

**The narratives of families affected by HIV/AIDS
in the Vaal Triangle**

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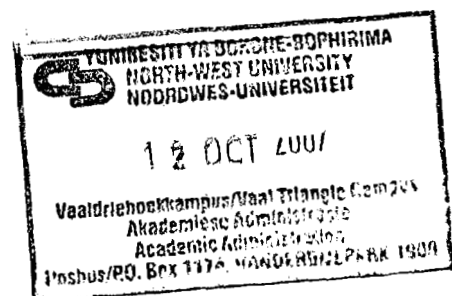
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SUMMARY

The aims of this research were to determine the narratives of families affected by HIV/AIDS, and to suggest ways in which to psychologically and socially strengthen these families.

On the one hand, the literature investigation revealed that HIV/AIDS has led to the emergence of new family forms such as "skip-generation" families, where the parent generation has succumbed HIV/AIDS-related illnesses and the families are made up of grand-parents and orphaned grand-children; and child-headed families, where an older sibling cares for the younger ones. Usually, grandparents and other relatives are not available.

On the other hand, the empirical investigation narratives revealed that HIV/AIDS is still a taboo even in families with HIV positive members, and family members affected by HIV/AIDS suffer discrimination within their families and their communities.

The study recommended, among many other things, the infusion of narrative therapy in programmes geared to help families affected by the HIV/AIDS epidemic deal with their psycho-social plights. The use of a reflecting team was highlighted as useful as a way to generate new ideas and expand narrative therapeutic possibilities for both the family affected by AIDS and psychotherapists. The use of a reflecting team was also highlighted as offering families an opportunity to connect and collaborate in ways that remove hierarchical barriers and open the communication for co-constructing new meanings and co-generate options for action in their struggle to live with the fatal disease in their family. The goal of a reflecting team is to maintain a collaborative stance by recognizing the family members' expertise of lived experiences. A need for schools to develop a training curriculum in HIV-related mental health issues for children and their families for mental health was highlighted, covering stage-specific issues occurring over the course of HIV progression, parental death and family reconfiguration. The curricular format can include didactic material and illustrative clinical material and can

utilize an interactive approach to improve the skills and knowledge of children and their families.

OPSOMMING

Die doelstellings van hierdie navorsing was om die bekendmakinge van gesinne deur MIV/VIGS aangetas te verkry en om dan maniere aan te beveel waardeur sulke kinders psigologies en sosiaal versterk kan word.

Aan die een kant het die literatuuroorsig aangetoon dat MIV/VIGS gelei het tot die navore tree van nuwe gesinstipes, generasie-oorslaan gesinne, waarin die ouerlike generasie as gevolg van MIV/VIGS afgesterf het, waar hierdie gesinne dan oorslaan na 'n gesin wat bestaan uit die grootouers en weeskinders – wat soms insluit kind-hoof gesinne- laasgenoemde waar grootouers nie beskikbaar is vir die weesgelate kinders nie.

Aan die anderkant het die emprise narratiewe laat blyk dat MIV/VIGS stees taboe is, selfs in gesinne met MIV aangetaste gesinslede en waar gesinslede deur MIV/VIGS aangetas is, diskriminasie binne hulle gesinne en gemeenskappe ondervind.

Onder andere, beveel hierdie studie aan, dat narratiewe terapie toegepas word wat daarop gemik is om daardie gesinne wat deur MIV/VIGS aangetas is, deur hierdie epidemie by te staan in hulle psigo-sosiale besoekinge deur die program by te staan. Die gebruik van besinningspanne is benadruk, as synde goeie maniere te wees om nuwe idees na vore te bring en om terapeutiese moontlikhede vir beide daardie gesinne deur VIGS geraak en vir psigoterapeute: daar is verder benadruk, dat sulke besinningspanne aan gesinne die geleentheid sou bied om saam te werk en in verbinding te kom by wyse van die verwydering van hiërargiese hindernisse en om kommunikasie te bevorder vir die herkonstruksie en gesamentlike konstruksie van nuwe sienswyses: asook om gesamentlik aksies te skep vir die bekamping van hierdie stryd om binne gesinne teen fetale siekte te stry. Die hoofdoel van die besinningspan is dan om 'n gesamentlike front vol te hou deur erkenning te gee aan gesinslede se kundigheid ten opsigte van die beleefde besoekinge. Die noodsaaklikheid van 'n opleidingskurrikulum in die geestelik verwante en MIV-verwante geestes gesondheid vir kinders en hulle gesinne is

ook benadruk: hierdie kurrikulum sal dan ook te make hê met fase-spesifieke sake wat voorkom in die gang van HIV, die afsterf van ouers en gesinskonfigurasie. Die kurrikulum kan onder andere insluit didaktiese materiaal asook illustratiewe kliniese materiaal wat 'n interaktiewe benadering kan gebruik om die vaardighede en die kundigheid van kinders en hulle gesinne te verbeter.

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CHAPTER ONE

ORIENTATION TO RESEARCH

1.1 INTRODUCTION

More than twenty years after HIV/AIDS had been discovered medically in 1981, it became clear, that it is more than just a medical issue. It pervades all areas of human beings' social, economic, political and cultural lives. UNAIDS (2004:5), Avert Organisation (2005:2) and Kinghorn and Kelly (2005:490) reveal, that in 2003 alone, almost five million people in the world became newly infected with HIV, the greatest number in any one year since the epidemic was discovered. The number of people living with HIV has now grown from 35 million in 2001 to 44 million in 2004 and more than 20 million people have died since the first cases of AIDS were identified (UNAIDS, 2004:7).

From the foregoing paragraph it is clear that HIV/AIDS has not only been an individual problem, but also a social epidemic within other social epidemics such as poverty, gender injustice, social discrimination of certain groups, war, violation of children's rights and cultures of inequality. One of its most visible social impacts, is seen on families. The impact of HIV/AIDS on families is seen most dramatically in the wave of AIDS orphans numbers that had by December 2004 grown to an estimated 15 million worldwide (UNICEF, 2004:5; Kinghorn & Kelly, 2005:495; Bennell, 2005:442). UNICEF (2004:3), predicts that by 2010 this number is expected to increase to over 25 million worldwide. The WHO (2004:2) reveals that the vast majority of children affected by HIV/AIDS today are concentrated in Africa, with 70% of them living in Sub-Saharan Africa, with an additional 10% in other areas on the continent. Similar crises are building in Asia, Eastern Europe, Latin America, and the Caribbean. UNAIDS (2004:9) reports that in Asia, HIV sero-prevalence rates are lower than in Sub-Saharan Africa, but the combination of large populations and rising incidence of HIV infections suggest that it will be affected severely as well.

For years the world has been beleaguered by wars, famines, natural disasters, mass migration, and diseases which threatened the health and well-being of children, but the social impact of HIV/AIDS on children, families, and communities is unique. For children, living with infected parents, is associated with elevated psychological distress and diminished emotional support prior to and following parental death (Kinghorn & Kelly, 2005:491). Relative to unaffected youth, children whose parents become infected, face higher rates of psycho-social problems such as:

- having to dropout of school to become wage-earners and care-providers;
- experiencing loss of access to economic resources and inheritance assets;
- diminished access to basic needs, including nutrition, shelter, health care, clothing; and
- being open to increased vulnerability to exploitation, violence, abandonment, and abuse – particularly for girls in societies with inadequate social, legal, and cultural protections (Coombe, 2000:16).

In addition, affected children from communities unwilling or unable to provide adequate psycho-social support, face additional problems such as inadequate housing or homelessness, financial hardship, substance abuse, HIV risk-taking, and initiation or exacerbation of psychological well-being and behavioural disorders (Theron, 2005:57).

In many parts of the world, it is no longer divorce that creates single-parent and step-families, but parental death and orphanhood due to the HIV/AIDS pandemic. New family forms are emerging, such as "skipgeneration" families, where the parent generation has succumbed to HIV/AIDS-related illnesses and the families are made up of grand-parents, orphaned grand-children; and child-headed families, where children have to take care of their siblings (Kinghorn & Kelly, 2005:495).

The next section states the problem which leads to this research.

1.2 STATEMENT OF THE PROBLEM

In the light of the literature review findings from the above-mentioned facts, the impact of HIV/AIDS on families needs special research attention if the world is to succeed in developing psycho-social fortitude of all its children and adolescents. Educational psychologists; this research is conducted from the educational psychology perspective; as specialists in childhood and adolescence need to be social-constructivist in their psychotherapeutic and research interventions with AIDS orphans (Bennell, 2005:477). The social constructivist educational psychologists are solution-focused, strength-based, conversational, and collaborative in their psychotherapeutic approaches, with a special interest in listening to clients' lived stories. Such an approach is effective in assisting AIDS orphans in separating themselves from the dominant traumatic and distressing HIV/AIDS-associated stories they have internalized so that space can be opened for the creation of alternative life stories (World Bank, 2002:8), such as days when they were resourceful in the presence of their healthy parent (s).

Various national and international researchers have investigated the impact of HIV/AIDS on families, but none has particularly done research on the narratives of families in the Vaal Triangle.

The dearth of such research creates a void in understanding the new roles that HIV/AIDS programmes on families should play in facilitating and advocating for healthy families within the context of the Vaal Triangle communities. South Africa and the world-at-large need a theoretically and empirically based research which will answer the following questions, among many others:

- What are the narratives of families affected by HIV/AIDS?
- What is the nature of the narratives and families affected by HIV/AIDS?
- What can be done to psychologically and socially strengthen these families?

1.3 THE OBJECTIVES OF THE RESEARCH

On the basis of the research questions presented in section 1.2 above, the objectives of this research were to:

- determine the narratives of families affected by HIV/AIDS;
- determine the nature of the narratives and families affected by HIV/AIDS; and
- suggest ways in which to psychologically and socially strengthen these families through narrative therapy.

1.4 SOCIAL CONSTRUCTIVISM AS THE THEORETICAL FRAMEWORK OF THIS RESEARCH

This research was conducted from a social constructivist perspective. Social constructivism provides a context for this research because of its post-modernism and its ability to create a broadened understanding of social processes. Its theoretical premise is that knowledge, understanding and reality constructions of all kinds are created by communication, especially conversations (Dattilio, 2001:5). So, creating knowledge by research in the area of psychotherapy, is actually conversations about conversations, or conversations about psychotherapeutic conversations, which create new constructions and in turn, influence subsequent ones, i.e. open for new dialogues (Leahy, 2002:420).

According to Reinecke, Dattilio and Freeman (2002:26), social constructivism regards the social context and the use of effective communication through the language as significant in the expressions of lived experiences and alternative stories among human beings. Such a theoretical framework is crucial in dealing with experienced psycho-social problems of families affected by the HIV/AIDS epidemic (Watson & Tharp, 2002:447).

1.5 METHODS, PROCEDURES AND TECHNIQUES

1.5.1 Research Methods

This was a qualitative research employing the methods of narrative analysis. In narrative analysis, the first-person accounts in story form, biographies, autobiographies, life histories, oral histories, auto-ethnographies, and life narratives are used in data analysis. Common types of analysis are psychological, biographical, and discourse analyses. The defining feature of this type of qualitative research is that the data are in some form of story (Denning, 2000:46).

The data that was derived from the HIV/AIDS affected families lived experiences and alternative stories, was regarded as meanings they have constructed of their lived experiences and was understood from their frames of reference. In this regard, reporting rich with thick descriptions such as quotations, narrations, and detail. No questionnaire was developed for data collection but the researcher was an instrument for data collection and analysis through observing, participating, and interviewing.

Many researchers, particularly qualitative researchers, elect to use interviews. As Leedy and Ormrod (2005:146) suggest ' . . . the interview is a critical tool for developing new frameworks and theories based on people's formulations.' By entering into dialogue with others, narrative interviewers may unearth hidden or subordinated ideas (Cooper & Lesser, 2005:163). These ideas are important because they may cast doubt on official accounts and established theories (Morgan, 2000:36). In turn, the 'findings' produced, may lead to the development of new theories that resonate more with people's lives (Payne, 2000:76).

Because narrative research is orchestrated around story-telling, researchers ordinarily use a conversational style of interviewing (Winsdale & Monk, 2000:35). Engaging participants in relatively informal and friendly ways, researchers sometimes process stories with participants along the way, and allow for stories or comments that do not appear to be immediately relevant. Blurring the boundaries between participants and the researcher, the

researcher took care not to rush participants or infer that their stories 'don't make sense' (Freedman & Combs, 2002:15).

Narrative researchers usually recognize, that participants may use qualifying statements and hesitating 'riders' to convey complexities and invite responses from 'listeners' (White, 2005:34). Similarly, they appreciate that personal stories often contain circular, overlapping and 'slightly chaotic' utterances (Cooper & Lesser, 2005:27). Because they value connectedness and appreciate uncertainty, they do not treat this style of communication as inferior to more literal and linear question/answer forms of talk. Exploring the ways meanings are created among conversants, including those who collaborate to narrate a single story, they are particularly sensitive to the ways fragments of ideas might be expressed (Morgan, 2000:35). The researcher was especially conscious of this when she discussed matters of a personal nature.

1.5.2 Sample selection

The sample of this research comprised of two cases of HIV/AIDS-affected families from two townships in Gauteng, which are Palm Springs and Sebokeng. Members of two families, the first made up of a grand-mother, mother, sister, brother and the HIV-infected learner; the second made up of a mother, father, a boy and a girl (n=10) and people associated with these families such as an aunt, neighbour, a boyfriend an educator and a principal (n=5) were interviewed.

A purposeful sampling method was used in this research. Purposeful sampling is composed of elements that contain most of the characteristics that are representative or typical of the population (White, 2005:120). Concerning the first family, a convenience sampling method was used. White (2005:120) indicates, that in a convenience or availability sampling respondents are usually those who are the nearest and most easily available to the researcher. In this study the infected learner disclosed to her class educator who happens to be the researcher at the school. For the second family a snowball sampling method was used. White (2005:122) states, that snowball involves approaching a single case (which is the first family) that is involved in the

phenomenon to be investigated so as to obtain information about another similar person (which is the second family).

1.5.3 Data collection

A literature review on families affected by the HIV/AIDS epidemic and narratives was undertaken in order to develop the theoretical framework and basis for the research with affected families and their families.

The following key words were used to conduct the electronic search for relevant national and international literature data: affected families due to HIV/AIDS, narratives, narrative therapies, and social constructivism theory.

1.5.4 Data analysis

Before the collected data was analysed, it was 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 look at the frequency of occurrences with the purpose of producing a body of instances (Leedy & Ormrod, 2005:136; De Vos, 2001:342). Thereafter, analysis, the process of searching for patterns and forming hypotheses about the functions fulfilled by what the AIDS orphans are saying and the effects thereof, began. The emerging linguistic similarities and differences across the two families were noted.

1.5.5 Validation

By using the four main analytic techniques of coherence, participant orientation, new problems and fruitfulness, the findings were validated and then a report was written.

1.5.6 Ethical issues

In order to facilitate the participants' giving their fully informed consent, all the necessary information pertaining to the research, including the nature, purpose and usefulness, procedures, confidentiality and the protection of

anonymity and the voluntary nature of participation in the research were given.

1.6 CHAPTER DIVISION

Chapter One: Orientation to the research

Chapter Two: Impact of HIV/AIDS on families

Chapter Three: Literature review on HIV/AIDS

Chapter Four: Qualitative research design

Chapter Five: Data analysis and interpretation

Chapter Six: Recommendations, summaries and conclusions

1.7 CONCLUSION

This chapter presented the problem statement and its setting, the aim of this research and the methodology employed.

In the next chapter the review of literature on families affected by HIV/AIDS and narratives is presented.

CHAPTER TWO

THE IMPACT OF HIV/AIDS ON FAMILIES

2.1 INTRODUCTION

By the late 1990's, many governments and major international donors reacted to the growing evidence of the impact of HIV/AIDS on households, by suggesting that "traditional" coping mechanisms would minimize the impact of HIV/AIDS and allow households and communities to absorb the loss of members and of their income, assets and social contributions (Bechu, 1998:31). This belief had an important political dimension. By acknowledging this element of the African societies' traditional strengths, governments and international agencies were not obligated to respond to the multiple crises they faced as a critical emergency. As the impact of the epidemic has deepened and broadened, however, new evidence has been gathered that suggests these broad generalizations about the impact of HIV/AIDS must be supported with credible evidence and qualified in particular circumstances. The slow evolution of the impact of HIV/AIDS does disguise the immediate general effects, but the cumulative effects registered over several years or one or two decades are already producing, and will continue to produce, significant changes across society (Floyd, 2003:24; Mturi & Nzimande, 2003:33).

The need for a degree of caution in assessing the impact of HIV/AIDS on families, is because other factors are at work at the same time. Dramatic economic changes in Sub-Saharan Africa over the past several decades, for example, have left some households more exposed to the impact of HIV/AIDS than have others (Policy Project, 1998:27).

In most societies, health and illness are at one level a private, individual matter, while at another, they have implications for relationships and social functioning. As with all illnesses, the HIV disease affects the entire family system. Disruption in families affected by HIV, may take many forms as relationships and roles undergo change (World Bank, 1997:36). While each

family has to process and adjust to these changes in its own way, research has not as yet revealed a clear view of how culture, ethnicity or religion mediates this process, although the implications of HIV for an individual are inextricably linked to the social context where prevention, infection, illness, treatment and care occur (Rau, 2003:29). An understanding of the impact of HIV/AIDS on the family needs to be translated into supportive and therapeutic actions with individual family members and the family system as a whole (Tumushabe, 2003:76). Approaches to counselling and support for people with HIV disease have tended to focus on the individual rather than on the whole family system. Therapeutic work with the family and the wider system has only recently been described (Payne, 2000:31).

By studying the impact of HIV disease on the family, the world comes to understand, in part, the social context of the HIV disease. At present, the world lacks extensive empirical data that would yield important insights into how HIV/AIDS has affected families (Human Rights Watch, 2002:44). As the focus for treatment in HIV care in the 1990s shifts from the individual to the family, the world can anticipate a concomitant change in the focus of psychosocial research. The world's understanding of the impact of HIV/AIDS on families worldwide may then become clearer (WHO, 2002:16).

This chapter outlines the definition of important concepts, the major impacts of HIV/AIDS on the social and economic structures of families. It continues with a discussion of some of the most significant responses to the HIV/AIDS epidemic, some organized by communities themselves, others facilitated by outside agencies. Section 2.3 summarizes the relevant and current information on the social impacts of HIV/AIDS. It includes discussion of changes in family structure and the multiple impacts on women, girls and boys. Section III deals with the income costs of the epidemic on families. Section 2.4 identifies some key responses at all levels that seek to mitigate the impacts of HIV/AIDS.

2.2 THE NATURE OF A NARRATIVE AND A FAMILY

This section presents the nature of both narratives and families.

2.2.1 The nature of a narrative

A narrative or story in its broadest sense, is:

- anything told or recounted; more narrowly, something told or recounted in the form of a causally-linked set of events; account; tale; and
- the telling of a happening or connected series of happenings, whether true or fictitious (Freeman, Epston & Lobovits, 1997:56).

Narrative meaning is, therefore, created by establishing that something is a part of a whole and usually that something is the cause of something else. It is usually combined with human actions or events that affect human beings. The meaning of each event is produced by the part it plays in the whole episode (White & Epston, 1996:121). To say what something 'means', is to say how it is related or connected to something else. To ask the meaning of an event, is to ask how it contributed to the story in which it occurs. It is the connections or relations between events.

From the foregoing paragraph, it is clear that meaning is a social phenomenon. Meaning is produced not only by individuals but by groups, communities, societies and cultures which maintain - through language and agreed understandings - knowledge of the connections between signifying sounds and signifying events.

Groups, communities, societies and cultures also preserve collections of typical narrative meanings in their myths, fairy tales, legends, histories and stories. To participate in a group, community, society or culture, requires a general knowledge of these accumulated narrative meanings. The cultural stock of meanings are dynamic and are added to by new contributions from members and deleted by lack of use (Niyongabo, 2001:35).

Narrative meaning is also about connections. It links individual human actions and events into inter-related aspects of an understandable composite. Narrative displays the significance that events have for one another. The anti-story makes explicit, that events do not have causal connections between

each other. In this respect, stories fill our lives in the way that water fills the lives of fish. Stories are so all-pervasive, that human beings practically cease to be aware of them (Payne, 2000:9).

The products of human beings' narrative schemes are ubiquitous in their lives: they fill their cultural and social environments. They create narrative descriptions for themselves and for others about their own past actions, and they develop storied accounts that give sense to the behaviour of others. They also use the narrative scheme to inform their decisions by constructing imaginative "what if" scenarios (Morgan, 2000:51).

According to Winslade and Monk (2000:56), the narratives of the world are without number and are present at all times, in all places, and in all societies. Winslade and Monk (2000:56) further assert that the history of narrative begins with the history of mankind and that there does not exist, and never has existed, a people without narratives.

From the foregoing paragraphs it is clear, that the word "narrative" refers to the importance that is placed upon the stories of people's lives and the differences that can be made through specific telling and retelling of these stories. These stories are examined like literary criticism, in which the story-line is deconstructed and the plot, characters, and timeline are individually inspected for importance (Cooper & Lesser, 2005:35). Every person experiences and create, many different stories in their life. These stories may be separate from each other, but often they occur at the same time or even overlap. It is even possible that the same event creates many different stories in a person's life. No single story can summarize a person's life, and so many stories and examination of these stories are required to help understand the person telling them (Morgan, 2000:18).

The narratives are based on the premise, that people are the experts of their own lives. When they examine themselves, they view their problems as separate from themselves. Within the narrative practice, outsider witnesses are invited as listeners to a therapy conversation. They are a third party, neither the client nor the therapist, who is invited to listen and acknowledge

the chosen stories and identifying issues of the client. These witnesses participate in the therapy process only after the client and the therapist has concluded their discussion (Diabetes Counselling, 2006:8).

Freeman and Combs (1996:43) assert, that when it is time for the outsider witnesses to participate, they do not directly comment on the story told by the client. Instead, the witnesses should focus on parts of the stories that caught their interests or engaging. Although the witness is speaking to the client at this time, it is not an actual conversation, as the interaction between the client and witness is limited.

There are many aspects of the client's voicing of the story that the outsider witnesses may comment on. A witness may respond on how the stories provided by the client, reminded them of people, events, or feelings that happened in their own lives. They may also report on the language and the feelings that the client invoked within them and how it affected them personally. A witness can also voice to the client how the telling of their story has changed them as persons due to the client's narrative (White, 2005:15).

Once the outsider witnesses have given their account of the client's story, the client has the opportunity to respond to their comments. The client can respond in any fashion they desire. This feedback, although possible gratifying to the witnesses, helps reinforce successes and knowledge acquired throughout the therapy, and also shows steps the client is making to reach set goals (White & Epston, 1996:44).

Epston and White (1992:53) argue the concepts that constitute narrative approaches, are premised on the notion that people organize their lives into stories, thus the use of the narrative or text metaphor. Identity conclusions and performances that are problematic for individuals or groups, signify the dominance of a problem-saturated story. Problem-saturated stories gain their dominance at the expense of preferred, alternative stories that often are located in marginalized discourses. According to Denning (2000:35), these marginalized knowledges and identity performances are disqualified or invisibilized by discourses that have gained hegemonic prominence through

their acceptance as guiding cultural narratives. Examples of these subjugating narratives include; capitalism; psychiatry/psychology; patriarchy; heteronormativity; and eurocentricity. Furthermore, binaries such as healthy/unhealthy; normal/abnormal; and functional/dysfunctional, ignore both the complexities of peoples' lived experiences, as well as the personal and cultural meanings that may be ascribed to their experiences in context (Payne, 2000:32). By conceptualizing a non-essentialized identity, narrative practices separate persons from qualities or attributes that are taken-for-granted essentialisms within modernist and structuralist paradigms. This process of externalization, according to White and Epston (1996:27), allows people to consider their relationships with problems, thus the narrative motto: "The person is not the problem, the problem is the problem." So-called strengths or positive attributes are also externalized, allowing people to engage in the construction and performance of preferred identities. Operationally, narrative involves a process of deconstruction and meaning-making achieved through questioning and collaboration with the clients. While narrative work is typically located within the field of family therapy, many authors and practitioners report using these ideas and practices in community work schools (Winslade & Monk, 2000), and higher education.

2.2.2 The nature of a family

Attempting to explore the nature of the concept 'family' in HIV research places the researcher in double jeopardy. On the one hand, some traditional conceptualizations tend to be narrow as they focus either on blood relationships or the idea of a common household, while on the other hand, other conceptualizations emphasize the social network, which may come to include any provider of social support (UNAIDS, 1999:9). There are, in addition, both legal and sociological conceptualizations of 'the family'. It is clear, that there is neither consensus as to what constitutes the family nor a concept of a 'traditional' family. The fact that HIV affects social networks beyond the 'nuclear family' (comprising two parents and children living in the same household) has meant that researchers have had to re-examine definitions of the family. The social networks of African families are of

particular relevance in this research as the devastating impact of HIV disease on African families has been the subject of considerable research (Schubert, 2003:27).

The African family is characterized by numerous bonds which range from consanguinity, affinity, adoption, and propinquity, to surname identification. The extended family in Africa is not merely a large social network (FAD, 2003:26). It has important functions with regard to production, economic and social support, and socialization of new members and may be characterized by several key features: it is a kin-based group usually living in close proximity (although some may have migrated or dispersed for economic, social or political reasons) who can identify a common household head, who recognize reproduction as being central to the survival of the clan, and who co-operate in economic matters, among other spheres of activity (Hosegood, Herbst & Timaeus, 2003:42). Ainsworth and Semali (1995:61) note, that traditional African families have had to adapt to the pressures of economic stress, urbanization, education, Christianity and neo-colonial cultural influences which in some cases, have weakened bonds. It is not within the scope of this research to provide a comprehensive account of how the African family deals with illness, preventive treatment and death. According to Bachmann and Booyesen (2003:27), it is important to stress, however, that illness and death have a profound effect on all spheres of family life, including the social, economic, reproductive and political functioning. An epidemic such as HIV disease has a ripple effect throughout the family and kin system, threatening their capacity to adapt and replace some of the functions and roles that each member is expected to uphold.

The advent of HIV disease has prompted researchers to re-examine accepted definitions of the family and to take into account the diverse social networks affected by the disease. The 'meaning' conveyed by the term 'family' probably relates to the setting or culture in which the family is studied (Desmond & Gow, 2001:40). For the purposes of this research, biological (blood) relationships will be viewed within the context of family functioning. A broad definition of the family, incorporating this idea, is offered by Menon (1998:326)

who posits, that family members are individuals who by birth, adoption, marriage, or consanguineous commitment, share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need.

This research defines the family and reviews key studies describing the impact of HIV/AIDS on the family. This is discussed in the context of communication within the family, how the family copes with illness, and changes in the roles and structure in the family.

2.3 IMPACT OF HIV/AIDS

2.3.1 The social impact of HIV/AIDS

2.3.1.1 HIV/AIDS and the family

Most studies of the psychosocial implications of HIV/AIDS have been focused on the individual. This sub-section reviews the small but growing body of research into the impact of HIV/AIDS on the family system (McDonagh, 2001:16). The impact of HIV/AIDS on the family, is discussed in terms of social stigma, isolation and secrecy, stress and coping, social support, communication and disclosure, responses to illness, and changing structure and roles in families. It is anticipated that in the 2000's, the study of the family will become a dominant topic in HIV/AIDS-related research (Niyongabo, 2001:36).

Since the beginning of the epidemic, the HIV (Human Immunodeficiency Virus) virus has been viewed as a social problem that has repercussions for relationships by virtue of the social stigma and isolation experienced by those affected, as well as the fact that HIV is transmitted among others, through sexual contact (Namposya-Serpell, 2000:29). Published research in the 1980s and 1990s has described the implications of HIV virus for the individual, rather than for the family or other social systems. Yet, for every person infected with HIV, there is a family and social support system that will also be affected (Mutangadura, 2000:30).

The family is probably the most important social system that people inhabit and their risk for or adaptation to illness is best understood within this context. As the problems faced within the family and other support systems become clearer, there is likely to be a shift in focus in HIV care in the 2000's from the individual to the family system (Nandakumar, Schneider & Butera, 2000:6).

Distinctions can be drawn between theoretical writings and research studies, and between quantitative and qualitative research methods. This is because family therapists, as well as a range of social scientists have become interested in this topic. The 'scientific' literature comprises case studies, clinical reports, process research and empirical studies. Even though the results of all of these are included in this research, it should be possible to distinguish between these approaches by the way in which research is described and reported (Odipo, 2000:9). There is a certain danger that non-empirical research studies may propagate many of the unsubstantiated myths surrounding this sensitive area.

It has not been possible within the scope of this research to include a thorough review of all issues which relate to HIV/AIDS and the family. For this reason, the researcher has addressed the key areas believed to be of specific interest and relevance to family therapists who may require some insights into the range of problems and issues that may arise when treating families affected by HIV/AIDS in the therapeutic setting (Mturi & Nzimande, 2003:15). From the researcher's experience, these often include themes relating to social stigma, isolation and secrecy, stress and coping, social support, communication and disclosure, response to illness and changing structure and roles in families. There have been surprisingly few studies in literature addressing the important issues of the economic impact of HIV/AIDS on the family (Silomba, 2002:19).

2.3.1.2 Social stigma

It is common knowledge that people react differently to the threat or confirmation of illness. What is striking about families affected by HIV/AIDS is that, among many of the issues that most families face in dealing with an ill

member, the additional issue of social stigma associated with the diagnosis will also arise (Topouzis, 1994:27). The marginalization of people with the HIV disease, is as a direct consequence of their sexual behaviour or drug use, fear of an infectious disease, as well as social unease with death and dying. Some authors view infection with HIV as the fault of the individual and AIDS as punishment for immoral or offensive behaviour (VSO-RAISA, 2003:67).

Disclosure of the diagnosis in the family, may confront its members with revelations about lifestyle or behaviour, such as infidelity. Even though there is some evidence of more enlightened views towards this stigmatized population, Steinberg (2002:17) notes, that on a global scale, there is increasing discrimination against people with HIV infection. Family members are also affected by a social stigma and may experience rejection from friends, loss of jobs and harassment, as well as more subtle gestures such as neighbours not visiting and children and not being invited to parties.

2.3.1.3 Isolation and secrecy

Social isolation resulting from a fear of stigma is one of the most challenging problems faced by the families affected by HIV. On the one hand, family members may draw a boundary between the family and others outside this system by not disclosing the diagnosis to more distant relatives, friends, close colleagues and others who comprise the social support system. There may also be secrets within the family unit where children are not told the diagnosis or elderly parents are 'protected' from the news, where there is a belief or myth that this would compromise their health. Secrets 'involve information that is either withheld or differentially shared between or among people' (Waller, 1998:31).

There is an important difference between secrets and confidential information. The latter may be viewed as a secret shared between a group of people who have an interest in knowing this information and in withholding it from others. It is appropriate that some information is kept confidential within families, and this may be determined by boundaries between generations and relationship sub-systems (Lundberg, Over & Mujinja, 2000:10). It is generally

inappropriate, for example, for children to be part of a discussion about the parents' sexual relationship. Developmental issues may also come into play. What is said to a five-year-old about sex and reproduction is probably different from what is said to a thirteen-year-old (Caiaffa, 2003:76).

Secrets may have both positive and negative consequences. The aim of protecting others from adverse consequences may be viewed as a positive or functional aspect of secrets. On the other hand, secrets in families may reveal dysfunctional relationships and be physically or psychologically damaging (Bautista, 2004:23). Where an HIV-infected man refuses to inform his wife of his diagnosis, for example, and to take precautions during sexual activities to protect her, the destructive sequelae of secrets clearly outweigh any positive consequences. It remains to be seen whether secrecy-related problems in HIV/AIDS diminish as social stigma towards those affected decreases (Lamptey, Wigley & Carr, 2002:17).

2.3.1.4 Stress and coping

Stress is commonly seen in family members who may react to news of the diagnosis with disbelief, shock and confusion. The feelings experienced by family members where someone is dying, may include guilt, helplessness, depression, anger, confusion and despair. There may be more rules prohibiting emotional expression, greater anxiety about illness and less trust in families affected by HIV/AIDS (Mallmann, 2003:45). This may be a further manifestation of pre-existing relationship problems in the family, in addition to the stress arising from illness in the family and a fear of social stigma. For this reason, it is reasonable to conclude, that families affected by HIV/AIDS may face more complex problems in their adjustment to, and coping with, illness than other families having to deal with death and dying (Ross & Deverell, 2004:61).

Many families affected by HIV/AIDS experience similar concerns or fears. In two studies of families affected by HIV disease, certain themes emerged from interviews with patients and their families. Urban families in Uganda and patients attending a London hospital (Thwe, 2004:15) described and ranked

their main fears about illness in the family. The fear of the death of a loved one, concern over the burden of care (both physical and psychological) of a sick family member and a sense of despondency and failure about the future, were commonly raised. Fear of becoming infected (through social or intimate contact), and helplessness may also be experienced at different stages in the course of illness (Mwaluko, 2003:47).

Some family members may become immobilized by not being able to identify the challenges and problems facing them or to assign priority in dealing with them. Stress of this kind can become 'infectious' while others may start to doubt their ability to cope and manage their stress (Parker & Muwandarara, 2002:29). A cycle of symptomatic behaviour may follow in which depression in one family member triggers either same or its complement in another (Kidane, Banteyena & Nyblade, 2003:12). This, in turn, may be exacerbated by secrets about how family members appear to be coping. Some families function best by 'putting on a brave face' and concealing their hurt, anger, disappointment or anxiety. Others may become overwhelmed by their reaction and seek counselling and psychotherapy in order to allow them to manage their anxiety and to find more adaptive ways of coping with stress (Groenewald, 2005:67).

Family members may display the same psychological symptoms as the infected person, ranging from fear, anger, agitation and withdrawal, to anxiety and depression (Hepburn, 2002:36). This, in turn, may lead some family members to feel as if they are 'toxic' and to resist getting emotionally close to others (Coombe, 2003:9), which may serve as a protective mechanism against a fear of rejection. In contrast, the need for social support and close emotional attachments may be at its greatest at times of personal stress, misfortune and for those affected by illness (Dickinson, 2003:50). Obstacles to adjustment, acceptance and reconciliation between family members may arise at different stages in the course of illness as issues about lifestyle and blame re-emerge. The stress that emanates from these conflicting forces, can lead to suicidal thoughts, paranoid beliefs and even psychosis (Brown, 2003:49).

Arguments, threats, accusations, alcohol and drug abuse, and treatment non-compliance may be symptoms of psychological problems in families, arising

from ambivalent feelings between members. Periods of stress and anxiety in a family do not automatically lead to a crisis and symptoms of psychopathology. However, some families may experience ongoing stress and may lose the capacity to differentiate between adaptive and dysfunctional coping (Asamoah-Odei & Calleja, 2004:16). Behaviour in the family may become dysfunctional where reality is denied (for example, in a family where both parents are infected with HIV, yet make no provision for the future care of their children), or where illness becomes the only reality that they attend to (for example, day-to-day activities are neglected). As with all families which experience or are threatened by rapid and profound change, there is an increased risk of psychological problems. This risk is probably greater where external support networks, such as the extended family and friends, have not been told the diagnosis and are, therefore, excluded from providing a supportive and normalizing experience for the family (Chakraborti, 2006:90).

Studies which compare stress and coping in families affected by HIV who have engaged external support systems with those who have not, will throw light on this important issue.

2.3.1.5 Social support

Studies of social support and emotional well-being have demonstrated, that people with AIDS report fewer feelings of depression and helplessness if they have close friends or relatives to talk to about emotional and illness-related problems (Ekra, 2004:16). People with HIV who fear disclosing their negative status to others and are socially isolated, may be at increased risk in respect of psychological problems. Experiencing of psychological problems, is positively correlated with sedative use, traumatic stress responses and uptake of psychological services (Gaillard, 2004:15).

Contact with friends and other caregivers may decrease with the onset of illness (Keeton, 2002:26). Mothers and close friends have been found to be the most supportive of all caregivers. Even though social support may act as a buffer against stress for people with HIV, caregivers may themselves require support in order to carry out their tasks (Meyer, 2003:82). In some cases, the

physical manifestations of illness, including fatigue, weight loss and skin complaints, may have interfered with their capacity to enter into and maintain relationships.

2.3.1.6 Communication and disclosure between adults

Foremost, among the problems with implications for relationships that people infected with HIV may face, is information about the disease and the person's condition, and the dissemination thereof. The fear of social stigma and the loss of relationships resulting from disclosure of HIV status is a powerful force that may lead to secrets or deception in relationships. A decision to inform others of the diagnosis, carries the risk of a double disclosure: it may simultaneously reveal a previously hidden lifestyle (Nemoto, 2004:27).

While stigma-related experiences or a fear of stigma are commonly discussed by people with HIV, researchers are only beginning to study patterns of disclosure of the HIV status in families. Contrary to some popular wisdom, there is now evidence to suggest, that most relationships seem to endure the crisis of disclosure. In a study of HIV-infected women in Kenya attending an antenatal clinic (Oliver-Smith, 2004:10), two-thirds of the women had told their partner their diagnosis.

Approximately 7% of the sample reported, that they were separated or divorced as a result of the disclosure, although many of the other women found that the stress arising from the diagnosis disrupted their marital relationships. Failure to communicate, stemmed from a fear of anticipated consequences, including disruption, separation or abandonment, which in turn may lead to a loss of economic and social support. Those who were widowed, tended to remain unmarried. Pick's (2003:26) results can be compared with those from a similar study in Zimbabwe. Of 69 HIV-infected patients, 51 had a steady sexual partner, of whom 31 were informed of the positive test result. Fifteen were unwilling to inform their partner and a further five were not told because they lived and worked far away (Solomon, 2004:156). Reasons for non-disclosure related to a fear that the relationship would break up, and feelings of guilt and fear of rejection. Living together, was found to be a

decisive factor in whether to inform a partner: 23% of relationships in which the partner was informed, did indeed break up. It is unclear whether this was as a direct result of the disclosure, or whether the disclosure highlighted or exacerbated an existing problem in the relationship (UNAIDS, 2005:17).

Although most relationships undergo some change where either or both spouses are infected with HIV, it is not possible to predict the nature and outcome of these changes (Walker, 2004:11). Some couples, for example, may become closer, others remain companions but cease sexual relations, while some relationships end abruptly or deteriorate over time. In spite of health prevention efforts of carers and counsellors, the disequilibrium that results where one partner is infected, may result in sexual risk-taking in order to restore a balance in the relationship (USAID, 2002:31). Either or both partners may also experience increased alienation in the relationship as they adapt to and cope with HIV in different ways. A proportion of families will seek counselling and therapy to deal with relationship problems (Van Dyk, 2005:20).

2.3.1.7 Communication and disclosure between parents and children

The dynamics of relationships between parents and their children and disclosure of HIV/AIDS to them is a more complex matter. Infants and children may be either infected with HIV or affected by other family members who are themselves infected. Most children worldwide who have been diagnosed with HIV infection, were infected perinatally and for this reason the mother and possibly other family members will also be infected (Sullivan, 2004:12). Parents face the difficult task of achieving some balance in the child's life between normal routines and the added demands placed on all spheres of life brought on by illness (Walker, 2004). Whether or not the child has been infected with HIV, there is a chance that children in the family will become orphans, which may lead to social and emotional deprivation (Rhodes & Simic, 2005:221).

Parents of an HIV-infected child face the dilemma of 'if, 'how' and 'when' to tell their child his or her HIV status. Most research into this problem has been

conducted with families in which the child was infected through contaminated treatment for haemophilia (Mugurungi, 2005:23) or through blood transfusions. In most of these cases, there is a greater chance that only the child in the family has been infected. The issue of disclosure to non-infected siblings in the family has been addressed in clinical practice, but has not been the subject of research (Kelly, 2002:17).

In a study by Giese (2003:30) the majority of parents (80%) had not told their HIV-infected child the diagnosis even though their average age was ten years, while most children presumably would be aware of health-related problems as a consequence of regular visits to the hospital. Some reasons parents gave for the disclosure, were: 'I knew it was the right time', 'We disclosed in response to our child's negative comments about AIDS' and 'There was unplanned disclosure in the emergency room'. The terminology used by parents when breaking the news to their child, was varied: 'You have bad blood', 'You have something like AIDS', 'Santa Claus will come to take you away when you are asleep' and 'Take your medicines so you won't die'. The reasons given for not disclosing the diagnosis to children, included fear of the child disclosing to others, which may threaten parental confidentiality, fear that disclosure may exacerbate the disease process, and concern about the effect on family stability (El-Rahman, 2004:16).

The stage at which parents choose to disclose the diagnosis to a child, and how they do this, is an important topic as it yields insights into family dynamics and how each member comes to terms with the diagnosis and illness. There is little in the way of research, however, into this important issue and we have no way of comparing the different approaches to disclosure in families and the effects of this on individual and family development (Dixon, McDonald & Roberts, 2002:233).

2.3.1.8 The family's response to illness

According to Booysen (2003:27), most families have to endure a long period of uncertainty about the course of HIV. This is because the latent period before overt clinical symptoms of HIV virus, are diagnosed, can last a decade

or more. The anticipation of a loss through physical illness in the family can disturb the current functioning of each family member who may be immobilized by the fear or dread of facing the loss.

The shift from an asymptomatic to a symptomatic phase of HIV may reactivate stress in the family system. Shock, fear, isolation, guilt, blame, feelings of being overwhelmed and psycho-physiological distress may all resurface (Case, Paxson & Ableindinger, 2004:490), although this is commonly tempered by a measure of relief as the course of illness becomes clearer and more certain (Duncan & Arntson, 2003:16). Family members may be called on to provide greater material and emotional support at this stage. Changes in family relationships may be quite marked at this point of transition, sometimes punctuated by emotional tension, fighting or withdrawal. This stems from anxiety over people's needs not being met or an excess of support, both of which may become destructive to relationships (Corbett, 2002:79).

Family members face a particular dilemma at the symptomatic phase of the disease. On the one hand there is a social expectation that they will offer hope and support to the member who is unwell, while at the same time they are faced with the reality, that treatment and resources may be limited or ineffectual. This can lead to secrets in the family, as some members, including the infected family member who is unwell, are protected from the gravity of the situation (Hargreaves & Glynn, 2002:489).

The family looks inward as the illness progresses and death becomes imminent, and rivalry may surface between family members as they struggle to redefine their relationship with the dying person. At this stage, the parents, siblings and, where appropriate, the patient's partner, become the most important source, of emotional support (Mohlala, 2002:20). There may be arguments about approaches to care and decisions about advanced life support directives such as resuscitation (Pretorius, 2002:35). Friends and more distant relatives may seek to create some distance between themselves and the family by decreasing their contact and visits through fear or a difficulty in dealing with separation, loss and dying. Themes of blame and guilt may resurface and may serve to protect family members from the emotional pain

relating to '.....separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, exhaustion and desperation' (Van Aard, 2002:43).

The feelings may be both intense and ambivalent; there may be a desire to be closely and deeply connected with a family member and, at the same time, a need to escape the emotional pain and a longing to feel disconnected from the person and the problem (Riono & Jazant, 2004:221).

2.3.1.9 Changes in family structure and roles in the family

In addition to the profound psychological changes that a family may undergo when confronted with illness relating to the HIV disease, important changes in the structure of families can also be observed. Illness almost always places a financial burden on families. This results from the direct costs of care and treatment and the disruption caused by loss of productivity (Phimphachanh & Sayabounthavong, 2004:96). Where ill health interferes with the family breadwinner's mobility and employment, income may need to be replaced by other family members. In some cases, the role of the breadwinner cannot be substituted or replaced by others, either because they are too ill themselves to work or they are fully committed to caring for other family members who may be unwell. This scenario is now all too common in parts of Sub-Saharan Africa (Murphy, 2004:67).

Changes in the structure of the family may become evident at different stages of illness or points of crisis. Assumptions may have been made about who is the next-of-kin, as this may not have been openly discussed in the family. There may be a need to clarify who has responsibility for making decisions on behalf of the patient if his or her health were to deteriorate (Mateo, 2003:44). Where both parents are infected their children will be orphaned. As the number of 'AIDS orphans' worldwide increase and the extended family becomes overburdened with orphans, an increasing number will have to be cared for in institutions rather than within the extended family. Those not accommodated will grow in child-headed households or become street children (Hien, 2004:16).

Traditional views and attitudes towards sex, marriage and emotional bonds between spouses may result in sexual risk-taking in spite of health education messages (Chimwaza & Watkins, 2004:798). Termination of the mother's childbearing has profound implications not only for her nurturing role, but also for the family's relationship with the extended family and the community, and for future economic security. Even where targeted counselling is offered to couples where one or both partners are infected with HIV, there may be an overriding desire to have a child (Birdthistle, 2004:39). There may also be periods of 'relapse' into unsafe sexual practices as a means of revitalizing or redressing the balance in a sexual relationship in which one partner is infected (Chisholm, 2004:208).

Normal developmental patterns are reversed in the HIV disease. Children may die before their parents, leaving grandparents to look after themselves at a time when they might have looked forward to increased support from their own children. Grandparents may have to take on the responsibilities of a parent once again and care for grandchildren orphaned by the loss of their parents. In other cases, young adults come home to die at a stage where children would be establishing themselves away from home (Human Rights Watch, 2005:16).

2.3.1.10 The impact of bereavement on survivors

Research in social psychiatry has demonstrated that the death of a partner, spouse or other relative can affect the psychological and physical health of survivors or others who are bereaved. Furthermore, caregivers increasingly have to address the psychological needs of children and adolescents whose parents have died from AIDS (Kayirangwa & Hanson, 2004:35). These findings have important implications for those affected by HIV, as some of those who are bereaved may themselves be infected with HIV. Recent studies have sought to investigate whether bereavement has an adverse effect on the function of the immune system; whether survivors infected with HIV progress to AIDS more quickly than others who have not experienced bereavement; and whether social support buffers people infected with HIV from stress and the deleterious effects of adverse life events. Results of a study (Mbulaiteye,

2002:27) suggest that the survivor's immune system is not adversely affected by an AIDS-related bereavement. The effects of the death of a partner on depressive symptoms, anxiety and morale in both HIV-infected and non-infected gay caregiving men, was also investigated. Results of this prospective study revealed that prior to the death of the partner; HIV-infected caregivers were less distressed than those who were not infected. The profile was reversed after the death of the partner: HIV-infected partners displayed greater distress than did the non-infected men. The latter may have experienced relief after the death of their partner, while HIV-infected men were left on their own to confront their disease (UNAIDS, 2004:17).

In parts of Africa which have been heavily affected by deaths resulting from AIDS, rituals associated with funeral arrangements and mourning have had to be abandoned. Financial and other demands on kinsfolk and neighbours have become a significant burden as a result of multiple deaths (Tawfik & Kinoti, 2002:20). The survival of some clans in Africa could be threatened by a lack of available marriage partners for both young adults reaching maturity and those who have been widowed. A trend towards marrying very young women, who are seemingly free from infection, has also been noted (Rugamela & Akoulouze, 2003:46).

2.3.1.11 The burden of care and women exploitation

Women and girls tend to provide most of the care for sick individuals, but men do play an important (albeit less full) role, especially in the care of other men. Also, the differences in the time spent on care between women and men, may not be as great as sometimes assumed, although the evidence is incomplete (Pokrovskiy, 2005:26). A survey of households affected by HIV/AIDS in several provinces of South Africa found, that in more than two thirds of households, women or girls were the primary caregivers. Almost a quarter of caregivers (23 per cent) were over the age of 60 while just under three-quarters of these were women (Kelly, 2002:46). Similar findings were seen in Zimbabwe. There, most people caring for children orphaned by HIV/AIDS, were over 50 years of age. Of those, over 70 per cent were 60 years or older. The stress of caregiving was clear. Caregivers report regular concerns about

adequate food and clothing, the high cost of medical fees, and an inability to pay school fees for orphans. Indeed, the health of the older caregivers had deteriorated as a result of the physical and emotional stress of assisting the children (Hargrove, 2005:36).

The burden of care on households is significant. A study of urban and rural households in the Free State Province found, that caregivers devoted four hours a day to care for sick relatives, including additional time to accompany a sick relative to a health facility (Gwyther & Marston, 2003:29). Interestingly, for most caregivers, the assistance they provided came on top of regular work. When a person became terminally ill, the time devoted to care nearly doubled to 7.5 hours per day. A household survey in Côte d'Ivoire found no respondents with AIDS hospitalized over the four months of the last survey round, indicating that care was provided at home (Hunter, 2002:103).

Further, urban-based relatives often return to a rural home when they become too sick to work or care for themselves, thereby shifting primary caregiving to family members. On the other hand, some rural-based civil servants apply for transfers to urban posts when they become ill, so as to be closer to medical facilities (Fares, 2004:33). Caregiving involves opportunity costs. In South Africa, 40 per cent of caregivers took time off from work or income-generating activities. Children took time off from school or studying in order to provide care. Food production and household chores all suffered in lieu of caregiving in 60 per cent of affected households (Bogardi, 2004:76).

Women and girls face an inordinate burden in the era of HIV/AIDS. Not only are girls and young women at a greater risk of HIV/AIDS than their male counterparts, the impact of household illnesses and deaths causes greater sacrifices by females. This is not to minimize the impact of HIV/AIDS on boys and men, but economic, social and cultural patterns place males in more favourable positions to cope with the impact (Askew & Berer, 2003:55). Existing gender inequalities intensify along with the pandemic. Gender inequalities are likely to be intensified by the presence of HIV/AIDS. Women may have to give up jobs and income earning to care for a sick spouse or relative. The burden of caregiving falls primarily on women, and that burden

carries over into dealing with the possible loss of assets to relatives upon the death of a husband. Girls tend to be withdrawn from school earlier than or rather than boys, to assist with caregiving, household chores and family income support (Duraiappah, 2004:26).

There are widespread anecdotal reports of men seeking younger girls for sexual purposes, including under twelve years of age, on the assumption that the girls are not HIV-infected or that the man will be cured of his infection. Girls in households affected by HIV/AIDS are twice as likely as boys to have dropped out of school, because families could not pay the school fees or needed the children for household help (Letteney, 2006:69). In addition, girls and women are subject to sexual exploitation and abuse. A study in Kenya found, that the most important reason for high infection rates among girls, is the frequency of sexual intercourse with older men. "Sugar daddies", as they are known around the world, seduce naïve and impressionable girls with offers of cash, consumer goods, and supposed status (Maman, 2000:460). In the war-like conditions of Burundi, the threat of forced sex is a weapon used by men against women and girls. In turn, women and girls may agree to sexual relationships in exchange for some level of physical and material security. Household violence toward women and girls is increasingly being documented and linked to HIV/AIDS transmission. Girls who have been orphaned by HIV/AIDS and who lack strong family support and peer networks, may become vulnerable to further sexual harassment and exploitation (Monze, 2004:16).

Lack of appropriate legal mechanisms to address such abuse, creates conditions where this can continue. Amongst children aged five to fifteen, sexual abuse by older males may well account for the majority of, if not all new HIV/AIDS infections. This is partly a reason for the major disparities in HIV/AIDS infection rates between adolescent girls and boys (Mudandi, 2005:37). For example, in major urban areas of eastern and southern Africa, epidemiological studies have shown that seventeen to 22 per cent of girls aged fifteen to nineteen are already HIV-infected compared with three to seven per cent of boys of similar age. In addition to possibly becoming the

head of a household, women face other burdens. A study in the early 1990s in areas of Uganda highly affected by HIV/AIDS, noted the following potential situations faced by widows (Ono-Kihara, 2001:158). The scenarios can be applied to many societies. Women may experience:

- the loss of land and perhaps the right to use the land;
- the loss of their property to the husband's family, unless the husband has left a will. Women often do not inherit property when their husbands die;
- being brought into a relationship with the late husband's brother or other male relative, otherwise they may be forced to return to their maternal home;
- assuming sole responsibility for the children, with limited outside support;
- a significant loss of cash income;
- the loss of access to support services that traditional go to men, such as agricultural services and the loss of farm production knowledge for work done by men; and
- an increased workload as they struggle to meet basic needs (Schiff & McKay, 2003:106).

The report further notes, that HIV/AIDS contributes to a dramatic rise of female-headed households and that many of these women are younger, with young children, than previously has been the case of female-headed households (Department of Health, 2005:24).

Most female-headed households tend to be among the poorest in communities across Africa. Again, HIV/AIDS is intensifying, if not deepening, the gender inequities of society. In western Kenya, a study found, that some households cope with the loss of an adult member by encouraging the marriage of a teenage daughter in order to gain the financial assets (i.e., cattle or other livestock) of a dowry (St John, 2003:28). The same study noted, that in households in which a female spouse had died, children were likely to be

sent to live with relatives or in other households. In contrast, the death of a non-spouse female adult is associated with an increase in the number of boys in the household. This is most likely to help out with household activities formerly handled by the now-deceased female adult. This indicates, as might be expected, that the effects of adult death do not depend only on the age and gender of the deceased, but also the position of the individual in the household (Zhang, 2004:40).

HIV/AIDS is costly to most households and communities. During periods of illness, medical costs rise, work and income are disrupted, family members are drawn away from work in order to provide care and in some instances children have to work to supplement household incomes (UNAIDS, UNIFPA & WHO, 2004:18). After death, funerals can be costly, sometimes more than the amount previously spent on medical care. The loss of an adult undermines a family's income-generating abilities, adding to the work burden of surviving family members, including children. AIDS-affected families may experience rapid transition from relative wealth to relative poverty (Mendel, 2002:32). For poorer and rural households, the ability to cope with external shocks, such as drought or increases in the prices of staple products, will be reduced further. What stands out from numerous studies over the past decade, is how HIV/AIDS induces impoverishment of many (but not all, and how many in a particular community or region is unclear) affected households. Income is lost and assets are sold or rented in order for those concerned, to get cash. Widespread disinvestment of assets appears to be occurring as households spend their savings and wealth to cope with HIV/AIDS. This section sets out some of the economic conditions that follow HIV/AIDS (Mahomva, 2004:17).

2.3.1.12 Orphaned Children

As young and middle-aged adults die of HIV/AIDS, hundreds of thousands of children are orphaned. The growing number of orphaned children is most evident in southern and eastern Africa, but such girls and boys can be found wherever HIV/AIDS is present. In Sub-Saharan Africa, an estimated eleven million children had lost their mothers or both parents as of 2001; the number is expected to climb to 20 million by 2010 (Avert Organisation, 2005:26).

Although children are orphaned for a number of reasons, by 2010 in Zambia, Swaziland, and Namibia, 75 per cent of all orphans will result from AIDS (Coombe, 2003:5). Though the absolute numbers are important, perhaps more important, is the speed at which the numbers are increasing, indicating the mushrooming pressures on households, communities, government services, and civil society to address the needs of orphaned children. Local community leaders regularly report that their groups are overwhelmed by the number of orphaned children they find and who need various forms of assistance (Clinton, 2003:18).

In addition to the daily care of people ill with HIV/AIDS or related illnesses, the care of children while a parent is dying and after the death, is a major burden for immediate and extended families. Increasingly, one hears that the extended family system is overwhelmed by the magnitude of the burden of caring for so many orphaned children (Chakraborti, 2006:91). The changes in living arrangements, well-being and opportunities for a secure future for children are of the most significant long-term outcomes of the HIV/AIDS pandemic. Although HIV/AIDS is but one cause of orphanhood, it plays an ever-increasing role in removing parents from their children (Butler, 2005:16). A sizeable portion of children in southern and eastern Africa are orphans. For example, one study found, that almost a quarter (22 per cent) of all children under the age of fifteen in the South African sample, were maternal orphans in that they had lost either their mother or both parents. The greater number of these orphans are girls (Duncan & Arntson, 2003:27).

Children experience the stresses of parental illness due to HIV infection. They may be withdrawn from school in order to reduce expenses as medical costs rise or to assist in the care of the sick relative. The emotional upheaval of seeing a dying parent, may leave children feeling abandoned and so have to increase their susceptibility to sexual abuse. A study in South Africa found, that illness or death had resulted in twelve per cent of households sending children away to live elsewhere (Giese, 2003:27). Some children are encouraged by parents or foster parents to work to supplement household incomes. Others work out of economic necessity. An already bad situation is

then exacerbated by the fact that many of these children wind up in the worst forms of child labour. Most working orphans surveyed in a study in Tanzania, complained of a whole complex of problems, among them going without food, forced initiation to commercial sex work, and failure to receive wages (Lamptey *et al.*, 2002:120).

Recent ILO-sponsored surveys in Tanzania, South Africa, Zambia and Zimbabwe (Chimwaza & Watkins, 2004:797) confirmed the linkage between HIV/AIDS orphanhood and a likelihood that a child would frequently work outside of the household and in conditions that are sexually and economically exploitative and prone to harassment or violence. Orphaned children in Zambia have been found to be twice as likely to be working as non-orphaned children (Mallmann, 2003:65). At home, once a household member became ill, the children's participation in domestic and farm work increased, often interfering with schooling, and being detrimental to health. AIDS orphans were also found to shoulder a big portion of the household and farm chores in foster homes (Murphy, 2004:71). Although most children are cared for within some family arrangement, there are a significant and growing number who have lost both parents and live in child-headed households without an adult presence. It is estimated that nearly seven per cent of Zambia's nearly two million households are without any adult member, and are headed by a boy or a girl aged fourteen or younger (Rhodes & Simic, 2005:20). Surveys found between two and four per cent of children in Gweru, Zimbabwe, lived in child-headed households.

A similar survey in Tanzania found, that over nine per cent of children lived on their own, essentially heading a household at least where a house and living arrangements actually existed. While they represent only a small proportion of all households, child-headed households and children living on the street without any adult supervision, present an especially important challenge for policy-makers, programme planners, and service agencies alike (Thwe, 2004:175). The existence of children living on their own, is a new phenomenon in Africa and is a manifestation of social disruption and social inequalities associated with HIV/AIDS. Child-headed households exist

because no relatives are left to care for the children, or else the surviving relatives are already too burdened to adequately care for the children they have inherited (Sullivan, 2004:62). Many children who become household heads, have little other option but to seek work to support themselves and their siblings. Stories exist of older children earning the cash to keep younger siblings in school; however, continued schooling for any of the children in these households is problematic. Orphaned children, including children in households with a parent ill with HIV/AIDS or related illness, may find their education cut short and future economic opportunities compromised (Hunter, 2002:111).

Children from families where one or more adults are HIV-infected, are more likely than are children in non-affected households to be withdrawn from school because families can not afford the school costs, need the children to help supplement household income, or need them to help care for sick relatives (Van Aard, 2002:34). These trends are especially evident in countries with high HIV/AIDS rates and where school fees and costs are relatively high for low income groups. In Zambia, rural orphaned children have a 20 per cent higher rate of non-school attendance than have non-orphaned children (UNAIDS, 2005:16). In western Kenya, 20 per cent of households with orphaned children report having no children in school, primarily because of lack of money. Girls, more often than boys, are withdrawn from school or have an entry to postponed (Binagwaho, 2005:11).

2.3.1.13 Changes in extended family systems

One of the major issues arising from the impact of HIV/AIDS on households, is the ability and willingness of extended family members to assist in the care of remaining family members, especially children who have been orphaned. As noted earlier, a prevailing assumption in many national HIV/AIDS policies is, that "traditional" family structures could and will cope with the pressures caused by the epidemic (Clinton, 2003:26). A growing number of field studies bring that assumption into doubt. Particularly in light of major social and economic changes of the past several decades (and stretching back well into the colonial era), what is often referred to as the "extended family" takes

numerous forms across Africa and offers numerous variations on coping with the impact of HIV/AIDS (Kelly, 2002:48). At the most simplistic, family members who have settled for two or three decades (or more) in urban centres may have weak links with their wider family. Social networks may actually have become stronger than family membership for some people (Mahomva, 2004:16).

Families which have little contact with their extended family members, have greater likelihood of orphans being abandoned, should the current caregiver die. While it is not an either/or situation (i.e., extended families are coping or they are not), it does appear that HIV/AIDS is inducing new pressures on many families that increasingly find it difficult to cope (Rugalema & Akoulouze, 2003:35). A good portion of the burden of support for affected families and family members falls to older adults. A study in rural Zimbabwe found that grandmothers were the primary caregivers for orphaned children or children left behind when one or both parents went to look for work (or land) elsewhere (WHO, 2005:28). Another study in Zimbabwe found, that half of all foster parents for orphaned children were grandparents and that over 60 per cent of fostering households were headed by women (Asamoah-Odei & Calleja, 2004:76).

A study in KwaZulu-Natal found, that 57 per cent of households caring for orphaned children were headed by women who, on average, were 59 years old i.e. likely to be grandmothers (Giese, 2003:27). Yet a fourth study from rural southern Zambia, found that nearly 70 per cent of all households caring for orphaned children, were headed either by a woman or an elderly person. In other cases, relatives with jobs, are expected to play a larger role in direct support for extended family members (such as fostering a child) or indirect support (providing money for medical expenses or school fees). It is not unusual in eastern and southern Africa to find salaried workers supporting two, three or more extended family members with their earnings (Case, Paxson & Ableindinger, 2004:485).

2.3.1.14 The dissolution of households

Under the impact of HIV/AIDS, it appears that a significant number of households cease to exist, especially if the deceased is a woman. A widowed woman may return to her home community and some of the children are dispersed to other relatives. If both parents die, the children are likely to live with other relatives, or, as noted, care for themselves (Booyesen, 2003:26). In a study covering both rural and urban areas of Zimbabwe, 65 per cent of the households where the deceased adult female used to live before her death were reported to be no longer in existence. Other studies have found, that deceased wives are more likely to be replaced – the widowed man remarries (Cheluget, Marum & Stover, 2004:63). However, the children from the previous marriage may still be sent away, and so remarriage does not necessarily mean that the members of the original household stay together. Either migration or dissolution seems to follow the death of an HIV-infected responsible adult in a family, according to a study in rural KwaZulu-Natal Province, South Africa (Groenewald, 2005:104). There, households where an adult member has died of HIV/AIDS or related causes, were nearly three times more likely to have dissolved by the end of the year than were other households. Another aspect of household change is that where a married woman may leave her husband to care for a parent or for siblings who have been orphaned (Kidanu, Nyblade & Rohini, 2003:39).

2.3.1.15 Loss of income

The economic impact of HIV/AIDS is significant and often dramatic in terms of a change in income, asset wealth and longer-term prospects for economic security. A study in KwaZulu-Natal, South Africa found, that households that had experienced a death in the previous 12 months (not only from HIV/AIDS, it needs to be pointed out), had a mean monthly income equal to only 64 per cent of households that had not experienced a death (Parker & Mundawarara, 2002:26). Another South African study in the Free State Province found, that HIV/AIDS-affected households tended to have monthly incomes one-third less than have non-affected households. In the Côte d'Ivoire, the income of

affected families was half that of the total average household income (Pick, 2003:33).

2.3.2 The impact of HIV/AIDS on children

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

2.3.2.1 Growing up with the HIV Epidemic

HIV and AIDS are brutal escalators of other cruelties which children endure. In today's world the majority of people living in poverty are women and children. Three-quarters of the 24,000 daily deaths (more than 8 million every year) related to hunger, are among those under the age of five; The Hunger Project (Dean & Moalusi, 2002:26). One hundred and twenty million children between the ages of 5 and 14 work in conditions hazardous to the healthy growth and development (ILO). Estimates suggest that as many as 100 million children worldwide are homeless or spend most of their time surviving on the streets (WHO/EMRO, 2005:12). Massive populations of families with children are displaced and often separated because of conflict and natural disasters. According to the United Nations Expert Report on the Impact of Armed Conflict on Children, prepared by Graça Machel, more than half of the near 60 million people displaced by war, are children, with millions separated from their families (El-Rahman, 2004:20). Millions more have been injured, disabled, orphaned and have died in armed conflict. Children are used as soldiers and forced to kill; raped by soldiers or made to watch their mothers and sisters being raped and their families murdered. Added to these, children are victimised and trafficked as commodities for sale in local and global sexual prostitution and pornography industries (Montgomery, 2003:29). Estimates are that at any time, as many as one million children are involved in the commercial sexual exploitation arena every day. (ECPAT, World Congress against Commercial Sexual Exploitation of Children). Countless others are

physically, sexually and psychologically abused in what should be the secure confines of their homes and neighbourhoods (Murphy, 2004:60).

The roles that children fill as poor, hungry, exploited and abused human beings, increase their vulnerability to HIV infection. This can occur directly through those activities known to be associated with transmission, or indirectly as occurs when earlier harm turns children into vulnerable adults (Prabhu, 2004:4). For example, those which have a history of childhood physical or sexual abuse have also been found in adolescence or adulthood to be more likely than non-abused peers to engage in behaviours that place them at high risk of HIV infection (Giuliane, 2005:29).

Children and young adults currently between the ages of 15 and 24 were born and grew up as the first generation to experience childhood during the HIV/AIDS epidemic. Today it is among this same population of 15 - 24 year-olds that new HIV infections are concentrated (UNAIDSWHO, 2004:17). According to recent United Nations estimates, more than 50% of the 16,000 new HIV infections which occur daily are within this age group. An additional 10% of new infections occur among children under the age of 15. Since the virus was first identified in 1981, more than 3 million children have been born HIV positive and the mothers of over 8 million children have died from AIDS (Shisana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Jooste & Pillay, 2005:13). By the year 2010, it is predicted, that as many as 40 million children in developing countries will have lost one or both parents to HIV/AIDS. In some countries this is equivalent to one in every 4 to 6 children (Statistics S.A, 2005:16). The effects of HIV and AIDS on children who are orphaned, or in families where parents are living with the virus, not include only these calculable losses, but also the immeasurable effects of altered roles and relationships within families. Clearly HIV infection has its greatest impact on the young (WHO, 2005:18).

Although "childhood" might differ for every human being and numerous interpretations of the concept exist, common to all is a period in the early years of human life, marked by rapid growth and development. During the years of physical growth in which a child matures towards adulthood, the child

is also developing psychologically and in ways that define intellectual, social, spiritual and emotional characteristics (Cheluget, Marum & Strover, 2004:16). The circumstances or conditions, in which this growth takes place, can limit or enhance development. Physical and emotional well being and social and intellectual development can be permanently limited for a person deprived of the opportunities and time to grow and develop successfully during their childhood (Asamoah-Odey & Calleja, 2004:27).

The most universally accepted statements with regard to children and childhood can be found in the U.N. Convention on the Rights of the Child (UNCRC). Having been ratified by all but two member nations of the United Nations, this international covenant can rightfully be utilised as a guide for ensuring universally accepted goals for childhood (Human Rights Watch, 2005:41). The individual articles of the UN Convention on the Rights of the Child address rights related to survival, protection, development and participation that enable a child, a person under the age of 18, to achieve the goals of childhood successfully (UNAIDS, 2005:17). It confirms, as did the Universal Declaration of Human Rights, ".....that childhood is entitled to special care and assistance. This care and assistance are designed to promote and provide for, among other things, the "....full and harmonious development of his or her personality" and ".....that the child be fully prepared to live an individual life in society" (WHO, 2005:8). To this end, the UNCRC declares that the "....family, as the fundamental group of society and the natural environment for growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities in the community" (UNAIDSWHO, 2005:37).

2.3.2.2 Losses for children that last a lifetime

While the majority of the 2.3 million predicted HIV/AIDS-related deaths this year will occur in developing countries, this is also where 87% of the world's 2 billion children will be trying to grow up (Shisana *et al.*, 2005:18). Although life-saving drug regimens have dramatically decreased mother-to-child transmission of HIV and have kept mothers well and alive longer in the

industrialised world, poverty and the lack of necessary social and medical infrastructure and services make them inaccessible in those places where they are most needed (Choi, 2003:25). Many women who know that they have tested positive for HIV, may have no choice but to breast-feed their babies when clean water and formula are unobtainable, even though they risk transmitting infection to their babies (Monitoring the AIDS Pandemic Network, 2005:60). Without access to health care or a nutritious diet, infected infants often die before they are two or three years old. For children who survive longer, for uninfected children whose parents or guardians are incapacitated by HIV/AIDS, and for those who are orphaned, childhood can be dramatically shortened in other ways (Solomon, 2004:16).

The illness or death of parents or guardians because of HIV/AIDS can rob a child of the emotional and physical support that defines and sustains childhood. It leaves a void where parents and guardians once provided love, protection, care and support (Zhang, 2004:39). Since HIV is often (but by no means always) transmitted to sexual partners, children are more likely to lose both parents to HIV/AIDS. Someone is needed to step into parental roles so that children can survive and develop into healthy and productive adults (Binagwaho, 2005:91). Grandparents, aunts, uncles or other caring adults frequently assume responsibilities that enable children to remain in their homes or take them into their own families and households. However, where the infection rate is high or harsh social or economic conditions exist, adults may be unable to assume the additional responsibilities of these families and children affected by HIV/AIDS (Pokrovskiy, 2005:15). Other barriers grow out of ignorance and social attitudes. Fear of discrimination leads to families keeping secret the knowledge of HIV infection and AIDS within the household rather than seeking help. Others seek help, but are rejected or abandoned, even by family members, when they reveal the nature of the illness (Auvert, 2001:15). Fear, discrimination, ignorance, and social stigma associated with HIV/AIDS, in addition to overwhelming demands on caring adults, leave children isolated with their grief and suffering while they watch parents and other loved ones die and their families languish (Thwe, 2004:74).

2.3.2.3 Children in adult roles: working to maintain home and family

In the absence of capable adult caretakers, children themselves take on responsibilities for the survival of the family and home. Undeniably children in most families share duties even when parents are healthy (UNAIDSWHO, 2004:19). In economically disadvantaged communities, a child's contribution is often necessary for the survival of the household. But in numerous HIV/AIDS-affected households, children have not simply increased the amount of work that they do, but have also assumed decision-making and responsibilities that transform roles within families and households (Evian, 2003:69). Children assume adult roles as heads of the household, because there are no alternatives. They care for parents and younger siblings who are sick and dying from HIV/AIDS. They take charge of the care and running of the home for themselves and their siblings (Ntuli, 2004:19). They work long hours doing household tasks, supervising younger children and engaging in income-generating work in order to support the family. Many quit school and jeopardise their own health and developmental needs to take on roles as a parent, nurse and provider (Worthington & Myers, 2003:40).

2.3.2.4 Failing to meet the goals of childhood

In many families and communities the environment for healthy growth and well-being has been devastated by HIV/AIDS. Instead of receiving special care and assistance, childhood is spent providing care and assistance (Salomon, Hogan, Stover, Stanecki & Walker, 2005:23). Children become decision-makers, responsible for the social and economic future of the family, and fill these roles without the physical and emotional protection, guidance and support that, as children, they deserve. They may act like adults, but it cannot be forgotten that these "heads of households" are children, but children whose childhood has been impoverished by HIV/AIDS (Mpiima, 2003:13). In such households, all children are affected. The care that older siblings can provide for younger children, is likely to be inadequate because of the increased poverty of the household and the lack of maturity and experience of the caretaker, leading to poor health, hygiene and nutrition; absence from school, and developmental delays (Montano, 2005:40). The

loss of material, emotional and developmental support from an adult exposes children to the distress which results from lack of affection, insecurity, fear, loneliness, grief or despair. It limits the possibility of a successful childhood which, in turn, affects the future as adults (Jordan-Harder, 2004:8).

In this world where some children are fortunate enough to be loved and nurtured in ways that respect their rights as children and are supported in ways that enable them to become independent, competent adults, while others are treated as little more than property or tools to be used for the benefit and satisfaction of adults, the idea of "treating a child like a child" has contradictory meanings (Cowan, 2005:28).

2.3.2.5 Vulnerabilities of childhood

Even when adults intervene and take responsibility for children who are left without parents or guardians because of HIV/AIDS, it cannot always be assumed that children benefit. The limitations that adult society places on them because of their assumed immaturity (while often to their advantage) can also leave children powerless and defenceless (Department of Health, 2005:16). Precisely because they are children, in most societies, children have no direct right to own or control property, nor to take responsibility for important decisions concerning their own future (Human Rights Watch, 2005:47). While the right to participate in such decisions is confirmed in the UN Convention on the Rights of the Child, this is often ignored. As a result of the sickness or death of parents or guardians, children are often made to leave the place that they have always known as "home" and sometimes are separated from their closest remaining family members, their siblings (Mahomva, 2004:22). They are dependent on the abilities and attitudes of adults who are given ownership or control over their property and decision-making about their future life. Separated from close family members, without a secure home, the vulnerabilities of childhood can take on new dimensions (Kayirangwa & Hanson, 2004:60).

Since the need for caretakers of infants and very young children is obvious and immediate as a matter of basic survival, they are taken into the homes of

family members, placed with foster parents or guardians or in group homes or larger institutions (Hargrove, 2005:14). However, the needs of older children (approximately 8 to 18 years of age) can be more easily under-served, overlooked or underestimated, since the risks to their survival are less apparent (Grund, 2005:16). Even under good conditions, where resources and caring adults are available, it is not easy for a child who has lost everything to recover and adjust. Some are offered a home with caring adults but nonetheless, resist being absorbed into new families and homes because of fear and distress. For the majority, counseling and psychological support services are unavailable (Mundandi, 2005:73). Some react with behaviour which provokes rejection. Others run away. Where infection rates are high within a family or community, even the most loving guardians must focus their energy on the survival of those households where large numbers of children have been taken in and need care and support (UNAIDSWHO, 2004:16). Although these guardians or foster parents work hard to furnish a caring substitute home and family for children, there are often limits to how much care and support they are actually able to provide. Children may be unable to go to school, because there is no money to pay for books and fees or because they experience rejection or discrimination (Hien, 2004:85). Some must leave school to help care for younger children or to earn an income to help support the household. Fear and frustration lead children to run away in search of a better life, often only to join the growing numbers of homeless and exploited children (Monze, 2004:94).

The experience of older children who have lost their homes or families to HIV/AIDS-related illness and death, is insufficiently documented. However, in a world where millions of children are neglected, exploited and abused every day, it is reasonable to assume that these children can become easy prey to adults who are unconcerned with the child's best interest (Mugurungi, 2005:57). Some adults might take children into their households to serve an ulterior purpose. Children are easy to intimidate and control. Children can provide extra income or free labour and can be treated like property or servants, kept from school and given inferior food and care (Wawer, 2005:17). Millions of children suffer neglect and physical and sexual abuse. In the

absence of alternatives, more and younger girls marry early. Boys and girls trade abusive situations for the streets where life and survival are even more difficult. The risk of HIV infection rapidly increases as children are exposed to drug use and engage in unprotected sex (willingly or coerced), exacerbated by the increased susceptibility to infection of bodies which are still in the process of physical development and maturation (Nemoto, 2004:31).

Children are affected by HIV/AIDS in ways that can diminish their childhood and as a result, limit choices and opportunities for successful survival throughout their lives (Ono-Kihara, 2001:57). Circumstances of an individual's life and their social context in family and community during childhood can increase the probability they will one day be exposed to, and infected by, HIV. In order to develop appropriate means of enabling and protecting people, either as children or as adults against infection and the effects of HIV/AIDS, adequate and judicious attention needs to be given to the rights and realities of childhood (Phimphachanh & Sayabounthavong, 2004:91).

2.3.2.6 Physical impacts

UNICEF's State of the World's Children 2000 highlights the reversal in child and infant mortality rate in Sub-Saharan Africa (USAID, 2004:105). Currently there are an estimated 300 000 AIDS orphans in South Africa as a result of the HIV/AIDS epidemic. By 2015 there will be almost 2 million AIDS orphans, an increase of over 60 per cent (Shisana *et al.*, 2005:27). This is clearly a catastrophe of considerable magnitude as these children could also be infected. These children, growing up without parental guidance, will for the most be unloved, uncared for, un-socialised and uneducated. Extended families absorbing these children, are finding themselves with fewer resources, both psychological and financial, for existing family members (Rhodes & Simic, 2005:23).

HIV/AIDS causes damage to the well being and smooth functioning of the societies affected, with the rise in prevalence rates at antenatal clinics exceeding 40 per cent, as in areas of KwaZulu Natal, and with a nation-wide adult prevalence rate in excess of the critical threshold of 20 per cent, South

Africa is one of the countries most severely affected by this new challenge (Butler, 2005:14). The overall problem posed by AIDS, has now been recognised, on most countries, including South Africa, the specific impact of HIV/AIDS on children, with the exception of the orphans and the infected poorly documented, analysed and understood, most of the recent debate on the impact of the HIV/AIDS has focused on adult prevalence and deaths rates, ways to control the spread of the disease over the short term and its economic impact (Chisholm, 2004:8). This approach has diverted people's attention from the recent changes in infant mortality, enrolment rates and child malnutrition, from the new ways through which HIV/AIDS affects the child's well being, and from mitigating effects of old and new policy responses that need to be introduced under these circumstances (Giiese, 2003:61).

Core indicators such as infant and child mortality rates, immunisation and nutritional status of children have worsened. The latest data, and the projections based thereon, show a direct correlation between HIV/AIDS and both child and adult mortality indicators (Lyon & Woodward, 2003:99). The impact is highly visible and measurable at community and household levels in both urban and rural areas, although it does not yet form part of the national picture of the epidemic (Gwyther & Marston, 2003:35). National statistics on the cause of childhood deaths cite diarrhoea as the cause of 25 per cent of fewer than five deaths and acute respiratory infection as the cause of ten per cent of such deaths. While these are commonly AIDS-defining diseases, the deaths cannot be isolated as being AIDS-related. The official categorisation of deaths such that preventable but fatal childhood illnesses are recorded as natural causes, also obstructs analysis (Butler, 2005:12).

The rise in the CMR is directly due to HIV/AIDS, that is through mother-to-child transmission (MTCT), and illustrates the vicious circle of the link between AIDS and poverty. A woman living in poverty, is more vulnerable to HIV infection, less likely to be able to negotiate safe sex and does not have access to mother-to-child transmission prevention (MTCTP) treatment if she becomes pregnant (Ross & Deverell, 2004:56). She will also not have access to anti-retroviral drugs and other treatment and will, therefore, get sick and die

sooner than a woman who can afford treatment. The HIV positive child and his/her siblings in the impoverished family, will then be orphaned and plunged into deeper poverty. The HIV-positive child is then likely to die without treatment (Ntuli, 2004:90).

2.3.2.7 Emotional/Psychological impacts

Aspinwall and Staudinger (2003:15) assert, that the HIV/AIDS epidemic is contributing to psychological problems, especially among young children. The emotional well being of children is threatened. This is evidenced by the increase in the number of children coming onto the streets, not only in the major cities but also in small towns. In HIV/AIDS-affected families, relevant factors include bereavement and psychological depression in surviving parent or caregiver, which tends to incapacitate them in child-rearing and impair their abilities to work, obtain food, and provide adequate meals for their children (Duncan & Arntson, 2003:30). There are severe psychological health impacts for children of bereavement due to AIDS and indirect impacts from being cared for by someone who is exhausted, distressed and desperately poor. The effects of the bereavement on children and on the way that AIDS related illness and death are being explained (or not) to children, can be devastating (Ross & Deverell, 2004:50).

2.3.2.8 Developmental impacts

Prior to the emergence of HIV, large numbers of children and families already lived in poverty. The epidemic is worsening and deepening the poverty experienced by the poorest children and families. HIV/AIDS is contributing to increased vulnerability to poverty (Duraiappah, 2004:1). The media has cited many examples of children taking physical care of their ill HIV/AIDS parents and relatives. Increasing numbers of children are leaving school due to AIDS related poverty, despite free education since 1994 (Department of Education, 2005:70). Although caregivers can insist on the right to free education, pressure from principals of impoverished schools to pay school fees (48 per cent of schools still do not have electricity), on equally impoverished parents, is considerable. Currently 1.6 million learners are cut off from school. Without

treatment intervention to improve and prolong life of HIV-positive mothers, the number of maternal AIDS orphans is expected to rise from some 300 000 currently to around 3 million by 2011 (Birdthistle, 2004:100). Taking into account the number of orphans, the increased care/dependency ratio due to these deaths, the level of impoverishment due to loss of breadwinners and the burden of care for those dying, the impact on education – recognised as providing the best chance of escape from poverty, is probably incalculable. All over Sub-Saharan Africa, hard-won gains in school enrolment and the returns on investments countries have made to improve education, are being crowded (Bogardi, 2004:45).

2.3.2.9 Impact on learners' health and well being

Children who are HIV/AIDS orphans, are more likely than their peers to be malnourished, sick, abused and sexually exploited. They are at greater risk of dying from preventable diseases and are less likely than other children to be fully immunised (Case, Paxson & Ableindinger, 2004:83). This has implications for all children. As immunisation coverage decreases, the herd immunity declines and all children become more susceptible to common childhood illnesses, which in the case of HIV infected children, can be fatal (Amoroso, Spencer & Redfield, 2004:39).

With limited resources and inadequate adult supervision, HIV/AIDS-infected learners are more likely to drop out of school, leaving them with fewer opportunities for growth and development. They are also denied the benefit of the monitoring and support of teachers and peers and nutritional support offered through the primary school nutrition programme, which targets poor children at schools (Boyden & De Berry, 2004:36).

2.3.2.10 The impact of HIV on health services for children

Studies of paediatric admissions in hospitals have shown a marked increase in HIV-related admissions. HIV-positive children spend an estimated 3 to 4 times longer in hospital and require multiple admissions. In 1997 and 1998, 20 per cent of paediatric admissions at Chris Hani Baragwanath Hospital were HIV related (Friedman, 2005:176).

Increases in paediatric admissions in general over the past few years, are significant and entirely attributable to HIV/AIDS. In areas of the country with very high rates of infection, up to 75 per cent of beds in children's wards are occupied by children with AIDS-related conditions (Mallmann, 2003:70). As a result of the increased burden on health services, children suffering from conditions other than HIV, will have to wait longer for access to a bed and it can be expected, that there will be an increase in mortality among HIV-negative patients due to delayed treatment. As the epidemic progresses and more HIV-positive people develop AIDS, the impact on the health sector will grow exponentially (Department of Health, 2001:65).

The most obvious costs in caring for HIV-positive children, are those incurred by the health-care facility itself, but additional costs such as the cost to the parents for transport to and from hospital, reduced house income and the cost of outpatient visits, need to be considered when calculating the overall impact of HIV on the child (learner) and service delivery on the basis of current interventions offered to HIV-positive children at health-care facilities, acute health-care costs are expected to double in the public sector by 2010 (WHO, 2005:25). The estimated cost per year of treating an HIV positive child with the interventions currently available at public sector health-care facilities, is R17 000 (stage 4 of disease), R6 200 (stage3) and R1 300 (stage 1 and 2) (National centre in HIV Epidemiology and Clinical Research, 2003:34).

Government will be pressurised into increasing its expenditure on health services and the specific share of the budget allocated to the care of HIV-infected children. At the same time, rationing of services will have to occur as projected expenditure requirements, which are not sustainable (WHO, 2004:4). HIV-positive children are reported to being denied access to intensive care units in some provinces. Many HIV-positive children are denied access to medication on the assumption that the medication will do little to extend their life (Blower & Farmer, 2003:1). In a further attempt to deal with the epidemic, patients are being referred away from health facilities to more community-based programmes such as home-based care. Home-based models of care have been found to be very effective in reducing the rate of

hospitalisation and length of stay in hospital, reducing the costs of HIV/AIDS on primary health care services, reducing the costs and providing support for the family and increasing compliances to treatment regimes (De Jong, 2002:21). It is not surprising then, that this is being promoted by policy makers, but the existing health system lacks the infrastructure and resources to provide the necessary training and support to home-based care (Fleischman, 2003:32).

Health-care workers face difficult decisions as hospitals move towards providing palliative care for children with AIDS. All of these factors are likely to have an impact on the psychological well-being of service providers and increase rates of burnout and incidence of job-related stress. The growing demand on health-care service is exacerbated by an escalating TB epidemic, developing in the shadow of HIV. Currently, about half of all TB cases are thought to be attributable to HIV (Dean & Moalusi, 2002:3). As HIV weakens the immune system, it makes people more vulnerable to opportunistic infections and to developing active TB. With a greater number of HIV-positive people developing TB, HIV-positive and HIV-negative children will be exposed to a greater number of potential sources of TB infection (Holmes, 2003:52). The World Bank estimates, that 25 per cent of the TB-related health in HIV negative people in the coming years, will be a direct result of the HIV/AIDS epidemic (World Bank, 2002:17). In the Western Cape, the number of TB cases continue to increase, mainly due to HIV/AIDS and each new case of TB represents a further drain on the health system (Department of Health, 2001:70).

The impact of HIV/AIDS on the health sector, will also be felt through HIV-related illness and death of health-care workers, while increasing the demand on the health-care system. HIV simultaneously reduces the system's capacity to cope with the epidemic by killing health-care workers, the majority of whom are women (Hay, 2002:1). Rising rates of HIV infection among health-care workers will lead to increased absenteeism, reduced productivity and greater spending on treatment, death benefits, staff recruitment and training of new personnel. The burden of the HIV/AIDS epidemic will divert resources from

other essential health-care services and make it difficult to implement and maintain other key primary health-care programmes (Dixon, McDonald & Roberts, 2002:32).

2.3.2.11 The impact of AIDS on education

Education is driven by people and in Sub-Saharan Africa, many of the people integral to the education process, are dying. AIDS sabotages education in at least the following four ways:

- Educators are dying.
- The quality of education is being eroded (fewer experienced educators).
- The demand for education is decreasing (fewer children entering and or remaining at school).
- Education sector is soaring, as substitute educators are required (Meyer, 2003:30).

At least 12% of South African education administrative staff and educators are thought to be infected (World Bank, 2002:12). Ill educators are frequently absent, infected educators lose approximately six months of professional time before developing full-blown AIDS and 12 months thereafter (Department of Health, 2001:46). Many educators choose to relocate once they are visibly ill, or simply disappear, leaving classes without educators. Rural areas are especially affected, as infected educators require urban medical services. Ill educators, who remain in their posts, cannot provide the same quality teaching. Learners observe HIV positive educators' health decline, absenteeism grow and then eventual death. The value of educators as positive role models will be severely diminished. Absenteeism is not restricted to infected educators, educators who have infected family members, have a higher rate of absenteeism too, as they are engaged in caring for ill relatives or burying them (Kelly, 2002:8).

The ultimate death of infected educators saps available teaching resources and sector knowledge. In 1999, 100 000 South African learners lost educators

to AIDS. In 1999 and 2000 the mortality rates of female educators between the age of 30 and 34 increased by 70%. AIDS-related deaths of SA educators polled at 1% in 2000 and are projected to reach 5% by 2010 (Avert Organisation, 2005:18). In some African countries, it is estimated, that by 2010 two thirds of educators will be substitute educators for those who have died from AIDS (Giese, 2003:42). The consequence of teacher mortality is a vicious and perennial cycle of increased illiteracy, deterioration in human capital, national knowledge debilitation, a decline in economic growth, less fiscal support for education and ultimately, the prevalence of HIV is worsened (Mendel, 2002:8).

Healthy educators prefer to avoid densely populated AIDS-infected areas, increasing educator mobility and decreasing educator learner ratios. Temporary educators without adequate experience or scanty training, may be hired. Both of the aforementioned are detrimental to the quality of education (Coombe, 2003:30). The implications for remaining educators are also bleak. Healthy educators will have to contend with augmented workloads and height-work demand escalates, and as they witness HIV positive colleagues and or relatives die. The stigma of AIDS causes social isolation, which heightens trauma and decreases effective teaching (World Bank, 2002: 19).

2.3.2.12 Intergenerational impacts of HIV

The intergenerational effects of HIV and AIDS are the longest lasting of all and relate to the mechanisms whereby the epidemic intensifies poverty and leads to its persistence (Garcia, 2005:5). They are those processes which generate over time a culture of poverty not created by the HIV epidemic but undoubtedly strengthened by the direct and indirect effects of the epidemic, on social and economic development. They arise in part from the effects of the epidemic on human and institutional capacity where losses occur because of the erosion of human resources (Hepburn, 2002:40). It follows, that poverty reduction strategies will be increasingly ineffective in the face of an intensifying HIV epidemic which undermines sustainable development, thus reducing poverty through sustainable development, has become an even greater challenge than hitherto for countries in Africa (Letteneey, 2006:8).

Meehan (2004:16) asserts, that it is possible to disaggregate the effects of the epidemic so as to perceive what is going on at the levels of families and communities. These will have their effects over many years and unlike the coping strategies noted above, are longer term in their consequences. These experiences are now being repeated a million-fold by other children throughout Africa, children who represent the future -- who are the future of the continent.

Children who have lost both parents are left isolated and access to most forms of social support. The mechanisms for socialisation of children no longer operate, so that systems for acculturation do not function and the children become alienated from their community. It is the beginning of the process of alienation and anomie which have socially destructive outcomes for children and their communities, and ultimately for society (Mohlala, 2002:30).

There are also the direct effects of what has happened to the children which are material and damaging to their futures. Poor nutrition leads to poor health, which is an important cause of low labour productivity and thus, the persistence of low incomes for the poor (Mpiima, 2003:37). Poor and damp housing is a major factor in causing illnesses such as TB which is itself exacerbated by the HIV epidemic (where there is now a dual epidemic underway in Africa). These children will continue to experience poor health status over their lifetimes, with all kinds of social and economic consequences for them and their families (Department of Health, 2001:45).

Children's chances of escaping from their poverty depend on access to resources which are evidently missing. These include access to education which is the primary mechanism that the poor have for social mobility. But education is one thing that these children will not have access to in accordance with their abilities most evidently in the case of girl children (Schiff & McKay, 2003:6). A generation is thus emerging with poor health status and few skills (not even those necessary for rural development), low levels of literacy and numeracy, little or no access to financial and other real assets (where their property and other rights will often have been infringed), and who

have been deprived of normal processes of socialisation and social inclusion. Indeed, they will face additional social exclusion because they come from families who have experienced AIDS (Department of Education, 2003:36).

These children display, in other words, all those characteristics typical of the poor and the disadvantaged. They are in effect the next generation of the poor, and are the outcome of ongoing structural processes which are being intensified by the HIV epidemic currently affecting so many Africans of all social classes and all ages (Mwaluko, 2003:29). They also represent both the future and the challenge for sustained development in Africa. If their educational, health, housing and other psycho-social needs are not addressed through specific policies and programmes, then it is difficult to see how national development objectives can possibly be achieved (Kelly, 2002:17). Just as important, is the fact that large numbers of children growing up in poverty will adopt precisely those behaviours which lead to HIV infection. They will in effect become the next cohort of the HIV-infected; a state of affairs which will permit the epidemic to continue and intensify (Jordan-Harder, 2004:90).

2.4 STIGMA AND DISCRIMINATION AND ITS IMPLICATIONS FOR LEARNERS LIVING WITH HIV/AIDS

From the moment scientists identified HIV and AIDS, social responses of fear and denial, stigma and discrimination have accompanied the epidemic (Lyon & Woodward, 2003:97). Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS. It goes without saying, that HIV and AIDS are as much about social phenomena as these are about biological and medical concerns (Anglo American Group, 2004:81). Across the world, the global epidemic of HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. But the disease is also associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds true

in the rich countries of the North as it also does in the poorer countries of the South (Bogardi & Birkmann, 2004:100).

Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. homosexuals, injecting drug users, sex workers) may predate HIV/AIDS, the disease has, in many cases, reinforced stigma (Chakraborti, 2006:72). By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations. This is seen, not only in the manner in which 'outsider' groups are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need (Stolte, 2002:19).

The potential impact of stigma and discrimination has been an ongoing concern to those involved in addressing the HIV/AIDS epidemic. Divides would be major implications for those who are vulnerable to infection and those who are more distant (Cheluget *et al.*, 2004:14). Stigma is common when societies face problems that seem inexplicable or outside their control such as HIV/AIDS epidemic. The direct experience of stigma is terrible when one considers how the impact is on those who feel the discrimination (Binagwaho, 2005:8). The implication of stigma goes even deeper to impact on multiple aspects of the lives of people living with HIV/AIDS and more broadly, on members of society, creating people's vulnerability to infection and reducing the overall caring capacity of communities. Stigma has had particular implications for South Africa, given its history of racism and other stigmatising beliefs (Keeton, 2002:57). Stigma is a deeply discrediting attribute that reduces a person to someone who is in some way tainted and can, therefore, be denigrated. It is a pervasive problem that affects health globally, threatening an individual's psychological and physical well being. Enacted stigma refers to the real experience of discrimination (Mbulaiteye, 2002:7). Discrimination constitutes acts or omissions in which the content of the stigma is applied, either at the individual or social/community level. Four components have been identified as being part of the stigma concept. These include

distinguishing and labelling differences, associating human difference with negative attributes separating “us” “them” and status loss (UNAIDSWHO, 2005:33). Ultimately stigma is entirely dependent on social, economic, and political power, as power is required to be able to introduce stigmatisation, stigma removes power from the stigmatised person, enhancing differences and reducing the stigmatised group or a person’s social status and self-worth (Ward, Walker & Ghys, 2004:25).

A major role that stigma plays in society, is to create “difference” and social hierarchy, and then legitimise and perpetuate this social inequality (Altaf, 2004:91). Discrimination arises out of any point of difference that can be consistently labelled, e.g. physical deformity or disfigurement, racial difference or any other factor that set up the person as different from the perceived norm (Wawer, 2005:11). Major discrimination has been on race gender, sexual orientation, handicap, religion and age. The attachment of discrimination to illness, has a long history with it, impacting on people with mental illness and physical disorders such as cancer, TB, STDs and leprosy. The nature of stigma and discrimination is complex, varying across time, person and context, making analysis and especially intervention very difficult (Mateo, 2003:43).

Stigma and discrimination are cruel social processes that offer some feeling of protection to the powerful, while increasing the load on the individual or group victimized in the process (Hien, 2004:28). Stigma can be seen as a tool used by mere powerful groups to protect themselves as people. It is, in turn, constructed as only impacting on directed recipients who are seen to be at blame anyway, so deserve this discrimination. Stigma has a far more insidious influence, going well beyond the individual and potentially impacting on all sectors of society (Monitoring the AIDS pandemic network, 2005:67).

2.4.1 AIDS and stigma

In many societies people living with HIV and AIDS are often seen as shameful. In some societies the infection is associated with minority groups or behaviours, for example, homosexuality; in some cases HIV/AIDS may be

linked to 'perversion' and those infected, will be punished (Riono & Jazant, 2004:78). Also, in some societies HIV/AIDS is seen as the result of personal irresponsibility. Sometimes, HIV/AIDS are believed to bring shame upon the family or community. Whilst negative responses to HIV/AIDS unfortunately widely exist, they often feed upon and reinforce dominant ideas of good and bad with respect to sex and illness, and proper and improper behaviours (Solomon, 2004:155).

Factors which contribute to HIV/AIDS-related stigma; are the following:

- HIV/AIDS is a life-threatening disease
- People are scared of contracting HIV
- The disease is associated with behaviours (such as sex between men and injecting drug-use) that are already stigmatised in many societies
- People living with HIV/AIDS are often thought of as being responsible for becoming infected
- Religious or moral beliefs lead some people to believe that having HIV/AIDS, is the result of a moral fault (such as promiscuity or 'deviant sex') that deserves to be punished (Yang, 2005:70; Balakireva, 2003:24).

Sexually transmitted diseases are well-known for triggering strong responses and reactions. In the past, in some epidemics, for example TB, the real or supposed contagiousness of the disease has resulted in the isolation and exclusion of infected people (Booth, 2004:82). From early in the AIDS epidemic, a series of powerful images were used that reinforced and legitimised stigmatisation.

- HIV/AIDS as punishment (e.g. for immoral behaviour)
- HIV/AIDS as a crime (e.g. in relation to innocent and guilty victims)
- HIV/AIDS as war (e.g. in relation to a virus which need to be fought)

- HIV/AIDS as horror (e.g. in which infected people are demonised and feared)
- HIV/AIDS as otherness in which the disease is an affliction of those set apart (Toole, 2005:55; Des Jarlais, 2002:165).

Together with the widespread belief that HIV/AIDS is shameful, these images represent 'ready-made' but inaccurate explanations that provide a powerful basis for both stigma and discrimination. These stereotypes also enable some people to deny that they personally are likely to be infected or affected (Gibson, Flynn & Perales, 2001:29).

Stigma surrounding AIDS is complex, whilst discrimination is prohibited; stigmatisation of infected person is entrenched response (Coombe, 2003:50). It is primarily caused by inadequate knowledge, fear of death and disease, sexual mores and poor acknowledgement of stigma. The stigma surrounding AIDS includes, amongst others, the following prejudiced perceptions.

- HIV is associated with sexual taboos and immoral behaviour.
- HIV is considered a punishment from God for sexual sin.
- HIV is caused by sorcery, witchcraft or ill-will.
- HIV can be casually transmitted, which engenders fear of HIV positive individuals.
- HIV results in painful death and, therefore, HIV positive individuals must be avoided (Human Rights Watch, 2005:10; Shakarishvile, 2005:57).

Stigmatization results in us/them distinctions and categorization of in-and-out groups. Clearly educator adherence to the above-stigmatised perceptions could lead to a decline in school and personal wellness (Rhodes, 2004:19).

HIV related stigma has its own unique qualities and is heightened as it is layered upon other stigmas associated with race, gender, homosexuality, drug use, and promiscuity. Discrimination is perpetrated against communities,

which are perceived to be affected by HIV these, can be physical criteria, such as skin colour, sexual orientation and type of work, such as prostitution (Caribbean Epidemiology Center, PAHO & WHO, 2003:41). Stigma affects not only the individual who is carrying the virus, but also increases the exclusion of already stigmatised groups associated with HIV/AIDS. A person could fall into more than one category of stigma and feel multiple burdens, e.g. a physically handicapped HIV positive learner. The learner may feel stigma in all areas, isolating her/him from different sectors of the community (St John, 2003:1).

Anger and fear contribute to the development of discrimination, both in those who are HIV-positive or HIV-negative. Morality has also become a key factor in the development of stigma in AIDS. A judgemental discourse has distinguished sharply between those “innocents” who contract HIV via organ or blood transfusion, the children of women with HIV, and women whose partners are unfaithful; and those that are considered guilty and at most, “deserve it” (Bautista, 2004:98). Religious groups may intentionally or inadvertently contribute to discrimination by making explicit or implicit judgements against those who are infected with HIV. There have been attempts to label the epidemic as God’s punishment for sinners, especially in respect of gays, prostitutes and drug users (Mejia, 2002:77).

To be able to blame others, is psychologically reassuring people, dividing the society into “us” and “them”. Others are guilty as a result of their behaviour. They are guilty not only of getting themselves ill, but also of infecting “innocents”. This increases the stigma load borne by groups seen as responsible (Pando De Los, 2003:35). The attachment of gender discrimination to HIV/AIDS stigma, has led to women being blamed for spreading the epidemic. Thus women are contradictorily expected to provide sexual services to men generally, be chaste and pure, and take on the responsibility of preventing pregnancy and disease (Dodds, 2005:65). Many types of discrimination are introduced by socially conservative governments, including policies of restriction of admissions, deportation of foreigners,

mandatory testing for those seeking work permits or tourist visas (Elford, 2004:51).

2.4.2 Forms of HIV/AIDS-related stigma and discrimination

In some societies laws, rules and policies can increase the stigmatisation of people living with HIV/AIDS. Such legislation may include compulsory screening and testing, as well as limitations on international travel and migration (UNAIDS, 2004:17). In most cases, discriminatory practises such as the compulsory screening of 'risk groups', both further the stigmatisation of such groups, as well as creating a false sense of security among individuals who are not considered at high risk. Laws that insist on the compulsory notification of HIV/AIDS cases, and the restriction of a person's right to anonymity and confidentiality, as well as the right to movement of those infected, have been justified on the grounds that the disease forms a public health risk (Segura, 2005:19).

Perhaps as a response, numerous countries have now enacted legislation to protect the rights and freedoms of people living with HIV and AIDS and to safeguard them from discrimination. Much of this legislation has sought to ensure their right to employment, education, privacy and confidentiality, as well as the right to access information, treatment and support (British Medical Association, 2005:33).

Governments and national authorities sometimes cover up and hide cases, or fail to maintain reliable reporting systems. Ignoring the existence of HIV and AIDS, neglecting to respond to the needs of those living with HIV infection, and failing to recognize growing epidemics in the belief that HIV/AIDS 'can never happen to us' are some of the most common forms of denial. This denial fuels AIDS stigma by making those individuals who are infected, appear abnormal and exceptional (Dougan, 2005:304).

Stigma and discrimination can arise from community-level responses to HIV and AIDS. The harassing of individuals suspected of being infected or of belonging to a particular group has been widely reported. It is often motivated by the need to blame and punish and in extreme circumstances can extend to

acts of violence and murder (Murphy, 2004:65). Attacks on men who are assumed gay have increased in many parts of the world, and HIV/AIDS-related murders have been reported in countries as diverse as Brazil, Colombia, Ethiopia, India, South Africa and Thailand (US Centers for Disease Control and Prevention, 2004:77). In December 1998, Gugu Dhlamini was stoned and beaten to death by neighbours in her township near Durban, South Africa, after speaking out openly on World AIDS day about her HIV-status (Giese, 2003:74).

In the majority of developing countries, families are the primary caregivers to sick members. There is clear evidence of the importance of the role that the family plays in providing support and care for people living with HIV/AIDS. However, not all family response is positive (Lyon & Woodward, 2003:8). Infected members of the family can find themselves stigmatised and discriminated against within the home. There is also mounting evidence that women and non-heterosexual family members are more likely to be badly treated than are children and men (Malebranche & Peterson, 2004:100).

2.4.3 Discrimination in South Africa

South Africa has reported a large number of incidents of stigma. These include the murder of Gugu Dlamini in December 1998 for openly stating that she was HIV-positive, the murder of Mpho Motlounq who was HIV-positive, together with her mother, by her husband who then committed suicide, not allowing HIV-positive children into schools, exclusion or attempted exclusion from the workplace and rejection by families. A recent case in 2004 is, that of Lorna Mlofane who was raped and later murdered after her three rapists had learned that she was HIV-positive (Myer, 2005:104).

The connection of stigma around HIV to historical racism and gender has developed a particular form of discrimination. Blame is often assigned to Black people or to women. Men blame women for affecting them and spreading the virus. In couples it can lead to violence against the woman or her exclusion from the household (Butler, 2005:26). Stigma around disease often attaches itself to existing stigmatising frameworks, for example, in South Africa AIDS

has been associated mainly with black people and women. Many research studies have found a significant number of respondents who want people living with HIV to be clearly identifiable, to be separated from contact in schools, work and social institutions (Chisholm, 2004:110). Reports about stigma are pervasive, extending even to the health professions. The AIDS Law Project reported, that the Health Professions Council of South Africa did not act, against twenty-eight doctors who breached patient confidentiality. The patients were domestic workers whose employers had been told the diagnosis and many were subsequently dismissed. Some health professionals have refused to treat people with HIV/AIDS, on the ground of possible risk of infection (Mallmann, 2003:56).

Children orphaned or rendered vulnerable by AIDS, are likely to experience increasing stigmatisation. Recently ninety children affected by HIV/AIDS spoke of their experiences of discrimination. They faced verbal and physical discrimination at school and in the community (Ross & Deverell, 2004:45). Orphans have also been identified as a major security threat for the future. While this may be a rational call for resources and intervention, it does also lay the basis for them to be identified as a special group for discrimination. Stigma would clearly worsen the situation of orphaned and vulnerable children, excluding them even further from resources and support (Ntuli, 2004:102).

2.4.4 Implications of discrimination

The extensive nature of the stigma against people with AIDS, is well-established. This has significant impacts on those immediately affected, but also has a number of implications for the epidemic and broader society. These insidious impacts must be acknowledged, if the work to eradicate stigma is to be taken seriously (Population Council Horizons Programme, 2001:14).

2.4.4.1 Making the epidemic invisible

A prime impact of discrimination is, that it pushes the epidemic underground, forcing people who have contracted HIV, and anything else associated with the disease, into hiding. An acknowledgement of HIV becomes difficult, if not

impossible. Likewise any association with the disease or people with HIV can be a basis for that person being excluded from the community, so is denial. The disease itself then remains hidden, so its perceived threat is reduced (Stolte, 2002:19). It also makes this disease someone else's problem. The stigmatising beliefs then facilitate the use by individuals and communities of denial and distancing as defensive processes against the epidemic, again reducing the need to adapt (Maman, 2000:59). Distancing or creating barriers between those infected and the rest of the population, consumes considerable energy that could be more profitably used, and robs the intervention of some of the best advocates for behaviour change, namely those who are directly affected (International HIV/AIDS Alliance, 2003:72).

Thus the epidemic disappears, or at least has few public faces, leaving the space open for scapegoating of any person or group associated with the disease. This scapegoating is dangerous, as they pin the blame on a small section of the population, leaving the rest with the mistaken belief that they are safe (Auvert, 2001:39). A greater problem arises when those with the power to construct interventions, use discrimination as a basis for not implementing such programmes for communities as a whole, or for those responsible for structuring interventions, blaming infected people can be a substitute for tackling the problem itself. So even when interventions are developed from this basis, they are constructed in such a way as to discriminate against those in affected groups and reinforce a false sense of safety in the majority of the population (UNAIDS, 2004:69).

2.4.4.2 Limiting access to treatment

Discrimination has significant impacts on the diagnosis and treatment. For the individual it can delay diagnosis and therefore, also delay entry into treatment and adoption of a healthy lifestyle. There is no motivation to be tested, as the person sees no benefit when the diagnosis of HIV is seen equivalent to death, and they are likely to experience discrimination (Binagwaho, 2005:99). In certain contexts research respondents have been shown to be more fearful of stigma than of the disease itself, so even with treatment, stigma may be a block to access (Cowan, 2005:25). This has already been shown to be a

problem in the case of PMTCT, where women have expressed fear of being tested. In the same way the use of formula-feeding rather than breastfeeding can become a problem. Many women feel restricted from being able to breastfeed for fear of family observation and questions (Mbulaiteye, 2002:47).

Even for those who are aware of their status, discrimination can limit access to care and treatment. Many are not able to acknowledge even to their families that they are infected, so are denied that level of care. If some level of general acceptance and support can be obtained for the person who is HIV positive, this can facilitate better results (National AIDS Coordinating Agency, 2003:16). The benefits of testing need to be openly acknowledged. Even minor modification of behaviour can improve life and the introduction of ARVs can considerably extend a person's life, even in resource-poor settings (Mundandi, 2005:16).

Impact on identity and coping of the person with HIV stigma, impact on the PLWH themselves, as it is internalised into their self-perception and sense of identity, impacting on the person's perceptions and how they interact in the world. Research has found, that people with HIV feel isolated, guilty, dirty and full of shame, which is then often incorporated into identity (Reproductive Health Research Unit, 2004:77). General participation in the activities of life is, therefore, restricted by stigmatisation. Shah, Altaf, Mujweb and Memon, (2004:209) found, that among gay men, the rejection experienced by the person who was HIV-positive, fed into their sense of self, causing them to feel compromised and to blame for their situation. Similar results were found with a sample of HIV-positive women (Filatov & Suharsky, 2002:111). When this stigma is internalised, it might influence the ways affected individuals look at themselves and how they interact with others, including health-care providers. (Eroshina, 2005:88). This again impacts on persons with AIDS coming to terms with their illness.

2.4.4.3 Disclosure, support and protection of those close to the infected person

In all relationships, discrimination counteracts trust. This often leaves those infected alone and distanced from the rest of their communities, colleagues and even family. The fear of discrimination has been shown to create problems for disclosure, since disclosure has the common reaction of rejections, leaving the person with HIV alone (Grund, 2005:49). This also increases the risk of infection for the sexual partner of the HIV positive person. Studies focusing on disclosure, have also begun to explore the processes of dealing with the negative reaction and the empowerment of the person who is disclosing their status (Lowndes, 2002:31). Social contacts and family members may also resist being informed, as too many become vulnerable to exclusion, by being associated with a person with HIV. This in turn, can lead to a breakdown in social commitments to care, as there is a fear of asking for care and a fear of offering care, both regarding the fear of disease and of association (Camara & Zaidi, 2005:14).

2.4.4.4 Impact on behaviour change

Discrimination and stigma have implications for the implementation of prevention efforts and have reduced the possible impact of these interventions. Certain behaviours such as the use of condoms, have become signifiers of the epidemic, leading to the possible rejection of those who initiate their use (Verevochkin, 2005:70). Thus many youths in South Africa are scared to use condoms, due to the felt implication. Even the option of being faithful, can be stigmatised. In a community where multiple partners are seen as an indicator of success or manhood, a person who has one partner may be marginalized (Khalsa, Francis & Mazin, 2003:1).

The intersection of these different points of discrimination can become a vicious circle of stigma with sex workers, gay men, the poor, Black women, etc, being seen as responsible for HIV/AIDS. However these are also the groups most vulnerable to infection, so they are more likely to contract the disease and thus increase the stigma again (Magis-Rodriguez, 2004:15).

Stigmatisation of at-risk groups or other stigmatisation based on race, gender, class, occupation or sexual preference, also puts people at greater risk of infection. There is pressure to deny being part of these groups in order to reduce the felt stigma, including refusing to use safer sexual practices that acts as markers of HIV. People who can define themselves outside of these groups, are also able to reject the need for safer sexual practices (Glynn & Rhodes, 2005:20).

In South Africa the attachment of AIDS to poor, especially poor Black women, has created additional risk-associated beliefs. Thus a sample of students at the university of Cape Town believe, that their educated status protected them and that it was others who were at risk. Many infected teenagers stated that since they would be facing rejection, they would try to spread the infection as far as possible so that they would not die alone (McMahon, 2004:38).

Stigma and associated beliefs can also impact on how people receive education inputs. At the level of providing education and getting people to listen, there are many taboos about sex from traditional culture, religion mortality, as well as the hidden nature and sensitive role sex plays in interpersonal relationships (Valleroy, 2004:16). The addition of information on a stigmatised disease like AIDS, makes intervention all the more complicated. It can also paralyse educational efforts; moreover, while AIDS remains a stigmatised disease it is more difficult for the government to take up the issue (Zamani, 2005:9).

Stigma impacts beyond the individual infected with HIV, to affect all those associated more generally, by the epidemic and undermining whatever behaviour and treatment interventions are already in place. Thus interventions need to be introduced to reduce stigma and encourage acceptance. Different political and social forces come to bear when considering interventions against stigma, and there needs to be openness by leadership figures to such issues (Sullivan, 2004:29). Working to reduce or end the stigma, is also not a short-term undertaking. As has been shown in attempts to end racism, stigma can be highly resistant to change. The popular notion and provision of information, are sufficient to change stigma. The link of information to belief

and behaviour has been shown to be insufficient in changing sexual behaviour in relation to HIV, and has also proved insufficient in addressing racism and sexism (Blower & Farmer, 2003:11).

Stigma towards people with AIDS is related to the incidence of all other kinds of stigma. So campaigns need to address or make space for changes of attitudes and beliefs about stigma based on race, gender, sexual orientation, physical illness and disability and class, amongst others (Caiaffa, 2003:70). This was supported by a call from Kofi Annan, UN Secretary General, at the World Conference Against Racism, where he made a combined call to end racism and discrimination against people living with AIDS, racism and HIV stigma support and uphold each other, so were in reality part of the same campaign with racism boosting the AIDS epidemic (Clinton, 2003:22)

There is a clear need to establish a research agenda for stigma related to HIV in South Africa. An initial priority, is the development of a greater understanding of nature and practice of stigma against HIV-positive people in South Africa. Stigma is a social phenomenon, so it needs to be understood at both individual and social levels (Hepburn, 2002:2). This work can lay the basis for directed campaigns and interventions against the practice of discrimination. This is a real and centrally important challenge for harnessing the HIV epidemic that needs to be taken seriously (Kilbourne *et al.*, 2002:9).

2.5 THE ECONOMIC IMPACT AND CONSEQUENCES OF HIV/AIDS ON HOUSEHOLDS AND COMMUNITIES

The burden of caregiving can deepen the poverty of households, moving some households into destitution. A household study in southern Zambia found households with very high dependency ratios of three to five times national averages, primarily, but not exclusively, due to the caring burdens created by HIV/AIDS (Solomon, 2004:155). In these households, labour that might contribute to household necessities or income, simply did not exist. Children in these households are likely to have to work in order to survive. Efforts are made to draw on resources from wherever possible, utilizing existing family and social networks (Van Dyk, 2005:48). A study

based on household data in Rakai, Uganda, one of the earliest centres of the HIV/AIDS epidemic, showed that extended family members, community members, and NGOs provided from 40 to nearly 70 per cent of the medical and burial costs experienced by affected families (WHO, 2003:16).

The burden of medical and related expenses induces changes in family spending patterns. In Côte d'Ivoire in the mid-1990's, households affected by HIV/AIDS spent nearly twice the proportion of their budgets on medical care as did households not affected by HIV/AIDS (Walker, 2004:12). In Rwanda, a household survey found expenses on health-care to be over twenty times higher in HIV/AIDS affected, as compared to non-affected households. Further, health care expenses for men were 2.6 times greater than for women, illustrating deep biases in accessing and using health-care (Mwaluko, 2003:47). Expenditures at this level, became a major burden on families budgets. Among households affected by HIV/AIDS in the Kagera region of Tanzania, almost all cash income was used to pay medical bills relating to HIV/AIDS. As medical expenses climb, spending on other items tends to decline. In South Africa, households with an AIDS-sick member were found to reduce spending on necessities (Letteney, 2006:77). The most likely expenses to be cut were clothing (21 per cent), electricity (sixteen per cent) and other services (nine per cent). Some six per cent of affected families reduced spending on food. While not as high a percentage as might be expected, most families reported that they already had insufficient food at various times (Hein, 2004:65).

Spending on food and education may be reduced significantly, as in Côte d'Ivoire, where spending on basic consumption items (food and accommodation) fell by 40 per cent after the death of a family member of AIDS (Dixon *et al.*, 2002:233). These cuts in basic necessities further contribute to overall household poverty as malnutrition, health of children and women, and future work opportunities are compromised. The "savings" incurred through these cuts in spending on necessities were used for medical care and drugs for the person living with HIV/AIDS (Corbett, 2002:79). The spending on health-care was far higher in rural than urban locations, and in

both cases was six to twelve times greater than the national average. Withdrawing children from school or delaying their entry is another way that some families adjust spending patterns.

Paying for the costs of HIV/AIDS households, meet the costs of HIV/AIDS in a variety of ways, in addition to changing spending patterns. New members may be added to the household in order to compensate for a lost adult member. Loans may be acquired from relatives or neighbours (Bogardi, 2004:34). Assets may be sold or rented. In cattle-owning communities, the sale of animals to meet costs, frequently occurs. For example, in pastoral communities in Uganda, over thirteen per cent of the households that had cattle, had sold off animals to meet family needs resulting from HIV/AIDS. In other cases, the animals had died due to poor management, or they were stolen after the death of able-bodied household members (Askew & Berer, 2003:55). In mixed farming households, nearly one-third (32 per cent) reportedly had sold animals to pay for medical care and other household expenses. In Namibia livestock and grain sales are commonly used to get money to meet illness-related expenses or to replace lost income. Therefore, the productive assets that livestock represent, are taken out of the farming system (Dickinson, 2003:52).

A study in western Kenya confirmed the trends in disinvestments of assets by households experiencing a prime-age adult death. Sales of small livestock would occur before that of cattle (Fares, 2004:13). As noted earlier, some households with a prime-age adult death, could even gain cattle through dowry, as daughters were married off. Studies in both Tanzania and Zimbabwe have found, that AIDS-afflicted households sold assets to cope with the death. Similar findings come from the Rakai region of Uganda (Keeton, 2002:28). The latter study found, that only those households that experienced a death due to HIV/AIDS (as opposed to a death due to other causes) experienced depletion in resources. Health-care and funeral expenses related to HIV/AIDS, coupled with loss of income, therefore leads to a rapid depletion of household resources (Lopez, Kreider & Caspe, 2004:26).

In one study in Zimbabwe, 24 per cent of surveyed households sold an asset to cope with the death of the adult female. There was a greater chance that assets would be sold among rural as opposed to urban households. Cattle and smaller livestock, clothing and household furniture, were the items more commonly sold. Disinvestment can continue after the death of a male adult in the household (Mateo, 2003:56). In the Oshana region of Namibia, it was found that in households where the husband died of HIV/AIDS, livestock, sometimes all animals, are taken by relatives from the surviving family members. Funeral expenses can add significantly to the economic burden of households and communities experiencing HIV/AIDS. One South African survey found that, on average, funeral costs were equivalent to one-third of annual household income (Pokrovskiy, 2005:66). In another study, this in KwaZulu-Natal, South Africa, funeral costs represented the equivalent of two months mean household income). In the months and years after a death, the ability to earn income is reduced and surviving households may sell additional assets, borrow, or search for new sources of income. In a household study in the Free State Province, South Africa, affected families (already poorer than non-affected families) tended to borrow first and then to sell assets (Tawfik & Kinoti, 2002:39). In that study, affected households spent the borrowed money largely on medical expenses and funerals, while unaffected households generally used the money for education, durables and clothing. The same study also found that HIV/AIDS impacts savings disproportionately. Affected households on average utilized 21 months' worth of savings, while non-affected households utilized only five months' worth of current savings (Phimpachanh & Sayabounthavong, 2004:94).

The ability to deal with the economic pressures arising from HIV/AIDS varies by the wealth, size, and social position of households. As might be expected, poorer households respond differently than do better-off households. Analysis of data generated in the Kagera region of Tanzania found, that among the poorer half of households, both food expenditure and food consumption fall dramatically in the six months following a death of an adult member of a household, in contrast to increases in non-poor households suffering a death (Monze, 2004:15). The differences are not simply a reflection of relative

wealth, but of decisions about how to cope with an adult death. One method used more by wealthier than by poorer people, is acquiring informal forms of credit and transfers; however, these forms of “informal insurance” are available only to a limited extent to the poorest households. However, the latter may get some assistance from formal structures, such as the government (Kidanu *et al.*, 2003:47).

Findings from a rural area of eastern Zimbabwe indicated, that the capacity of HIV/AIDS -affected households to cope with shock, is severely compromised by not having additional labour of their own to rely on, as opposed to non-affected households. Thus, the size of a household, the person who is ill/dies, the level of household assets, and the ability (with cash, kind or social arrangement) to call in additional labour play a pivotal role in managing an AIDS-related death and the time it takes to adjust to the loss (Hepburn, 2002:37). The death of an adult male is especially costly in terms of lost income and assets. By contrast, when the wife dies, livestock assets and grain production are less affected, in part because fewer resources are invested in the medical care of women. Grain production levels are usually maintained, although tasks normally done by women, such as weeding, may decline in intensity. However, high value or cash crop production does change when a male head dies, as the available household labour is devoted to food crops (Gwyther & Marston, 2003:15).

In Uganda, one study showed, that 44 per cent of respondents reported a reduced variety of crops in the last ten years, in response to reductions in labour supply due to AIDS. Reduction was more common in female-headed households (77.3 per cent), especially those where the woman was widowed (Gaillard, 2004:15). In Zimbabwe, food consumption in households where a woman had died declined and variety narrowed. It should be noted, however, that it is difficult to distinguish between changes in food consumption arising from the death of a woman or resulting from the economic hardships of a contracting economy. Of course, where households are already poor or very poor, there is little to sell (Corbett, 2002:85). Outside assistance by religious and community groups and family and friends played a large role in helping

HIV/AIDS-affected households in Rwanda in order to meet financial burdens arising from HIV/AIDS. In that country, two-thirds of surveyed households, were found to receive some kind of assistance. Eighteen per cent had to borrow money to pay for care, and five per cent had to sell assets (Brown, 2003:49). In Zimbabwe, following an adult female death, a study found, that female-headed households relied more heavily on remittance from family members, informal activities and agriculture and subletting. Male-headed households, on the other hand, depended more on the use of savings, followed by borrowing from informal sources and remittances from family members (Asamoah-Odeyi & Calleja, 2004:56).

For affected households and communities, HIV/AIDS is rapidly inducing and deepening conditions of poverty. In South Africa, a study found, that incomes of affected urban and rural families were, on average, just 60 per cent of unaffected families. Another South African study concluded, that HIV/AIDS has its greatest impact on poor people and deepens “poverty among the already poor” (Booyesen & Bachmann, 2002:20). The pattern of coping, outlined for poor and very poor urban households in Burundi, illustrates how the circumstances arising from the impact of HIV/AIDS intense poverty.

- Children are expected to work, and working children are seen at increasingly young ages.
- Decreased/interrupted payments for basic services (school);
- Interrupted debt reimbursements.
- Increased demands to the community for gifts in cash or kind;
- Sale of sex, for cash or in-kind payments.
- Begging.
- Sale of household goods.
- Shared housing, with 3-4 women plus children sharing one room (Floyd, 2003:47).

Clearly, the ability of poor households to deal with the multiple losses arising from HIV/AIDS, is pushing members into increasingly desperate and risky situations. For these households, the basic goal is to survive and on a daily basis, find ways to manage with minimal resources (Collins & Rau, 2000:28). Existing poverty is exacerbated by HIV/AIDS and is contributing to destitution. Larger and better-endowed households are less likely than are smaller households to become poor as a result of HIV/AIDS. They are better able to distribute the impacts of medical care and funeral expenses, as well as loss of labour and income across family members and through social networks (Greener, 2000:34). Simulation modeling in Botswana indicates a fall of eighteen per cent by 2010 in the average income of households in the lowest quartile. This is nearly double the income loss in the population as a whole. Similarly, modeling of the pandemic in Burkina Faso predicted that with a stabilized HIV prevalence rate of ten per cent in 2005, the incidence of poverty would increase from 45 to 52 per cent in nine years (from 1997 through 2005) and from 45 to 53 per cent after fourteen years (from 1997 through 2010) (Avert Organisation, 2005:27). The intuitive implication of these findings, is that HIV/AIDS intensifies prevailing income inequalities in society. However, the Botswana simulation does not predict any change in the level of income inequality. This is explained by an overall downward shift in per capita incomes. In other words, societies as a whole are becoming poorer as a result of HIV/AIDS (Bechu, 1998:39).

Three observations, however, arise from the findings of the Botswana simulation.

- Inequalities are already significant in Botswana. HIV/AIDS sustains those patterns during the overall downward shift in poverty levels across society.
- The models do not adequately take into account the most impoverished, the households that become destitute or dissolve altogether.
- Access to services, a factor of poverty and inequality, is not included in the equations (Garbus, 2002:14).

For Botswana, and other countries with advanced epidemics, the pandemic narrows the range of opportunities for reducing economic and social inequalities while deepening national poverty (Kaliyati, 2003:33). As noted earlier, access to education is already compromised for many children affected by HIV/AIDS. In the health sector, access to affordable treatment and adequate health services have become the most important differentiating factors between HIV-related survival in rich and poor countries and communities (Menon, 1998:330).

In summary, the economic impact of HIV/AIDS on households and communities is far-reaching and is likely to worsen over the coming decade. In the absence of significant subsidies for medical and drug care, households will be spending a significant portion of their incomes on health care. To pay for health-care, assets will be sold, further impoverishing many households (Kelly, 2002:28). Extended family and community members will find increasing demands on their resources to assist affected households. Some households will be better able to cope with these changes and will recover economic stability after several months or years. Others, however, will become economically worse off. Poverty will intensify (Mturi & Nzimande, 2003:25).

What proportion of all affected households will be most adversely impacted, remains speculative, but given the prevalence of poverty in many African countries, it is reasonable to suggest, that at least half of HIV/AIDS-affected households will experience long-term economic distress (Odipo, 2000:38). With national services and community and household resources already strained, it is difficult to foresee 'quick fixes' that will alleviate the economic and social impacts of HIV/AIDS. Rather, a development-based orientation is needed. Elements of a development response will include large-scale job creation and youth job training, infrastructure re-building, and substantial subsidies for local development initiatives. Whether it is through targeted initiatives or broad, national-scale programmes, development efforts must be designed and implemented that minimize the impoverishment and inequalities occurring in the wake of the HIV/AIDS epidemic (Nandakumar *et al.*, 2000:17).

Given the broad socio-economic impacts of HIV/AIDS on households and the communities in which they live and work, it is useful to focus a discussion of responses on those that address the nature of that broader impact. These are what can be called development-oriented responses, in contrast to responses that remain narrowly focused on immediate symptoms of the wider impact (Phiri *et al.*, 2001:36). The focus in this section, is primarily on community responses rather than on household coping mechanisms, which are discussed in the previous sections. However, it is obvious that neither individuals nor families can be separated from the communities in which they live. Development-oriented responses to HIV/AIDS are occurring on a small and very local scale (Schubert, 2003:29). They are seen in some community and NGO activities. However, the models of effectiveness and sustainability and local resource mobilization that those activities provide, have yet to find their way into national or international HIV/AIDS or national development policies and strategies (Topouzis, 1994:54).

2.6 MORBIDITY AND MORTALITY DUE TO HIV/AIDS

Morbidity and mortality due to HIV/AIDS and related illnesses are concentrated among adults between the ages of 25 and 50. People in this age group are often described as at the prime of their productive years, working and raising families. Illness and death of adult members of a household reduces the ability of families to provide for themselves (Steinberg, 2002:36). Dependency ratios increase, as fewer adults care for children and the elderly. Increasingly, older members of extended families assume a greater role in caring for and supporting remaining family members. As important is an adult death, whether that person was a woman or a man. The loss of a male adult can leave the remaining women and children with fewer economic opportunities and less control over productive assets, including equipment and land (Waller, 1998:63). The loss of a female may result in increased malnutrition and generally less care for the children. Especially in high-prevalence countries, the impact of HIV/AIDS on mortality, life expectancy, and household structures is increasingly evident. Changes that are occurring include the following.

- Increases in mortality are particularly noticeable among young children and people 20 to 50 years of age. In South Africa, HIV/AIDS accounted for 40 per cent of all adult deaths in 2000-2001, an increase from ten per cent in 1995-1996. In eastern and southern Africa, female mortality due to HIV/AIDS tends to occur five to ten years earlier than for men, because women are generally infected at earlier ages (WHO, 2002:20).
- Declines in life expectancy follow as adults die at younger ages than would have been the case without HIV/AIDS. Declines in life expectancy are not confined to the most severely affected countries. In Burkina Faso, where HIV prevalence was expected to reach “only” about ten per cent of adults in 2007, projections indicate, that life expectancy will fall by ten to eleven years by 2010 (UNICEF, 2004:16).
- Re-distribution of population: Infant and child mortality will increase, as will mortality in the age brackets of people 20 to 50 years old. In South Africa and elsewhere, young women will die at a younger age than young men, reflecting the earlier age at which women are infected. This may increase social tensions and gender violence as fewer younger women are available for partnering with young men. At the same time, it may give young women greater control over relationships as they may have greater flexibility in the choices of men they wish to be with (Avert Organisation, 2005:22).
- HIV/AIDS does not affect males and females at the same rate. A 2005 survey in Bobo-Dioulasso, Burkina Faso, showed that infection rates among young girls aged 13 to 24 were 5-8 times higher than those among boys of the same age. In lower prevalence situations, young men usually have higher infection rates than have young women; as the pandemic progresses, an increasing number of women are infected. Females have higher infection rates at an earlier age than have males, for a combination of socio-economic (e.g., gender discrimination in schooling, job access and wage rates, greater difficulty in accessing preventative and curative health care) and biological reasons (e.g., susceptibility to vaginal infections and abrasions, particularly at young ages) (Collins & Rau, 2000:75).

- Population growth will slow, as HIV/AIDS mortality increases. In Côte d'Ivoire, it is estimated, that the population growth rate will decrease by about 0.5 per cent per year as a result of HIV/AIDS. According to one assessment, the slowing down of the growth of the population, means that by the end of 2007, Côte d'Ivoire will have around one and a half million fewer people than it otherwise would have had. This will be as a result of two factors: first, increased mortality as a result of AIDS, and second, decreased fertility - fewer people of reproductive age etc. (Human Rights Watch, 2002:32).
- Household structures will change. As indicated above, households will change, with more female, child and elderly-headed households. Some households, however, will dissolve completely, either because of economic destitution or the death of parents and dispersal of children (Kurschner, 2002:17).

2.7 COMMUNITY MITIGATION EFFORTS AND INITIATIVES

The ability of households to manage the ill-health and death of one or more adult members, depends on numerous factors such as socio-economic status prior to the presence of HIV/AIDS, ability to minimize loss of assets and minimize debt, the support of extended family and of community and formal and informal support agencies (McDonagh, 2001:38). In addition, in many local communities such as those in Zimbabwe, families affected by HIV/AIDS become subject to stigmatization and discrimination, leading to secrecy around HIV/AIDS. These factors may be described in terms of stages in the sequence of impact and their reversibility. The first stage impacts include the reallocation of economic resources and labour. This impact may be temporary, and is reversible (Namposya-Serpell, 2000:33). The second stage is when family and household assets are sold in order to meet changed household needs. Children are deprived of education and care. This stage is difficult, if not impossible, to reverse. The household may then proceed to enter a stage of dependency on charity and aid, and/or eventually breaking up (Solomon, 2004:54). This is the third and final stage of impacts. This model is likely to be too simplistic for programming purposes, but it does outline an

initial method for a more thorough investigation of the patterns of impact. What has been done in areas of programming, helps fill in some of the outstanding questions about responding to the social and economic needs of HIV/AIDS-affected families and communities (Yang, 2005:16).

Turning to the secrecy resulting from stigma and discrimination, a South African survey reported, based on focus group discussions with people living with HIV/AIDS (PLWHA), that the negative orientation to people with HIV/AIDS, even when exhibited only by a minority of community members, and the fear of negative reactions from community members and other persons, is sufficiently strong to provide reason for PLWHA not to be open about their status in their own communities (Bachmann & Booyesen, 2003:67). PLWHA described how they had found it much easier to talk about their HIV positive status in other communities and only later within their own community. Interestingly, support networks did not seem to have evolved, and the individuals living with HIV feel very alone in their struggle to lead positive lives (Desmond & Gow, 2001:45). Social support networks are important for well-being, and a consequence of this finding is, that to build a strong support base for PLWHA, would be important. The same survey found that, as of 2001, little community mobilization in South Africa had occurred around HIV/AIDS issues, other than information campaigns run from outside communities (Engh, Stloukal & Du Guerny, 2002:32). This seems in line with findings in Zimbabwe, where affected households report often turning to extended family and/or community members for help. A study found, that about half of affected households studied in urban and rural areas of Zimbabwe had asked for some help with food or money from relatives, friends and neighbours within the previous twelve months (IFDA, 2003:51). One of the greatest needs was money for school fees. However, those same families reported that the help they needed, however, often was not forthcoming. While the above examples illustrate that the responses of communities can be negative, one feature in these examples is the absence of positive images and directions that can alter the negative images and response (Jordan-Harder, 2004:65). In the examples that follow, in many instances an outside organization or firm local leadership provides an alternative framework to the fear and stigma that may exist. Thus,

any discussion about community mobilization should understand and include the need to thoroughly describe the context, given the marked differentiation in forms, intensity, duration and levels of community mobilization to address various issues arising from HIV/AIDS (Garbus, 2000:42).

While a number of effective initiatives can be cited (see below), in other instances, relatively little is being done by and with communities. For example, in the Eastern Cape of South Africa, only 27 per cent of adults report ever having been to a meeting of people where AIDS has been discussed (Cogneau & Grimm, 2002:25). This supports the impression that there is very little community level mobilization around HIV/AIDS issues. Additionally, there is little evidence that structures for prevention, care or support, are emerging. There is a need for access to advice, information and support at village level, including remote villages with little access to services (IRIN, 2003:31). Although institutional support seems a critical factor in assisting households, some communities do provide support for affected households without external interventions. UNAIDS outlines the following forms of community-based responses to HIV/AIDS:

- Social support groups, including labour sharing, grain savings, and food donations.
- Savings associations.
- Emergency assistance associations, including interventions by faith-based groups.
- Self-help groups of people with HIV/AIDS. All of these are little understood in the context of addressing the impact of HIV/AIDS (Hosegood *et al.*, 2003:26).

Whether these local, informal and sometimes spontaneous responses can be strengthened from outside, is unclear. Imposing external views and expectations may undermine local initiatives and ownership. Poorly designed and externally imposed programmes could jeopardize fledgling community initiatives (Niyongabo, 2001:52). In addition, while the strengths and capacity

of local communities are often credited as substantive means to cope with the multiple impacts of HIV/AIDS, limits are imposed by wider economic conditions. The difficult economic conditions facing most people, prevented communities from offering any or much assistance in a study of both urban and rural locales in Zimbabwe (Mutangadura, 2000:30). While a grain savings scheme was highlighted for its effectiveness in providing for some of the needs of rural people, churches, savings clubs and other informal support networks offered only limited assistance to affected households. This, too, is likely due to the constraints imposed by the general economy (Rau, 2003:51). Evidence from Kenya, Tanzania and Uganda indicates active concern by such networks, but the demand far exceeds any one organization's ability to fully respond. The ability and willingness of communities to assist households affected by HIV/AIDS, varies greatly within and across countries. In many cases, communities would be willing to do more, but lack the resources (Silomba, 2002:28).

Thus, outside assistance is essential, or at least is an option for communities to access. Some well-studied programmes offer credible and effective models for working with communities. In cases where sensitive programmes, often led by NGOs with long-lasting community presence, have implemented flexible responses, the results reflect support that serves people's needs (Wilkins, 2003:43). Several of those NGO-supported programmes are outlined below:

- Families, Orphans and Children Under Stress (FOCUS) is a programme of FACT, a Zimbabwean AIDS service organization established in 1987. It is centered in eastern Zimbabwe and uses churches as a basis for its outreach to affected families and communities. Its purpose is to provide care and support to orphaned children. The programme relies on community volunteers, usually women (Asingwire, 1996:62). The programme emphasizes identification and monitoring of vulnerable children through visiting households regularly, providing community ownership, keeping children in school, establishing income-generating activities, and training and motivating volunteers. Volunteers identify unmet basic household needs and provide essential material support, including

maize seed, fertilizer, food, clothing, blankets, and school fees. The visiting volunteers also offer emotional and spiritual support to the children and their caregivers. In 2000, over 2,700 orphaned children were registered and supported by nearly 180 active volunteers. The total programme cost was US\$20,000-30,000 per year; a very modest sum (CADREC, 2002:39).

- The COPE Program in Malawi, operated by Save the Children (US), mobilized communities at area and village levels to address the needs of orphaned and other vulnerable children. In addition to community participants, government, religious and business groups were involved. With the facilitation by the COPE programme staff, area villagers came together to assess their concerns (Cogneau & Grimm, 2002:45). The number of COPE staff were eventually reduced substantially as village and area AIDS Committees assumed greater control and ownership over the functioning of activities. The local committees were linked to government and religious services, creating a stronger network of support in the process. By 2000, over 200 village AIDS committees existed. Over 12,000 orphaned children and nearly 12,000 families had received food and other material assistance. The average annual cost was US\$ 317,000 (Jordan-Harder, 2004:38).
- Chikankata is a mission-run health facility in southern Zambia. Over a period of ten years an HIV/AIDS programme has evolved, that is built on basic community development principles: strong local ownership and direction, building on the skills and knowledge of a wide range of people and groups, supplementing local resources with external aid. Initially, the medical staff of Chikankata sought to provide treatment for people living with HIV/AIDS through mobile clinics (UNDP, 2001:17). This proved to be too costly and insufficient to meet people's daily needs. Over time, the programme moved into family training for home-based care and then into mobilizing communities to be involved in care of people with HIV/AIDS. As community members confronted the needs of affected families, they designed initiatives that drew upon the resources all local government departments and organizations. The approach that has evolved at

Chikankata has, like the FOCUS and COPE programs, become models for other eastern and southern African groups (Steinberg, 2002:15).

- A programme in Luweero District, Uganda, illustrates the power of simple organization and local ownership. The programme is run by the African Medical & Research Foundation (AMREF) and is designed to address the range of needs of affected individuals and families (Tumushabe, 2003:27). It encompasses a variety of support functions, from assisting with school fees for orphaned and other vulnerable children, to developing water supplies, to microfinance loans for business activities. A three-tier structure has been created to respond to problems, including the large number of orphaned children in the area (Desmond, Michael & Gow, 2000:46). Organizationally, guardians of orphaned children are linked to Village Orphan Committees and select their representatives on those committees. Guardians may be grandparents, older siblings, aunts or uncles, or non-relatives. The Village Orphan Committees maintain a register of vulnerable children and help generate local resources to support the children and the guardians. In turn, the Village Orphan Committees select representatives to Parish Orphan Committees and these are linked to local government authorities (Evian, 2003:27). A sense of local ownership is strong at all these levels and the committees have begun tackling other development problems. Notable changes in the well-being of children and affected families are seen by community members. These and other examples of NGO-supported local programs illustrate some of the following key components of effective responses to the impact of HIV/AIDS (Barnett & Whiteside, 2003:30).
- Strong local ownership and control over decision making.
- The evolution of programmes over time, allowing for experiences to inform decisions.
- Facilitation, not control, from outside, especially with volunteers, and recognition of established or new leadership.

- Functional links to all levels of community resources, including government social services.

These examples reflect an integrated community response to HIV/AIDS. They are integrated in being able to draw upon the resources and skills of all community groups and agencies, not simply a health clinic or a school. They are also considered integrated, in that they address the underlying causes of issues, including the reasons for poverty and political disenfranchisement (Floyd, 2003:38). There are variations on the models, some with a formal centre from which the activities are coordinated and others more loosely organized. Some programmes use only a portion of the integrated community models. For example, many home-based care programmes in Southern Africa are designed to offer a continuum of care, especially palliative care, for PLWHA (Isaksen, Songstad & Spissoy, 2000:34). Often support for family members is included. A programme may be structured around a care centre or similar, located within the community, possibly attached to a church or school, where home-based care services are coordinated from. Volunteers, supported by medical and community development staff, play a major role in the functioning of this model (UNAIDS, 1999:19).

Some NGO programmes offer only specific services. For example, they may provide assistance to individuals and families in preparing for death and its consequences. This preparation may involve the making of individual memory books by ill parents that will be passed along to children, or the drafting of wills to formalize and legalize asset transfers. Such services may also be a part of a wider programme for PLWHA and affected families (Wilkins, 2003:36).

One area that is receiving growing attention for both infected and affected individuals and groups, is income-generating activities, sometimes involving small grants, other times small loans (micro-credits). A good deal of emphasis has been on increasing the economic well-being of affected households and of HIV-infected individuals (UNICEF, 2004:8). This has taken several forms: education grants for school children, food relief, and small loans/grants for what are generically called income-generating activities (IGA). Many of these

programmes arise from experiences over the past two decades with micro-finance to stimulate small business formation and economic security for groups of women and men (VSO-RAISA, 2003:24). Although there is much enthusiasm for IGA among NGOs dealing with HIV/AIDS in communities, implementation and sustainability remain to be fully assessed. To date, experiences with IGA loans and grants have very mixed records, with the trend toward initiatives that are non-sustainable in the absence of fairly substantial (by local standards) outside organizational support, or of such small scale as to offer little economic value to all but a handful of individuals (UNDP, 2001:56).

More effective were and are initiatives that have addressed the poverty underlying HIV/AIDS through established micro-finance agencies. The experience of working with micro-finance programs and recipients, as opposed to simply setting up income-generating activities with small grants, provides improved design and structures, greater sophistication in offering finance for a range of needs and uses, and usually involves facilitation for expanding community mobilization (Save the Children, 2002:16). Several programmes in Uganda and Zambia have been identified as exhibiting "best practices". In Uganda, these include a programme supported by The Foundation for International Community Assistance (FINCA) that offers loans for family health and funeral insurance and community mitigation efforts, while another, supported by the AMREF/Lutheran World Relief provide loans for business support and a strong community mobilization component (Rau, 2003:56).

In Zambia, the SCOPE project has been identified for the effectiveness of its loans to communities so as to develop mitigation activities. There remains, however, a need for more descriptive experiences with and critical analyses of micro-financing activities for HIV/AIDS prevention and mitigation, especially initiatives that engage communities (Policy Project, 1998:49).

2.7.1 Faith-based initiatives

Many faith-based groups are playing a significant role around HIV/AIDS issues. Congregations are involved in care and support for PLWHA, affected families and orphaned children. Home visits and spiritual support by congregation members are common. Arising from the policies and traditions of various faith-based groups, different activities are stressed (Niyongabo, 2001:31). The Catholic Church in many areas provides support for affected households and for orphaned children. Churches, such as the Evangelical Lutheran Church in Tanzania, run health facilities and provide medical attention. Two of the examples cited above of community mobilization, are associated with faith-based support and involvement: FOCUS in Zimbabwe and Chikankata in Zambia (Barnett & Whiteside, 2002:62).

Many faith-based responses go unreported. In part, because secular NGOs and international agencies have been cautious, if not skeptical, about the commitment of faith groups to address HIV/AIDS prevention. Controversies surrounding the promotion and use of condoms, symbols of sexual activity, are associated with some faith groups. Also, faith groups have not done a good job of illuminating their positive contributions (Booyesen & Bachmann, 2002:45). The lack of good documentation on the roles and contributions of faith groups remains a major gap in organizing and promoting society-wide responses to HIV/AIDS. What is clear is, that many local faith communities are highly concerned and actively involved in HIV/AIDS issues (Desmond & Gow, 2001:15). Church and mosque members provide spiritual, emotional and material support to affected households, contribute to the support of orphaned children, and take a lead in organizing other community members to mitigate the impact of HIV/AIDS. Denominations as a whole, however, have been slow to speak out on HIV/AIDS issues, invest substantial resources, or offer sustained leadership. This has made the work of local faith groups more difficult and isolated (Floyd, 2003:32).

2.7.2 Government responses

It appears, that only a small percentage of affected households benefit from state social welfare and support programs to mitigate the impact of HIV/AIDS or to reach very poor families. In Zimbabwe, it was reported, that no more than two per cent of people in need, receive such support (Human Rights Watch, 2002:22). A South African state grant programme for older adults does provide some minimal financial assistance, but usually not enough for grandparents to adequately care for fostered children. The state also offers grants for children, but not all parents/guardians are able to produce the required birth certificate to register for the grant. As of early 2000, less than five per cent of eligible children were benefiting from the monthly grants to guardians (IRIN, 2003:17). In Zambia, the Ministry of Labour and Social Security offers grants to implementing NGOs for street children projects. Education reforms that have recently occurred in many countries, are designed to offer free or reduced-fee education at primary school levels. These changes do offer some mitigation support to families, although many observers note, that other costs for school attendance remain (Greener, 2000:27).

It is clear that across Africa, governments are not prepared and are budgetary constrained in terms of offering financial support to individuals, families and communities affected by HIV/AIDS. In fact, most governments with HIV/AIDS policies and programmes, stress that care and support will fall primarily on families; little mention is made of mitigation as a role of government (Kelly, 2002:38). There is a growing willingness on the part of state governments to absorb some of the costs of providing antiretroviral drugs for pregnant women and newborn infants. Also, some governments are paying for (or preparing to pay for) the cost of antiretroviral drugs for a select group of people living with HIV/AIDS (Odipo, 2000:26). To date, only Botswana has implemented its programme to cover the costs of providing antiretroviral drugs to their citizens. As of mid-2003, some 9,000 people, in four priority groups, are receiving antiretroviral drugs in Botswana (Binagwaho, 2005:35).

Broad social welfare, social transfer and job creation schemes exist on paper in numerous countries, but have been undermined by prevailing economic conditions and practices over the past two decades (Case *et al.*, 2004:43). In one district in southern Zambia, half of one per cent of potentially eligible people receive state welfare assistance, for example. In most African countries, pensions and other old age funds exist primarily for permanent public service employees. Likewise, many governments pay funeral and some medical costs for civil servants, thus reducing some financial pressures on affected households. Civil servant beneficiaries are likely, also, to receive a death benefit or have access to pension benefits. However, civil servants represent only a small portion of all adults in most countries (Butler, 2005:59).

National policies offer frameworks for developing interventions and guidance for other sectors in setting priorities and designing actions. Most countries in Africa now have HIV/AIDS policies and structures designed to coordinate policy development and programme implementation. There are, however, wide differences between countries (and also within some countries) in the effectiveness of multi-sectoral coordination (Coombe, 2003:47). Malawi, for example, has on paper a structure that includes village AIDS committees that will facilitate local mobilization and activities. However, local committees have not, for the most part, been activated or supported by either communities or outside agencies (Evian, 2003:76).

The national policies of most countries include statements about community responsibilities. These tend to stress the importance of home-based care for HIV-infected individuals and care for orphaned children by the extended family and communities. In 1994, Malawi became the first country in the region to develop a policy statement and guidelines on the care of orphans (Hargreaves & Glynn, 2002:496). The guidelines emphasize community-based responses, but the ability of communities to cope with the demands of the growing number of orphaned children, prevents full and effective implementation of those community initiatives (Lopez *et al.*, 2004:44).

Several countries have policies, or drafts of policies, on child welfare. Most countries have signed ILO conventions that define a minimum age for work by

children and prohibit children from working in especially harsh and risky occupations. All African countries have signed the Convention on the Rights of the Child, and many have signed up to regional conventions such as the African Charter on the Rights and Welfare of the Child (Kelly, 2002:57). The ability of government authorities to fully enforce these and related international conventions is incomplete, however, especially given the stresses of poverty and the social and economic impact of HIV/AIDS on households. In most countries, obtaining the commitment of senior national political leaders to actual programme implementation, is difficult. Also, existing programmes and organizations addressing the needs of orphans and vulnerable children are too small to organize lobbying at the required level (Mendel, 2002:36).

The broad generalizations often drawn from the available evidence about the impact of HIV/AIDS, including the generalizations made in this paper, require further testing and specification. Even the most commonly accepted assumptions about the impact of HIV/AIDS, such as the inability or unwillingness of extended families and communities to cope, need to be tested (Schiff & McKay, 2003:25). It is not that the generalizations and assumptions are wrong. In many instances they are most likely correct, especially where evidence exists to confirm the statements. Rather, conditions of affected families and communities differ in respect of a number of factors: socioeconomic well-being prior to HIV/AIDS; size and demographic factors of households; prevailing social networks; local leadership; links to outside facilitating organizations and services (Solomon, 2004:78).

2.7.3 Narrative therapy: suitability for HIV/AIDS counselling and therapy

Narrative therapy is a form of psychotherapy which uses narratives, as an approach to helping people; this was developed during (and has evolved since) the 1970's and 1980's, in good part by Australian Michael White (Dulwich Centre) and his friend and colleague, David Epston, of New Zealand. Their approach became prevalent in North America with the 1990 publication of their book, *Narrative Means to Therapeutic Ends* (Epston & White, 1992).

Narrative therapy, finds ways of developing insight into the stories of the client's life. A therapist using narrative therapy is interested in the history of their client. They are searching for an in-depth account of the problems affecting the client's life. Narrative therapy is sometimes identified as having the client "re-authoring" or "re-storying" their experiences (Payne, 2000:36). These descriptions emphasize that the stories of people's lives are pivotal to an understanding of the individual. Within narrative therapy, people's beliefs, skills, principles, and knowledge will assist them in reducing the severity of their problems in their lives (Morgan, 2000:36).

Therapists can assist their clients in telling their story by acting like an "investigative reporter". The person who is telling the story, is intimately aware of the story they are about to tell to the therapist. The client can readily identify the antagonist of their story, and with minimal effort, they are able to identify successes they have achieved to combat this problem (White, 2005:2).

The therapist, as an investigative reporter, has many options for questions in the effort of exposing the successes the client has accomplished against their problems. These questions can open an examination of how the problem has influenced the person's life and what aspects of the problem keep the client from having a productive day. The investigative reporter can also examine the characters in the client's story in order to determine which are helping the protagonist, those who are assisting the problem, and what are their plans in the story (White, 2005:2).

Problems may be prevalent in a client's life. These problems rarely completely destroy their lives. Therapists, as investigative reporters, have many options for questions that are helpful in discovering successes that the client has achieved. The therapist can help the client identify the aspects of their life that are unaffected by their current problem and discover why they are safe (Cooper & Lesser, 2005:57). The therapist can also look into client's issues and find what skills and knowledge they currently possess to combat the problem and establish new ways to strengthen these skills. Identifying the client's desires for a better life can also give insights on successes in respect

of their problem, as well as views on how they would like their story to turn out (White, 2005:3).

Narrative therapy is premised on the basis that problems happen to every person in this world. On the day we are born, human beings are taken away from what is comforting and what is certain. As they progress through their lives, more problems emerge that they must face, and that causes them sorrow. This sorrow is identified by its bearer, and they remember it as they pass through life. Through the telling of this sorrow, the client and the therapist can identify what the client finds significant within their lives (Diabetes Counselling, 2006:25).

The examination of a client's sorrow can show them the inverse. This can broaden the client's understandings about their moral convictions and bring to light what beliefs and values they hold dear. This examination may also show them a purpose they have always had in life, but failed to recognize it, or important commitments within their lives that they have neglected (White, 2005:19).

Different experiences cause different levels of sorrow for every individual. The strength of this psychological pain can show to what degree they hold such values, morals, or purposes. By identifying the severities of their problems, the therapist and the client can understand what the client finds most important in their life (Mugurungi, 2005:71).

Within the process of therapy, these instances of pain and sorrow are identified and fully explored. Through this exploration, concepts that the client first believed as true, may now be identified as false. This revelation by the client can empower the client to make changes in their lives, improve their current situations, and alleviate their inner turmoil (White, 2005:20).

The term "Narrative Therapy" has a specific meaning and is not the same as Narrative Psychology, or any other therapy that uses stories. Narrative therapy refers to the ideas and practices of David Epston, Michael White and other practitioners who have built upon this work. The Narrative therapy focusses upon narrative while situated concepts are the therapy (White &

Epston, 1996:27). The narrative therapist is a collaborator with the client in the process of discovering richer ("thicker" or "richer") narratives that emerge from disparate descriptions of experience, thus destabilizing the hold of negative ("thin") narratives upon the client (Denning, 2000:35).

Although different narrative therapists work somewhat differently; for example, Epston uses letters and other documents with his clients; though this particular practice is not essential to narrative therapy), there are several common elements that might lead one to decide that a therapist is working "narratively" with clients (Barthes, 1996:32).

The common elements of narrative therapy are -

- an understanding of textual practices and, in particular, narrative as constitutive of reality, as when a client's presenting concerns are described as the "dominant narrative" in the client's life;
- an appreciation for the power of texts, especially in therapy, as when a client is given "A Graduation from Depression Certificate";
- an "externalizing" emphasis, such as by naming problems as if they were alive and separate from the client, as in "What does depression want your life to look like?";
- a focus on "unique outcomes" (a term of Erving Goffman): experiences that wouldn't be predicted by the plot line of the problematic story (Cooper & Lesser, 2005:27; Morgan, 2000:43).

2.7.4 Social Location as a story-telling method of teaching in HIV/Aids contexts

Research indicates, that HIV/AIDS is a complex issue involving the social, cultural, spiritual, physical, economic and political aspects of our lives. It is, therefore, more than just a health issue – it is also one of development. Other research expresses its complexity by saying HIV/AIDS is a social issue that highlights the consequences of social injustice, and calls human beings to work for justice in order to heal this world. Human beings, are therefore, urged

to mainstream HIV/AIDS in all aspects of their lives: that is, they must find ways – in whatever work they do – of dealing with prevention, delivering quality care to the infected, and mitigating the impact of the disease (Winslade & Monk, 2000:38).

This has repercussions for the teaching vocation. Educators need methods which will help them to deal with this complexity. Their ways of reading the scriptures, doing theology, counselling, preaching and HIV/AIDS project design, must enable their learners and parents to make an analysis that takes into consideration the social, economic, political and cultural aspects of individuals as social beings (Barnett & Whiteside, 2002:35). The methods of teaching must equip them to become champions of HIV/AIDS prevention and the provision of quality care. One theoretical method that has been found helpful in cultivating a deeper analysis, empathy and activism, is social location as story-telling and self-examination (CADREC, 2002:16).

2.7.4.1 Social location

Social location is a self-explanatory term, which refers to an individual's place or location in his/her society. People are socially located and socially constructed into a number of relationships that empower or disempower them: within the family, church, work-place, government and international class. Social location includes gender, class, race, ethnicity, history, health status, weight, height, and how these categories are valued by a particular society (Desmond *et al.*, 2000:33).

The social location theory, therefore, assumes that human beings are all located in society in relationships, institutions and values that are characterized by power. Their ways of seeing and hearing, are informed by their particular experiences in their society (Garbus, 2000:68). All human beings are socially located, and the factors of their social location empower them differently. They may be powerful or powerless, depending on where they are and the people with them, the institutions they occupy and the values that society attaches to all these areas. The importance of social location is, that it determines human beings' experience in the society and the world –

what happens or does not happen to them; what they see and hear and how they see and hear it, or, conversely, what they do not see or hear (Isaksen *et al.*, 2002:25).

From the foregoing paragraph the following become clear:

- First, social location allows human beings to talk about themselves. It is, therefore, a story-telling and analytical method: human beings tell stories of their lives in society (Freeman *et al.*, 1997:45).
- Second, it allows human beings to listen to each other's stories of social location. This helps them realize that, while they are indeed individuals with intellect and choices to make, these are determined by their position in society. Human beings can thus analyze how they are social beings, whose experiences, thoughts and feelings are not simply individual but are also affected considerably by the social institutions and relationships they occupy (Freedman & Combs, 1996:33).
- Third, it allows each human being to face the fact, that sometimes their social positions involve them in the oppression of other members of society. This approach of self-analysis creates a space for repentance and challenges human beings to opt for empowering those who are under their power and to confront the social institutions that distribute power unequally (Payne, 2000:34).
- Fourth, a critical self-awareness is in itself empowerment. Even those who find that they are socially marginalized, can begin to realize that they should and can resist their own oppression and seek empowerment. They come to understand that their oppression is social rather than natural or divine. If it is a social construct, then it can be deconstructed and reconstructed in order to affirm all members of the society. Social location as a story-telling method, therefore, should empower human beings to transform both their society and themselves (Winslade & Monk, 2000:43).

In this age of HIV/AIDS, this means that some factors of human beings' social location make them vulnerable to infection, such as being a woman who can

be raped at work, at home or on the street. Being a wife and mother means that a woman is much more likely to bear the heavy burden of care, should some of her family members fall sick (White, 2005:46). It also means a woman may not have the freedom to insist on safer sex and that "being faithful" may not work for her as a strategy of preventing HIV/AIDS, since she lives in a culture that more or less allows husbands to be unfaithful as long as they are discreet (Barthes, 1996:26).

When the method of social location is used, human beings are in a better position to understand why some people who abstain from sexual relations, who are faithful and who use condoms still become infected. It becomes clear why some people get infected and live productively for decades, while others die right away (White & Epston, 1996:35; Booyesen & Bachmann, 2000:63). For example, a non-working married woman, who may know that her husband is unfaithful and who risks being infected, is aware of the following:

- Her husband is culturally allowed to be unfaithful.
- She has no right to insist on safer sex, for he paid lobola (bride price).
- She is afraid to ask him to discuss HIV/AIDS for he is the head of the family.
- She is afraid to insist on a condom or to abstain, for he will leave her for another woman, and what will she and her children eat and where will they live?
- If she tests HIV-positive at the health clinic, she would not tell her partner lest she is blamed for bringing the virus home or for witchcraft.
- If the partner insists on having a child, even if the symptoms of HIV/AIDS are clear, she should oblige.
- If her husband dies, the relatives may ask her to choose another relative as husband.

In this analysis, educators or therapists are able to assess the social factors that make this woman more vulnerable to HIV/AIDS. They can identify culture, lack of economic and leadership power and gender as factors that expose her to infection. Having identified these, enables the learners and parents to continue to encourage ABC (Abstain, Be faithful and Condomize), but above all, to focus also on those social structures and social injustices that make certain groups and individuals of society more vulnerable to HIV/AIDS (Collins & Rau, 2000:63). It also challenges learners and parents to realize, that fighting HIV/AIDS is not as easy as ABC. Rather, it requires that we focus also on social structures that render certain groups vulnerable (Desmond & Gow, 2000:32). Above all, social location enables both learners and parents to realize that one cannot reduce HIV/AIDS to a disease of people who are immoral, or “those who deserve what they got”, or “those who are punished by God” (Bechu, 1998:36). If this was so, why is God punishing the least privileged members of the world with HIV/AIDS?

From the foregoing paragraph it is clear, that social location is having a potential to give HIV/AIDS-affected families a great deal of power – in terms of voice, access to resources and capacity to make and implement their own decisions – or they may have less of it, but most of the time they are in a mixed situation, depending on where they are. In short, all human beings experience life within their social locations and this largely shapes the choices they take (Asingwire, 1996:56).

Plotting their social locations, will confront human beings with how they use their power, if they have any, and possibly how they can use power positively. It will show them where they lack power and why. It will enable them to see where they need to give power and who needs to be given power (Engh *et al.*, 2000:49). It will also enable them to be sensitive to the needs of others. But above all, social location will enable them to be more alert to social structures and how they distribute power to the different members of society and hence, to challenge these structures to be just to everyone. In the HIV/AIDS era it will allow human beings to break the silence and see this epidemic as one within a wider range of other social epidemics of poverty, gender inequality, ageism,

racism, international injustice, ethnicity, sexual orientation, violence, violation of human rights and population mobility (Collins & Rau, 2000:74).

Because social location shapes human beings, experiences and their understanding of life, it also shapes how and what they read in the scriptures and the kind of theology they do. When they relate their social locations and listen to other people's social location, they have entered a realm of story-telling and self-examination (Birdthistle, 2004:54). They listen to each other's stories and they create a space of breaking silences, of understanding, of empathy, of being prophetic to one another and, hopefully, of giving justice a better deal (Cooper & Lesser, 2005:38). Within HIV/AIDS contexts it provides a space for breaking the silence, stigma and discrimination, as well as embarking on better informed prevention and care strategies (Wilkins, 2003:66).

Social location analysis works well with narrative theory, as, in a story, there are characters, events, places and times. When people read any story they are invited to enter its story world. But the story was written to persuade them they are not neutral (Denning, 2000:22). This lack of neutrality is added to by their social location. So the reading process becomes the meeting point of a written story, and their stories. When people read the story they identify and sympathize with those characters who best represent their own social location (Barthes, 1996:48).

At times, human beings may hate their own condition so much, that they respond by distancing themselves from those characters that are much closer to their lives. Reading then, is more like looking into a mirror and seeing a different face – they see themselves through the lives of those who are in the story (Winslade & Monk, 2000:37). Basically, what is said here, is best illustrated by the existence of different biblical and theological perspectives – liberation, Dalit, African women's, feminist, Black, Catholic, Lutheran: all these names denote that different readers propound different interpretations and theology, informed by their different backgrounds. People need to hear their stories and how they interact with the stories of others. Similarly, they need to articulate an HIV/AIDS theology – one that is informed by living in social,

national and global contexts shaped by this disease, and by other social epidemics that cultivate it (Morgan, 2000:36).

Group practical exercises which can help HIV/AIDS-affected families socially locate themselves, are:

- telling their stories;
- examining where they place themselves in regard to HIV/AIDS infection, care and treatment;
- reading the scriptural text through the windows of their own social location;
- plotting on own social location as honestly as possible in the graph provided;
- showing where one has power;
- showing how one uses one's power to empower oneself and others, or to oppress others; and
- showing where one needs to give power and who needs to give one power (Freeman *et al.*, 1997:53).

The above-mentioned exercises enable them to assess the power they have and how they can use it, as well as to seek ways of liberating interdependence within their institutions and relations.

2.8 CONCLUSION

This chapter explored and analysed the impact of HIV in families. In the next chapter a review of literature on HIV/AIDS is presented.

CHAPTER THREE

THE INCIDENTS OF HIV/AIDS: LOCAL AND INTERNATIONAL TRENDS

3.1 INTRODUCTION

HIV has found a wealth of opportunities to thrive among tragic human conditions fuelled by poverty, abuse, violence, prejudice and ignorance. Social and economic circumstances contribute to vulnerability to HIV-infection and intensify its impact, while HIV/AIDS generates and amplifies the very conditions that enable the epidemic to thrive (Mahomva, 2004:19). Just as the virus depletes the human body of its natural defences, it can also deplete families and communities of the assets and social structures necessary for successful prevention and provision of care and treatment for persons living with HIV/AIDS (Go, 2004:14). This is demonstrated by the estimated 30 million people living with HIV/AIDS, mostly in developing countries. Over 2 million people are expected to die from HIV related illnesses this year, adding up to nearly 12 million deaths attributed so far to the epidemic. The impact of HIV/AIDS extends beyond those living with the virus, as each infection produces consequences which affect the lives of the family, friends and communities surrounding an infected person (Avert Organisation, 2005:23). The overall impact of the epidemic encompasses effects on the lives of multiples of the millions of people living with HIV/AIDS or of those who have died. Those most affected by HIV/AIDS, are children (Butler, 2005:7).

This chapter analyses the impact of HIV/AIDS on children, factors that contribute to the rise of HIV/AIDS in South Africa, the South African HIV/AIDS strategic plan and stigma and discrimination and its implications for learners living with HIV/AIDS. Information about educator perceptions of learners with HIV/AIDS and HIV/AIDS programmes for learners will also be explored and analysed.

3.2 FACTORS CONTRIBUTING TO EXPLOSIVE RISE OF HIV/AIDS

South Africa has one of the highest levels of HIV prevalence in the world and with an estimated 4.2 million infections in 1999, it is estimated by UNAIDS to have more HIV positive citizens than any other country (USAID, 2002:65). According to the Department of Health (2001:13) the figure for 2000 is 4.7 million, but for various reasons this is probably an underestimate. According to the ASSA 2000 model, the figure is closer to 5.3 million. The epidemic has already reached catastrophic proportions in many parts of the country, and it is expected, that prevalence levels will continue to rise for some years to come. Even so, there is still very little understanding of how best to manage the epidemic or indeed, comprehensive system of measuring the impact of the epidemic. The first AIDS case in South Africa was diagnosed in 1982 (Dickinson, 2003:22) and since then, the prevalence recorded by the national antenatal sero-prevalence survey has risen steeply from less than one per cent in 1990 to nearly 25 per cent, years later. That the epidemic has spread so rapidly and extensively in South Africa in particular is not surprising. Kelly (2002:30) identified what they termed a high-risk situation as one characterised by impoverishment disfranchisement, rapid urbanisation, the anonymity of urban life, labour migration, widespread population movements and displacements, social disruption and wars, especially counter-insurgency wars. As Groenewald (2005:2) points out, that on any scale of high-risk situations, South Africa in the 1980s ranked near the top. A number of the factors that have contributed to the explosive rise in prevalence, are explored below.

3.2.1 Bio-medical factors

The most significant bio-medical factor driving the epidemic, is the high prevalence of sexually transmitted diseases (STDs). Genital sores and ulcers caused by these STDs greatly increase the risk of HIV transmission, and there is thus a significant correlation between levels of STD and HIV prevalence (Department of Health, 2001:10). The following figures bear testimony to the high levels of sexually transmitted infections.

- It is estimated, that there were 5 000 to 15 000 cases per cent 100 000 of syphilis in 1996.
- A study conducted in Carletonville found that 14 per cent of men, 22 per cent of women and 11 per cent of migrant mine workers were infected with syphilis, gonorrhoea or chlamydia (Booyesen, 2003:19).
- Avert Organisation (2005:12) estimates, that 25 per cent of women in rural KwaZulu-Natal have a least one STD.
- According to the South African Democratic NAD Health Survey (SADHS), about 12 per cent of men reported having suffered from an STD in the last three months (Holmes, 2003:55).

Levels of STD treatment are low for a number of reasons. Many STDs are symptomatic, and even when symptoms occur, they may not be recognised as being due to infection. A second problem is, that even when symptoms occur, individuals will often not seek treatment, either because treatment is inaccessible or because the infection is not regarded as being serious (Corbett, 2002:77). To aggravate the situation further, treatment is often ineffective. The high level of STD prevalence in South Africa and the rest of Africa, is thus a consequence of poor education on symptoms and causes of STDs, poor access to treatment, and poor quality of treatment (Askew & Berer, 2003:60). It has been suggested, that male circumcision may also be a significant bio-medical determinant of HIV incidence; the foreskin of the penis is providing a vulnerable portal of the virus. HIV prevalence was significantly lower among circumcised men than among uncircumcised men, and may to some extent also explain the high prevalence in the urbanised Black population, in which the practice of circumcision is becoming less common (Kilbourne, Herndon, Anderson, Wenzel & Gelberg, 2002:9). Bad sanitation and nutrition – to the extent that they influence the state of the immune system, may also affect the rate of transmission. The scarcity of water leads to sanitation, which in turn leads to a higher incidence of disease generally. Levels of nutrition are also low in many areas; the rate varies from 15 per cent

of households in Gauteng and the Western Cape, to 32 per cent of households in Mpumalanga (Statistics South Africa, 2005:12)

3.2.2 Sexual behaviour factors

Although a large number of public AIDS awareness and education programmes have been launched, there remains a significant proportion of the population that due to illiteracy, geographical isolation or misinformation, is still ignorant of the basic facts of AIDS (Brown, 2003:49). A recent survey of teenagers between the ages of 12 and 17 indicated that:

- levels of awareness of HIV/AIDS were high (91 per cent of respondents), but tended to be low in rural areas (86 per cent);
- seven per cent of respondents said, they believed, that one could be cured of AIDS by having sex with a virgin, and 12 per cent believed that one could get HIV/AIDS from condoms; and
- thirteen per cent said they believed that traditional Africa medicine had a cure for AIDS, while 15 per cent believed that Western medicine had a cure (Coombe, 2003:12; Mallman, 2003:15).

3.2.3 Sexual abuse and the status of women

Since the new political dispensation in 1994, much political emphasis has been placed on the right of women, and the need for gender equality. However, South Africa remains a fairly patriarchal society, in which women are vulnerable to sexual abuse. In 1998, South Africa had the highest per capita rate of rape in the world. Close to one million acts of rape occur in South Africa every year (Mitrani, Prado, Feaster, Robinson-Batista & Szapocznik, 2003:31). The World Health Organisation (2003:15) found, in a study of Black teenagers attending antenatal clinics in Cape Town, that 72 per cent of girls reported having forced to have sex at some stage, and 11 per cent reported having been raped. The South African National Youth Survey (Butler, 2005:16) also found, that 39 per cent of sexually experienced girls had been forced to have sex, and 33 per cent reported being afraid of saying 'no'

to sex. In many cases, therefore, women have limited control over their sexual activities, and are thus more vulnerable to HIV infection (Giese, 2003:21).

3.2.4 Prostitution and high-risk forms of sexual behaviour

Commercial sex workers are particularly at risk of infection. The first reason for this, is the high number of sexual partners that they have. The other reason is, that the sex workers are frequently forced to engage in high-risk forms of sexual intercourse, such as anal sex and dry sex. Women practising dry sex use drying agents (including cloth, soap, detergents, and traditional medicines) to tighten or dry their vaginas, in order to enhance the sexual experience of their partners (Hunter, 2002:99). It is believed that the use of these agents increase a woman's chance of infection, and Ntuli (2004:191) found, that HIV prevalence among women practising dry sex was higher than that for women not practising it, both among sex workers (91 per cent against 41 per cent). Only 3.2 per cent of those women sampled, were using drying agents, which suggests that the practice may not be as widespread as sometimes thought (Mwaluko, 2003:45). Sexual intercourse also greatly increases the risk of transmission, both for the penetrating partner and the receptive partner, and seven per cent of sex workers report practising anal sex at least once a week (Meehan, 2004:11). Risk of transmission is further increased by the lack of condom usage. Nineteen per cent of sex workers sampled by Rees, reported using a condom less than 50 per cent of the time, 51 per cent reported using between 50 and 75 per cent of the time and only 30 per cent reported using one more than 75 per cent of the time (Mahomva, 2004:20).

It should be recognised, that many women sell sex without regarding themselves as prostitutes, relying on regular financial support in return for sexual favour. The South African National Youth Survey (Department of Health, 2005:12) found for example, that 16 per cent of sexually experienced girls indicated having had sex for money, drink, food or gifts, and 20 per cent of sexually experienced boys reported having given a girlfriend pocket money, food or drink in exchange for sex. This widespread dependence on sex as a

source of income, creates an environment conducive to the rapid spread of HIV (Ekra, 2004:20).

3.2.5 Social risk factors

3.2.5.1 Migration patterns

South Africa has experienced a high level of political and economic migration in recent decades, both between its provinces, and between itself and neighbouring countries. Migration increases the extent of sexual networking and thus facilitates the swift spread of the HIV/AIDS epidemic (Meyer, 2003:86). This is demonstrated in a study of a rural community in KwaZulu-Natal people who had recently changed the place of residence, were three times more likely to be HIV positive than those who had not. It is, therefore, a concern that the rates of migrant employment are as high as 60 per cent of male and a third of females between the ages of 19 and 49 (Lyon & Woodward, 2003:196).

One of the reasons for the high level of migration, is the forced removal initiated by the 'apartheid' government; more than 3.5 million Black people were relocated to the twelve homelands. Black people were prevented from settling permanently in the urban White areas and had to retain a rural base in these homelands (Groenewald, 2005:7). It was estimated, that more than 2.5 million migrants drawn from rural areas and neighbouring countries, were working in mines, factories and on farms. These miners are accommodated by spouses and regular sexual partners (many of whom reside in rural areas); those living in single-sex hostels often engage in high-risk sexual activity with commercial sex workers (Pick, 2003:10).

Migrant workers who become infected in urban areas, then pass the virus on to their partners when they return to the rural areas. Evidence suggests, that transmission in the opposite direction may also occur (Shisan *et al.*, 2005:15). Statistics South Africa (2005:9) found, that for nearly 40 per cent of discordant migrant couples, it is the female partner who is infected with HIV, not the male. This may indicate, that those women are forced to rely on sex to supplement their incomes while their partners are away for long periods.

3.2.6 Political turmoil and war

Armed conflict has the effect of both displacing those seeking to avoid conflict, and destabilising the traditional power structure and value systems of society. It also creates movement of armed forces between regions. Many of the armed forces of the 'apartheid' government operated to the North of South Africa's borders, in Namibia and Angola (Mugurungi, 2005:15). Many of the former revolutionary cadres also fought in these regions, and were incorporated into the National Defence Force and placed in bases all over the country after 1994, without any HIV testing (Monze, 2004:25). The return of these security forces from the areas of high HIV prevalence to military bases throughout the country, has no doubt contributed in the rapid growth of the epidemic in South Africa (National AIDS Coordinating Agency, 2003:30).

Within South Africa, KwaZulu-Natal has been particularly afflicted by violence and political conflict between ANC and IFP supporters. This violence has led to a collapse of social cohesion and disintegration of parental authority, and is a significant factor contributing to the high levels of HIV prevalence in the province (Pick, 2003:34).

3.2.7 Overcrowding and poverty

Households and communities already suffering conditions of poverty are, usually, most harmed by the loss of adult members to illnesses, including HIV/AIDS. Female-and elderly-headed households are likewise least able to cope with the economic, labour and social losses arising from HIV/AIDS. Thus, if we want to know whether households are coping with the impact of HIV/AIDS, we need to include the wider socioeconomic context in the analysis and identify who is affected, and within that group, who is most affected. Differentiation of data by gender, age, and socioeconomic status is critical (Niyongabo, 2001:63).

Booyesen and Bachmann (2002:18) argue that another parallel change to the prevailing poverty in many societies, more directly associated with structural adjustment-induced reforms, is the greater cost and difficulty in accessing basic social services, including education and health-care by many families.

Again, these costs have been most deeply felt by lower income groups. The additional costs arising from medical care for people with HIV/AIDS and related illnesses, can readily deplete household savings and assets (Greener, 2000:30). Economically stressed families may withdraw girls and boys from school in order to reduce expenses, assist in the care of ill relatives and free up an adult (usually a woman) to seek work. Households with more assets, more adults able to contribute their labour for productive activities or care, and greater wealth, are usually better able to absorb the expenses of treating HIV/AIDS and related illnesses and the loss of one or more family members (Kaliyati, 2003:49). Three broad statements do seem reasonable at this stage in the pandemic:

- The presence of HIV/AIDS in a household quickly results in the depletion of the household income-earning capacity and of household savings and assets. Many households quickly move into conditions characterized by poverty: very little income or wealth, debt, reduced access to services, and fewer than ever options for attaining socioeconomic security. Women and girls, in particular, are likely to be most affected (Kurschner, 2002:14).
- HIV/AIDS exacerbates and is exacerbated by prevailing economic conditions. HIV/AIDS is not a stand-alone condition, but exists within a wider socioeconomic context that deepens the vulnerability of households, communities and nations (Phiri, Foster & Nzima, 2001:42).
- The economic costs of HIV/AIDS, the stigma surrounding the disease that leads to discrimination and withdrawal, and the ability to access social services, combine to expand socioeconomic inequalities in society. HIV/AIDS is not only killing people, it is further dividing national societies (Save the children, 2000:50).

Overcrowding and poverty are responsible for many of the social pressures that led to high-risk sexual behaviour. The forced removals described previously, led to an overcrowding in the former homelands, resulting in overgrazing and erosion in living conditions (Kumar & Singh, 2004:27). Poverty is clearly a factor in the spread and impact of HIV/AIDS. The struggle

to survive every day, overshadows attention and concern about a virus that does not demonstrate any immediate harm. HIV/AIDS is a distant threat until it has a visible presence manifested by illness and death (PAHO, 2005:30). Poverty in depriving people of access to health facilities, schools and media, also limits their access to information and education on HIV/AIDS. Poverty pushes families, often unaware of the risks, to send children into the work force or to hand them over to recruiters promising jobs in a distant place where, unprotected, they might be forced into a childhood of harsh labour or sexual abuse (Lambert, 2005:240). When HIV/AIDS appears in an already impoverished household, there are limited means for response, the mortality rate is high, the impact is severe and the pressures and pain of poverty increase (Bautista, 2004:98). As increasing numbers of infected young adults are unable to contribute to their communities through their work as parents, teachers, labourers, drivers, farmers, etc., entire economic and social structures of communities suffer and demands for services increase, with fewer able people to provide them (UNAIDSWHO, 2004:14).

The vast majority, over 90%, of all people infected with HIV since the beginning of the epidemic, are from the developing world. In Sub-Saharan Africa where two-thirds of the world's infections have occurred, more than 7.4% of the population between the ages of 15 and 49 is estimated to be infected with HIV (Jordan-Harder, 2004:287). In Zimbabwe infection rates are estimated to be in the region of 20% while in Botswana adult infections are thought to be approaching 25-30% of the population (Haggrove, 2005:15). In India, although the overall infection rate is still less than 1% of the population, this amounts to between 3 and 5 million people, most of whom are untested and unaware of their infection status. Ante-natal testing among those with access to health facilities, provides some staggering statistics: in Haiti the national rate is over 8%, while in some areas of Southern Africa local HIV infection rates among pregnant women of 30 - 60% have been reported (UNAIDS, 2004:32).

3.2.7.1 Economic factors

Income is one of the most significant factors correlated with HIV prevalence. The relatively poor members of society are most affected by the epidemic, as most of the risk factors described above, are linked to low socio-economic status (Booyesen, 2003:26). Mwaluko (2003:47) observes that the poor tend to work in high-risk occupations, and tend to be exposed to greater dangers in the course of their everyday life than do the relatively wealthy. Being relatively uneducated, they are also less likely to know what AIDS is and how the virus is transmitted. Many do not have access to proper treatment for STDs, or cannot afford treatment (Thwe, 2004:170). However, it should not be assumed, that HIV/AIDS is a disease affecting exclusively the poor. It can be argued, that as individuals earn more and their socio-economic status rises, they are able to attract greater numbers of sexual partners, who places them at greater risk of infection (Balakireva, 2003:15).

It is widely assumed, for example, that the teaching and nursing profession will be quite severely hit by the epidemic (Brown, 2003:49).

3.3 EMOTIONAL RESPONSES OF HIV/AIDS-INFECTED LEARNERS

Learners affected by HIV/AIDS, experience the following emotions: fear, loss, grief, anger, depression, feelings of dependency and hope (Clinton, 2003:19).

3.3.1 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 (Fassin & Schneider, 2003:95). Fear can aggravate depression symptoms and lead to feelings of hopelessness, frustration and being overwhelmed. 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 (Heyzer, 2003:38).

3.3.2 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 and housing, to name a few (Fleischman, 2003:27).

3.3.3 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, or 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; Salomon, Hogan & Stover, 2005:29).

3.3.4 Anger

Anger may be directed at several targets simultaneously. The person with the 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 (Choi, 2003:26). 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).

3.3.5 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 (Mendel, 2002:17). 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 (Lamprey, Wigley & Carr, 2002:18).

3.3.6 Feelings of dependency

People can experience feelings of dependency 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 (Mohlala, 2002:27; Kumar, Larkin & Mitchell, 2001:35).

3.3.7 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 (Tawfik & Kenoti, 2002:40). 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 (Van Aard, 2002:77).

3.4 THE HIV/AIDS STRATEGIC PLAN (HIVSP) FOR SOUTH AFRICA 2000-2005

The purpose of the plan is to guide the country's response to the epidemic. It is not a plan for the health sector, but a state of intent for the country as a whole. It recognises that no single sector, ministry, department or organisation is solely responsible for addressing the HIV epidemic. It envisages, that all government departments, organisations and stakeholders will use the HIVSP as the basis to develop their own strategic and operational plans so that all initiatives can be harmonised in order to maximise efficiency and effectiveness (Department of Health, 2001:34).

3.4.1 The national Integrated Plan (IP) for children infected by HIV/AIDS

The overall goal of the IP is to ensure access to an appropriate and effective integrated system of prevention, care and support services for children infected and affected by HIV/AIDS (Department of Health, 2001:18). This goal is to be achieved through four main programmes.

- Programme 1: Community-based care and support
- Programme 2: Strengthening Voluntary Counselling and Testing (VCT) initiative
- Programme 3: Life-skills and HIV/AIDS education in primary and secondary school
- Programme 4: Community outreach / community mobilisation

Programme one involves the development of strategies for the care of orphans and community-based models of care for people living with HIV/AIDS, focusing on policy development and the piloting of approaches (Blower & Farmer, 2003:1). Programme four involves community-based HIV/AIDS awareness programmes to link and promote the other three initiatives. This programme provides the thread that will link the other programmes together. It aims to focus on raising the level of awareness amongst community leaders of HIV/AIDS in general, existing and new HIV/AIDS programmes, and activities in the community on how to access services related to HIV/AIDS (Bell, Shantayanan & Hans, 2003:20).

The programmes will include the development of co-ordinating structures, income generation activities, and specific prevention activities targeting children and youth, community-based care, capacity building, access to grants and legal placements, training of teachers, as well as Voluntary Counselling and Testing (Caiaffa, 2003:76). These initiatives will be underpinned by a community outreach programme aimed at an increased HIV/AIDS awareness. The decision was for the life-skills programme in school to be the core of the initiative (Hargreaves & Glynn, 2002:98). Developing strategies for the care of children and community and home - based models of care for children living with HIV, would form smaller component. Strengthening current efforts to make available VCT facilities would also form a smaller component (Kidane, Banteyena & Nyblade, 2003:45).

3.4.2 The explicit programme objectives of the Integrated Plan (IP) or Integrated Strategy (IS)

The objectives of the programme are to:

- establish and implement integrated community-based care and support programmes for children infected by HIV/AIDS;
- improve access to VCT services for 12.5 per cent of the population aged 15-49 over three years, focusing on youth and rural communities;

- implement the life-skills and HIV/AIDS education programme in 20 per cent of primary and secondary schools; and
- mobilise communities through community-based HIV/AIDS awareness programmes (Department of Health, 2001:20).

Provinces are supposed to develop their own implementation plans within the principles and guidelines stipulated in the national plan (Askew & Berer, 2003:50). The departments that are to take the lead in implementation, are Health, Social Development (Welfare) and Education. The successful implementation of the plan requires a great deal of communication and co-ordination between the different spheres of government, the different departments at the provincial level and between families, communities and government (Coombe, 2003:20). This is particularly the case in the home-and community-based care and support programme. It involves the Health and Social Development (Welfare) department in provinces taking leading roles in projects. It involves families and community structures being involved in providing medical and other forms of care (Kelly, 2002:15).

The planning document envisages implementation over three years, starting 2000/01. All four programmes have to be implemented in the provinces Eastern Cape; Mpumalanga and the Northern Province; the Free State and Northern Cape. Programme included (Life-skills; VCT; Community-based care and support. Gauteng, Western Cape and KwaZulu-Natal were to implement the life-skills and VCT programmes only (Giese, 2003:5). A district approach is being followed, meaning that only one district per province was to see the implementation of the plan. The aim in the initial planning documents was to extend all four programmes in every province in districts of need over two and three of the strategy. By the end of the three-years period, it was envisaged that provinces would take financial responsibility for the programme in the Integrated Plan (IP) developing them further according to the need, while districts would take the lead role in delivery (Chisholm, 2004:9).

3.4.2.1 Care of HIV-infected children

The response to meeting the needs of HIV-positive children, has been similar to that experienced by adults and little evidence of a coordinated treatment strategy exists. Provincial and national guidelines for the management of HIV-positive children have been developed. In some instances the production of these guidelines has been supported by one-off training workshops for health-care workers (Pokrovskiy, 2005:10). However, no sustained programmes seem to exist for the ongoing distribution of guidelines or training of health-care worker (Rhodes & Simic, 2005:20).

The national guidelines are comprehensive, holistic and user-friendly; they are like adults guidelines. They do not include information on the role of ARV therapy. Once again, the HIV clinicians society has filled this gap by publishing its own recommendations (Gwyther & Marstone, 2003:30)

The essential drugs list for paediatric illness has no recommendations on HIV treatment, but does include one section on occupationally acquired HIV exposure. Apart from ARV and more specialised drugs, all the basic medicines required for the treatment of HIV-associated illnesses in children, are included in the list (Letteney, 2006:60).

The care of HIV-positive children in the private sector, is linked to that of their parents and is dependent on the medical insurance scheme to which they subscribe. The benefits to children are similar to those for adults and as mentioned above, an estimated five per cent of HIV-positive patient in the private sector being funded for ARV therapy, is a child (Lopez, Kreider & Caspe, 2004:15).

No objectives exist in the national strategic plan relating specifically to the treatment of HIV-positive children; however, children are included as recipients of care and treatment strategies (Malebranche & Peterson, 2004:97). The current status of child-targeted responses, is similar to that outlined above with respect to HIV-positive women.

- Local guidelines on the management of HIV-infected children, as well as on the uses of ARV drugs, have been developed.
- These guideline are, however, not widely available.
- Training programmes on the use of the guidelines, do not appear to exist.
- Support services and structures for the successful implementation of guidelines, are also inadequate. (Oliver-Smith, 2004:10).

3.4.3 Further action needed to increase the effectiveness of the interventions

There is no doubt that a wide range of comprehensive and effective strategies have been designed to meet the treatment needs of HIV/AIDS and related illness. Unfortunately, there is no doubt, that none of these interventions has been successfully implemented on a wide scale anywhere in the country. In looking at strategies to move from planning to implementation, a number of issues need to be reviewed (Schiff & McKay, 2003:101). These include the following:

3.4.3.1 Partnerships

In view of the limited resources, financial, material and skills within the country, especially within the private sector, collaboration with local, national and international parties, will require to supplement these possible partners which include foreign governments, multinational agencies, academic institutions and pharmaceutical companies. At present policies and mechanisms exist for collaboration and the development of partnerships, but these are to a large extent limited to the national and to a lesser extent, the provincial level. Collaboration also occurs through academic institutions. Mechanisms need to be developed to extent of the development of partnerships more broadly (Thomas, 2006:57).

3.4.3.2 Programmes and communication

The development of a programme is currently limited to a few role-players who are invariably centrally located within the national Department of Health

and academic centres. Neither of these parties is an implementing agents (Van Dyk, 2005:70). These programmes are then imposed vertically on implementing agents who were never consulted and were not party to their development. Not surprisingly, there is little sense of ownership of the programmes and often only half-hearted implementation (Walker, 2004:4).

Negotiations between the Pfizer and Ministerial Task Team for a two-year unlimited donation of Fluconazole from Pfizer to the Department of Health for the above programme were concluded towards the end of 2000 (Corbett, 2002:62). Representation on the ministerial task team was limited with no provincial representatives, no clinicians from the public sector and no paediatricians. The only clinical input was from Pfizer and the South African HIV Clinician Society. The agreed-upon programme is not acceptable to many clinicians working in the public sector hospital, due to inadequate diagnostic criteria, contradictor treatment protocols and the exclusion of children (Worthington & Myers, 2003:36).

3.4.3.3 Barriers to the use of protocols

In planning treatment intervention, many excellent protocols have been developed. Unfortunately many barriers to the effective use of these protocols appear to exist. The development of these protocols is often protracted (Gonzalez, Penedo, Antoni, Duran, Fernandez, McPherson-Baker, Ironson, Klimas, Fletcher & Schneiderman, 2004:13). Once developed, distribution has invariably been inadequate. Ongoing support such as training workshops, easy access to the recommended treatments and ongoing review and updating, is lacking. The attitude of many health-care workers to HIV, and their reluctance to deal comprehensively with HIV-positive individuals needs to be addressed (Wood, Hogg, Yip, Harrigan, O'Shaughnessy & Montaner, 2003:11). Uninterrupted access to materials and drugs required in the protocols, need to be guaranteed. This is critical as once the issue of partnerships is resolved, it is only a matter of time before ARV drugs will be available within the public health service and effective functioning systems need to be in place before ARV regimes can be implemented (Goetz & Darryl, 2005:53).

3.4.3.4 Drug donation

Now that the debate around parallel imports and drug patents is being resolved, the likelihood of partnerships between the government and global pharmaceutical companies is more realistic. Once this occurs, or failing this through the UNAIDS drug initiatives, access to a currently unavailable drug is likely to occur (UNAIDSWHO, 2005:5). Mechanisms, therefore, need to be established for the development of programmes that are relevant to welfare. This requires a shift from vertical programmes to partnerships between the provinces and national health and the inclusion of more clinicians in planning teams (Camara, 2003:14).

3.4.3.5 The availability of ARV

It is generally recognised, that it is only a matter of time before these become available through the public health sector. It is, therefore, essential that a process of developing appropriate, innovative, alternative ARV drug regimens start's now (Gaillard, 2004:36). A need exists for the development of regional centres of excellence in HIV treatment and ARV use to act as focal point for the expansion of programmes throughout all health regions (Palmer, 2002:30).

3.4.3.6 On-going training

Of all health-care workers in existing programmes and for the implementation of any new programmes for the treatment of HIV and related illnesses is probably the most single most important factor following the development of appropriate protocols and availability of resources (UNAIDS, 2004:16).

It is important to recognise that, despite the problem outlined, there are sufficient dedicated and committed personnel in the health sector for the effective implementation of existing treatment protocols (Bautista, 2004:98). For effective service delivery to become a reality, these individuals require effective support. This includes political and administrative commitment to addressing the issues, access to the necessary resources and appropriate skills (Garcia, 2005:12).

3.4.3.7 HIV/AIDS education

The government's policy on HIV/AIDS is set out in National Policy on HIV/AIDS (27/1996). It addresses issues such as disclosure and confidentiality, the constitutional right of learners; and education; non-discrimination and equality, what constitutes a safe school environment. It also mandates that age-appropriate life-skills be taught on a regular basis at school and institutions to all learners and staff. Another major policy document, is the Minister of Education Kader Asmal's implementation plan for Tirisano (Department of Education, 2001:15). This plan suggests how planners might create the means for understanding how HIV/AIDS is impacting on education. It is also aimed to ensure that life-skills and HIV/AIDS education would be implemented at all levels; that educators would be adequately trained and resourced, and awareness would be raised at all levels.

Another important policy document that describes how HIV/AIDS programmes should be implemented in schools, is the Gauteng Circular 33/2001 (Department of Education, 2001:12). Kelly's (2002:29) holistic approach to HIV/AIDS education corroborates the strategy of integration. He emphasises that HIV/AIDS education should engage the whole person, go beyond mere academic and intellectual knowledge, and should include suggestions for real-life action and behaviour (Kelly, 2002:29). The researchers found that very few programmes throughout the world actually focus on learners' experiences and that the usual emphasis is on changing risky behaviours. Coombe (2003:41) notes, that this strategy may actually increase the possibility of HIV infection.

3.5 EDUCATOR PERCEPTION OF HIV/AIDS

In this section educator perception of learners infected with HIV/AIDS, is discussed and analysed.

3.5.1 Educator perception of learners' HIV-status with a view to wellness promotion

The AIDS pandemic, which is “.....deadlier than war, tyranny and malaria, is putting the survival, especially of the African continent, at stake”. A contemporary study of African universities noted an “.....overwhelming atmosphere of ignorance, secrecy, denial and fear of stigmatisation and discrimination in relation to AIDS (World Bank, 2002:14). Preliminary research in the United States concerning educator perceptions of HIV-positive individuals suggests that despite widespread education concerning HIV/AIDS, there are still some educators that hold many negative perceptions. Such perceptions include projected desire to quit teaching before working with someone who has AIDS; fear at having to work with HIV positive individuals and a belief that AIDS is a just punishment for immorality (Tembon, Drake, Shairlaw, Connolly, Lee, Patrikios, Kaleeba, Mannathoko, Gillespie & Bundy, 2003:60). The focus of the study of Van Aard (2002:67) was on Gauteng educators' perceptions of the HIV status of learners and the impact thereof on educator and school well-being, with a view to making recommendations towards the empowerment of educators. Educators are in the epicentre of the reality of the HIV/AIDS pandemic, as outlined in the following literature overview.

3.5.1.1 Educator perceptions of AIDS

Perception can be broadly defined as the manner in which meaning is made. Meaning, in turn, impacts on attitude and behaviour. In a study conducted amongst rural high school educators, it was established, that educators are less likely to hold negative perceptions of AIDS/HIV-positive individuals, primarily they are educated individuals; a second study conducted, indicated that 96 SA educators suggested more mixed perceptions, educator responses generally expressed sympathy towards AIDS victims, but typical stigmatising responses were included (Dickinson, 2003:9). When perception is pervasively negative, wellness must necessarily suffer.

3.5.1.2 Wellness and empowerment

In order to consider the impact of educators' perceptions of the HIV status of learners and school well being, it is necessary to understand what is meant by wellness.

Wellness or holistic health can be defined as a state of complete physical, mental and social well-being (World Health Organisation, 2003:18). Such wellness is considered to be dynamic and is affected by both personal and environmental factors (Ross & Deverell, 2004: 14). When personal and or environmental factors are perceived as negative, stress ensues and a comprehensive physiological response (including mental, emotional; behavioural and physical components) is provoked. Chronic stressful responses are at loggerheads with emotional wellness or resilience (Schiff & McKay, 2003:102). Resilience can be seen as the capacity to continue experiencing wellness despite unfavourable personal and or environmental factors.

Perhaps one of the most crucial transformations within the psychological theory, is the notion that wellness can be nurtured and that environmental and intru-physic onslaughts can be mediated. In this way the individual can be empowered to function adaptively, regardless of deteriorating circumstances. This notion is termed health promotion (World Health Organisation, 2002:17).

Health promotion empowers both the individual and communities. Empowerment is a process through which people gain hegemony over choices and behaviour affecting their health. Empowerment (Thomas, 2006:60) is centred on the following.

- The acquisition of skills (including thinking and decision-making skills).
- The acquisition of assertiveness, interpersonal competence and cognitive knowledge (which includes a deeper understanding of the issue at hand).
- Psychological perception (including self-esteem and perceptions of control).

It is well-documented, that the HIV/AIDS pandemic is impacting adversely on families infected and affected by it; it is necessary to ascertain educator perceptions of the HIV-status of learners and the impact thereof on the HIV infected learner and school well-being (Sullivan, 2004:63).

Trends in educator perception are that educators generally perceived HIV -

- to be a sexually transmitted terminal disease. Stigmatisation was in the minority. Educators suggested, that AIDS is a moral scourge, reflective of sexual taboos or unwise sexual practices (Van Dyk, 2005:75);
- to be carried by positive individuals who are terminally ill people who may not be discriminated against;
- affects positive learners to be ordinary learners requiring special support and deserving of acceptance and care. Only 6 out of 5 of educators hold stigmatised perceptions of HIV-positive learners. Nevertheless, 15% of respondents suggested a need to be careful to avoid contact with HIV-positive learners (USAID, 2004:27); and
- -positive educators as terminally ill people who should be allowed to continue their profession without being discriminated against. There is a call for infected educators to be treated with dignity. Only 8,1% of the respondents suggested, that HIV-positive educators are immoral and irresponsible or should be barred from teaching; 6,5% of the responses reflecting negative perceptions came from White educators; 7,2% noted that ill educators are prone to absenteeism; 20% of Black educators' responses suggested a need to be careful to avoid contact with HIV positive educators; 65% respondents suggested, that HIV-positive educators are physically and emotionally ill, with concomitant poor teaching. Absenteeism and curriculum disruption, with an ultimate deterioration in school standard pervaded. Educators feared that in due course schools' reputations would suffer, which will, again result in a decline in learner enrolments (Department of Health, 2005:8).

Trends in educator perceptions are also, that the impact of HIV-positive educators -

- on learners' well-being, was also perceived as negative; 52% of all responses suggested, that learners well-being suffers as a result of disrupted education. Education is disrupted by frequent educator absence, educators' emotional distress and the use of substitute educators. HIV-positive educators pose a health risk to learners and colleagues and their continued service at schools sanctions immoral behaviour (Wood *et al.*, 2003:18); and
- on colleagues, wellness, was generally considered to be negative; 29% of educators responded that HIV-positive educators create tension. Such tension results either from a desire to avoid HIV-positive educators because of general discomfort in their presence or from the stress of providing support to HIV positive educators; 27% of all responses suggested, that increased workloads and overcrowded classes result when HIV-positive educators are ill and absent. The net result of both of the aforementioned, was that healthy educators couldn't function optimally (WHO, 2003:18).

Trends in educator perception are also that the knowledge that -

- colleagues might be HIV-positive and engendered an empathic response in 28% of respondents. Significantly, 24% of these responses were from Black educators. White educators typically responded, that such knowledge would have no or little effect. The latter might well suggest that white educators are in denial about the reality of the HIV pandemic or that they are not yet affected by it (Walker, 2004:10); and
- HIV is pandemic, impacted negatively on educators' personal wellness; 33% of educators were psychologically burdened because of the death of loved ones and friends and depressed by the stigma of AIDS. Furthermore, they experienced the added stress of responsibility for personal health and sexual practices. A further 19% project worried about the personal status

and the future of the country; 16% of educators did not elucidate how the HIV pandemic affects them personally. The latter may be because their lives have not yet been personally touched or because they prefer to deny the reality of the pandemic (Mitrane *et al.*, 2003:40).

In general, Black educators were of the opinion, that HIV should be demystified and seen as any other disease. School curricula should be adapted to accommodate an AIDS policy. Furthermore, Black educators were of the opinion that the government and the Department of Education should intervene in order to save the education system from certain crises (Chimwaza & Watkins, 2004:29). They call for an effective national HIV strategy, affordable, good drugs for all and care for AIDS orphans. White educators indicated concern about the impending education crisis (attrition rate of educators and learners) but suggested no solution. Instead they suggested an increased awareness of AIDS via education and the inculcation of morality (Educator perception of educator's and learner's HIV status, with a view to wellness promotion) (Birdthistle, 2004:115).

3.6 HOW FAMILIES COPE WITH HIV AND AIDS

Individuals, families and communities are impoverished by their experience of HIV and AIDS in ways that are typical for long drawn-out and terminal illnesses. It is a feature of HIV infection, that it clusters in families with often both parents HIV positive (who, in time, experience morbidity and mortality) (Parker & Mundawarara, 2002:13). There is thus enormous strain on the capacity of families to cope with psycho-social and economic consequences of illness, such that many families experience great distress and often disintegrate as social and economic units. This experience is well-reflected by children who have seen the expectations as a mother and grandmother completely overturned by HIV/AIDS (Rugamela & Akoulouze, 2003:24). Integral to her experience, is the disappearance of traditional support processes for the elderly who can no longer anticipate being supported by their children. Instead, the old are taking on burdens of care for children under conditions of increasing personal impoverishment and with associated living and other problems for both generations (Kumar *et al.*, 2001:39).

Poor families have a reduced capacity to deal with the effects of morbidity and mortality than do richer ones, for very obvious reasons. These include the absence of savings and other assets which can cushion the impact of illness and death. The poor are already on the margins of survival and thus are also unable to deal with consequent health and other costs (Mohlala, 2002:32). These include the costs of drugs when available, to treat opportunistic infections, transport costs to health centres, reduced household productivity through illness and diversion of labour to caring roles, loss of employment through illness and job discrimination, funeral and related costs, and so on (Kidanu, Nyblade & Rohini, 2003:57). In the longer term, such poor households never recover even their initial level of living as their capacity is reduced the losses of productive family members through death and through migration, and through the sales of any productive assets they once possessed. A true process of immiseration is now observable in many parts of Africa (Pick, 2003:17).

An important aspect of the coping experience of those infected and affected by HIV and directly related to poverty, is the survival time from initial HIV infection to death in Africa. HIV-infected persons in Africa live for a shorter time after the initial infection than in developed countries, and this is not simply related to access to new anti-retroviral treatments (although this is now an important factor in the differential experience of rich and poor countries) (Sonnenberg, 2004:57). Even prior to the availability of ARV in rich countries, the evidence was, that HIV-infected persons in Africa had a survival time from infection to death of approximately 5-7 years, about half in developed countries. The explanation is complex but is to a significant degree, related to the poverty of most of those infected with HIV in Africa (Shisana *et al.*, 2005:60).

Elements in the survival-time differential of Africans which are undoubtedly important, include the inability to purchase relatively inexpensive drugs to deal with HIV opportunistic infections (such as TB and diarrhoea), poor basic health and nutrition, limited psycho-social support and generally, poor quality care both in hospital and home settings (Meehan, 2004:12). These factors are

all remedial through programme activities which can be provided at relatively low cost by the state and NGOs, although they remain well beyond the capacity of poor households to provide for themselves. Once provided, they will extend and enhance the lives of those infected and will permit them to support both themselves and their families (Jordan-Harder, 2004:87).

Central to these processes often are conditions of isolation and discrimination, such that traditional forms of social support for the poor and the sick become inoperable. Societies characterised by random events such as illness and death, have developed mechanisms of social support traditional safety nets for those impoverished by disease and crop failure (Auvert, 2001:45). What appears to be happening, is that traditional systems of support are themselves in decline for structural reasons and are not being replaced by state mechanisms. At the same time, the clustering of poverty caused by HIV, which concentrates spatially and in certain communities, places demands on disintegrating social support systems to which they cannot respond (Altaf, 2004:21). Furthermore, because HIV and AIDS are viewed in many communities as the outcome of reprehensible behaviour, there is often an unwillingness both to seek help by those affected and negative responses often by those able to provide assistance. A dual process has emerged which is the antithesis of what is required if the poor are to deal with the social and economic costs of HIV and AIDS (Hargrove, 2005:10).

3.7 CONCLUSION

In summary, it is clear from the above sections that people suffering from HIV/AIDS feel isolated, guilty, dirty and full of shame. Their general participation in the activities of life is restricted by stigma, low self-esteem and how they are supported and interact with others. Discrimination counteracts trust, leaving those that are infected alone, distanced from the rest of their communities, families and friends. The support that these people should be getting from their family members and significant others, could be beneficial to how they experience being infected.

CHAPTER FOUR

RESEARCH DESIGN

4.1 INTRODUCTION

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

- determine the narratives of families affected by HIV/AIDS;
- determine the nature of the narratives and families affected by HIV/AIDS; and
- suggest ways in which to psychologically and socially strengthen these families through narrative therapy.

4.2 QUALITATIVE RESEARCH DESIGN

The use of narrative metaphor was used as the basis, but the angle of incidence for the examination, is from a qualitative approach. Merriam (1998:15) characterized qualitative research as an “umbrella” concept covering several forms of inquiry. This analogy helped explain the meaning of social phenomena with as little disruption of the natural setting as possible, and in which the focus of the study is on interpretation and meaning. Patton (2001:27) regarded qualitative research as devoted to developing an understanding of human phenomena and experience, which helps explain how “...the persons involved their behaviour and perceptions, and the influence of the physical, social, and psychological environment or context on them”. According to Cresswell (2003:15), qualitative research is an inquiry process of understanding, based on distinct methodological traditions of inquiry that explore a social or human problem. In the process of a study, the

researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting.

A comprehensive definition of qualitative research is that of Denzin and Lincoln (2005:143):

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

Qualitative research studies have many typologies and traditions. Denzin and Lincoln (2005:24) provided different approaches to qualitative study, which include case studies, ethnography and participant observation, phenomenology and ethno-methodology, grounded theory, the biographical method, historical social science, participative inquiry, and clinical research. In addition, Leedy and Ormrod (2005:156) analyzed the above approaches of qualitative study and provide three major issues that focus on:

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

The qualitative research designs appropriate for this research, include the following.

- **Case studies.** According to Leedy and Ormrod (2005:135), a particular individual is studied in-depth for a defined period of time. In this study two cases were studied, which are different in certain ways, such as the fact that in one case there is a father, a mother and children and in the other case, a social system of matriarchy.
- **Ethnography.** The researcher looked at the entire family more specifically, (as every member of each family was interviewed) in its natural setting for a period of four months. The focus of the investigation was on their everyday behaviours with the intent to identify their beliefs and how they cope with HIV.
- **Phenomenology.** In this research, a phenomenological study was used to understand families' perceptions, perspectives and their understanding of being affected by HIV/AIDS. In other words, the phenomenological study tries to answer the question: 'What is it like to experience being affected by HIV/AIDS?'

It seems obvious, that these characteristics of qualitative research are appropriate for studying experiences of families affected by HIV/AIDS.

4.3 JUSTIFICATION FOR USE OF QUALITATIVE RESEARCH

Three reasons account for this choice; firstly, it is a multi-perspective approach to social interaction, aimed at describing, making sense of, interpreting or reconstructing interactions in terms of the meanings the families which participated in this research, attach to it. Secondly, it is a type of formative research that could offer specialized techniques for obtaining in-depth responses about what families affected by HIV/AIDS experience, how their members live with the virus, problems they encounter because of being affected by HIV, their feelings, and their needs and wants, as it is exploratory and interactive. Qualitative research enables the researcher to gain insight into families affected by the HIV/AIDS reality. Thirdly, qualitative research provides a rich texture and context through which to learn about family members affected by HIV/AIDS as individuals without losing the rich

descriptions of their attitudes and feelings and the essence of their experiences.

4.4 NARRATIVE INQUIRY

People are born in stories. Their social and historical contexts force them to tell their meaningful experiences and to leave out the less important experiences. In the light of this, the definition of the construct narrative is borrowed from White and Epston (1996:9), namely that it is a unit or meaning that provides a frame for lived experience. The use of the narrative metaphor makes one think of people's lives as stories. By asking questions, the researcher can understand the participant's story better, so that the participant can also experience his or her own life-story as being meaningful and fulfilling. In this regard, Patton (2001:3) writes that '.....our lives are ceaselessly intertwined with narrative, with the stories we tell and hear, those we dream or imagine or would like to tell, all of which are reworked in the story of our own lives that we narrate to ourselves in an episodic, sometimes semi-conscious, but virtually uninterrupted monologue. We live immersed in narrative, recounting and reassessing the meaning of our past actions, anticipating the outcome of our future projects, situating ourselves at the intersection of several stories not yet completed.

One of the semantic constructions frequently identified with the qualitative interview data, is a 'story'. Telling stories is considered a primary way of making sense of an experience. The underlying premise of narrative inquiry, is a belief that individuals make sense of their world most effectively by telling stories (Patton, 2001:46).

Marshall and Rossman (1999:12) defined narrative research as a study that uses or analyzes narrative material. The data were collected as a story through interviews and as field notes from observation. According to these authors, it can be used to learn about social phenomena or represent a certain lifestyle of specific sub-groups in society. They argued, that by studying and interpreting narratives, the research could not access only the individuals, but the system as well as the meaning in the culture. Shank

(2002:86), considered narrative methods as real-world measures that are appropriate when real-life problems are investigated. During the interviews, the participants suffering from HIV/AIDS spoke not only about themselves, but also included the social context in which they live and find themselves in.

People are considered by Maxwell (2004:56) and (Barton, 2000b:213) as storytellers by nature. Stories, they continue, provide coherence and continuity to a person's experiences. Individual narrators present stories about their lives and their experienced reality, which in turn, also shape and construct the narrator's reality. Each story is thus affected by the context within which it is narrated. Life-stories also construct and transmit individual cultural meaning. The unstructured interview is normally used in a study of this nature and a semi-structured was employed in this one. The researcher had a list of topics to explore with each participant but, since each person had a different life context, no interview was similar to the other.

4.5 THE PURPOSE OF THIS STUDY

The aims of this study were to determine the life experiences of families affected by HIV/AIDS and determine ways in which the narratives of families affected by HIV/AIDS can be used in developing policies and programmes which governments, schools and communities can utilize to deal with the psychological and social plights that these families experience.

Through a qualitative design, this study examined and integrated the in-depth experiences of two families affected by HIV/AIDS. In-depth descriptions of experiences are provided through the inclusion of actual personal accounts or case studies. The case studies were analyzed for common themes and patterns that were contributory to psychological and social support of infected learners.

4.6 DATA COLLECTION

This section discusses the way the participants are selected, how the data were gathered and how these were transcribed and thematised.

4.6.1 Sampling

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

- record and understand families in their own terms;
- observe natural, ordinary experiences of families affected by HIV/AIDS; and
- generate detailed data about the families studied and also to provide a contextual understanding (De Vos, 2001: 177).

There are different types of purposeful sampling. Network sampling is one of the types mentioned in Merriam (1998:137). The researcher decided to utilise network sampling. Patton (2001:182) argues, that this strategy involves identifying cases of interest from people who know what cases are information-rich; that is, good examples for the study, good interview subjects. In purposeful sampling, size and specific cases depend on the study purpose. The researcher used her network of friends who are also HIV-positive and social workers to conduct network sampling. The researcher decided to approach a social worker working with street, abandoned, orphaned and neglected children. The interviewer requested the social worker for assistance, as it was difficult to get this kind of information at schools. The social worker assisted the researcher with identifying two families who happened to be affected with HIV/AIDS. In the first case study the infected learner, her mother, grandmother, brother, sister, mother's boyfriend, neighbour, class teacher and the principal of the school the learner attends, were interviewed. In the second case study, the infected learner, her mother, father, grandmother, brother and the cousin were interviewed.

4.6.2 Case study formulation

Case studies are a form of qualitative research, as well as a methodology. De Vos (2001:112) describes case studies as "...an end-product of field-oriented research," which means the end-report of a case investigation. It is in this

context, that the case study method was selected for this research. A case study can be defined in terms of process and can be used to carry out an investigation or inquiry of bounded systems or units of analysis selected for study. *Verbatim* data from each of the transcripts were reviewed repeatedly through the case study formulation, compared to the audiotape, summarized and reported in case study format (see Chapter 5). Careful and repeated review of the data was carried out in order to ensure accuracy in the final case study report. The case studies included an in-depth and thorough explanation of the respondents' personal experiences as told by the respondents/interviewees. The case studies were presented as a holistic and descriptive personal account of the individual respondents. Unique experiences of each of the respondents were provided through direct quotes and details of influential factors. Basic information on family background was contained in the case studies.

4.6.3 Research instrument

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

4.6.3.1 Interview procedure

Face-to-face interviews were conducted with all participants in this research. This type of interview is a pipeline for extracting and transmitting information from the interviewee to the interviewer. The interviews were unstructured with a schedule, and in-depth. The aim of unstructured interviewing is to actively enter the worlds of people and to render these worlds understandable from the stand-point of a theory grounded in behaviours, languages, definitions, attitudes and feelings of those studied (De Vos, 2001:300) Prior to the beginning of the interview, the participants were read the procedures the research was going to employ. This procedure specified, that confidentiality would be preserved during the documentation and reporting process; the identity of the respondent would remain confidential throughout the research project and the respondent was asked to select a pseudonym, which was used for the recorded interview, the transcription and the reporting process in

this dissertation. It was stated that the interview tapes and transcribed documents would be available only to the transcriber and the committee of the University of the North West (Vaal Campus).

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

4.6.3.2 Interview setting

Because participant observers generally believe, that human behaviour is influenced in many ways by the milieu or settings in which it occurs, they believe that researchers should as far as possible visit and preferably spend considerable time in their participants' natural habitat where they can obtain first- hand data on how participants go about their everyday lives (De Vos, 2001:280). It is for this reason that participants in this research were encouraged to select an interview setting that would be private, convenient and comfortable. Respondents agreed to be interviewed at their home and the shelter. The choice of home and the shelter as a setting, was convenient for both the interviewees as it provided them with privacy and comfort. Participants were asked to allow two hours for the complete interview. Participants were told that the interview would be transcribed and audio-taped and asked if they had any objections to this process. All respondents agreed to be audio-taped.

4.6.4 Transcriptions and analysis

Transcriptions were made of all the audio-taped interviews. The researcher compared audiotapes to transcripts and reviewed each transcript so as to ensure that it contained the *verbatim* recorded interview. These steps were

important for the accuracy of the design and for the identification of emergent issues, which were to form themes.

Leedy and Ormrod (2005:142) indicate, that there is no single 'right' way to analyse the data in a qualitative study. The researcher began with a large body of information and through inductive reasoning sorted and categorise it and gradually boil it down to a small set of abstract underlying themes (see section 5.3). Data collection and analysis are not independent processes in qualitative research design. While data collection actually entail the process of interviewing, informal analysis of the respondents was also conducted during the interview. Handwritten assessment notes taken during and after the interview, constituted part of the initial data analysis. An immediate review of audiotapes, a *verbatim* review of the interview transcript and notes to the methodological log, were additional analysis steps that intertwined with data collection. Thus, analysis was ongoing and occurred during the process of data collection.

Content analysis was also used in this research; this, according to Leedy and Ormrod (2005:142), is a detailed and systematic examination of the contents of a particular body of material for the purpose of identifying patterns, themes or biases.

4.7 ETHICAL CONSIDERATIONS

Due to the charged and emotive nature of the HIV/AIDS phenomenon, certain ethical considerations assumed particular importance. De Marrais (1998:230) note, that the very nature of the aim of a phenomenological study, namely to access the individual's life-world, is obtrusive. In this study, this obtrusiveness will further be exacerbated by the sensitivity of the topic under investigation. First and foremost, the researcher will have a responsibility to respect the rights, needs, values and wishes of the participants (Berg, 2003:112). In order to protect the participants' rights, the following safeguards as listed by Cresswell (2003:123), are employed.

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

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

4.8 CONCLUSION

This chapter presented a research design employed in this study. The next chapter will deal with analyses and interpretation of data collected by means of interviews.

CHAPTER FIVE

AN ANALYSIS AND INTERPRETATION OF THE EMPIRICAL RESEARCH RESULTS

5.1 INTRODUCTION

This chapter provides an analysis and interpretation of the responses that the interviewees (15= participants) who participated in this research, gave to the questions that the interviewer posed to them.

The transcript of each case is placed first, followed by an analysis and interpretation of each participant's responses to the questions asked by the researcher. Themes emerging from each educator participant's responses, are also highlighted.

5.2 TRANSCRIPT OF CASE STUDIES

The first transcript centres around Sandra's case, her family background and the proceedings of the interview between the researcher and Sandra, Sandra's mother, Sandra's brother, Sandra's grandmother, Sandra's mother's boyfriend, Sandra's educator, Sandra's sister, a neighbour and the school principal.

The second transcript centres around Siphos case, his family background and the proceedings of the interview between the researcher and Siphos, Siphos father, Siphos mother, grandmother, Siphos aunt and the neighbour.

5.2.1 Case study 1: Sandra's case

5.2.1.1 Family background

Sandra was born on the 23rd of June 1986. She became infected through Mother To Child transmission (MTCT). From the day that she was born, she was sick. After a blood test, it was confirmed that she was HIV-positive. Her life expectancy was more or less 2 years, but she is now ten years old. Both parents tested HIV- positive, her father died of pneumonia when she was one

year and six months old. She is treated at Baragwaneth hospital. When Sandra was enrolled for grade one at her school, her mother disclosed her positive status to both her educator and her principal. Sandra is now in grade four, very active and dedicated to her school work.

Sandra lives in a household that consists of four children, an elder brother, two elder sisters and herself. They live with their mother and grandmother and they have very close ties with their grandfather. Sandra's elder brother and sisters are HIV-negative, as their parents became infected later. Sandra's grandmother drinks a lot, especially during week-ends. This does not affect Sandra directly, but it causes tension within the family as her reason is, that she loves her children too much, so she would rather die first than to watch them dying a slow death. Recently Sandra's mother went for a check-up and it was found, that her CD4 count had decreased to 450.

5.2.1.2 Interview with Sandra

The following oral exchanges were noted.

Interviewer: How old were you when your mother first told you that you are HIV- positive?

Sandra: I was seven years old; it was my first year at school.

Interviewer: What led your mother to disclose your positive status to you?

Sandra: There was this other learner who didn't want to sit, play or share the class toys with me. I did not understand why, so I decided to tell my mother about this. My mother then told me about my status.

Interviewer: How did that learner know that you are HIV- positive?

Sandra: My mother said she was told by her mother as we are neighbours, my mother had to confide in her mother.

Interviewer: Did you report the matter to your educator?

Sandra: I didn't. I just decided to tell my mother, but my mother came to talk to the educator about it. The class educator requested to see the learner's parent, I do not know what they said to Lebo's mother. I was just called to tell them how she was treating me. Lebo's mother indicated that she does not want me near her child. I must go and play with other children who are HIV-positive and to leave her child alone. After sometime Lebo's behaviour changed, she became friendlier and caring, and we became friends.

Interviewer: How was your educator after the meeting?

Sandra: She still treats her the same way, there is no change.

Interviewer: What were your thoughts/feelings when your mother first told you that you are HIV- positive?

Sandra: I didn't really understand what my mother was talking about. I knew that there was something wrong with me, because Lebo didn't want to play with me, and my mother looked very sad when she told me. After a lot of explaining, I began to understand, but now I know what is happening with me.

Interviewer: Does your brother and sisters know about your positive status?

Sandra: Yes they know, although we have never talked about my HIV-positive status or about HIV/AIDS in general, I can see that they know. They are so protective of me, when Lebo didn't want to play with me, they wanted to confront her; they always treat me nicely, I get everything I want from them. They really spoil me.

Interviewer: How are other kids at school?

Sandra: Everything is normal; they play with me and we share food with them; they do not have a problem.

Interviewer: Where is your father?

Sandra: My father passed away when I was about one year eight months old. They say he was HIV-positive and he died of pneumonia.

Interviewer: Are you taught about HIV at school?

Sandra: Yes, we are taught about it during the life-orientation class. There are days at school when people come and perform dramas about HIV/AIDS; there is also a lot of reading material at our library about the subject.

Interviewer: Does your grade four educator know about your status?

Sandra: Now that I am in the intermediate phase, I had to tell all the teachers that teach me, that I am HIV-positive. I just thought that it would help to tell them.

Interviewer: Why did you think, it would help to disclose your HIV-positive status?

Sandra: I thought that they should know so that if I can get sick at school, they will know what to do. They would be able to help or when I am absent from school, they need to know that it is either that I am sick or I have gone to the hospital for treatment.

Interviewer: Do you get information on what was done in class during your absence?

Sandra: No, but when I return to school I am free to ask the teachers where I do not understand. They do not re-teach what they have taught; in my absence, they just carry on.

Interviewer: Has your status affected your performance in any way?

Sandra: I really try my best, but being absent from time to time and the fact that in other days I cannot concentrate when I feel sick, it affects my performance.

Interviewer: What are your dreams for the future?

Sandra: I'd like to become a doctor so that I could be able to help other children in the same situation.

Interviewer: Do you take any medicine for HIV?

Sandra: Yes, I take ARV's daily and some other supplements.

Interviewer: What is your CD4 count?

Sandra: At the moment it is at 1112.

Interviewer: Do you attend any support group?

Sandra: Yes, we go once a month to the CHBH and we also attend one at the Palm Springs clinic.

Interviewer: How do people in your community react to the fact that you are HIV-positive?

Sandra: Generally they accept me; most of them know that I am HIV-positive. Every year when I celebrate my birthday, my mother would invite almost every member of the community to come and celebrate with us. I would get a chance of telling people that I am HIV-positive. People from the Health Department and newspapers would also come. I have never experienced any problems, except for one girl who sent me a snippet of an article on HIV/AIDS she had cut out from a magazine; she wrote my name on this.

Interviewer: How did that make you feel?

Sandra: I was very upset, I kept asking myself whether she wanted to help or hurt me.

Interviewer: What did you do with the snippet?

Sandra: I gave it to my mother; after she read it, she took it with her to the girl's family. They could not understand why she was upset about this as they said that if I am HIV-positive, I should just accept it. The family have not spoken to us ever since.

Interviewer: What do you do during your spare time?

Sandra: I play netball and enjoy reading books.

Interviewer: Do you attend church?

Sandra: Yes, we go to church on a regular basis.

Interviewer: Do people in your church know that you are HIV-positive?

Sandra: Our pastor knows; he told other members of the church; they often come to my house to pray.

Interviewer: What keeps you healthy?

Sandra: My mother always cooks fresh vegetables and buys fruit on a regular basis and because I play netball, I get plenty of exercise.

Interviewer: Do you ever feel lonely?

Sandra: Yes, I do feel lonely especially when I am at school with the other kids. When I am like this, I sit alone and think about my future and my life. I ask God why does it have to be me?

5.2.1.3 Interview with Sandra's mother

Interviewer: When did you find out that you are HIV positive?

Mother: It was revealed to me at the clinic when I took my daughter who was then 6-8 months for her check-up.

Interviewer: How did it happen?

Mother: My daughter was sick most of the time so we spent most of her first months in and out of the hospital; eventually the doctors decided to run some tests on her; she was diagnosed HIV- positive. I then also tested and I was also found to be HIV-positive. I never tested when I was pregnant.

Interviewer: What was your reaction to the news?

Mother: I was very shocked, as at that time I did not show any signs of having any problems with my health. I also could not understand why I had HIV.

Interviewer: Did you tell your husband about this? If yes, what was his reaction?

Mother: Yes, I was forced to tell him although we never talk about HIV/AIDS. I was afraid to tell him this. I did not know where to start. At the same time I was very angry as I felt that he knows about my status. When I told him he just admitted that he knew that he was HIV-positive. He tested and never told me that he was going to test or about the results for that matter. I was angry, and confused. I couldn't understand why a person who I thought loved me, could do something so horrible to me. I couldn't believe it was happening to me. I had so many questions to ask him, like for how long had he known this? Why hadn't he told me? But at that time I could not even speak.

Interviewer: What happened after your husband's confession?

Mother: My husband suggested that we should go back to the Baragwaneth hospital for counselling. The session was so effective, that as from that date we never fought about his infecting me and why. He was supposed to have left that day as he was a truck driver for long distances. Instead he decided to be with us for the whole week to support me.

Interviewer: Did you continue with counselling?

Mother: Yes, we continued with counselling; it was the only thing that kept me sane.

Interviewer: Did your daughter get anything to relieve her as the doctors now knew what was wrong with her?

Mother: My daughter continued being sick and the doctor said that she cannot live past two years; and here she is all grown up, but her father passed away.

Interviewer: What did you think when your daughter was about to be two years old?

Mother: I was very worried. I did not want to see my daughter die so young, but I knew that I had to be strong. My husband tried to be strong; you could see that the thought of his daughter dying, was eating him up.

Interviewer: How were you after your husband's death?

Mother: Life became unbearable. I started drinking and roaming the streets at night. I hoped someone would kill me on my way home at night. I was scared of what my family and community members would say, as at the time of his death, only he and I knew that we were HIV-positive.

Interviewer: What did your family and community members do?

Mother: They stopped visiting me for some time; they all knew that my husband died of HIV/AIDS. News travels fast in our vicinity and other people came just to make sure that what they had heard was true, after confirming that what they had heard about my husband was true, they told me to stop visiting them. My friends were afraid of being associated with people who are HIV-positive.

Interviewer: Are you still drinking?

Mother: No, I am no longer drinking. One night I found my baby asleep and looking so innocent and at peace. I looked at her for quite some time. I realized that I should be protecting this innocent precious baby instead of drinking and roaming around the streets at night, trying to get myself killed. I started thinking about what protected me at that time during these nights. I realized that if God wanted me to be killed, I should have been dead by now. From that night onwards I took a decision to care and raise my daughter and become a good mother to her. I started attending support groups.

Interviewer: How did the support groups help you?

Mother: It was a difficult decision to stop drinking after I had done that for four years. There were days when I felt down and depressed; these were days when I felt like drinking again. The people in our support group understood; it became easy for me to tell them about everything that bothered me. They advised me to bring my family to our next meeting. The reason for this, was also to tell my family that I am HIV-positive. I did not have the courage to do this. I asked the members if one of them could tell them on my behalf; they agreed. It is then that my family came to know about my HIV-positive status.

Interviewer: What was your family's reaction after they had been told about your HIV-positive status?

Mother: They were very shocked, but after some counselling, they were supportive.

Interviewer: Has there been any change; in your relationship with your family after the disclosure?

Mother: I really didn't notice any change; instead they were very supportive. What changed, is the fact that my mother decided to come and stay with us. She was not part of my life for a long time as we did not keep in contact. After she had found out that I was HIV-positive, she made her decision. She is the most supportive member of my family.

Interviewer: How does she support you?

Mother: There are days when I am sick and cannot take my daughter for treatment and cook for the family. She will take over and do everything I am supposed to do.

Interviewer: Does she still attend support groups?

Mother: Yes, she still attends, she does everything they advise her to do to support and assist us.

Interviewer: How have your other children reacted to all this?

Mother: They were shocked, they were also afraid that they might also be HIV-positive. They could not believe me when I told them that they might not be positive. They insisted on being tested and their results came back negative. They were very relieved and they support me in every way. My eldest son is now working; he makes it a point that we have groceries every month. He also gives us money for other things we might need.

Interviewer: Besides being what you get from your son, do you get any other form of financial support?

Mother: We receive a monthly government grant for Sandra.

Interviewer: Can you say things are fine?

Mother: No, things are far from being fine. I feel a little bit stressed; my parents are fighting over me. My dad feels that I should stay with him since we have been staying together ever since our mom left us. My mother has been supporting me, I need her. I have to decide whether I stay with my dad as he never abandoned me. And live with my mother. This affects my health a lot.

Interviewer: What have you decided to do to solve the problem?

Mother: Well, I have shared my problem with the members of the support group. Some of them suggest, that I should go and stay with my father as my mother has a drinking problem. I had not taken a decision yet. My father and my mother had been separated for many years. What is happening now, is that they both would like to support me, but they cannot stay under the same roof.

Interviewer: As a mother, what kind of support do you render to your daughter?

Mother: I make sure that she eats food that is nutritious everyday. I make sure that she gets her treatment every time when it is due and I take her along to the support groups. I feel good doing this, but what worries me, is the fact that I cannot talk to her about what is going to happen to me or

her in future. We do not talk about HIV/AIDS; we are both free to do so with other people.

Interviewer: What are your wishes for your child?

Mother: I wish that God could bless her with more years so that she becomes the doctor she wants to be.

Interviewer: How are other siblings supporting her?

Mother: They help her with homework; they help her in the morning to get dressed in time for school and they also take her to the clinic for treatment.

Interviewer: Do you think you can still get married again?

Mother: Yes, I do not have any problem with that as long as it is a person who understands my situation. I have a boyfriend who is also HIV-positive. We met at the support group. Our relationship is okay; we see each other occasionally and discuss our problems. The only problem with him, is that he has not yet accepted that he is HIV-positive. I have tried helping him accept his status, but it does not seem I am making any sense to him. He is so much in denial and this is not helping him in any way. I wish there could be a cure to HIV while I am still looking healthy.

Interviewer: Would you start your own support group?

Mother: Yes, I can. Some people do not get the right type of counselling, I would like to ensure that people, especially those who have just been diagnosed HIV-positive, get the support and counselling they deserve.

Interviewer: Is the support grant you receive, enough for your needs?

Mother: Not really, it doesn't cover much of our expenses. I also receive money from my son, father and my mother from their pension.

Interviewer: Why are you not working?

Mother: I had been working before but we got retrenched. I have not searched for a job ever since; besides I have constant headaches; I can't work.

Interviewer: Do you use any other type of medication besides the one you get from the clinic?

Mother: I do not use any other type of medication. You see, I am a research patient, so the researchers would like to see if the medication is effective without any other supplements.

Interviewer: Has the medication been effective?

Mother: Yes, I can say that the medication has been very effective because ever since I have been using it, I have not been sick.

Interviewer: How often do you have to take the medication?

Mother: I take the medication three times a day; it has to be the same times every day; and it lasts me for a month.

Interviewer: How are the members of the community you are living in?

Mother: There are members in my community who are still ignorant concerning HIV/AIDS; they think their children can get infected by playing with me. There are others who will not sit next to me in a taxi or in our society meetings.

Interviewer: How are your in-laws?

Mother: They have not spoken to me ever since my husband died. They think I had killed him. To them I am the one who infected my husband with HIV. I pray to God that they would one day realise that they blamed me for nothing.

Interviewer: What do they say about your children?

Mother: They talk to my other children who are not HIV-positive. They say that Sandra is HIV-positive. Serves me right, as I must feel the pain that they also felt about their son.

5.2.1.4 Interview with Sandra's brother

Interviewer: How did you react when you were told that your younger sister is HIV-positive?

Brother: I was shocked. I never expected that to happen to my family. I was also very confused as the other children including myself were HIV negative. I took time to figure out what had happened.

Interviewer: How did you react when you were told that your mother is HIV-positive?

Brother: I was very angry with my father; he is the one who infected my mother. As truck drivers, they know about HIV/AIDS; he chose to live a life that is detrimental to the health of my mother- something that affected the whole family. I was waiting for him to give me advice that I should use a condom I would have told his that he should have done that himself. He died before we could talk about his being infected and infecting my mother. It is a pity that I do not feel comfortable to talk about HIV/AIDS with my mother; she does not know that I am angry.

Interviewer: Do you attend support groups?

Brother: Yes, I do. I usually go with my mother and sister when they attend.

Interviewer: Do you think these support groups help in any way?

Brother: Yes, I think so. We get so much information on how to support people who are HIV-positive. We get to understand the emotions people with HIV go through. We also get to understand why they react negatively and get angry very easily. We are taught to be patient with them.

Interviewer: How do you support your sister?

Brother: I wish I could always be there to protect her from other children who make fun of her. I support her financially, as I am working. I am not at home most of the time. I think that is the best I could offer.

Interviewer: Do you ever talk to your younger sister about HIV/AIDS?

Brother: No we do not talk about HIV/AIDS. I do not think it would be wise to do so. I do not want to hurt her. What I do, if there is a movie about people who are HIV-positive we watch it together but after this I still do not feel comfortable to even comment about the movie.

Interviewer: What are your wishes for your sister?

Brother: I wish she could live longer. I enjoy her, I also wish she could get the necessary education she deserves.

Interviewer: What would you say to other brothers in your position?

Brother: I would tell them to be as supportive as they could be to members of their families who are HIV-positive, as their support would make a difference.

Interviewer: How does your mother treat her HIV-positive child?

Brother: She loves her very much, but I think she also as strict as she is with all of us.

5.2.1.5 Interview with Sandra's grandmother

Interviewer: How did you find out that your daughter was HIV-positive?

Grandmother: My daughter called a family meeting and at this meeting, she disclosed her HIV-positive status.

Interviewer: What do you think, pushed her to disclose her status?

Grandmother: I think the person who counselled her, suggested that she disclose her status. Whatever pushed her to do that, I think it is good that she told us. I would not have come home to support her if I didn't know.

Interviewer: How did you respond to the news?

Grandmother: We were quite shocked, because this is not what you usually wish for your child or anyone's child, for that matter. I knew that I have to be supportive, no matter what. I was very angry at my son-in-law who definitely infected her.

Interviewer: Why do you think it is your son-in-law who infected her?

Grandmother: He is the one who spent most of the time out driving trucks; everybody knows that long distance truck drivers get AIDS from prostitutes they come into contact with. Any way, I could not do anything about it as we knew after he had died, that he also had AIDS.

Interviewer: How was your ex-husband after he had been told about this?

Grandmother: He was very upset; he blamed himself for this ordeal. He thought that his daughter could have been sleeping around, as people think that people who have AIDS, have been sleeping around.

Interviewer: Is he still angry?

Grandmother: He is no longer angry and he does not blame himself for this. Our daughter took us to the clinic. We were counselled and we had time to ask them about everything we did not understand about HIV/AIDS. I think that is how he came to understand and accept her condition.

Interviewer: Does your daughter and your granddaughter show any signs of being HIV-positive?

Grandmother: No they do not. I think they were very fortunate to be part of the research group at the Chris Hani hospital where they get ARV's. I think, as a result of the ARV's, they look very healthy and strong and they do not show any signs that they are HIV-positive.

Interviewer: Do they get sick?

Grandmother: Yes, my daughter gets migraine; it is very painful. When she has, it she doesn't wake up for days. My granddaughter's problem is, that she always has flu and her nose bleeds whenever she has flu.

Interviewer: What support do you give them?

Grandmother: I help around the house with cooking and cleaning. When my daughter is sick, I am always there to give her medication. I also take her to the clinic.

Interviewer: Do they ever go to church?

Grandmother: We all attend a church service. Every Sunday we have a church hall just down the road. I like the fact that my daughter agreed to come to church with me as at least, she is going to be able to pray to God for all the problems she encounters, including their positive HIV-status.

Interviewer: When you are busy helping them, do you ever think of being infected?

Grandmother: No, at the clinic they told me what to do and what not to do when helping them. I take precautionary measures.

Interviewer: Does your daughter allow your grandchild to go out and play or go to parties with the other children?

Grandmother: Yes, she is okay with that, she allows her to play with other children. She even plays netball. There are other families in our community who do not want my grandchild to play with their children. We monitor her. We do not want her to play with people who do not accept her status. Generally, she tries to give her normal life.

Interviewer: Do you ever talk about HIV/AIDS when your granddaughter is around?

Grandmother: No, I do not talk about that, except when she asks me something she didn't understand from school. I just give an answer to what she has asked me. It is difficult to talk to children about HIV/AIDS,

especially a grandchild. We do not talk about HIV/AIDS with their mother who is my daughter; we only talk about her health. I hide my fears and hurts and I know she also does the same. We are both worried about what is going to happen in future, but we do not talk about it.

Interviewer: Since grandmothers are known to have knowledge of traditional herbs and how they work; do you have any traditional mixtures you advise your children to have?

Grandmother: Yes, there are traditional herbs I know, but at the hospital they told us not to use anything else except the treatment my daughter and grandchild receive.

Interviewer: What do you feel when you look at your granddaughter?

Grandmother: I really love my family. I wish I could die before they start becoming very sick. I do not think I will be able to bear the pain of losing one of them. I sometimes contemplate committing suicide, so that I could die before they do.

5.2.1.6 Interview with Sandra's mother's boyfriend

Interviewer: How did you meet Sandra's mother?

Boyfriend: We met at the clinic where we meet our support group.

Interviewer: Did you know that she is HIV-positive?

Boyfriend: No, because people come to support groups for different reasons. Some are parents of infected teenagers while others have close relatives who are HIV-positive. So you can't just assume that a person is HIV-positive because s/he has come to the meeting.

Interviewer: How did you find out that she is HIV-positive?

Boyfriend: Well, the more we met at the support groups, the more we spoke about ourselves and we then disclosed our HIV- positive status.

Interviewer: What attracted you to her?

Boyfriend: I think it was sympathy. I used to watch her and her daughter coming to the meetings without a husband to support her. When I realized that they were both HIV-positive, I decided to befriend her so that I could support her. We are also attracted to each other; I love and understand her. I think it is better to have an affair with a person who is HIV-positive, as you are going to support each other, rather than a person who is not.

Interviewer: What challenges do you face as a couple?

Boyfriend: We are unable to express our love sexually sometimes, as one of us, or sometimes both of us, are sick at the same time. We need to use a condom always, otherwise we can be re-infected. We cannot be together all the time, as we need to be home at certain times to take our medication. We cannot have children of our own. I also have to solve the problems we have with my wife. I pray to God that she gets a husband that can marry her. We no longer love each other; there is no point in staying together. If she can get a man who can marry her, I would be free to marry Sandra's mother.

Interviewer: What was your reaction when you first heard that she is HIV-positive?

Boyfriend: It is always a shock when you find out that someone is HIV positive, I could not believe it, she is so beautiful and she showed no signs of being ill.

Interviewer: Do you think you have a future together?

Boyfriend: It is a bit difficult to say. There are a lot of things to consider, like our families. It would be nice though if we could stay together.

Interviewer: How did you know about your status?

Boyfriend: I found out about my status when my wife was pregnant with our first-born. She was tested at the clinic and diagnosed HIV-positive.

Interviewer: What do you think about HIV-positive children?

Boyfriend: Well this makes me sad, because these kids are so innocent; they do not deserve this. Most of them are suffering because of what their parents did; they are prone to more sickness.

Interviewer: What was the most painful thing you thought of when your positive status was revealed to you?

Boyfriend: It is when I realized that my life could come to an end any minute. The thought of leaving my wife and my daughter, also disturbed me.

Interviewer: Where is your wife?

Boyfriend: At the moment she is not at home. She goes off from time to time and comes back when she is pregnant. We always fight when we are together. I even prefer that she stays where she wants to. We started fighting after we had been diagnosed HIV-positive. That is when we started blaming each other for our HIV-positive status. She has three other children that she left with me at home. These children are all HIV-positive. She claims, that they are all mine. She is the one who infected me with the virus.

Interviewer: Where do you work?

Boyfriend: I am a stock-taker.

Interviewer: What support do you get from work?

Boyfriend: They understand that I have to get to the clinic for treatment.

They allow me time to do so. They allow me to work extra hours to make up for the time I have lost when I am sick.

Interviewer: How is your relationship with your co-workers?

Boyfriend: We have a very good relationship. They understand my situation. They even remind me to take my medication. We have a gym at work where we get together and work out.

Interviewer: What keeps you healthy?

Boyfriend: I go to the gym regularly and eat healthy food all the time. I need to attend the support group meeting occasionally and I never forget my medication.

Interviewer: How do you respond when people talk about HIV/AIDS?

Boyfriend: I get really angry. It is as if they are talking about me or they know that I am HIV-positive. I wish I could make them stop or shout at them. I think I do not want to hear people talking about HIV/AIDS.

Interviewer: Do you ever watch programmes about HIV/AIDS on TV?

Boyfriend: Yes, as much as I can. It is always comforting to know that there are other people out there in the same situation. These programmes also shed some light for other people who do not understand. It is quite educative.

Interviewer: What types of medication do you take?

Boyfriend: I take ARV's three times a day and also take supplements just to boost my immune system.

Interviewer: Do you think having HIV/AIDS is the same as having sugar diabetes or high blood pressure?

Boyfriend: I do not think it is the same as having other diseases; there is no cure for HIV.

Interviewer: What do you say to other people who are HIV-positive who have not yet accepted their positive status?

Boyfriend: I tell them to take their medication regularly. Denying is not going to make HIV go away, so they should find a way of coming to terms with the fact that they are HIV-positive.

5.2.1.7 Interview with Sandra's educator

Interviewer: How did you find out about the learner's HIV-positive status?

Educator: Sandra's mother came to disclose her HIV-positive status.

Interviewer: How does your learning area help Sandra?

Educator: I teach her Economics and Management Sciences and in class, she became aware that the government pays for treatment of HIV-positive patients.

Interviewer: Does your school have an HIV/AIDS policy?

Educator: Yes, we have a policy and it requires that all learners should be treated with respect, regardless of their colour and health status. We follow the guidelines of this policy I can say, is functional.

Interviewer: How do these policies help HIV-infected learners?

Educator: In these policies we ensure that learners infected with HIV, are protected against discrimination and they are able to attend school for as long as they are capable of doing so. But we have incidents of learners who are discriminated against and mocked by other learners. Sometimes we hear about this after a long time when there is nothing we can do.

Interviewer: How do you regulate the rate of absenteeism of HIV-positive learners?

Educator: Well, there is nothing that one can do about these learners' high rate of absenteeism, as they have to get their treatment from hospitals and clinics and be checked occasionally. What I can do, is to make sure they understand their work.

Interviewer: Do you have a first-aid programme known by all the learners?

Educator: Yes, learners are taught first-aid rules and we have a first-aid kit that is available to all educators in the case of any emergency. Learners have also been taught to take precautionary measures in and out of the classroom.

Interviewer: How is Sandra's performance?

Educator: She copes very well. She is a very bright child. She is always willing to do more. She even assists others when she understands something well.

Interviewer: What is Sandra's level of interaction with other learners?

Educator: She interacts well with other learners. She educates them about HIV/AIDS. She is very aware that she is HIV-positive and that she can't put herself in dangerous situations. The kids are not afraid of her; they like her.

Interviewer: Do you have a catch-up programme for learners who are frequently absent because of HIV/AIDS?

Educator: We do not have a catch-up program for these learners. We just try to make them understand sections that are difficult when they are better. We cannot re-teach what we taught other learners in their absentia as we would not be able to finish the learning program.

5.2.1.8 Interview with Sandra's sister

Interviewer: How do you feel about your sister's being HIV-positive?

Sister: I feel sad, especially when people are mean to her; it causes me to cry. That is when they do not treat her well or do not want her near them. It really hurts me to see her in pain when she is sick. I feel as if I could do something or at least, be able to take away the pain from her.

Interviewer: How do you treat your sister?

Sister: We really do not concentrate on the fact that my sister is HIV-positive. Yes, we have to look after her, but also we envy her for her strength and her will to live. I never talk to her about HIV/AIDS or her being positive. I am tolerant and patient though with her than with other siblings. I am more careful with my life. I do not have any one-night stands with strangers, as I can understand what the consequences of being reckless are.

Interviewer: In what way have you prepared yourself for the death of your sister?

Sister: Even though I know that she might die some day, I do not think I will ever be prepared for that. I never really think she will die. I just hope there will be a cure before she gets to the late stages of the disease.

Interviewer: When Sandra is playing with other children, how do you make sure that they do not hurt her?

Sister: I cannot always be with her, especially when she is playing with other children. I feel that she needs to be protected from neighbours and community members. Sometimes I feel like living her life for her, but I cannot! I encourage her to be open about her status and answer the questions her friends might ask. I also tell her not to be sensitive to things people say about her, because people sometimes make comments without realizing that they are hurting her, but sometimes they hurt her deliberately. There are those who call her names like saying she is three words, which means that she has HIV. She knows that she can tell me anything that bothers her and I help her to the best of my ability.

Interviewer: What do you fear most when you look at your sister?

Sister: I think of what could happen to her if hospitals would run out of ARV's, the fact that they find a cure for HIV and having to see my sister when she has reached the last stages of the disease.

Interviewer: When your sister does something wrong, do you reprimand her?

Sister: I do not treat her in any special way; she is a kid when she does something wrong she knows that she has to be reprimanded. She has to grow up like any other child.

Interviewer: If your sister can stay alive until you start working, what would you do for her?

Sister: I would try to make her life as easy as possible. I would ensure she always has veggies and fruits and also provide her with enough money for taxi to the support group meetings and provide her with the necessary education that will make it easier for her to be independent.

Interviewer: Do you take your sister's and your mother's HIV-positive status as a curse?

Sister: At first I thought that we were really cursed or we had bad luck. I even thought that this was a punishment from God, He just does not love us, but now I just take it as one of those things. I have come to realize that there are other families in the same predicament. I think to focus on good things and be positive in life, helped me.

Interviewer: How exactly do you help your sister?

Sister: I help her with her homework. We are also very good friends I also help her with any problems she encounters.

5.2.1.9 Interview with a neighbour (nursing sister)

Interviewer: As a neighbour and a health-worker, how do you help Sandra's family?

Neighbour: I give them tips on how to live positively. I advise them on what to do and not to do, especially when Sandra is sick, how to cook their food and about the importance of cleanliness.

Interviewer: Have you always had a close relationship with this family?

Neighbour: Sandra's positive status has no bearing on our relationship with her family. We have been close for as long as I can remember, Sandra's mother is a very strong woman. She came to tell me about her and Sandra's HIV-positive status. I can also safely say that she trusts me.

Interviewer: Does your relationship with Sandra's family affect her in any way?

Neighbour: I do not think she is bothered. She takes me as family. She is quite comfortable with me. She asks me questions sometimes about HIV/AIDS and I realize her fears.

Interviewer: As a neighbour, how do you caution your children and regulate their interaction with Sandra?

Neighbour: Sandra and my children know almost everything they need to know about HIV/AIDS. I gave all of them lessons on what to do to protect themselves when they are playing. I do not have any fears of what would happen in the case of an emergency. I have taught them well.

Interviewer: Can you comment on any positive or negative behaviour of Sandra's family regarding HIV?

Neighbour: The only negative thing is, that they are over-protective of Sandra, anything that is said by other members of the community about Sandra, even if it is a small thing, they take it personal and can lead to a conflict. They are also very sensitive. You cannot just talk about AIDS or people who have AIDS in general. They take it as referring to them. I do not blame them sometimes, as other members of the community do not invite them or come to their parties, as they say they do not want to be with HIV-positive people.

5.2.1.10 Interview with the school principal

Interviewer: What is the level of communicating this pandemic within your school?

School Principal: Through functions, especially the first of December, on the AIDS Day, through sports, assembly, and through drama. We also have T-shirts designating messages around the pandemic.

Interviewer: What are you doing as a leader to supplement this level of communication?

School Principal: I usually communicate through circulars and school journals, I talk about HIV/AIDS frequently during contact time.

Interviewer: Does the school policy on HIV/AIDS address issues for a specific community, or is it just general?

School Principal: It is general, as our communities is comprised of diverse community members.

Interviewer: What monitoring tool do you use to ensure policy adherence; does the tool you use, help learners living with HIV/AIDS?

School Principal: Any noticeable defect or non-compliance is recorded and an analysis is made every week-end, and corrective measures are applied.

Interviewer: How do you integrate HIV/AIDS with the curriculum?

School Principal: Over and above the inclusion policy, Art and Culture and Life Orientation fully present pandemic, while other learning areas are integrated in it.

Interviewer: How does your health programme assist learners living with HIV/AIDS within the school?

School Principal: The school supplies them with vegetables from the garden; they are also taught cleanliness and hygien.

Interviewer: Does your school policy address skills and economy in general?

School Principal: The school provides shoes made of plastic material (raphia) as a resource and learners are taught how to bake cakes. They design AIDS emblems, making use of beads, especially red-and-white beads. These products are sold in order to help sustain the project.

Interviewer: What is the level of accepting and accommodating infected learners and the personnel in your school?

School Principal: The slogan “a friend with AIDS is still my friend” is emphasized and orchestrated by the school community.

5.2.2 Case Study 2: Siphó’s Case

5.2.2.1 Family background

This is a family of six, consisting of two parents and four children, namely Siphó, Sibongile, Thembi and Themba. The latter, Themba, is the father’s child from a previous marriage, whilst Sibongile was adopted from the aunt who passed away as a result of HIV/AIDS. Only two of these kids belong to the current marriage.

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

Over and above those grants, the father supplements by selling liquor and cigarettes at a profit to the community. The income added together does not meet the needs of the family.

Siphó and Thembi are still attending school and educators are aware of the family’s HIV-positive status. The educators provide maximum support to both learners to the extent of providing food parcels and vegetables from the school garden. Both learners perform well at school; they also participate in extra- curricula activities where they play soccer, as they wish to play for Bafana Bafana in future. Their social interaction is also good at home, where they enjoy overwhelming support from the neighbours, as they are aware of their status. Among the supportive activities the family enjoys, is the support around family business where the selling of liquor and cigarettes reach certain heights.

Selling liquor does not bother this family, as their privacy is not invaded; the father is known to be a disciplinarian and a comedian by nature. The family has accepted their status support of each other; interacting well with the

neighbours, responding well to the medication and coping with different situations.

5.2.2.2 Interview with Sipho

Interviewer: How did you discover that you are sick?

Sipho: Both my father and mother are HIV-positive, so the chances are, that I am also HIV-positive. I was tested at Kopanong hospital and the results were positive. My HIV-positive status was revealed to me two years ago when I was nine years old. My parents took me to hospital because my younger sister was very sick. The doctors could not detect what was wrong until such time that she was tested for HIV. The doctor said that it was necessary for me to be tested as well. The results were positive for both of us. Then she started to be better, because she was given antiretro-viral syrup, of which she has to take 10ml once a day. She is much better; her weight has gone up. The nursing sisters are now complaining when we take her for check-ups, that she is too fat.

Interviewer: Do your teachers know that you are HIV-positive?

Sipho: My parents told the teachers that I am sick. One day my parents came to school to report that they don't have money to pay the school funds, because they are not working and they are both sick. I attend school at Maboeleng primary school. The school is just around the corner. I am in grade six. Teachers are aware that I am HIV-positive. My parents were unable to pay for school-fees, they were called in by the principal. The principal could see that both my parents are very sick. She advised them to go to the social worker who will assist them with grants so that they can be able to pay school fund.

Interviewer: Did your parents go to the social worker?

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

Interviewer: Does your friends know that you are HIV-positive?

Sipho: Probably, because my parents informed the neighbours about their status.

Interviewer: What was your reaction after hearing that you are HIV-positive?

Sipho: I felt so bad and unhappy the whole day. I could not eat. The counsellor told me in the presence of my parents. When the counsellor saw that I was crying, she counselled me, telling me that it is not the end of the world, that my parents love me so much and everybody else, and that if I live positively I will live longer.

Interviewer: What did your parents do?

Sipho: My parents were so supportive. They told me that they are in the same situation. I must be strong. They will be there for me. They hugged me and we went home, but it was a bad day, I'm telling you.

Interviewer: How was the situation at home?

Sipho: Everything was okay; it seemed as if there was nothing wrong. We carried on with our daily duties. Life is much better because of the grant we get every month and the profit my father is getting from selling liquor and cigarettes. People who buy liquor, are not causing trouble or stress to for us. My father has a special way of handling them. There is a special room where they sit and drink liquor.

Interviewer: Who else knows that you are positive?

Sipho: All my relatives know that I am positive. Some of them are supportive, but others do not like my father; they blame him for my mother's positive status. Those who have accepted us, sometimes bring food and vegetables. They love, hug and kiss me and this makes me feel accepted and happy. We no longer visit the members of the family who are not supportive; they do not want us to visit their homes, they say we will bring them bad luck.

Interviewer: Do you attend church?

Sipho: Yes, we attend church at Zion Christian Church. This is where we pray for our health or a miracle from God. I have not told the members of the church; I do not have confidence to do so. The pastor sometimes talks about it, that we should support people and children who are HIV-positive, should abstain from sex, that adults should use condoms, and we should eat healthy food.

Interviewer: Do you watch programmes, which are about HIV/AIDS?

Sipho: Yes I do watch them; they are educative. We learn a lot from them e.g. that we must eat healthy food that HIV-positive people must be treated like other people. They must not be discriminated against and they must also be cared for and loved.

Interviewer: Do you ever get sick?

Sipho: Yes, sometimes headache and flu are the main problems. I usually go to Kopanong hospital at Vereeniging when I am sick. They give me Bactrim syrup, of which I must take 10ml once a day. I have to go for treatment once a month for a check-up. My CD4 count is 1000.

Interviewer: What support do you get from parents?

Sipho: They support me with everything I want to do, e.g. homework and sport. The only thing I am not satisfied about is that we never talk about HIV/AIDS. As I said that I sometimes become angry with them for infecting me. If we can talk, maybe I could understand and forgive them for what they have done. They both support me; they come to school together to check on my progress. They wash my clothes and prepare food for me.

Interviewer: Does your school have a feeding scheme?

Sipho: Yes we have a feeding scheme at school and a vegetable garden. We eat meat, pap, soup, fruits and vegetables.

Interviewer: Do you receive a social grant?

Sipho: No, the application was not successful, because I don't have a birth certificate. I think my birth certificate caught fire where we were staying before. We never have found it till today.

Interviewer: Do you have a vegetable garden at home?

Sipho: No we don't have a vegetable garden at home. The space around our home is too small to make a garden. I wish we had enough space.

Interviewer: Are you taught about HIV/AIDS issues at school?

Sipho: Yes we learn about HIV/AIDS at school, especially during the periods of Life Orientation. Sometimes we watch programmes of HIV/AIDS at school; we have a school TV. Sometimes we have plays where learners would act being HIV-positive, as performed by learners at our school or by other learners from neighbouring schools or, by non-governmental organisations.

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

Sipho: Yes, the teachers invite motivational speakers from different organisations, churches and from the district of education.

Interviewer: What can you say to other learners of your age about HIV/AIDS?

Sipho: I can tell them that AIDS is there and it kills. You have to accept your status in order to live positively and healthy and that if you are positive, you have to take good care of yourself. They are supposed to eat healthy food with vitamins, e.g. fresh vegetables and fruits etc.

Interviewer: What makes you ill?

Sipho: I am not supposed to move around in cold or rainy weather. I cough a lot when I hang around a person who is smoking.

Interviewer: Do you do some exercises?

Sipho: Yes, a lot. I play soccer at school and at home and take a walk with my parents on weekends. I also attend aerobics at home.

Interviewer: Do you ever talk about HIV/AIDS with your friends?

Sipho: Yes, if the topic arises, maybe from the programme we have been watching or a lesson, as presented by the teacher or from the play we have been watching. I usually don't start the topic.

Interviewer: How did you contract this HIV?

Sipho: I contracted it from my parents, they are both positive. I am sometimes angry with them, because they should have taken precautions but sometimes I accept that I am HIV-positive, there is nothing I can do to. I also don't blame God for that, because He is the only one who makes everything for us. He is the Alpha and Omega and He does not make mistakes.

Interviewer: How is the reaction of your brother, since he is the only who is negative?

Sipho: He is supportive; plays with us; helps me with my homework, but if I am injured, he refuses to help me and asks my parents. He is afraid that I would infect him; he is sometimes frustrated to have a half-brother that is HIV-positive. This makes our relationship not to be good at times. I wish we could be able to talk about my status; he is one person who can support me if he can understand my situation. I am afraid to initiate the topic about HIV/AIDS.

Interviewer: How is your performance at school?

Sipho: My performance is good, because I have enough support at school and at home. My teacher, parents, my brother and even relatives and my grandmother, all support me. I like English because in future I would like to communicate with different people, so it will be much easier if I will be able to fill forms in English. I also like Life Orientation, because we learn

about different diseases and the teacher's presents this learning area so well.

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

Sipho: I want to be a medical doctor. I want to help people who are sick; maybe I will be able to find a cure for AIDS. I will also like to specialize in kids' illnesses.

Interviewer: What do you wish for HIV-positive people?

Sipho: I wish that God could give them a longer life. I wish they could have equal lives like any other person. Stigma should be removed from people who are HIV-positive. I wish my parents could live a better life. May God give them a longer life so that I can complete my studies, and help them. I wish I can complete my studies and my treatment will keep me well.

Interviewer: What support do you give to sisters?

Sipho: I love them, hug them; play with them; feed them when my parents are not around and protect them from anything that can harm them.

5.2.2.3 Interview with Sipho's father

Interviewer: When did you know that you are HIV-positive?

Sipho's Father: I started to know that I am HIV-positive in 2003. I no longer enjoyed life because at that time I was not working. I did not have enough money to meet daily needs; I did not have money to pay school fees for my children. My health deteriorated.

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

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

Interviewer: Do you take treatment for HIV/AIDS?

Sipho's Father: Yes, I take ARVs, one twice a day. My CD4 count was about 313 last month when I checked. My wife is also HIV-positive. I am the one who infected her and she infected the children through breastfeeding.

Interviewer: How did your wife react when she discovered that you have infected her?

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

Interviewer: Who are you staying with?

Sipho's Father: We used to stay with my sister, but because we were always fighting, we decided to move out. My sister stays with her two daughters in a four-roomed house. The first one is 18 years and the second child is one year old. My parents left the house with us. I built two outside rooms where I stay with my wife and children. My sister blamed my wife for my status this caused serious problems as the rest of our family were divided.

We had a family meeting where all our relatives were invited. It was decided, that we should move out. We built ourselves two rooms at the back in our parents' yard. Things are better, as my sister accepts my status. She is supportive. We eat together, and she cooks for us. She loves my children a lot; she kisses and hugs them. We make jokes together and laugh.

Interviewer: Where are your parents?

Sipho's Father: My parents passed away when we were still young; maybe I was doing grade 1.

Interviewer: Do your customers know about your status?

Sipho's Father: Yes, they know about my status. Some of them are also HIV positive. They enjoy buying at my place, because I make jokes and we laugh. Sometimes we even talk about HIV/AIDS; they ask questions and I answer them. Although I rinse the glasses well, there are others who do not want to come and drink at my shebeen in fear of being infected. They say they cannot use glasses that have been used by people with HIV/AIDS. I do not get enough from selling liquor, but it is much better than having a grant only. It helps, as I also drink with my customers in order to relieve my stress.

Interviewer: Are your family and relatives supportive?

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

Interviewer: Why is your grant not cancelled, because your CD4 count is over 200?

Sipho's Father: My grant is for TB; that is why it is not cancelled, they cancel it, if it is for HIV/AIDS.

Interviewer: What do you wish for people who are HIV-positive?

Sipho's Father: I wish that HIV-positive people should not be stigmatised. I also wish that HIV-positive people who stay around the Vaal, Parys and the Free State, get things like Soweto, Pretoria and East Rand e.g. people who live in the Vaal Triangle's grant is cancelled if the CD4 count goes

beyond 200 and people staying at Soweto do not have their grants cancelled; they get it continuously until they die.

Interviewer: What else do you wish for people who are HIV-positive?

Sipho's Father: I wish that HIV-positive people should not be placed in isolation, e.g. in hospitals they have their own wards. Why can't they mix with other or why other conditions are not separated from one another e.g. people with cancer should have their own wards. Why they are not separated from those who have stomach-ache or headache?

Interviewer: Is that all that you wish for people who are HIV-positive?

Sipho's Father: I also wish that people who work at the dispensary at the clinic should take care of HIV-positive people. When they give them tablets (ARV's) they mix them with previous ARV's, which they had got the previous months. If I am left with three or four tablets, I take the container to the clinic. They do not throw away those tablets they just mix them with new ones in another container. We can end up drinking tablets that are expired.

Interviewer: What is the best thing to do when you are HIV-positive?

Sipho's Father: First you have to accept your status and live with it; take your treatment, exercise; eat vegetables and fruit; take a walk; talk to people about it; drink water and juice everyday.

Interviewer: What other help do you wish to get from the government?

Sipho's Father: I wish that the grant can be increased by R300.00 in order to help us meet our daily demands and we can get even groceries. This can help us buy skin ointments for those who have skin problems.

Interviewer: Can you get a job?

Sipho's Father: No, because I cannot work for more than four hours I get tired very easily. Selling liquor doesn't bind me; anyone is able to sell if I don't feel well. If a burglary happens, I will take things easy the way they

come; I will not stress up if they don't buy or if someone steals. My relatives will take over, but my neighbours and the community members are supportive, they will help if the need rises.

Interviewer: What other kind of business would you like to start?

Sipho's Father: I would like to make shoes. I know how to make raffia shoes; somebody taught me how to make them. I just need somebody to buy me different colours of raffia needles and soles, then I will be okay. It will be a good start; I will be able to generate some money from the first pairs.

Interviewer: Are you able support your sick children and wife?

Sipho's Father: Yes I am able to support them and I am always there for them; feeding them; washing them; taking them to hospital for treatment; and helping them with their homework. We usually pray and go to church together.

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

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

Interviewer: Have you ever gone to the support group?

Sipho's Father: Yes, I used to go to the support group, but we had some problems. Nowadays I don't go there, because the money we raised, was not properly used. We no longer attend a support group.

Interviewer: Do you assist Sipho with his schoolwork?

Sipho's Father: Yes, I make time for him; between 6 and 7 o'clock we do homework; if he doesn't have homework; he reads something from his English or SeSotho book. Those are the languages he uses at school.

Interviewer: Have you ever thought of death?

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

Interviewer: Have you ever thought that these children will grow up to this day?

Sipho's Father: Yes, but through prayers; strong support from the family and neighbours; taking treatment and eating healthy food, has made them grow till today.

Interviewer: Do they know that you are sick at church?

Sipho's Father: No they don't know. I think if they knew, they would support me, but at the Zion Christian Church priests usually visit everybody at home to give support. Even if you are not sick, they visit you to support you and I think that support is enough. I am not yet ready to disclose my status to them.

Interviewer: Does the church contribute money to people who are destitute or HIV-positive?

Sipho's Father: No they don't contribute any money. They have a burial society whereby each church member contributes R26 once a month. It covers the whole family for funeral only.

Interviewer: Do you drink alcohol?

Sipho's Father: Yes, I must have a way of forgetting my problems. I also started smoking after I was diagnosed HIV-positive. It is easy to be drunk, especially weekends some of my friends get their salaries and have

enough money to buy liquor. It is also very difficult to sell liquor to people if you do not drink.

5.2.2.4 Interview with Sipho's mother

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

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

Interviewer: How did you feel about the results?

Sipho's mother: I felt sad; devastated; I wanted to kill myself; I cried the whole week. We fought a lot as I felt that he robbed me of my health. I never thought that I could be infected with HIV/AIDS. I was very angry with him. I really did not want to see him. I thought he did this deliberately and that he did this, because he hated me. It took me time to get used to the diagnosis.

Interviewer: Do you show signs and symptoms of HIV/AIDS?

Sipho's mother: No, I don't have signs and symptoms, the only thing I have, is Arthritis. My fingers are swelling. It is difficult to bath and wash clothes for my kids. My husband washes our clothes. I only struggle to wash my kids and myself. Flu is the only problem that I have. I cough a lot, especially during wintertime. When I am sick, I usually go to Kopanong hospital. They give me a cough syrup.

Interviewer: How long have you been diagnosed HIV-positive?

Sipho's mother: This is the third year.

Interviewer: It is not true that HIV-positive children pass away when they are two years of age?

Sipho's mother: Yes, it is not true, because all my HIV-positive children are above two years now and they don't easily get sick.

Interviewer: How do you support these kids throughout their daily lives?

Sipho's mother: I support them by giving them treatment daily; cooking healthy food for them; buying vegetables, fruit, and juice for them; helping them with their homework for those who attend school and taking them to the clinic when they are sick.

Interviewer: Have you ever gone for counselling?

Sipho's mother: The counselling was good, because after being counselled; I accepted my status and learnt to live positively. Those counsellors are very good.

Interviewer: I think you are affected by your status-your husband's as well as children's status-what do you do to relieve your stress?

Sipho's mother: We usually pray together. As a family, we feel that it is only God who can help us. We discuss our problems, make jokes and laugh and we usually play gospel music, which makes us to be calm and relieved.

Interviewer: Why don't you talk to your husband when you are stressed?

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

Interviewer: Does Sipho's teachers know about his status?

Sipho's mother: Yes, they know about Sipho's status. Yes, they support him a lot. They give him vegetables from their garden. They have a feeding scheme at their school.

Interviewer: What can you tell people who have the same status like you?

Sipho's mother: They must continue to take their treatment; do exercises; eat healthy food; attend support groups and live positively. The youth must use condoms or abstain from sex. They must take good care of themselves, but they must also enjoy life.

Interviewer: Do you approve of your sisters and brothers going to parties?

Sipho's mother: No, I do not. I do not want them to get infected as I am; they must take good care of themselves. If I were HIV-negative I would not have gone anywhere, except to work, to protect myself from being infected with HIV.

Interviewer: Have you ever watched TV programmes where they talk about HIV/AIDS?

Sipho's mother: Yes, I enjoy them, because they sometimes solve the problems I have being HIV-positive. I can see how other people solve their problems. They also help me to lead a positive life. I watch (Phamokate) on Wednesday 09H30 and Soul Buddyz at 08H30 (both TV programmes).

Interviewer: Have you talked about HIV/AIDS with your neighbours or friends?

Sipho's mother: Yes, they ask some questions, because they know my status. We talk a lot about HIV/AIDS; e.g. everybody must go and do an HIV test.

Interviewer: How do your parents support you?

Sipho's mother: They usually send us money-vegetables and fruit. Sometimes they come to visit us; help us with some cleaning, and washing and cooking.

Interviewer: How do you support Themba who is HIV-negative?

Sipho's mother: I support him by helping with his homework; talking to him about our status and answering some of the questions he asks. He is

affected by my status because he always wonders what will happen to him when we die.

Interviewer: What do you say to him when he feels like that?

Sipho's mother: I talk to him; telling him that God is the only one who knows. I tell him to pray when he feels like that: play some gospel music and go out with friends to the soccer field.

Interviewer: If you can get work, will you be able to work?

Sipho's mother: Yes, it will depend on the type of work, e.g. talking to people or counselling. I can do that, but cleaning by using cold water and washing I cannot do, because of arthritis.

Interviewer: What do you wish for children who are HIV-positive?

Sipho's mother: I wish them to grow more than this; I wish that they can be educated, and have their own careers and children; I wish that the cure could be found before they die. I never knew that my first child was HIV-positive until when I delivered my second child. She was sick and the doctors tested her for HIV/AIDS and the results were positive. You can stay for a long time without knowing that you are HIV-positive. Now that I know, I won't even try to have another child. It will be making conditions worse.

Interviewer: Do you have friends?

Sipho's mother: Yes, I have friends. We talk about everything, including HIV/AIDS; that is, to take good care of yourself, eat healthy food, exercise, take treatment and disclose your status so that you can live a longer life.

Interviewer: How do you take care of yourself when you are sick?

Sipho's mother: I take treatment and go to the hospital for check-ups and do exercises.

Interviewer: What support do you get from your cousins?

Sipho's mother: We do not get a lot of support from them; they are still too young. They are aged 20 and the other one is 2 years old. We send them to shops if we need something. The older one sometimes takes care of us when we are sick. They are not scared that they can be infected; they know what to do.

Interviewer: What do you say to them when you are together?

Sipho's mother: They must be careful of what they do and take precautions when the need arises.

Interviewer: What are your wishes about HIV/AIDS?

Sipho's mother: I wish that doctors could get a cure before I become worse and treatment should be available for everybody. I wish that the community can come together and talk about HIV/AIDS people, while HIV/AIDS must not be stigmatised.

5.2.2.5 Interview with grandmother

Interviewer: Do you know that your daughter and your son-in-law are sick?

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

Interviewer: How did they tell you?

Grandmother: They asked me to visit them and we sat around the table together and they told me. My daughter told me she was very sad and she was crying. The situation was very tense. I felt angry, sad and devastated, but later on I became sympathetic and supportive. I thought later that if I became angry, I could destroy them forever.

Interviewer: Do you still love your son-in-law, even if you feel he has infected your daughter?

Grandmother: Yes, I still love him. I cannot change just because he is sick. There are times when I feel that he is the one who brought this curse upon our family. When their HIV positive status was revealed to me, I was angry with him, I wanted my daughter to leave him. After some time I realised, that HIV/AIDS is just like any other disease. I now tell my daughter that God only knows and that she must trust Him with her life. The best medicine is to pray. My son-in-law usually tells us that he loves her and we can see that from his behaviour. He cares for his family and us. He washes the clothes, his children and even cooks, because his wife has arthritis. She complains if she works with water for a long time.

Interviewer: Do you know that your children are also sick?

Grandmother: Yes, I know that my grandchildren are sick. I give their parents money so that they can buy them nice things or they can use the money for their daily needs. Their grandfather passed away in 1970. When he died, he was not aware that his daughter and son-in-law were HIV-positive.

Interviewer: Are you in good terms with your son-in-law's parents?

Grandmother: Not really, because we do not visit each other and they are also not supportive.

Interviewer: Do you ever think that God has cursed your family?

Grandmother: No, I do not think that God has cursed my family and nobody has bewitched my family. This is a disease like any other.

Interviewer: Do you attend church?

Grandmother: Yes, I attend the Methodist church. I usually take my grandchildren to church when they visit me. I pray that my family can live

longer, until doctors find a cure for HIV/AIDS and that they should care for each other.

Interviewer: What advice do you give to them, as a grandmother?

Grandmother: I have told my daughter to use garlic when she cooks for her family. Prayer is most powerful of all the things that we use.

Interviewer: Have you prepared anything for your daughter's family?

Grandmother: I am banking money from the old age grant I receive every month so that they can attend school of their choice. We also have a burial society at our street. I do not think they will die now they get a lot of support. We pray hard. They also attend check-ups, take treatment and eat healthy food. I would like to make a thanks-giving if I get enough money, because I thought that they would have died by now, but God is still with them. People say that children with HIV/AIDS, die at the age of 0-2 years.

Interviewer: Do you ever talk to other family members about HIV/AIDS?

Grandmother: No, we do not talk about HIV. We talk about other things like our problems and family quarrels.

Interviewer: Do you ever visit them?

Grandmother: Yes, I visit them and stay for three to four days, but not now and then because of our culture. I should not stay with my son-in-law for a long time. There is nothing much to do, I just help them to wash their children. They cook and wash for me. I support them by listening to them when they share their problems with me. We also pray together and make jokes so as to relieve stress.

Interviewer: Do your neighbours know about the status of your children?

Grandmother: No, they are not aware or they do not want to talk about it, but they are amazed that my children and grandchildren had passed away.

Interviewer: Would you like your daughter to have another child?

Grandmother: No, I won't let that happen. I think my grandchildren are enough. By having more children, they will be complicating the situation.

5.2.2.6 Interview with sister-in-law

Interviewer: Do you know that your brother and sister-in-law are sick?

Sister-in-law: Yes I know, they told me. When they told me I felt pity for them. I am now strong for their sake. I told them that it is not the end of the world; they should pray hard, get treatment and attend counselling.

Interviewer: What do you do to support them?

Sister-in-law: I give them money to buy daily needs; sometimes we pray together and listen to gospel music that makes us to feel better. I make sure that they eat healthy food and take their treatment. I am not afraid that I can be infected. I know how HIV/AIDS is transmitted.

Interviewer: Do they have support groups in their Zone?

Sister-in-law: Yes, they have a support group. They attend every Tuesday. They do not get food parcels from this support group; they just sit and discuss their problems.

Interviewer: How do you feel when your brother and your sister in-law are sick?

Sister-in-law: I feel pity, terrible and bad; I wish I could take their pain and bear it with them. Their children would cry out for them, waiting to be picked up hugged and loved. When one of them is sick, I usually call the ambulance to take their parent/s to hospital. I realised that these children feel very bad when one or both their parents are sick. I usually remain with them try to comfort them, as they usually cry.

Interviewer: When your brother's wife has cooked food, do you eat?

Sister-in-law: Yes, I eat a lot, I even forget that they are HIV-positive and if I do not eat, they feel bad. I make it a point to enjoy the meal.

Interviewer: What makes them feel uncomfortable or bad?

Sister-in-law: They do not like me to drink. They say I misbehave when I am drunk. They complain that I do not look after their children well when I am drunk. They become worried when they are at hospital sick, that I will leave their children alone at night, especially over weekends. I feel bad when they talk about my behaviour; there is nothing I can do. I cannot bear the fact that they can die any time and I will be left to raise their children. This to me is a way of forgetting the problems we have as a family. I have a lot of friends who drink; it is difficult for me not to drink; as they come and fetch me. Sometimes we come back in the early hours of the morning. If I want to drink alcohol, I go away for a weekend and come back sober, because I do not want to hurt them. During these days they are left without my support.

Interviewer: What do you tell your children about HIV/AIDS?

Sister-in-law: I tell them to use condoms, abstain from sex, take their treatment and live positively if they are HIV-positive.

Interviewer: Are you worried about your brother's and sister-in-law's positive status?

Sister-in-law: No, I am not worried about their health. My brother and his family are positive about their status. We are supported by members of the community. However, I am worried about what we are going to do as a family about their children when they die. I have two children of my own. I am not working. I do not think I would be able to support six children, including my brother's.

Interviewer: What other problem do you have, besides the fact that your brother is HIV-positive?

Sister-in-law: The problem is, that I am doing odd jobs. Sometimes I do not have work for a long time. They have to support my children and me. This is a problem. My brother helps me with my daily needs, while he is also having his own problems.

5.2.2.7 Interview with neighbour

Interviewer: Are you aware that your neighbours are sick?

Neighbour: Yes, we are aware that our neighbours are sick they have told me that they are HIV-positive. It is now a long time since their status was revealed to them. If the sister-in-law is not at home, I remain with their kids.

Interviewer: What was your impression when they first broke the news to you?

Neighbour: I was shocked. It was unbelievable and incredible. I could not come to terms with it. I could not imagine how I was going to live with such neighbours. I saw a devastated family which is going to die from this disease in a cruel manner- the family which will affect mine, where I will take responsibility on a make-shift basis.

Interviewer: How did you come to terms with this condition?

Neighbour: I could not avoid the fact that they are my neighbours and that I need to help them. Secondly, I was encouraged by their morale in dealing with conditions as they were prepared to help themselves and disclose to other neighbours and appeal for assistance when the need arises.

Interviewer: How is your relationship with them?

Neighbour: Our relationship is very good. They are very kind; the father usually makes jokes. He is always surrounded by people. They enjoy to be around him, because he makes them laugh and forget about their problems. The positive status has not affected our relationship. Our

children play together; we have taught them that if one of them is injured, they would have to report the matter to an older person.

Interviewer: Do you provide them with any formal assistance?

Neighbour: When the parents are hospitalised or if they are committed elsewhere, I take care of the other family members. When parents themselves have problems, I get notified and I intervene. I also take the little ones to the clinic in times of ill health.

Interviewer: How do you ensure that your children use precautionary measures when playing with your neighbour's children?

Neighbour: I have taught my children to use precautionary measures when they play with my neighbour's children or other children in our neighbourhood. I have also told them to ask for help when they feel that they cannot handle a situation.

Interviewer: What are the most crucial encounters you have had with your neighbours?

Neighbour: There was a time when all members of the family were sick at the same time. I had to assist them with the cleaning of the house and making sure that they eat.

Interviewer: What is your anticipation regarding the future of your neighbours?

Neighbours: The family will survive for quite a long time. They adhere to medical instructions and health advices; they enjoy support from some of the community members.

Interviewer: What can you ask from the government concerning people who are HIV-positive?

Neighbour: I would ask for the government not to separate people in hospitals who are HIV-positive. I think they feel bad that they are to remain in separate wards.

5.3 ANALYSIS AND INTERPRETATIONS

In this section analysis and interpretations of narratives of families infected with HIV/AIDS, will be provided. These narratives are analysed and interpreted

by means of themes. Themes are written first, then analysis and interpretation of each theme follows.

5.3.1 Theme 1: HIV/AIDS impact on the families' psychological well-being

All members of the family are psychologically affected by the impact of HIV/AIDS. They indicated the following.

'... my mother looked very sad when she told me'; 'I was very shocked at that time'; 'I was angry, confused, I couldn't understand why a person whom I thought he loved me, could do something so horrible to me'; 'I couldn't believe it was happening to me'; 'There were days when I felt down and depressed'; 'They were shocked, they were also afraid that they might also be HIV-positive'; 'I was shocked - I never expected that to happen to my family'; 'I was also very confused I was very angry at my son in law who definitely infected her'; 'He was very upset he blamed himself for this ordeal'; 'It is always a shock when you find out that someone is HIV positive, I could not believe it'; 'Well this makes me sad, because these kids are so innocent.'

Literature supports the notion of the psychological impact of HIV/AIDS on family members where it indicates, that they may experience psychological depression, which tends to incapacitate them and impair their abilities to work (see 3.2.1.6). The participants mentioned sadness, shock, disbelief depression, confusion and blame. This situation could lead to feelings of hopelessness, frustration and being overwhelmed.

5.3.2 Theme 2: After the HIV-positive status has been revealed people's first reaction is that of denial

Family members indicated, that when their/family member's HIV-positive status was first revealed to them, they were in denial:

'I also could not understand why I had HIV'; 'I couldn't believe it was happening to me'; 'They could not believe me when I told them that they might be positive'; 'I could not believe it, she is so beautiful and she showed no signs of being ill'; 'I think I do not want to hear people talking about HIV/AIDS.'

Most people who are diagnosed HIV-positive, are in denial. These are most common responses for people who are in denial. According to literature, denial fuels the AIDS stigma by making those individuals who are infected, appear abnormal and exceptional (see 3.6.2).

5.3.3 Theme 3: Where HIV/AIDS rages, the relationship between family members is negatively affected

Participants indicated, that relationships between family members turn sour immediately they become aware of one of the members' positive HIV status. They indicated that:

'...the family have not spoken to us ever since'; 'I couldn't understand why a person whom I thought he loved me can do something so horrible to me'; '...my parents are fighting over me. This affects my health a lot'; '.....they both would like to support me but they cannot stay under the same roof'; 'They have not spoken to me ever since my husband died. They think I killed him'; 'We always fight when we are together. I even prefer that she stays where she wants to. We started fighting after we were diagnosed HIV positive'; '...but others do not like my father'; 'I am sometimes angry with them, because they should have taken precautions'; 'I was waiting for him to give me an advice that I should use a condom I would have told him that he should have done that himself'; '.....he is sometimes frustrated to have a half brother that is

HIV positive. This makes our relationship not to be good at times'; '...my wife did not want to talk to me for a long time'; 'We used to stay with my sister but because we were always fighting we decided move out, this caused serious problems as the rest of our family was divided'; '...other relatives do not want anything to do with us'; 'We fought a lot as I felt that he robbed me of my health'; 'I really did not want to see him'; 'When their HIV positive status was revealed to me I was angry with him, I wanted my daughter to live him.'

It is worrying that family members react this way in times when they were supposed to unify and support the HIV-infected member. It is unfortunate, that family members start blaming the infected member as if s/he has been irresponsible. Literature indicates, that HIV/AIDS is believed to bring shame upon the family (see 3.6.1).

5.3.4 Theme 4: HIV positive members of the family usually blame each other for their HIV-positive status

Family members blame each for positive HIV status. Their opinions were as follows.

'I couldn't understand why a person whom I thought he loved me can do something so horrible to me'; '...we never fought about him infecting me and why he is the one who infected my mother'; 'As truck drivers they know about HIV/AIDS he chose to live a life that is detrimental to the health of my mother something that affected the whole family'; 'I was very angry at my son-in-law who definitely infected her'; 'She is the one who infected me with the virus'; '...we started blaming each other for our HIV- positive status they blame him for my mother's positive status'; 'I am sometimes angry with them, because they should have taken precautions'; 'I think she was blaming me although she did not say so'; 'My sister was blaming my wife for my status this caused serious problems as the rest of our family was divided'; 'We fought a lot as I felt that he robbed me of my health'; 'I thought he did this deliberately; that

he did this because he hated me'; 'There are times when I feel that he is the one who brought this curse on to our family.'

HIV-infected family members are usually blamed for their status, religious and moral beliefs lead some people to believe that having AIDS, is the result of a moral fault that deserves to be punished (see 3.6.1). These HIV-infected family members are made to feel guilty not only of getting themselves ill, but also of infecting 'innocents'. The blame among family members, seems to be motivated by the need to blame and punish the infected members and can be a substitute for tackling the problem itself.

5.3.5 Theme 5: Being HIV-positive has brought the infected and their families closer to God

The participants indicated praying to God for a cure and/ or divine intervention. For some of these participants, God becomes the only hope. Prayer helps as they have done something instead of watching their relatives dying. One of the respondents also prayed to God for others to realise that she is innocent. The participants indicated the following:

'Yes, we go to church on a regular basis'; '...they often come to my house to pray'; 'I wish that God could bless her with more years'; 'I pray to God that they would one day realise that they blamed me for nothing'; 'We all attend a church service every Sunday we have a church hall just down the road'; 'I like the fact that my daughter agreed to come with me to church as at least she is going to be able to pray to God for all the problems she encounters including their positive HIV status'; 'I pray to God that she gets a husband that can marry her'; 'Yes, we attend church at Zion Christian Church This is where we pray for our health or a miracle from God'; 'We usually pray and go to church together'; 'We usually pray together as a family, we feel that it is only God who can help us; I now tell my daughter that God only knows and that she must trust Him with her life'; 'The best medicine is to pray'; 'I pray that my family can live longer until doctors find a cure for HIV/AIDS and that they should care for each other.'

The implication is, that all respondents came closer to God. Sometimes respondents pray that God can take HIV-positive people relieve them of their suffering. They also realise, that if they cannot find help on earth they can negotiate and bargain for divine help. The idea of being closer to God, raises hope that things would be better. Feelings of hope fluctuate daily and sources of hope differ from person to person (see 3.4.7).

5.3.6 Theme 6: HIV/AIDS is still a taboo, even in families with HIV positive members

Participants indicated, that it is difficult to talk to family members about HIV or their HIV-positive status. The participants reacted as follows:

'...although we never talk about my HIV-positive status or about HIV/AIDS in general'; 'We do not talk about HIV/AIDS we are both free to do so with other people'; 'It is a pity that I do not feel comfortable to talk about HIV/AIDS with my mother'; 'No we do not talk about HIV/AIDS I do not think it would be wise to do so. I do not want to hurt her'; 'I do not talk about that except when she asks me something she didn't understand from school. I just give an answer to what she has asked me. It is difficult to talk to children about HIV/AIDS, especially a grandchild. We do not talk about HIV/AIDS with their mother who is my daughter we only talk about her health'; 'I hide my fears and hurts and I know she also does the same'; 'I never talk to her about HIV/AIDS or her being positive I wish we could be able to talk about my status; he is one person who can support me if he can understand my situation'; 'The only thing I am not satisfied about is, that we never talk about HIV/AIDS'; 'I do not feel comfortable to talk to her about my HIV-positive status or hers, for that matter'; 'We are not used to talking to each other about our emotions let alone HIV/AIDS. It is better for me to talk to my mother about my fears but also not about HIV/AIDS'; 'No we do not talk about HIV; we talk about other things like our problems and family quarrels.'

It is worrying, that at this time and age people still feel reluctant to talk about HIV/AIDS. It seems that these participants are afraid of the reaction of their

family members; it could also be a way of forgetting about the ordeal and pretend as if nothing has happened. This situation is detrimental to the infected members as they need all the support they can get. Talking about an adverse situation, brings relief to the person who is overburdened.

5.3.7 Theme 7: Family members with HIV, suffer discrimination within their families and their communities

Participants indicated being discriminated against by their family and community member. Their opinions were as follows.

'There was this other learner who didn't want to sit, play or share the class toys with me. Lebo's mother indicated that she does not want me near her child'; 'I must go and play with other children who are HIV-positive and live her child alone'; 'After confirming that what they heard about my husband was true, they told me to stop visiting them. My friends were afraid of being associated with people who are HIV-positive'; 'There are other families in our community who do not want my grandchild to play with their children'; 'We monitor her; we do not want her to play with people who do not accept her status. That is when they do not treat her well or do not want her near them. There are those who call her names like saying she is three words meaning she is HIV'; 'I do not blame them sometimes as other members of the community do not invite them over or come to our parties as they say they do not want to be with HIV-positive people'; 'We no longer visit the members of the family who are not supportive; they do not want us to visit their homes they say we will, bring them bad luck'; 'Although I rinse the glasses well there are others who do not want to come and drink at my shebeen in fear of being infected. They say they cannot use glasses that have been used by people with HIV/AIDS.'

The disease is associated with stigma and discrimination as individuals have been rejected by their families, their loved ones and their communities (see 3.6). Stigma is a deeply discrediting attribute that reduces a person to

someone who is in some way tainted and can therefore be denigrated (see 3.6).

Resulted in the isolation and exclusion of people.

5.3.8 Theme 8: Challenges that family members infected and affected by HIV/AIDS, face

Participants indicated the following regarding the challenges they face.

'We are unable to express our love sexually sometimes, as one of us or sometimes both of us are sick at the same time. We need to use a condom always otherwise we can be re-infected. We cannot be together all the time as we need to be home at certain times to take our medication. We cannot have children of our own. Even though I know that she might die some day I do not think I will ever be prepared for that. I cannot always be with her, especially when she is playing with other children. I feel that she needs to be protected from neighbours and community members. Sometimes I feel like living her life for her but I cannot! I think of what could happen to her if hospitals could run out of ARV's; the fact that they find a cure for HIV and having to see my sister when she has reached the last stages of the disease. I think to focus on good things and be positive in life, helped me. You have to accept your status in order to live positively and healthy and that if you are positive, you have to take good care of yourself. I am worried about leaving my children with my wife; that would be a bad thing. I do not talk to them about death; I am afraid to do so. I do not even talk to my wife about death.'

It seems that these are unable to continue living their lives normally as families who are not affected and infected.

5.3.9 Theme 9: HIV/AIDS impact on the families' physical wellbeing

Family members physically affected by HIV/AIDS say the following.

'I feel a little bit stressed; my parents are fighting over me. I have not searched for a job ever since; besides, I have constant headaches, I can't work. Yes, my daughter has migraine; it is very painful; when she has it she doesn't wake up for days. My granddaughter's problem is that she always has flu and her nose bleeds whenever she has flu. Yes, sometimes headache and flu are the main problems. I cough a lot when I hang around a person who is smoking. I have pneumonia, backache, and skin problems; my skin colour has changed to a darker colour and I am light in complexion, and I cannot work more than four hours; my chest and bones are painful and I become weak and tired. No, because I cannot work for more than four hours. I get tired very easily. the only thing I have, is arthritis; my fingers are swelling, it is difficult to bath and wash clothes for my kids. Flu is the only problem that I have.'

The literature indicates, that as HIV weakens the immune system, it makes people more vulnerable to infections and it develops active TB (see 3.2.1.9). People infected with HIV/AIDS, experience physical deformity/disfigurement, physical disorders such as cancer, skin colour etc. - a situation which can lead them to being isolated.

5.3.10 Theme 10: Members of families infected with HIV/AIDS, still have dreams about their future

Family members affected and infected, still have dreams about their future: this is evident from the following utterances.

'I wish that God could bless her with more years so that she becomes the doctor she wants to be', 'I wish I could always be there to protect her from other children who make fun of her', 'I wish she could live longer. I enjoy her. I also wish she could get the necessary education she deserves. I wish that God could give them a longer life. I wish they could have an equal life like any other person. I wish that HIV-positive people should not be stigmatised. I also wish that HIV-positive people who stay around Vaal, Parys and Free State get things like Soweto, Pretoria and East Rand e.g. people who live in the Vaal Triangle have had their grant

cancelled; if the CD4 count goes beyond 200 and the grant of people staying in Soweto is not cancelled; they get it continuously until they die.: I wish that HIV-positive people should not be placed in isolation e.g. in hospitals they have their own wards: I also wish that people who work at the dispensary at the clinic should take care of the HIV-positive people when they give them tablets (ARV's); they mix them with previous ARV's, which they had the previous months. I wish that the grant can be increased by R300.00 to help us to meet our daily demands and with an increase, we can even get groceries. I wish them to grow more than this; I wish that they can be educated, and have their own careers and children; I wish that the cure could be found before they die. I wish that doctors can get a cure before I become worse and treatment should be available for everybody. I wish that the community can come together and talk about HIV/AIDS; people with HIV/AIDS must not be stigmatised. I wish I could take their pain and bear it for them.

It is applauded that these families still have hopes for the future, whilst they are living in adverse situations. People who are resilient, are able to bounce back from adverse situations like these.

5.3.11 Theme 11: Family members who are infected and affected by HIV/AIDS, use coping strategies that are detrimental to their own health

Family members affected and infected by and with HIV/AIDS, are not coping well. This is what they said:

'I have been drinking for about four years after my husband's death. Yes, I must have a way of forgetting my problems I also started smoking after I had been diagnosed as being HIV-positive. It is easy to be drunk, especially during weekends some of my friends get their salaries and have enough money to buy liquor. I feel bad when they talk about my behaviour. There is nothing I can do. I cannot bear the fact that they can die anytime and I will be left to raise their children, this to me is a way of forgetting the problems we have as a family.'

It is worrying that these participants do not cope. According to literature, there is enormous strain on the capacity of families to cope with psycho-social and economic consequences of illness, such that many families experience great distress and often disintegrate as social and economic units (see 3.8).

5.4 CONCLUSION

This chapter analysed and interpreted the results of the empirical research. In the next chapter the summary, conclusions and recommendations will be presented.

CHAPTER SIX

SUMMARY, FINDINGS AND RECOMMENDATIONS

6.1 INTRODUCTION

In this chapter, a summary of the five preceding chapters is presented; firstly of the findings from literature which as highlighted in chapters 1, 2 and 3 presented, followed by the findings of the empirical research as revealed in chapter 5. The summaries of the literature findings and empirical research, will enable the researcher to formulate recommendations for families affected by HIV/AIDS.

6.2 RESEARCH FINDINGS

6.2.1 Findings from the literature study

The literature investigation revealed the following.

- HIV/AIDS has not been only an individual problem, but also a social epidemic, classed with social epidemics such as poverty, gender injustice, social discrimination of certain groups, war, violation of children's rights and cultures of inequality (see 1.1).
- HIV/AIDS is a complex issue involving the social, cultural, spiritual, physical, economic and political aspects of people's lives. It is, therefore, more than just a health issue (see 2.6.4).
- HIV/AIDS exacerbates and is exacerbated by prevailing economic conditions that deepen the vulnerability of households, communities and nations. The presence of HIV/AIDS in a household, quickly results in the depletion and disintegration of the household's income-earning capacity, household savings and assets (see 2.1).

- HIV has found a wealth of opportunities to thrive in tragic human conditions fuelled by poverty, abuse, violence, prejudice and ignorance (see 3.1).
- The family is probably the most important social system that people form part of and their risk for or adaptation to illness, is best understood within this context (see 2.3.1).
- HIV/AIDS also impacts on learners' health and wellbeing, health services for children and on education (see 3.2) and is a brutal escalator of other cruelties which children endure (see 3.2.1).
- Instead of receiving special care and assistance, childhood is spent providing care and assistance. Children become decision-makers, responsible for the social and economic future of the family, and fill these roles without physical and emotional protection, guidance and support that, as children, they deserve (see 3.2.1.3).
- The narratives are based on the premise, that people are the experts of their own lives. When they examine themselves, they view their problems as being separate from themselves. Within the narrative practice, outsider witnesses are invited as listeners to a therapy conversation (see 2.2.1).
- These above emphasize, that the stories of people's lives, are pivotal to an understanding of the individual. Within narrative therapy, people's beliefs, skills, principles, and knowledge will assist them in reducing the severity of their problems in their lives (see 2.6.3).

6.2.2 Findings from the empirical investigation

The empirical investigation revealed that -

- HIV/AIDS impact on the families' psychological well being (see 5.3.1);
- after the HIV-positive status has been revealed, people's first reaction, is denial (see 5.3.2);

- where HIV/AIDS rages, the relationship between family members is negatively affected. HIV-positive members of the family usually blame each other for their HIV-positive status (see 5.3.3);
- Being HIV-positive, has brought the infected and their families closer to God (see 5.3.4);
- HIV/AIDS is still a taboo, even in families with HIV-positive members (see 5.3.5);
- Family members with HIV, suffer discrimination within their families and their communities; challenges that family members infected and affected by HIV/AIDS face (see 5.3.6);
- Most family members who are infected and affected by HIV/AIDS, would like to take care of others who are infected, as a full-time job (see 5.3.7);
- HIV/AIDS impact on the families' physical wellbeing (see 5.3.8);
- Members of families infected with HIV/AIDS, still have dreams about their future (see 5.3.9); and
- Family members who are infected and affected by HIV/AIDS, use coping strategies that are detrimental to their own health.

6.3 RECOMMENDATIONS

6.3.1 There is a need for infusing narrative therapy in all psycho-social programmes so as to assist families affected by HIV/AIDS

In this counselling approach, the child or adult uses story-telling as a means of dealing with past and unresolved issues. People tell their own stories and recreate their pasts. They can, for instance, construct stories in which they overcome an obstacle. Narrative therapy opens a space for thinking about alternative stories that can be told, suggesting a way forward for those whose stories have had to be suppressed. It provides an opportunity for creating positive memories.

Narrative therapy should encapsulate memory work and life-stories. Memory books contain records of families, where the family came from, what their fore-parents' interests were, and a family tree, to show the other members of the family. Families are also encouraged to write about their dreams for the children's future, and remember any special things that the children did, or how the parent felt when the child was born. Memory boxes are similarly a way for families to keep precious items from their fore-parent(s) and from early childhood. Memory books may also contain a place for the birth certificate and any other legal documentation. They can also contain photographs, baby hand- and foot-prints, letters to be read at special stages of the child's life, and video recordings.

Memory work is a family-friendly approach to counselling, that includes aspects of play, narrative, and art therapy, as well as music and dance. Memory work has its roots in life story work and it is widely recognised as one of the most cost effective ways of addressing the psychosocial needs of children and families, given the vast numbers of bereaved and dying people in Africa; The focus is on:

- preparatory bereavement work;
- planning for the future care of children; and
- dealing with past, present, and future issues.

Memory boxes/books ensure that:

- family origins and traditions are passed on;
- children have a sense of history and belonging;
- dying parents have values, beliefs, and aspirations for children's future lives documented;
- communication channels in family are opened up;
- plans for the future care of children occur in a timely manner;

- children are prepared to cope with losses and changes that lie ahead; and
- each child's sense of identity is built up.

Memory work can be used in group or individual settings, with or without traditional counselling.

The foregoing paragraphs highlight the fact, that narrative therapy should be part of counseling families affected by HIV/AIDS. Counseling objectives could be:

- assessing what the family already knows about HIV/AIDS;
- assisting the family in making an informed decision on an HIV/AIDS disclosure;
- helping a family identify and strengthen their coping capacity;
- helping the child to develop positive attitudes towards life;
- assessing the needs of the family in order to determine a family's needs, available resources, vulnerable areas, and established strength;
- establishing a trusting relationship; and
- staying in touch with the family over time.

6.3.2 Communication in families affected by AIDS, could be encouraged as follows.

6.3.2.1 Communication with children

Communication is the foundation of the relationship between parents infected with HIV/AIDS and their children; Communication with children should be developmentally appropriate and sensitive and should address the different needs of children, including the following.

- Emotional needs: Many children with HIV/AIDS, have the need to be involved in the decisions concerning their lives and to be told what they are suffering from.
- Social needs.
- Physical needs.
- Spiritual needs. Children, like adults, have spiritual needs. These include love, hope, and trust in a higher power in order to take control of their situation. Palliative care should provide children with the opportunity to appreciate the meaning and purpose of life. They should have hope in future life and be able to express their contentment with life. Signs of spiritual health include:
 - feeling forgiven;
 - being free from feeling guilt;
 - expressing love for others through actions; and
 - having hope.

Communication should specifically address the concerns, fears and questions of the child. Children should not be forced to tell their story. If a child cannot communicate verbally about something, there will be good reasons why that is the case, including:

- cradition and cultures: in Africa tradition children are 'seen but not heard';
- children in African cultures are not allowed to disagree with adults; they are brought up and always instructed to be quiet and humble and never to talk when adults are talking;
- children feel embarrassed to discuss HIV/AIDS with adults, because it relates to taboo subjects such as sex; and

- children might fear hurting adults; they might fear and hide their feelings in order to protect their parents, particularly if parents or guardians are unhappy;

All communications with children on the effects of HIV/AIDS, should centre on the best interests of the child, namely the following.

- **Nondiscrimination between children:** Children sick with a terminal illness such as HIV/AIDS should not be discriminated against; an inclusive approach should be followed while dealing with sick children.
- **Openness and truth:** Most children prefer to know the truth and view disclosure of their sickness positively. Openness and truth prepare children and parents for impending death. Secrecy and denial can have effects on children's long-term psycho-social health.
- **Preparing children and parents for impending death:** Discussing children's illness helps to overcome their fears and worries. Understanding and addressing the fears facilitate children's capacity to cope with grief.
- **Recognizing the individuality of children:** The way that illness and death are explained, should be appropriate to the needs of each child. Children will respond differently to situations and will have their own psycho-social needs.

Communication with children should also involve disclosure on all the family members infected with HIV/AIDS. The risks of non-disclosure to children affected and infected by HIV/AIDS also could be as follows.

- Keeping secrets increases the stigma.
- Child/parent communication is depreciated and children lose confidence in parents.
- Children may receive wrong information from playmates and neighbours.

- Children who do not know their own HIV status, may not receive all the support they need, participate in their own care, or be adherent to medications.
- Adolescents with HIV, may become sexually active and unknowingly infect a partner.

Guidelines for disclosing to children, could consist of the following.

- For young children, parents should provide simple information in language they can understand; and focus on the nature of their illness;
- For school-aged children, parents should be clear about the disclosure; discuss the role of treatment where available, provide hope and encourage adherence; and answer all questions truthfully and honestly.

Educational/counseling/clinical psychologists can also be employed to communicate with children. Educational/counseling/clinical psychologists approach to communicating with children should also -

- insist on child-focused, not parent-focused, sessions;
- talk with the child, rather than to, or about him/her;
- handle the likely reactions and questions during the process of counseling;
- assure confidentiality or be honest beforehand about any one who will be told what the child confides;
- be approachable;
- avoid a commanding tone or judgmental attitude;
- avoid imposing adult values on children;
- avoid comparing the behaviour of children infected and affected by HIV/AIDS to other children; and
- don't make empty promises.

6.3.2.2 Using reflecting teams with families affected by HIV/AIDS

The reflecting team has been useful as a way to generate new ideas and expand therapeutic possibilities for both the family affected by AIDS and psychotherapists. It offers an opportunity to connect and collaborate in ways that remove hierarchical barriers and open communication for co-constructing new meanings and co-generating options for action. The goal of a reflecting team, is to maintain a collaborative stance by recognizing the family members' expertise of lived experiences. A session structure consists of the following.

- First, the therapist and the family talk in a room with the team members listening from a corner.
- Second, the team members talk about what they had heard, while the therapist and the family listen.
- Finally, the family comments on the team's talk.

The reflecting process offers families an opportunity to listen to multiple perspectives and ideas about their dilemmas. The reflecting process is useful for activating and mobilizing families' resources, support and normalize the impact of the illness, such as suffering from HIV/AIDS.

6.4 MENTAL HEALTH ISSUES AND INTERVENTIONS WHICH SCHOOLS COULD USE WITH FAMILIES AFFECTED BY HIV/AIDS

HIV-infected parents and their children commonly struggle with pre-existing mental health problems associated with substance abuse and complicated, stage-specific individual and family mental health issues throughout the course of HIV illness progression. After a parental death, new caregivers, affected children and adolescents often cope with complicated bereavements and adjustment to family re-configuration.

On the basis of the latter paragraph, there is, therefore, a need for schools to develop a training curriculum in HIV-related mental health issues for children and their families for mental health, and substance abuse. This curriculum can use a modular format, covering both background mental issues in families

affected by substance abuse and modules covering stage-specific issues occurring over the course of HIV progression, parental death and family reconfiguration. The curricular format can include didactic material and illustrative clinical material and can utilize an interactive approach to improve the skills and knowledge of children and their families.

Within the workshop format, specific material in the following areas can be presented.

- Mental health profiles of families affected by HIV and substance abuse, with an emphasis on recognition and assessment of pre-existing mental health problems complicating adjustment to HIV illness.
- Therapeutic issues and interventions with parents in order to facilitate communication and planning with HIV illness progression.
- The impact of parental HIV illness on children and adolescents, with the explication of normative and non-normative responses in different developmental stages.
- Therapeutic issues and interventions with children and adolescents so as to facilitate adjustment to parental illness.
- Therapeutic issues and interventions with children and adolescents and new caregivers after parental death, with the emphasis on complicated bereavement and adjustment to re-configured families.

6.5 FAMILIES AFFECTED BY HIV/AIDS SHOULD BE INFORMED OF THE BENEFICIAL IMPACT OF GOOD NUTRITIONAL STATUS

Families affected by HIV/AIDS, should be informed of the beneficial impact of good nutritional status, both on the prevention of HIV-infection and on the course of the disease. Nutrition education and communication strategies in this regard, should include appropriate dietary recommendations for individuals suffering from the disease, taking into account local food sources and production systems.

Since nutrition requires an integrated approach to household food security, health and care, it forms a logical entry point for assisting HIV/AIDS-affected families in coping with the epidemic. The following key points, should therefore, be considered.

- Appropriate nutrition education is required, as well as the transfer of knowledge and skills to prevent their loss to the household and the wider community.
- Participatory techniques are fundamental in the development of a comprehensive understanding of the specific constraints that HIV/AIDS-affected communities are facing, as well as in the design of adequate responses.
- Since behavioural change is needed for effective prevention and mitigation of the epidemic, and since HIV/AIDS issues are highly sensitive, the development of appropriate communication strategies is crucial.

6.6 LIMITATIONS OF THE STUDY AND SUGGESTIONS FOR FURTHER RESEARCH

The limitation of this research is its small sample which only consisted of two families in the Vaal Triangle area of the Gauteng Province. This make it difficult for the researcher to generalize her findings and deductions without raising questions of validity and reliability of her research. However, the researcher wishes to highlight the fact that since HIV/AIDS is not yet a notifiable disease in South Africa, it is difficult to identify families affected by HIV/AIDS because also of the stigma that goes with the disease. Interviews are also time consuming and very expensive to conduct because of the traveling that a researcher should undertake to meet participants in persons.

There is a need for this research to be widened to all the provinces of South Africa with a view to investigating the nature and extent of families affected by HIV/AIDS in the whole country. Such a study could shed more light on the nature and extent of families, especially children whose parent(s) are still

alive, affected by HIV/AIDS in South African schools, and ways in which these children and their families could be helped.

6.7 CONCLUSION

This research investigated, by means of a literature review and an empirical research, the narratives of families affected by HIV/AIDS. On the basis of both the literature review and empirical research methods, recommendations were made in Chapter 6.

It is hoped, that this research will make a contribution to the understanding of learners affected or orphaned by HIV/AIDS.

BIBLIOGRAPHY

- AINSWORTH, M. & SEMALI, I. 1995. The Impact of Adult Deaths on Household Composition, Mimeo. World Bank, Washington DC, USA.
- ALTAF, A. 2004. Harm reduction among injection drug users in Karachi, Pakistan. Paper presented at the XVth International HIV/AIDS Conference. July. Bangkok.
- AMOROSO, N., SPENCER, T. & REDFIELD, V. 2004. Improving on success: What treating the urban poor in America can teach us about improving Antiretroviral Programmes in Africa. *AIDS*, 18 (3): S39-43.
- ANGLO AMERICAN GROUP. 2004. Anti-retroviral therapy programme. Progress Report. New York: Pelgrave Macmillan.
- ASAMOAH-ODEI, E. & CALLEJA, T. 2004. HIV prevalence trends in sub-Saharan Africa: an analysis of 5 years' ANC data. Slide presentation to the 'Evidence and causes of declines in HIV prevalence and incidence in countries with generalised epidemics' workshop. Harare, Zimbabwe, 15-17 November. Sponsored by UNAIDS, WHO, CDC and UNICEF.
- ASINGWIRE, N. 1996. AIDS and Agricultural Production: Its Impact and Implications for Community Support in ACORD Programme Areas, Mbarara District, a consultancy report.
- ASKEW, I. & BERER, M. 2003. The contribution of sexual and reproductive health services to the fight against HIV/AIDS: A review. *Reproductive Health Matters*, 11(22): 51-73.
- ASPINWALL, L.G. & STAUDINGER, U.M. 2003. A psychology of human strengths: fundamental questions and future directions for a positive psychology. Washington, D.C.: APA Books.
- AUVERT, B. 2001. Male circumcision and HIV infection in four cities in sub-Saharan Africa. *AIDS*, 15(Supplement 4): S31-S4.

- AVERT ORGANISATION. 2005. South Africa HIV and AIDS statistics. [Web:] <http://www.avert.org/safricaststs.htm>. [Date of access 15/1/2006].
- BACHMANN, M. O. & BOOYSEN, F. L. R. 2003. Health and economic impact of HIV/AIDS on South African households: a cohort study, *BMC Public Health*, 3(14).
- BALAKIREVA, O. 2003. *The Prospects for Development of HIV Prevention Programmes among Injecting Drug Users*. UNICEF, UNAIDS, Social Monitoring Centre. Kiev.
- BARNETT, T. & WHITESIDE, A. 2002. *AIDS in the Twenty-First Century: Disease and Globalization*. New York: Palgrave MacMillan.
- BARTHES, R. 1996. *Introduction to the Structural Analysis of the Narrative*, Occasional Paper, Centre for Contemporary Cultural Studies, University of Birmingham.
- BARTON, E. 2000. More methodological matters: against negative argumentation. *College composition and communication* 51(2): 399-416.
- BAUTISTA, C.T. 2004. Seroprevalence of and risk factors for HIV-1 infection among South American men who have sex with men. *Sexually Transmitted Infections*, 80:498-504.
- BECHU, N. 1998. The impact of AIDS on the economy of families in Côte d'Ivoire: Changes in consumption among AIDS-affected households, in *Confronting AIDS: Evidence from the Developing World*. European Union, Brussels, Belgium.
- BENNELL, P. 2005. The impact of the AIDS epidemic on teachers in Sub-Saharan Africa. *Journal of Development Studies*, 41(3): 440-466.
- BELL, C., SHANTAYANAN, D. & HANS, G. 2003. *The long-run economic costs of AIDS: theory and an application to South Africa*. Washington, D.C.: World Bank.

- BERG, B.L. 2003. *Qualitative research methods for the social science* (5 th ed) Boston: Allyn & Bacon.
- BINAGWAHO, A. 2005. Epidemiological developments regarding HIV/AIDS in Rwanda: 2005. Briefing paper. CNLS, TRAC, UNAIDS. Kigali.
- BIRDTHISTLE, I. 2004. Understanding the needs of orphans and other children affected by HIV and AIDS in Africa: the State of the Science. Paper prepared for the support for analysis and research in Africa (SARA) Project, April 2004. Washington, D.C.: Academy for Educational Development.
- BLOWER, S. & FARMER, P. 2003. Predicting the public Health impact of antiretroviral s. preventing HIV in developing countries. *AIDS Science*, 3(11): 1-187.
- BOGARDI, J. 2004. Hazards, risks and vulnerabilities in a changing environment. The unexpected onslaught on human security. (*In Global Environmental Change*. Chichester: John Wiley).
- BOGARDI, J. & BIRKMANN, J. 2004. Vulnerability Assessment, the first step towards sustainable risk reduction. (*In Malzahn, D. & Plapp, T., eds. Disasters and Society – From Hazard Assessment to Risk Reduction*. Tokyo: UNU Press).
- BOYDEN, J. & DE BERRY, J. 2004. Children and youth on the front line: ethnography, armed conflict and displacement. New York: Berghahn.
- BOOTH, RE 2004. Predictors of Self-Reported HIV Infection Among Drug Injectors in Ukraine. *Journal of Acquired Immune Deficiency Syndromes*, 35(1):82-88.
- BOOYSEN, F. 2003. Poverty dynamics and HIV/AIDS-related morbidity and mortality in South Africa. Paper presented at the scientific meeting on empirical evidence for the demographic and socio-economic impact of AIDS, Durban, South Africa, 26-28 March.

- BOOYSEN, F. R. & BACHMANN, M. 2002. HIV/AIDS, Poverty and Growth: Evidence from a Household Impact Study conducted in the Free State province, South Africa. Paper presented at the Annual Conference of the Centre for Study of African Economies, 18-19 March, St Catherine's College, Oxford, UK.
- BRITISH MEDICAL ASSOCIATION 2005. Sexually transmitted infections (STI): An update. Fact sheet. January. Available at <http://www.bma.org.uk/ap.nsf/Content/STIupd05~UK>.
- BROOKS-GUNN, J. & MARKMAN, L.B. 2005. The contribution of parenting to ethnic and racial gaps in school readiness. *The Future of Children*, 15(1): 139–168.
- BROWN, L. 2003. Interventions to reduce HIV /AIDS stigma: what have we learned? *AIDS Education and Prevention*, 15(1) : 49–69.
- BUTLER, A. M. 2005. The negative and positive impacts of HIV/AIDS on democracy in South Africa. *Journal of Contemporary African Studies*, 23(1): 3-25.
- CAIAFFA, W.T. 2003. The Dynamics of the Human Immunodeficiency Virus Epidemics in the South of Brazil: increasing role of injection drug users. *Clinical Infectious Diseases*, 37(5): 76-81.
- CAMARA, B. 2003. The Caribbean HIV/AIDS epidemic epidemiological status / success stories: A summary. *CAREC Surveillance Report*, 23.
- CAMARA, B. & ZAIDI, I. (2005). The future of the HIV/AIDS epidemic in the Caribbean. *CAREC Surveillance Report Supplement 1* (June).
- CARIBBEAN EPIDEMIOLOGY CENTRE, PAHO, WHO (2003). *Success stories in the fight against HIV/AIDS in the Caribbean—An update*. Port of Spain, CAREC. December.

- CASE, A., PAXSON, C. & ABLEINDINGER, J. 2004. Orphans in Africa: parental death, poverty, and school enrolment. *Demography*, 41 (3): 483-508.
- Centre for AIDS Development, Research and Evaluation-Cadre (CADREC). 2002. Integrated Community-based Home Care (ICHC) in South Africa: A review of the model implemented by the Hospice Association of South Africa. The POLICY Project, Cape Town, South Africa.
- CHAKRABORTI, C. 2006. Ethics of care and HIV: a case for rural women in India. (*In Developing World Bioethics* 6, no. 2. p. 89-94).
- CHELUGET, B., MARUM, L. & STOVER, J. 2004. *Evidence of declining HIV prevalence and risk behaviour in Kenya*. Presentation to the UNAIDS Reference Group on Estimates, Modelling and Projections. 15-17 November. Harare.
- CHIMWAZA, A.F. & WATKINS, S.C. 2004. Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care*, 16(7): 795-807.
- CHISHOLM, L. 2004. The state of South Africa's schools. (*In Daniel, J., Southall, R. & Lutchman, J., eds. State of the nation: South Africa 2004-2005*. Cape Town: HSRC Press. 201-226).
- CHOI, KH 2003. Emerging HIV-1 epidemic in China in men who have sex with men. *Lancet*, 361:2125-26.
- CLINTON, B. 2003. Turning the tide on the AIDS pandemic. *New England Journal of medicine*, 348 (18): 18-120.
- COGNEAU, D. & GRIMM, M. 2002. AIDS and Income Distribution in Africa: A Micro-simulation Study for Cote d'Ivoire. DIAL, Paris, pp. 24-25.
- COLLINS, J. & RAU, B. 2000. AIDS in the Context of Development. Geneva: United Nations Research Institute for Social Development.

- COOMBE, C. 2000. HIV/AIDS and Educational Perspectives in Education. *Education*, 26(2): 1-175.
- COOMBE, C. 2003. HIV and AIDS in context: the needs of learners and educators. Paper prepared for consultation on HIV and AIDS and teacher education in East and Southern Africa, Johannesburg: University of Pretoria.
- COOPER, M. & LESSER, J. 2005. Clinical Social Work Practice: An Integrated Approach, 2nd ed., pp. 162. New York: Pearson Education, Inc.
- CORBETT, E. 2002. HIV/AIDS and the control of other infectious diseases in Africa. *Lancet*, 359(9324): 77-87.
- COWAN, F.M. 2005. Evidence of a decline in incidence of HIV infection among young people in rural Zimbabwe. Abstract MP-022. Paper presented to the 16th biennial meeting of the International Society for Sexually Transmitted Diseases Research. 10-13 July. Amsterdam.
- CRESWELL, J. W. 2003. Research design: qualitative, quantitative and mixed methods, approaches (2nd ed.). Thousand Oaks, CA: Sage.
- DATTILIO, F.M. 2001. Cognitive behaviour family therapy: contemporary myths and misconceptions. *Contemporary Family Therapy*, 23(1): 3-18.
- DEAN, N. & MOALUSI, R. 2002. Aids biggest killer of young women. [*In Mail & Guardian*, Nov. 22-28: p.3.]
- DE JONG, J. 2002. Public mental health, traumatic stress and human rights violations. New York: Free Press.
- DENNING, S. 2000. The Springboard: How Storytelling Ignites Action in Knowledge-Era Organizations. Boston, London, Butterworth Heinemann, October.
- DENZIN, N. & LINCOLN, M.Y. 2005. The Sage book of qualitative research (3rd ed.). Thousand Oaks, CA: Sage

- DES JARLAIS, D.C. 2002. HIV risk behaviour among participants of syringe exchange programmes in central/eastern Europe and Russia. *International Journal of Drug Policy*, 13:165-170.
- DESMOND, C & GOW, J 2001. "The cost effectiveness of six models of care for orphans and vulnerable children in South Africa". Report for UNICEF, Pretoria: Health Economics and AIDS research Division, University of Natal, and Durban.
- DESMOND C., MICHAEL, K. & GOW, J. 2000. The Hidden Battle: HIV/AIDS in the Family and Community. Health Economics & HIV/AIDS Research Division, University of Natal, Durban, South Africa.
- DE VOS, AS. 2001. Research at grass roots: a primer for the caring professions. Pretoria: Van Schaik.
- DIABETES COUNSELLING. 2006. Outsider Witness Register. [Online] <http://www.diabetescounselling.com.au/witness.html> [Date of access: 23/11/2006].
- DICKINSON, D. 2003. HIV/AIDS peer educators in the workplace, *South African* different approach to inclusion. *Principal*, 79 (4): 48, 50-51. Discussion at SSI 2002 with 2003 update included. Johannesburg: Rand Afrikaans University.
- DIXON, S., MCDONALD, S. & ROBERTS, J. 2002. The impact of HIV and AIDS on Africa's economic development. *British Medical journal*, 324: 232-234.
- DODDS. J.P. 2005. *HIV prevalence and sexual behaviour in community samples of men who have sex with men in Brighton, Manchester and London*. Abstract no. MP-100. Paper presented to the 16th biennial meeting of the International Society for Sexually Transmitted Diseases Research. 10-13 July. Amsterdam.

- DOUGAN, S. 2005. HIV infections acquired through heterosexual intercourse in the United Kingdom: findings from national surveillance. *British Medical Journal*, 330:1304-1305. 4 June.
- DUNCAN, J. & ARNTSON, L. 2003. Children in crisis: good practices in evaluating psychosocial programming. Washington, D.C.: Save the Children Federation, Inc.
- DURAIAPPAH, A. 2004. Exploring the links: human well-being, poverty, and eco-system services, *Online EcoHealth Network*, 27(1): 1-32.
- EKRA, A. 2004. Evidence for changes in sexual behaviour and HIV incidence in Cote d'Ivoire. Presentation to the UNAIDS Reference Group on Estimates, Modelling and Projections. 15-17 November. Harare.
- ELFORD, J. 2004. Trends in sexual behaviour among London homosexual men 1998-2003: implications for HIV prevention and sexual health promotion. *Sexually Transmitted Infections*, 80:451-454.
- EL-RAHMAN, A. 2004. Risky behaviours for HIV/AIDS infection among a sample of homosexuals in Cairo city, Egypt. XV International AIDS Conference. Abstract WePeC6146. Bangkok. 11-16 July.
- EPSON, D & WHITE, M. 1992. Experience, Contradiction, Narrative and Imagination: Selected papers of David Epston & Michael White 1989-1991 Adelaide, South Australia: Dulwich Centre Publications.
- EROSHINA, K. 2005. Cohort study on the effectiveness of Russian needle exchange programs. Handbook of the 16th Conference on the reduction of drug related harm. March. Belfast, Northern Ireland.
- EVIAN, C. 2003. Primary HIV/Aids care, 4th ed. Houghton: Jacana.
- FAD 2003. The Issue of Poverty among Female-Headed Households in Africa. [Online] <http://www.ifad.org/gender/learning/challenges/women/60.htm>

- FARES, E. 2004. Epidemiological surveillance of HIV/AIDS in Algeria, North Africa, based on the sentinel sero-surveillance survey. XV International AIDS Conference. Abstract C10572. Bangkok. 11-16 July.
- FASSIN, D. & SCHNEIDER, H. 2003. 'The politics of AIDS in South Africa: beyond the controversies', *British Medical Journal*, 326(2): 495-8.
- FILATOV, A. & SUHARSKY, D. 2002. Peculiarities of HIV infection among intravenous drug users in Mirninsk district, Yakut area. 4th European AIDS Conference, Vilnius, Lithuania.
- FLEISCHMAN, J. 2003. Fatal Vulnerabilities: Reducing the Acute Risk of HIV/AIDS among Women and Girls. Washington, DC: Center for Strategic and International Studies.
- FLOYD, S. 2003. The impact of HIV on household structure in rural Malawi. Paper presented at the conference on the 'Empirical evidence for the demographic and socio-economic impact of AIDS', Durban, South Africa.
- FREEMAN, J. & COMBS, G. 1996. Narrative Therapy: The social construction of preferred realities. New York: W.W. Norton & Co.
- FREEDMAN, J. & COMBS, G. 2002. Narrative therapy with couples...and a whole lot more! A collection of papers and essays and exercises. Adelaide: Dulwich Centre Publishers.
- FREEMAN, J., EPSTON, D. & LOBOVITS, D. 1997. Playful approaches to serious problems: Narrative therapy with children and their families. New York: Norton.
- FRIEDMAN, I. 2005. CHWs and community caregivers: towards a unified model of practice. (In Ijumba, P. & Barron P., eds. South African health review. Durban: Health Systems Trust. p. 176-189).
- GAILLARD, E.M. 2004. Evidence for changes in sexual behavior and HIV incidence in Haiti. Slide presentation. 15-17 November. UNAIDS/WHO/UNICEF. Harare.

- GARBUS, L. 2000. Zimbabwe Context of the Epidemic. HIV InSite. <http://hivinsite.ucsf.edu/InSite?page=cr-02-01&doc=2098.4176>
- GARCÍA, R. 2005. Reduction of mother-to-child transmission of HIV in Colombia: Two years of national experience, 2003-2005. Submitted for publication, July.
- GIBSON, D.R., FLYNN, N.M. & PERALES, D. 2001. Effectiveness of syringe exchange programs in reducing HIV risk behavior and HIV sero-conversion among injecting drug users. *AIDS*, 15:1329-1341.
- GIESE, S. 2003. Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS: research report and recommendations. Cape Town: Children's Institute of the University of Cape Town. 29.
- GIULIANI, M. 2005. Increased HIV incidents among men who have sex with men in Rome. *AIDS*, 19(13): 29-31.
- GLYNN, M. & RHODES, P. 2005. Estimated HIV prevalence in the United States at the end of 2003. National HIV Prevention Conference. June. Atlanta, USA.
- GO, V.F. 2004. High HIV prevalence and risk behaviors in men who have sex with men in Chennai, India. *Journal of Acquired Immune Deficiency Syndromes*, 35(3): 14-19.
- GOETZ, C. & DARRYL, C.W. 2005. Systemic Healing: an ecosystemic biopsychosocial integration applied to clinical practice in the care of sick children. *Clinical Child Psychology and Psychiatry*, 10(1): 53-63.
- GONZALEZ, J.S., PENEDO, F.J., ANTONI, M.H., DURÁN, R.E., FERNANDEZ, M.I., MCPHERSON-BAKER, S., IRONSON, G., KLIMAS, N.G., FLETCHER, M.A., & SCHNEIDERMAN, N. 2004. Social support, positive states of mind, and HIV treatment adherence in men and women living with HIV/AIDS. *Health Psychology*, 23 (4): 413-418.

- GREENER, R. 2000. Impacts of HIV/AIDS on Poverty and Income Inequality in Botswana. Botswana Institute for Development Policy Analysis, Gaborone, Botswana.
- GROENEWALD, S. 2005. Mortality and causes of death in South Africa, 1997-2003, Statistics South Africa. Identifying deaths from Aids in South Africa. *AIDS* 19(2): 2-315.
- GRUND, J.P 2005. Role of Injecting Drug Users in the Development of the Epidemic of HIV-Infection in Ukraine (Rus.). Ukrainian AIDS Centre. Kiev.
- GWYTHYER, L. & MARSTON, J. 2003. Dealing with the symptoms of AIDS. Home-based HIV/AIDS care, eds. Uys, L. & Cameron, S. Cape Town: Oxford University Press.
- HARGREAVES, J. R. & GLYNN, J. R. 2002. Educational attainment and HIV infection in developing countries . a systematic review, *Tropical Medicine & International Health*, 7(6): 489-498.
- HARGROVE, J.W. 2005. Declining HIV prevalence and incidence in women attending maternity clinics in greater Harare, Zimbabwe. (Submitted for publication).
- HAY, R.J. 2002. Infection, skin disease, and developing countries. *Skinmed*, 13(1): 1-87.
- HEPBURN, A. 2002. Increasing primary education access for children in AIDS-affected areas. *Perspectives in education*, 20(2): 2-44.
- HEYZER, NOELEEN. 2003. "Enlisting African Women to Fight AIDS." *The Washington Post*, HIV/AIDS and Education. Rome: FAO/UNDP. *HIV/AIDS in the world of work*, ILO/AIDS Working Paper No. 7. Geneva: ILO

- HIEN, N.T. 2004. *Risk factors for HIV seropositivity among young heroin injecting drug users in Quang Ninh province, Viet Nam*. Submitted for publication.
- HOLMES, C. 2003. Review of human immunodeficiency virus type 1-related opportunistic infections in sub-Saharan Africa. *Clinical Infectious Diseases*, 36(2): 52–62.
- HOSEGOOD, V., HERBST, K. & TIMAEUS, I. 2003. The impact of adult AIDS deaths on households and children's living arrangements in rural South Africa. Paper presented at the conference on the 'Empirical evidence for the demographic and socio-economic impact of AIDS' Durban, South Africa.
- HUMAN RIGHTS WATCH 2002. Positively abandoned: Stigma and discrimination against HIV-positive mothers and their children in Russia. July. Human Rights Watch. New York. Available at <http://hrw.org/reports/2005/russia0605/>
- HUMAN RIGHTS WATCH. 2005. Clear the filth: Mass evictions and demolitions in Zimbabwe. Briefing paper. September. Human Rights Watch. New York. Available at <http://www.hrw.org/backgrounder/africa/zimbabwe0905/>
- HUNTER, M. 2002. The materiality of everyday sex thinking beyond "prostitution". *African Studies*, 61(1): 99-120.
- IRIN. 2003. BOTSWANA: More than money needed for successful AIDS programme. Press release 4 Aug 2003. <http://www.irinnews.org>
- INTERNATIONAL HIV/AIDS ALLIANCE 2003. Positive Prevention: Prevention strategies for people living with HIV/AIDS. Brighton.
- ISAKSEN, J., SONGSTAD, N. G. & SPISSØY, A. 2002. Socio-economic effects of HIV/AIDS in African countries. Bergen: Chr Michelsen Institute.

- JORDAN-HARDER, B. 2004. Thirteen years HIV-1 sentinel surveillance and indicators for behavioural change suggest impact of programme activities in south-west Tanzania. *AIDS*, 18(2):287-294.
- KALIYATI, J. 2003. HIV/AIDS and child labour in Zimbabwe: A rapid assessment, Paper No. 2, ILO/IPEC and Institute of Development Studies, University of Zimbabwe, Geneva and Harare.
- KAYIRANGWA, E. & HANSON, J. 2004. *Recent trends in HIV prevalence in Rwanda*. Presentation to the UNAIDS Reference Group on Estimates, Modelling and Projections. 15-17 November. Harare.
- KEETON, C. 2002. Spectre of Aids haunts starving region. *Sunday Times*, p.24:35.
- KELLY, K. 2002. Pathways to action, HIV/AIDS prevention, children and young people in South Africa, a literature review, Pretoria: Van Schaik.
- KELLY, M. 2002. Preventing HIV transmission through education. *Perspectives in education*, 20(2): 1-12.
- KENYA. Ministry of Health. 2005. AIDS in Kenya, 7th edition. National AIDS and STI Control Programme (NAS COP), Ministry of Health. Nairobi.
- KIDANE, A., BANTEYENA, H. & NYBLADE, L. 2003. Stigma and related discrimination in Ethiopia: causes, consequences and coping mechanism. Addis Ababa: Miz-Hasab Research Center.
- KIDANU A, NYBLADE, L. & ROHINI, P. 2003. Knowledge, attitudes, and behavior related to HIV and AIDS stigma in Ethiopia. Abstracts of the 13th International Conference on AIDS and STIs in Africa 2003, Nairobi: Abstract Wed.
- KILBOURNE, A.M, HERNDON, B., ANDERSEN, R.M., WENZEL, S.L. & GELBERG, L. 2002. Psychiatric symptoms, health services and HIV risk factors among homeless women. *Journal of Health Care for the Poor and Underserved*, 13(1): 9-65.

- KINGHORN, A. & KELLY, M.J. 2005. 'The impact of the AIDS epidemic' articles by Paul Bennell: some comments. *The Journal of Development Studies*, 41(3): 489-499.
- KHALSA, J.H., FRANCIS, H. & MAZIN, R. 2003. Bloodborne and Sexually Transmitted Infections in Drug Abusers in the United States, Latin America, the Caribbean and Spain. *Clinical Infectious Diseases*, 37(Suppl 5):S331-7.
- KUMAR, N., LARKIN, J. & MITCHELL, C. 2001. "Gender, Youth and HIV Risk." *Canadian Woman Studies/les cahiers de la femme*, 21(2): 35-40.
- KUMAR, A. & SINGH, B. 2004. Impact of the AIDS Prevention Program on trends in prevalence and incidence of HIV infection among pregnant women in Barbados. XV International AIDS Conference. Abstract ThPeC2782. Bangkok. 11-16 July.
- KURSCHNER, E. 2002. The Poverty- HIV/AIDS -Interface Lessons and Needs in the Context of the Poverty Reduction Strategy Paper (PRSP)—Process with a focus on the African continent. GTZ (German Technical Cooperation), Eschborn, Germany.
- LAMBERT, M-L. 2005. Street youths are the only high-risk group for HIV in a low-prevalence South American country. *Sexually Transmitted Diseases*, 32(4):240-242.
- LAMPTEY, P., WIGLEY, M. & CARR, D. 2002. Facing the HIV/AIDS Pandemic. *Population Bulletin*, 57(2): 1-133.
- LEAHY, R. L. 2002. Cognitive therapy: current problems and future directions. [In R. L. Leahy & E. T. Dowd (Eds.), *Clinical advances in cognitive psychotherapy: Theory and application* (p 418-434). New York: Springer.]
- LEEDY, P.D. & ORMROD, J.E. 2005. Practical research, planning and design. New Jersey: Pearson Prentice Hall.

- LETTENEY, S. 2006. When it happens to your family. One social worker's response. *Journal of HIV/AIDS & Social Services*, 5(1): 67-84.
- LOPEZ, M.E., KREIDER, H. & CASPE, M. 2004. Co-constructing family involvement. *The evaluation exchange*, 10(4). Cambridge: Harvard Family Research Project. Uninsky, P. B. (n.d.).
- LOWNDES, C. M. 2002. Female injection drug users who practice sex work in Togliatti City, Russian Federation: *HIV prevalence and risk behaviour*. XIV International AIDS Conference. Abstract MoPeC3501. Barcelona.
- LUNDBERG, M., OVER, M. & MUJINJA, P. 2000. Sources of Financial Assistance For Households Suffering an Adult Death in Kagera, Tanzania. Paper produced for the World Bank, Washington DC, USA.
- LYON, M.E. & WOODWARD, K. 2003. Non-stigmatizing ways to engage HIV-positive African-American teens in mental health and support services: a commentary. *J Natl Med Assoc.*, 95(3): 196-200.
- MAGIS-RODRÍGUEZ, C. 2004. Migration and AIDS in Mexico: An overview based on recent evidence. *Journal of Acquired Immune Deficiency Syndromes*, 37(Supplement 4):S215-S226.
- MAHOMVA, A. 2004. Trends in HIV prevalence and incidence and sexual behaviour. Presentation to the UNAIDS Reference Group on Estimates, Modelling and Projections. 15-17 November. Harare.
- MALEBRANCHE D.J., PETERSON J.L. 2004. Race and sexual identity: Perceptions about medical culture and healthcare among Black men who have sex with men. *J Natl Med Assoc*, 96(1): 97-107.
- MALLMANN, S.R.S. 2003. Building resilience in children affected by HIV/AIDS, revised ed. Cape Town: Maskew Miller Longman.
- MAMAN, S. 2000. The intersections of HIV and violence: directions for future research and interventions. *Social Science and Medicine*, 50:459-78.

- MARSHALL, G.B. & ROSSMAN, C. 1999. *Designing qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.
- MATEO, R.J. 2003. HIV/AIDS in the Philippines. *AIDS Education and Prevention*, 16(Supplement A):43-52.
- MAXWELL, J.A. 2004. *Qualitative research design: an interactive approach* (2nd ed). Thousand Oaks: Sage.
- MBULAITEYE, S.M. 2002. Declining HIV-1 incidence and associated prevalence over 10 years in a rural population in south-west Uganda: a cohort study. *The Lancet*, 360. July 6.
- MCDONAGH, A. 2001. *Microfinance Strategies for HIV/AIDS Mitigation and Prevention In Sub-Saharan Africa*. Social Finance Unit working paper no. 25, , Geneva, Switzerland: International Labour Organization.
- McMAHON, E. 2004. Increased sexual risk behaviour and high HIV sero-incidence among drug-using low-income women with primary heterosexual partners. XV International AIDS Conference. Abstract TuOrD1220. Bangkok. 11-16 July
- MEEHAN, A. 2004. Prevalence and risk factors for HIV in Zimbabwean and South African women. XV International AIDS Conference. Abstract MoPeC3468 Bangkok. 11-16 July.
- MEJÍA, A. 2002. HIV-1, syphilis and hepatitis B virus prevalence and risk factors among commercial sex workers, Bogota, Colombia, 2002. XV International AIDS Conference. Abstract WePeC6251. Bangkok. 11-16 July.
- MENDEL, G. 2002. *A broken landscape, HIV/AIDS in Africa*. Johannesburg: Van Schaik.
- MENON, R. 1998. The economic impact of adult mortality on households in Rakai district, Uganda, in *Confronting AIDS: Evidence from the Developing World*. European Union, Brussels, Belgium, pp. 325-339.

- MERRIAM, S. 1998. Qualitative research and case study applications in education: a qualitative approach. San Francisco: Jossey-Bass.
- MEYER, S. 2003. HIV/AIDS and Education in Africa, A Sencer Backgrounder for Discussion at SSI 2002 with 2003 update included. Johannesburg: Rand Afrikaans University.
- MITRANI, V.B., PRADO, G., FEASTER, D.J., ROBINSON-BATISTA, C. & SZAPOCZNIK, J. 2003. Relational factors and family treatment engagement among low-income, HIV+ African American Mothers. *Family Process*, 42(4): 31-45.
- MOHLALA, T. 2002. A helping hand for AIDS orphans. *Mail & Guardian*: 29.
- MONITORING THE AIDS PANDEMIC NETWORK (MAP) 2005. *Drug injection and HIV/AIDS in Asia—MAP Report 2005*. July. Geneva
- MONTANO, J. 2005. Prevalence, genotypes and risk factors for HIV transmission in South America JAIDS 40:1.
- MONTGOMERY, J.P. 2003. The extent of bisexual behaviour in HIV-infected men and implications for transmission to their female sex partners. *AIDS Care*, 15(2): 29-37.
- MONZE, M. 2004. Evidence for declines in HIV incidence: Zambia. Presentation to the UNAIDS Reference Group on Estimates, Modelling and Projections. 15-17 November. Harare.
- MORGAN, A. 2000. What is narrative therapy? [Online] <http://dulwichcentre.com.au/alicearticle.html> [Date of access: 25/11/2006]
- MPIIMA, E.T. 2003. Increased demand for VCT services driven by introduction of HAART in Masaka District, Uganda. Poster presentation to the Second IAS Conference on HIV Pathogenesis and Treatment, Paris, 13–17 July, cited in UNAIDS (2004a).

- MTURI, F. & NZIMANDE, E. 2003. HIV/AIDS and child labour in South Africa., Geneva Switzerland: International Labour Organization/IPEC.
- MUGURUNGI, O. 2005. HIV in Zimbabwe. In: Glynn JR, Carael M (eds.) HIV, Resurgent Infections and Population Change in Africa. pringer.
- MUNDANDI, C. 2005. Sexual behaviour change, spatial mobility and stabilisation of the HIV epidemic in eastern Zimbabwe. Poster Exhibit 3495. 12 July. XV International AIDS Conference, Bangkok.
- MURPHY, G. 2004. HIV incidence appears constant in men who have sex with men despite widespread use of effective antiretroviral therapy. *AIDS*, 18(2): 65-72.
- MUTANGADURA, G. B. 2000. Household welfare impacts of mortality of adult females in Zimbabwe: Implications for policy and program Development. Paper presented at the AIDS and Economics Symposium, Durban, South Africa.
- MWALUKO, G. 2003. Trends in HIV and sexual behaviour in a longitudinal study in a rural population in Tanzania 1994–2000. *AIDS*, 17(18): 45-51.
- MYER, L. 2005. Bacterial vaginosis and susceptibility to HIV infection in South African women: a nested case-control study. *Journal of Infectious Diseases*, 192.
- NAMPOSYA-SERPELL, N. 2000. Social and Economic Risk Factors for HIV/AIDS - Affected Families in Zambia. Paper presented at the AIDS and Economics Symposium, IAEN, 7-8 July, Durban, South Africa.
- NANDAKUMAR, A.K., SCHNEIDER, P. & BUTERA, D. 2000. Use of and Expenditures on Outpatient Health Care by a Group of HIV Positive Individuals in Rwanda. Bethesda, Maryland: Abt Associates Inc.
- NATIONAL AIDS COORDINATING AGENCY, 2003. Botswana 2003 second generation HIV/AIDS surveillance: *Technical report*. December. Gaborone.

- NATIONAL CENTRE IN HIV EPIDEMIOLOGY AND CLINICAL RESEARCH. 2003. HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia annual surveillance report. Sydney: National Centre in HIV Epidemiology and Clinical Research.
- NEMOTO, T. 2004. HIV/AIDS surveillance and prevention studies in Japan: Summary and recommendations. *AIDS Education and Prevention*, 16(2): 27-42.
- NIYONGABO, C. 2001. Impact of HIV/AIDS on Poor Urban Livelihoods. Presentation for Save the Children UK, Gitega, Burundi.
- NTULI, A. ed. 2004. South African Health Review. Durban: Health Systems Trust. 191-211.
- ODIPO, G. 2000. Adolescent AIDS epidemic in Kenya: Lessons from child abuse proportion. Paper presented at East Cape Training Centre, Port Elizabeth, South Africa.
- OLIVER-SMITH, A. 2004. Theorizing Vulnerability in a Globalized World: A Political Ecological Perspective. [In Bankoff, G., Ferks, G. & Hilhorst, D., eds. Mapping Vulnerability. Disasters, Development & People. London: Earthscan 10-24].
- ONO-KIHARA, M. 2001. Sexual practices and the risk for HIV/STDs infection of youth in Japan. *Journal of the Japan Medical Association*, 126(9):157-160.
- OSIMANI, M.L. 2003. The Challenge of Implementation of Preventive Programs in a Developing Country: Experiences, Situations and Perspectives in Uruguay. *Clinical Infectious Diseases*, 37(5): 22-26.
- PATTON, M. Q. 2001. Qualitative research and evaluation methods (3rd ed.). Thousand Oaks, CA: Sage.
- PAHO. 2005. Care fact sheets. Pan American Health Organization. Washington DC, USA.

- PALMER, C.J. 2002. HIV Prevalence in a Gold Mining Camp in the Amazon Region, Guyana. *Emerging Infectious Diseases*, (8)3. March. Available at <http://www.cdc.gov/ncidod/eid/vol8no3/01-0261.htm>.
- PANDO De Los, A. 2003. HIV immunodeficiency virus type 1 seroprevalence in men who have sex with men from Buenos Aires, Argentina: risk factors for infection. *International Journal of Epidemiology*, 32:735-740.
- PARKER, W. & MUNDAWARARA, M. 2002. Living openly, HIV positive South Africans tell their stories, Department of Health: Beyond Awareness Campaign. Pretoria: HIV/AIDS and STD Directorate.
- PAYNE, M. 2000. Narrative Therapy, An Introduction for Counsellors. London: Sage Publications.
- PHIMPHACHANH, C. & SAYABOUNTHAVONG, K. 2004. The HIV/AIDS/STI situation in Lao People's Democratic Republic. *AIDS Education and Prevention*, 16(Supplement A): 91-99.
- PHIRI, S. N., FOSTER, G. & NZIMA, M. 2001. Expanding and Strengthening Community Action: A Study of Ways to Scale Up Community Mobilization Interventions to Mitigate the Effect of HIV/AIDS on Children and Families. Displaced Children and Orphans Fund of the United States Agency for International Development, Washington DC, USA.
- PICK, S. 2003. HIV/AIDS our greatest challenge yet! 2003. Cape Town: Paarl Print.
- POKROVSKIY, V. 2005. HIV/AIDS in Russia. Presentation to HIV/AIDS in the Russian Federation and Ukraine workshop, Geneva. January.
- POLICY PROJECT. 1998. HIV/AIDS Policy Compendium. Washington DC: The Futures Group International.
- POPULATION COUNCIL HORIZONS PROGRAM 2001. HIV voluntary counselling and testing among youth ages 14 to 21. Washington DC.

- PRABHU, R. 2004. The bisexual bridge revisited: sexual risk behaviour among men who have sex with men and women, San Francisco, 1998-2003. *AIDS*, 18(11):1604-1606.
- PRETORIUS, C. 2002. AIDS epidemic killing Africa's teachers, *Sunday Times*: 6.
- RAU, B. 2003. HIV/AIDS and Child Labour: A State-of-the-art Review. IPEC paper no. 6, Geneva: International Labour Organization.
- REINECKE, M., DATTILIO, FM. & FREEMAN, A. 2002. Casebook of cognitive-behaviour therapy with children and adolescents. 2nd ed. New York: Guilford Press.
- REPRODUCTIVE HEALTH RESEARCH UNIT. 2004. HIV and Sexual Behaviour Among Young South Africans: A National Survey of 15-24 Year Olds. April. Reproductive Health Research Unit, Johannesburg.
- RHODES, T. 2004. Injecting equipment sharing among injecting drug users in Togliatti City, Russian Federation. *Journal of Acquired Deficiency Syndromes*, 35(3):293-300.
- RHODES, T. & SIMIC, M. 2005. Transition and the HIV risk environment. *British Medical Journal*, 331:220-223.
- RIONO, P. & JAZANT, S. 2004. The current situation of the HIV/AIDS epidemic in Indonesia. *AIDS Education and Prevention*, 16(SupplementA):78-90.
- ROSS, E. & DEVERELL, A. 2004. Psychosocial approaches to health illness and disability. Pretoria: Van Schaik.
- RUGALEMA, G. & AKOULOZE, R. 2003. Identifying Promising Approaches in HIV/AIDS and Education. Rome: FAO/UNDP.
- SALOMON, J.A., HOGAN, D.R. & STOVER, J. 2005. Integrating HIV prevention and treatment: From slogans to impact. *PLoS Med* 2: e16.

- SALOMON, J.A., HOGAN, D.R., STOVER, J., STANECKI, K.A. & WALKER, N. 2005 Integrating HIV prevention and treatment: From slogans to impact. *PLoS Med* 2: e16.
- SAVE THE CHILDREN, 2000. Children living with HIV/AIDS in South Africa – A Rapid Appraisal. Npl: Johannesburg, South Africa.
- SCHIFF, M. & MCKAY, M. 2003. The role of personal contact with HIV-infected people in explaining urban, African American preadolescents' attitudes toward peers with HIV/AIDS. *Am J Orthopsychiatry* 73(1): 101-8.
- SCHUBERT, B. 2003. Social Welfare Interventions for AIDS Affected Households in Zambia. GTZ, Lusaka, Zambia.
- SEGURA, M. 2005. Cohort of Men who have Sex with Men: recruitment, retention and seroincidence of HIV and other sexually-transmitted infections. Poster presentation to the IAS Pathogenesis conference 2005. Rio de Janeiro, Julio 2005.
- SHAH, S.A., ALTAF, A., MUJEEB, S.A. & MEMON, A. 2004. An outbreak of HIV infection among injection drug users in a small town in Pakistan: potential for national implications. *International Journal of STD & AIDS*, 15(3):209-210.
- SHAKARISHVILI, A. 2005. Sex work, drug use, HIV infection and spread of sexually transmitted infections in Moscow. *The lancet*, 366(2): 57-60.
- SHANK, G. 2002. Qualitative research: a personal skills approach. Upper Saddle River, N.J.: Prentice Hall.
- SHISANA, O., REHLE, T., SIMBAYI, L.C., PARKER, W., ZUMA, K., BHANA, A., CONNOLLY, C., JOOSTE, S. & PILLAY, V. 2005. South African National HIV prevalence, HIV incidence, Behaviour and Communication Survey, 2005. Cape Town: HSRC Press.

- SILOMBA, W. 2002. HIV/AIDS and Development—the Chikankata Experience, in *One Step Further—Responses to HIV/AIDS*. SIDA Studies no. 7, Swedish International Development Cooperation Agency, Stockholm, Sweden.
- SOLOMON, S. 2004. A review of the HIV epidemic in India. *AIDS Education and Prevention*, 16(2):155-169.
- SONNENBERG, P. 2004. HIV and pulmonary tuberculosis: the impact goes beyond those infected with HIV. *AIDS*, 18(4): 657-662.
- SOUTH AFRICA. Department of Education 2001. *The HIV/AIDS Emergency: Department of Education Guidelines for Educators*. Pretoria: Government Printer.
- SOUTH AFRICA. Department of Education. 2003. *HIV/ AIDS in your school: what parents need to know*. Pretoria: Department of Education.
- SOUTH AFRICA. Department of Education. 1996. *National policy on HIV/AIDS, Act 27 of 1996*. Pretoria: Government Printers.
- SOUTH AFRICA. Department of health. 2001. *National HIV and Syphilis sero-prevalence survey of women attending public antenatal clinics in South Africa 2000*. Pretoria: Government Printers.
- SOUTH AFRICA. Department of Health. 2005. *National HIV and syphilis antenatal sero-prevalence survey in South Africa 2004*. Pretoria: Government Printers.
- STATISTICS SOUTH AFRICA. 2005. *Mortality and causes of death in South Africa, 1997-2003*. Pretoria: Statistics SA.
- STEINBERG, M. 2002. *Hitting Home: How Households Cope With the Impact of the HIV/AIDS Epidemic: A Survey of Households Affected by HIV/AIDS in South Africa*. Washington DC: Henry J. Kaiser Family Foundation and the Health Systems Trust.

- St JOHN, M.A. 2003. Efficacy of Nevirapine Administration on Mother-to-Child Transmission of HIV using a modified HIVNET 012 regimen. *West Indian Medical Journal*, 51 (3):1-87.
- STOLTE, I.G. 2002. A summary report from Amsterdam: increase in sexually transmitted diseases and risky sexual behaviour among homosexual men in relation to the introduction of new anti-HIV drugs. *Euro Surveill* 7(2): 19–22
- SULLIVAN, E.A. 2004. HIV, Hepatitis B and other sexually transmitted infections and associated risk behaviours in Pacific-island seafarers, Kiribati. XV International AIDS Conference. Abstract ThP2C735. Bangkok. 11-16 July.
- TAWFIK, L. & KINOTI, S.N. 2002. "The Impact of HIV/AIDS on the Health Sector in Sub-Saharan Africa: The Issue of Human Resources." Support for Analysis and Research in Africa (SARA) Project. Illinois: F. E. Peacock.
- TEMBON, A., DRAKE, L.J., SHIRLAW, L., CONNOLLY, M., LEE, S-H., PATRIKIOS, A.E., KALEEBA, N., MANNATHOKO, C., GILLESPIE, A. & BUNDY, D.A.P. 2003. HIV/AIDS and Education: Ensuring Education Access for AIDS Orphans and Vulnerable Children. Geneva: World Bank Publications.
- THERON, L.C. 2005. An exploration of educator perception of educators/ and learners' HIV status and the impact thereof on educator and school wellness. *South African Journal of Education*, 25(1): 56-60.
- THOMAS, N. 2006. Giving positive HIV test results to clients: a comparative analysis of six sites. *Journal of HIV/AIDS & Social Services*, 5(1): 57-66.
- THWE, M. 2004. HIV/AIDS education and prevention in Myanmar. *AIDS Education and Prevention*, 16(3): 170-177.
- TOOLE, M. 2005. Study of young men's sexual behaviour: Vientiane, Lao People's Democratic Republic, August-November. Burnet Institute.

- TOPOUZIS, D. 1994. Uganda - The socio-economic impact of HIV/AIDS on rural families with an emphasis on youth. Rome: Food and Agriculture Organization of the United Nations
- TUMUSHABE, J. 2003. Situational analysis of AIDS-induced child labour in Uganda and experience of community empowerment to manage the crisis. Paper presented at the ILO/IPEC Technical Workshop on HIV/AIDS and Child Labour, Lusaka, Zambia.
- UGANDA. Ministry of Health. 2005. Uganda HIV/AIDS Sero-behavioural Survey 2004-05: Preliminary Report. Ministry of Health. Kampala.
- UNAIDS. 1999. HIV/AIDS Related Opportunistic Diseases. Technical Update. Geneva.
- UNAIDS. 2004. Report on the global AIDS epidemic. Geneva.
- UNAIDS. 2005. Intensifying HIV Prevention Policy Position Paper. Geneva.
- UNAIDS, UNFPA & WHO. 2004. Position Statement on condoms and HIV prevention, Geneva.
- UNAIDS/WHO. 2004. AIDS epidemic update. Geneva.
- UNAIDS/WHO. 2005. Progress on global access to HIV antiretroviral therapy: An update on '3 by 5'. UNAIDS/WHO. Geneva.
- UNICEF. 2004. Girls, HIV/AIDS and Education. December. UNICEF. New York. Available at http://www.unicef.org/publications/index_25047.html
- UNDP. 2001. Human Development Report 2001, Burkina Faso. Ouagadougou, Burkina Faso: UNDP.
- USAID. 2004. Children on the Brink 2004: a joint report of new orphan estimates and a framework for action. The fourth edition of a report by The Joint United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Children's Fund (UNICEF), and the United States Agency for

- International Development (USAID). Using C2V3 Region of the Env Gene. Abstracts of the 39th Annual Medical Conference 2003, Addis Ababa: Abstract AB55. 105-121.
- USAID. 2002. "Tips for Developing Life Skills Curricula for HIV Prevention Among African Youth: A Synthesis of Emerging Lessons." Technical Paper No. 115. Washington, DC: APA books.
- US CENTERS FOR DISEASE CONTROL AND PREVENTION. 2004. HIV/AIDS Among African Americans. Fact Sheet. US centres for Disease Control and Prevention. Atlanta, U.S.A. Available at <http://www.cdc.gov/hiv/pubs/facts/afam.htm>
- VALLEROY, L.A. 2004. The bridge for HIV transmission to women from 15- to 29-year-old men who have sex with men in 7 US cities. XV International AIDS Conference. Abstract ThOrC1367. Bangkok. 11-16 July
- VAN AARD, C. 2002. The demographic and economic impact of HIV/AIDS in South Africa. Inaugural speech delivered at UNISA.
- VAN DYK, A. 2005. HIV/AIDS care and counselling. A multidisciplinary approach. Cape Town: Maskew Miller Longman.
- VEREVOCHKIN, S.V. 2005. High prevalence of HIV infection among IDUs: No significant changes. *Russkii Zhurnal. SPID, Rak I obshchestvennoe zdorov'ye*, 9 (2). Presented at the 14th International Conference on AIDS, Cancer and Public Health. 23-27 May. St. Petersburg.
- VSO-RAISA. 2003. Men, HIV & AIDS: regional conference 2003 report back. Voluntary Service Overseas, Pretoria, South Africa.
- WALKER, J. 2004. Cost and cost-effectiveness of HIV-AIDS prevention strategies in developing countries: Is there an evidence base? *Health Policy and Planning*, 18(1): 4-17.
- WALLER, K. 1998. The Impact of HIV/AIDS on Farming Households in the Monze District of Zambia. Research Paper, University of Bath, UK.

- WARD, H., WALKER, N. & GHYS, P.D. 2004. Methods and tools for HIV/AIDS estimates and projections. *Sexually Transmitted Infections*, 80(Supplement 1). August.
- WATSON, D. L. & THARP, R. G. 2002. Self-directed behavior: Self-modification for personal adjustment. Pacific Grove, CA: Brooks/Cole.
- WAWER, M. 2005. *Declines in HIV prevalence in Uganda: Not as simple as ABC*. Abstract 27 LB, 12th Conference on Retroviruses and Opportunistic Infections, February 22-25, 2005. Boston U.S.A.
- WHITE, C.J. 2005. *Research: a practical guide*. Pretoria: Ithuthuko Investments.
- WHITE, M. & EPSTON, D. 1996. *Narrative Means to Therapeutic Ends*. New York: W.W. Norton & Co.
- WHO. 2003. *Antiretroviral therapy in primary health care: experience of the Khayelitsha programme in South Africa: case study*. Geneva.
- WHO. 2005. *Multi-country study on women's health and domestic violence against women*. Geneva.
- WHO/EMRO. 2005. *Progress Report on HIV/AIDS and '3 by 5'*. July. WHO, Cairo.
- WILKINS, C. M. 2003. *Re-stabilising family structures affected by HIV/AIDS: Is there hope? Zimbabwe Case Study*. School for International Training, Brattleboro, Vermont, USA.
- WINDSLEY, J & MONK, G. 2000. *Narrative Mediation: A New Approach to Conflict Resolution*. San Francisco: Jossey-Bass.
- WOOD, E, HOGG, R.S., YIP, B., HARRIGAN, P.R., O'SHAUGHNESSY, M.V. & MONTANER, J.S. 2003. Is there a baseline CD4 cell count that precludes a survival response to modern antiretroviral therapy? *AIDS*, 17(1):711-20.

- WORLD BANK. 1997. *Confronting AIDS: Public Priorities in a Global Epidemic*. Oxford University Press, New York, USA.
- WORLD BANK. 2002. "Ecuador Gender Review: Issues and Recommendations." A World Bank Country Study. Washington, DC: The International Bank for Reconstruction and Development/World Bank.
- WORLD HEALTH ORGANIZATION. 2002. *World Report On Violence and Health*. Geneva, Switzerland: WHO.
- WORLD HEALTH ORGANIZATION. 2003. *HIV-infected women and their families: psychosocial support and related issues. A literature review*. Geneva: Department of Reproductive Health and Research, World Health Organization.
- WORLD HEALTH ORGANIZATION. 2004. *The World Health Organization's Information Series on School Health, Document 8. Family Life, Reproductive Health, and Population Education: Key Elements of a Health-Promoting School*. Geneva: WHO, UNESCO, UNICEF, EDC, World Bank, PCD, EI
- WORTHINGTON, C. & MYERS, T. 2003. Factors underlying anxiety in HIV testing: risk perceptions, stigma, and the patient-provider power dynamic. *Qual Health Res*, 13(5): 636-55.
- YANG, H. 2005. Heterosexual transmission of HIV in China: A systematic review of behavioural studies in the past two decades. *Sexually Transmitted Diseases*, 32(5):270-280. May.
- ZAMANI, S. 2005. Prevalence of and factors associated with HIV-1 infection among drug users visiting treatment centers in Tehran, Iran. *AIDS*, 19:709-716.
- ZHANG, K.L. 2004. Epidemiology of HIV and sexually transmitted infections in China. *Sexual Health*, 16:39-46.

APPENDIX 1

INTERVIEW WITH SANDRA

How old were you when your mother first told you that you are HIV- positive?

What led your mother to disclose your positive status to you?

How did that learner know that you are HIV- positive?

Did you report the matter to your educator?

How was your educator after the meeting?

What were your thoughts/feelings when your mother first told you that you are HIV- positive?

Does your brother and sisters know about your positive status?

How are other kids at school?

Where is your father?

Are you taught about HIV at school?

Does your grade four educator know about your status?

Why did you think, it would help to disclose your HIV-positive status?

Do you get information on what was done in class during your absence?

Has your status affected your performance in any way?

What are your dreams for the future?

Do you take any medicine for HIV?

What is your CD4 count?

Do you attend any support group?

How do people in your community react to the fact that you are HIV-positive?

How did that make you feel?

What did you do with the snippet?

What do you do during your spare time?

Do you attend church?

Do people in your church know that you are HIV-positive?

What keeps you healthy?

Do you ever feel lonely?

INTERVIEW WITH SANDRA'S MOTHER

When did you find out that you are HIV positive?

How did it happen?

What was your reaction to the news?

Did you tell your husband about this? If yes, what was his reaction?

What happened after your husband's confession?

Did you continue with counselling?

Did your daughter get anything to relieve her as the doctors now knew what was wrong with her?

What did you think when your daughter was about to be two years old?

How were you after your husband's death?

What did your family and community members do?

Are you still drinking?

How did the support groups help you?

What was your family's reaction after they had been told about your HIV-positive status?

Has there been any change; in your relationship with your family after the disclosure?

How does she support you?

Does she still attend support groups?

How have your other children reacted to all this?

Besides being what you get from your son, do you get any other form of financial support?

Can you say things are fine?

What have you decided to do to solve the problem?

As a mother, what kind of support do you render to your daughter?

What are your wishes for your child?

How are other siblings supporting her?

Do you think you can still get married again?

Would you start your own support group?

Is the support grant you receive, enough for your needs?

Why are you not working?

Do you use any other type of medication besides the one you get from the clinic?

Has the medication been effective?

How often do you have to take the medication?

How are the members of the community you are living in?

How are your in-laws?

What do they say about your children?

INTERVIEW WITH SANDRA'S BROTHER

How did you react when you were told that your younger sister is HIV-positive?

How did you react when you were told that your mother is HIV- positive?

Do you attend support groups?

Do you think these support groups help in any way?

How do you support your sister?

Do you ever talk to your younger sister about HIV/AIDS?

What are your wishes for your sister?

What would you say to other brothers in your position?

How does your mother treat her HIV-positive child?

INTERVIEW WITH SANDRA'S GRANDMOTHER

How did you find out that your daughter was HIV-positive?

What do you think, pushed her to disclose her status?

How did you respond to the news?

Why do you think it is your son-in-law who infected her?

How was your ex-husband after he had been told about this?

Is he still angry?

Does your daughter and your granddaughter show any signs of being HIV-positive?

Do they get sick?

What support do you give them?

Do they ever go to church?

When you are busy helping them, do you ever think of being infected?

Does your daughter allow your grandchild to go out and play or go to parties with the other children?

Do you ever talk about HIV/AIDS when your granddaughter is around?

Since grandmothers are known to have knowledge of traditional herbs and how they work; do you have any traditional mixtures you advise your children to have?

What do you feel when you look at your granddaughter?

INTERVIEW WITH SANDRA'S MOTHER'S BOYFRIEND

How did you meet Sandra's mother?

Did you know that she is HIV-positive?

How did you find out that she is HIV-positive?

What attracted you to her?

What challenges do you face as a couple?

What was your reaction when you first heard that she is HIV- positive?

Do you think you have a future together?

How did you know about your status?

What do you think about HIV-positive children?

What was the most painful thing you thought of when your positive status was revealed to you?

Where is your wife?

What support do you get from work?

How is your relationship with your co-workers?

What keeps you healthy?

How do you respond when people talk about HIV/AIDS?

Do you ever watch programmes about HIV/AIDS on TV?

What types of medication do you take?

Do you think having HIV/AIDS is the same as having sugar diabetes or high blood pressure?

What do you say to other people who are HIV-positive who have not yet accepted their positive status?

INTERVIEW WITH SANDRA'S EDUCATOR

How did you find out about the learner's HIV-positive status?

How does your learning area help Sandra?

Does your school have an HIV/AIDS policy?

How do these policies help HIV-infected learners?

How do you regulate the rate of absenteeism of HIV-positive learners?

Do you have a first-aid programme known by all the learners?

How is Sandra's performance?

What is Sandra's level of interaction with other learners?

Do you have a catch-up programme for learners who are frequently absent because of HIV/AIDS?

INTERVIEW WITH SANDRA'S SISTER

How do you feel about your sister's being HIV-positive?

How do you treat your sister?

In what way have you prepared yourself for the death of your sister?

When Sandra is playing with other children, how do you make sure that they do not hurt her?

What do you fear most when you look at your sister?

When your sister does something wrong, do you reprimand her?

If your sister can stay alive until you start working, what would you do for her?

In what way have you prepared yourself for the death of your sister?

When Sandra is playing with other children, how do you make sure that they do not hurt her?

What do you fear most when you look at your sister?

When your sister does something wrong, do you reprimand her?

If your sister can stay alive until you start working, what would you do for her?

Do you take your sister's and your mother's HIV-positive status as a curse?

How exactly do you help your sister?

INTERVIEW WITH A NEIGHBOUR (NURSING SISTER)

As a neighbour and a health-worker, how do you help Sandra's family?

Have you always had a close relationship with this family?

Does your relationship with Sandra's family affect her in any way?

As a neighbour, how do you caution your children and regulate their interaction with Sandra?

Can you comment on any positive or negative behaviour of Sandra's family regarding HIV?

INTERVIEW WITH THE SCHOOL PRINCIPAL

What is the level of communicating this pandemic within your school?

What are you doing as a leader to supplement this level of communication?

Does the school policy on HIV/AIDS address issues for a specific community, or is it just general?

What monitoring tool do you use to ensure policy adherence; does the tool you use, help learners living with HIV/AIDS?

How do you integrate HIV/AIDS with the curriculum?

How does your health programme assist learners living with HIV/AIDS within the school?

Does your school policy address skills and economy in general?

What is the level of accepting and accommodating infected learners and the personnel in your school?