you been treated badly because of the health of your sick family member?

Have you ever been sexually abused?

Have you ever been emotionally abused?

Have you ever been verbally abused?

Who verbally or emotionally abused you?

Have you ever been physically abused?