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CHAPTER 2:
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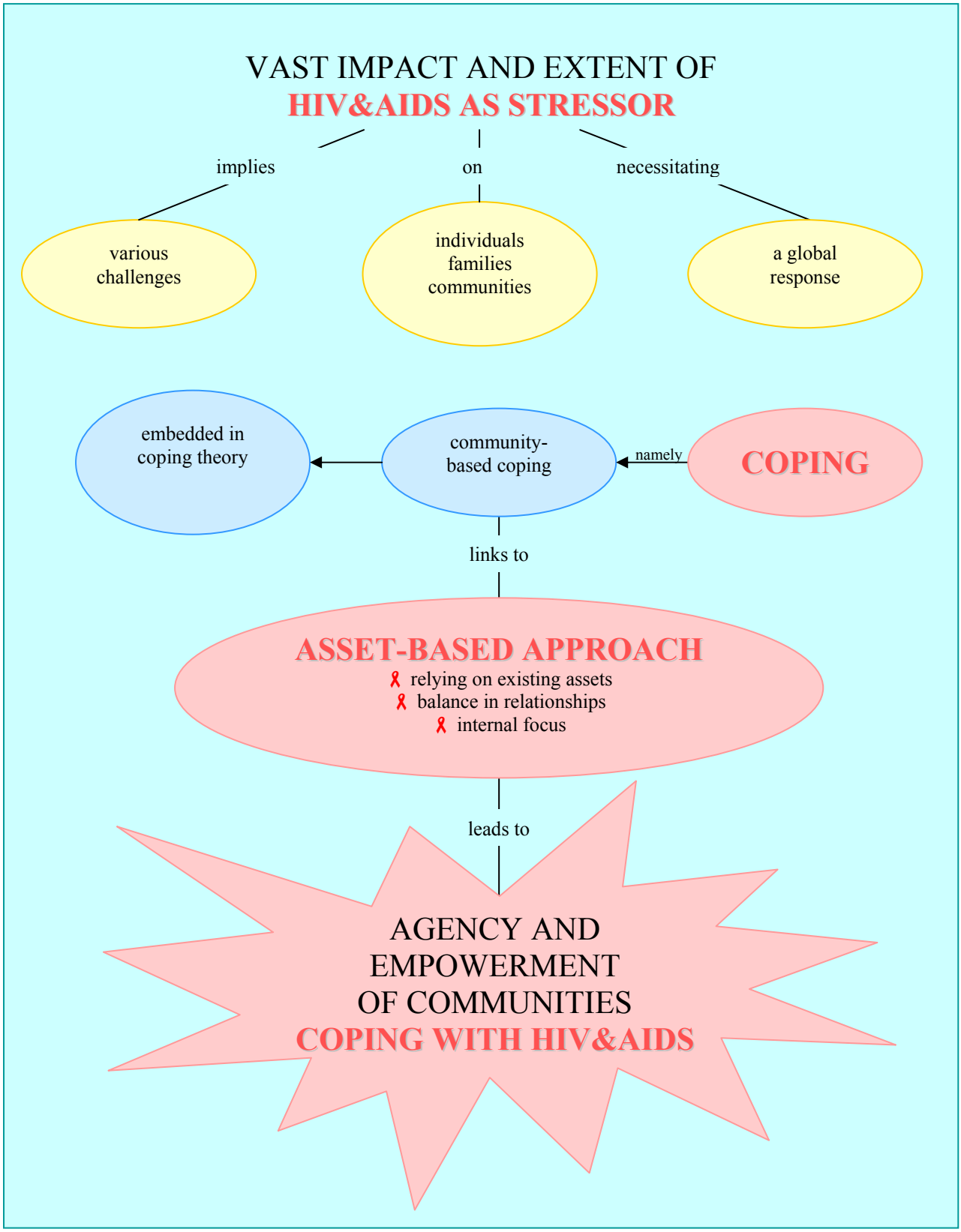
CHAPTER 2 AT A GLANCE



2.1 INTRODUCTION

In this chapter I outline the conceptual framework of my study. For this purpose, I reviewed numerous sources on HIV&AIDS, the theory of coping and the asset-based approach (although the sources in this area are fairly limited). I therefore commence the chapter by reviewing existing literature on HIV&AIDS, followed by discussions of coping theory and the asset-based approach. In reviewing existing literature I was guided by the focus of my study, in terms of my research questions and the purpose of the study. I present the three main sections of the chapter in terms of existing knowledge, limitations in the knowledge base and where my research fits into the existing base of knowledge. In each section, I also continually identify potential areas in which my study might contribute to the existing knowledge base. I conclude the chapter by presenting my conceptual framework for this study.

By engaging in a critical discussion of the various theoretical components and after I have completed my study, I shall endeavour to elaborate on the existing body of knowledge. My focus will specifically centre on the *asset-based approach* within the context of *coping with HIV&AIDS*.

2.2 CONTEXTUAL BACKDROP: HIV&AIDS

HIV&AIDS is a global pandemic impacting on individuals, families and communities in countries worldwide, including the informal settlement community where I conducted my study. Sayson and Meya (2001:542) summarise the global impact of the pandemic: '*As when a stone is dropped into a pool, ripples from AIDS move to the very edge of society, affecting first just one person in a family, then the entire family, then the community, and finally the nation*'. The ripples of HIV&AIDS have indeed reached nations across the globe.

The impact of HIV&AIDS is widespread and recognised in various sectors, such as economical, health, social and educational areas. Countries with limited resources are particularly vulnerable. In addition to challenges like these, an increase in the

number of children orphaned by HIV&AIDS results in even higher levels of financial strain, as well as the need for emotional support and provision of food, shelter and care for these children. Due to their vulnerability, as well as factors like poverty and neglect, these children sometimes end up as street children, and become involved in at-risk sexual behaviour or even child prostitution.

Before focusing on the challenges and stressors experienced by communities within the context of HIV&AIDS, I provide an overview of the extent and potential impact of the pandemic, as this serves as background information to understanding the vulnerability of the community where I conducted my study, as well as the challenges faced by the community in coping with the pandemic. I conclude the section with a discussion on required responses, once again providing the background information with which I entered the research field. Possible ways of coping with HIV&AIDS are dealt with in section 2.3.2, as part of my discussion on coping.

2.2.1 EXTENT OF THE PANDEMIC

I find the statistics provided on HIV&AIDS infections and deaths to be overwhelming. Although I do not accept these as absolute figures, statistics provide me with an estimate of the extent of the challenge faced by communities worldwide. In 2005 it was estimated that 40.3 million people were living with HIV worldwide, of which 2.3 million were children under the age of 15 years. Vertical transmission of the virus accounts for most of the infections in this age group. It was further estimated that 4.9 million people were newly infected during 2005 – 4.2 million adults and 700 000 children younger than 15. Up until now, more than 25 million people have already died of AIDS, of which 3.1 million deaths occurred in 2005, including 570 000 children (Page *et al.*, 2006; Brouard, Maritz, Pieterse, Van Wyk & Zuberi, 2005; Department of Economic and Social Affairs of the United Nations, 2005a; Department of Economic and Social Affairs of the United Nations, 2005b; Shisana *et al.*, 2005; UNAIDS/WHO, 2005; Tindyebwa, Kayita, Musoke, Eley, Nduati, Coovadia, Bobart, Mbori-Ngacha & Kieffer, 2004; UNAIDS, 2004; Department of Social Development, 2002; UNAIDS, UNICEF & USAID, 2002). To me, statistics like these emphasise the extremes that the pandemic has reached, despite ongoing research and preventative measures employed since the outbreak of the HIV&AIDS

pandemic. Against the background of these statistics reporting on the global extent of HIV&AIDS, I shall now investigate the impact of the pandemic on the African continent and, in more specific terms, on local ground.

Sub-Saharan Africa is reported to have been hardest hit by the pandemic, with 25.8 million, or approximately two thirds of the people, living with HIV. In addition, the highest number of children living with the disease (90% of children under 15 years of age), as well as the highest number of children orphaned by AIDS, applies to Africa. It was estimated that 2.4 million deaths in sub-Saharan Africa during 2005 could be ascribed to HIV&AIDS-related illnesses and that 3.2 million people were infected with HIV during that year. In 2003, more than 400 000 children under the age of 15 died of AIDS in sub-Saharan Africa (Page *et al.*, 2006; Brouard *et al.*, 2005; UNAIDS/WHO, 2005; Cabassi, 2004; Miamidian, Sykes & Bery, 2004; Tindyebwa *et al.*, 2004; UNAIDS, UNICEF & USAID, 2002).

On an even closer level, I view the impact of HIV&AIDS on South Africa as one of the most intense and probably the most serious in the world. I regard both the vast rate of increase in infections and deaths, as well as the extraordinary scale of the pandemic in South Africa, as being significant. By 2004, between 2.6 and 3.1 million men, between 3 and 3.6 million women, and more than a 100 000 babies were estimated to be living with HIV – an estimated 12% of the South African population being infected with the virus. Seventy six percent of these people were in the age group 15 to 34 years. In addition, the estimation of AIDS-related deaths in South Africa for that year was 500 000 (Department of Health, 2005; Marais, 2005; UNAIDS/WHO, 2005). Statistics like these resulted in my anticipation (prior to entering the research field) that the South African community in which my study is located might have to support numerous community members living with HIV&AIDS. It made me wonder in which manner the selected community might be coping with such (theoretically) vast numbers of cases in need of care and support.

It is estimated that more than five million South Africans are presently living with HIV&AIDS and that 50% of the South Africans within the age group 15 to 24 years will die of AIDS. Nine hundred people die of AIDS in South Africa daily, whilst more than 1 500 become HIV infected. It is projected that half a million South Africans will

die annually from AIDS-related causes by the year 2008 (Page *et al.*, 2006; Brouard *et al.*, 2005; Department of Economic and Social Affairs of the United Nations, 2005a; Department of Economic and Social Affairs of the United Nations, 2005b; Department of Social Development, 2002; UNAIDS, UNICEF & USAID, 2002). The pandemic is further expected to only peak in South Africa between 2010 and 2020. In this regard South Africa is predicted to be one of five countries that will experience a negative population growth due to AIDS mortality by 2010, with the growth rate estimated at -1.4% (Richter, Manegold & Pather, 2004; Stanecki, 2002).

To me, the numerous sources on HIV&AIDS-related statistics confirm the fact that research in the field of HIV&AIDS is ongoing and relevant. However, the fact that the extent of the pandemic seems to be vaster than predicted makes me wonder as to how successful research and intervention initiatives with regard to prevention are. In addition, I am increasingly aware of the fact that communities are facing a challenge that they need to cope with, and that more research relating to possible ways of coping is continually required.

Furthermore, the high HIV prevalence rate in South Africa implies an increase in the number of orphans in the near future, rendering our country one that has not yet experienced the full impact of the orphan crisis. In my view, this prediction (that the impact of HIV&AIDS will be experienced as even more harsh in future) once again emphasises the importance of communities being prepared to cope with the impact that is foreseen. Seeking answers to questions like the following might provide insight into the existing coping practices of communities (as I also aimed to obtain in my study): *How do communities address and cope with so many cases of loss? How is daily functioning and productivity impacted upon by HIV&AIDS? How do community members cope with the emotions related to loss and grief?*

The current HIV&AIDS scenario, as described in the previous paragraphs, necessitates ongoing research as well as attempts to prepare and support communities to cope with the challenges related to the pandemic. As HIV&AIDS implies various associated stressors, communities will in future have to cope not only with an increase in HIV&AIDS-related deaths, but also with an increase in the number of children orphaned due to HIV&AIDS. Upon gaining insight into the extent

of the pandemic, I ponder on the question as to whether South African communities are ready and equipped to cope with the challenges and vulnerabilities implied by the pandemic. In this manner, I realise the potential that my study may hold for possibly contributing to the knowledge base on coping with the challenge of HIV&AIDS. Concerning the estimated numbers of future orphaned children, I question the predictions, against the background of anti-retroviral treatment (supposedly) being provided to people living with AIDS. If anti-retroviral treatment extend people's lives, future statistics on children orphaned due to HIV&AIDS might turn out not to be as steep as predicted. However, I do accept the reality that the numbers will be rising and counting for enormous numbers of children left vulnerable and in need of care.

2.2.2 IMPACT OF HIV&AIDS

The Department of Social Development (2002:10) describes HIV&AIDS as the '*most urgent health, welfare and socio-economic challenge in South Africa*'. I regard the pandemic as a cross-sectoral developmental issue, impacting and posing challenges on numerous levels, such as health, economic, social, agricultural, policy level and many other areas (Brookes *et al*., 2004; Smart, 2003b). I henceforth discuss the impact of the pandemic in terms of the developmental impact implied, the interrelatedness between poverty and HIV&AIDS, and, lastly, the sectoral impact on health care, education, the private and industrial sector, as well as the macro-economic level.

2.2.2.1 Impact on the development of individuals, families and communities

HIV&AIDS impacts on the individuals, social safety nets and households of communities – people having to cope on a primary level with the challenges implied by the pandemic. Upon becoming ill, family members might experience physical and psychological pain and suffering, and are often not able to contribute to the household income any more. As a result, people's involvement is reduced on various levels, for example in the agricultural and mining sectors. The pandemic therefore reduces labour and productivity, and by implication also the capacity to provide health services, which are urgently demanded by the pandemic (Barolsky,

2003; Ramsden, 2002; UNAIDS, UNICEF & USAID, 2002; Kelly, 2001a; Kelly, 2001b; Ngcobo, 2001; World Bank, 1999; Mkwelo, 1997).

In addition, families' expenses increase when a family member becomes ill (in order to obtain treatment, health care and healthy dietary requirements), resulting in food insecurity and ultimately the weakening of the nutritional status of the people involved. As such, HIV&AIDS intensifies poverty and negatively impacts on family life and family relationships, as well as families' access to social and economic resources. Concerning the influence on family structure, HIV&AIDS leads to an increase in single parent families, as well as children living in households headed by elderly relatives or siblings (Ramsden, 2002; UNAIDS, UNICEF & USAID, 2002; Kelly, 2001a; Kelly, 2001b; Mkwelo, 1997). Being aware of the potential impact of the pandemic on individuals, families and communities provided me with an overview of the challenges that the participants (community members) in my study need to cope with. It guided me in planning and conducting data collection activities, in terms of potential areas to explore. For the purpose of my study, I assumed that the members of the selected informal settlement community were indeed coping with these challenges at the time of my study.

Furthermore, I continuously kept in mind that some family members might start missing school or work, in order to care for those who are sick. I considered the thought that the death of a parent could result in further financial obligations (like funeral expenses), permanent loss of income, and children being orphaned and in need of care. In some cases, children (or widows without an income) might turn to sex work for an income, thereby increasing the risk to be infected with HIV. In this manner, HIV&AIDS does not merely lead to financial strain and sometimes the loss of savings, it also adds greatly to the psychological distress experienced by the person being infected or ill, as well as other family members involved. Family members experience stress with regard to being financially needy and not being able to provide for their basic needs, as well as from the illness they need to cope with. In the case of extended family members taking care of children affected by HIV&AIDS, financial demands are added to their households (SAHIMS, 2004; Barolsky, 2003; UNAIDS, UNICEF & USAID, 2002; Cross, 2001; Kelly, 2001a; Kelly, 2001b; Ngcobo, 2001; Ratsaka-Mothokoa, 2001; Townsend, 2001; World Bank, 1999; McDonald,

1998). Within the context of my study, the potential impact of HIV&AIDS on family members and family life guided me to explore the manner in which relatives are coping with the challenges implied by a family member living with HIV&AIDS, as actualised in the community in which my study is located.

2.2.2.2 Interrelatedness between poverty and HIV&AIDS

The interrelatedness between poverty and HIV&AIDS has been widely documented, with poverty being both a cause and a consequence of risk within the context of HIV&AIDS. In addition to poverty increasing the possibility of people becoming involved in behaviour that might lead to HIV infection, the impact of HIV&AIDS is intensified by poverty itself, and more so in communities where the necessary infrastructure is lacking and community members do not have access to basic services. As such, I believe that these individuals and families are facing double discrimination, firstly for living with HIV&AIDS, and secondly for suffering from poverty. Poverty leads to a decline in the quality of the lifestyle maintained by a family, not only adding to the vulnerability of people but also intensifying the harshness of the impact of the pandemic. In extreme cases, it might lead to increased levels of crime when individuals become desperate. This inevitably culminates in a never-ending circle of ever-increasing poverty and hardship (Department of Economic and Social Affairs of the United Nations, 2005a; Marais, 2005; Brookes *et al.*, 2004; Cabassi, 2004; Tindyebwa *et al.*, 2004; Akintola & Quinlan, 2003; Richter, 2003; Smart, 2003a; Clacherty & Associates, 2002; Oni, Obi, Okori, Thabede & Jordan, 2002; McDonald, 1998).

In selecting an informal settlement community characterised by poverty and limited infrastructure, I was able to perceive the interrelatedness between poverty and HIV&AIDS. Being a poverty-stricken community, the factors relating to poverty are a reality in the daily lives of the community, negatively impacting on individuals, families and the community at large. I constantly had to be aware of this link and reflect on the underlying cause for the raw data that I obtained and observed throughout, in an attempt to understand the experiences of the participants within this context of poverty.

2.2.2.3 Sectoral impact of HIV&AIDS

HIV&AIDS impacts on health care, education, the private and industrial sector, as well as the macro-economic level. The need for ***health care*** with regard to HIV&AIDS and other related illnesses has vastly increased since the disease started, in terms of both the need for medication and treatment, as well as the need for hospital care, which is often marked by limited resources. In addition, the pandemic leads to the death of health care staff, decreasing the possibility of sufficient treatment and care even further. On a general level and to summarise, HIV&AIDS leads to an increase in mortality (both adults and children), a decrease in life expectancy and a reduction in population growth, thereby necessitating an extension of health care services (Department of Economic and Social Affairs of the United Nations, 2005a; Marais, 2005; Akintola & Quinlan, 2003; Smart, 2003b; Kelly, 2001a; Kelly, 2001b; Subbarao, Mattimore & Plangemann, 2001; Broughton, 1999). During my study, I had to be cognisant of and compassionate towards this realm of decline in the provision of health services. As a result, I attempted to reflect on the impact of the limitations, but also the available resources related to the health sector, in terms of the selected informal settlement community's way of coping with HIV&AIDS.

In terms of the impact on ***education***, the education and training systems have been steadily weakened by the HIV&AIDS pandemic. Besides children infected with and affected by HIV&AIDS dropping out of school, educators are also infected, thereby decreasing the workforce of the education sector. Factors like educator absenteeism; a low morale; poor school attendance by children; trauma, grief and mourning experienced in schools when people die; as well as insecurity and anxiety, further influence the quality of education that is provided in schools (Marais, 2005; World Bank, 2002; Kelly, 2001a; Kelly, 2001b; World Bank, 1999). As the core group of participants in my study were educators, I was very much aware of the potential impact of the pandemic on the education sector as well as the manner in which this impact might expand to the wider community, in terms of its coping with the challenges implied by the pandemic.

In the ***private and industrial sector*** HIV&AIDS reduces productivity, thereby influencing resources, increasing costs and having an effect on the market for

business products, as people are not able to buy products or pay for them after they have been purchased. On a ***macro-economic level***, economic growth is influenced negatively in respect of human, physical and social capital (Marais, 2005; World Bank, 2002; World Bank, 1999). During my study, I had to constantly focus my reflections in terms of the availability of resources, but also the reality of challenges faced by the community in coping with HIV&AIDS, in both the private and industrial sectors, and on a macro-economic level. In selecting a community characterised by limited infrastructure and resources, I was faced with the reality of the sectoral impact of HIV&AIDS, such as limited availability of health care and social services.

2.2.3 POTENTIAL CHALLENGES AND STRESSORS WITHIN THE CONTEXT OF HIV&AIDS

Living with HIV&AIDS implies various challenges and consequences for the individuals, families and communities involved. I henceforth explore the potential challenges implied by the pandemic in terms of the vulnerability of people living with HIV&AIDS, and secondly, the challenge of supporting others living with HIV&AIDS.

2.2.3.1 Vulnerability of people living with HIV&AIDS

People living with HIV&AIDS undergo many changes. As such, I had to be aware of, and prepared to possibly be confronted with, the ***personal vulnerability*** of participants, in terms of their initial reactions like anger, fear, loss, grief and denial, as well as mood swings. In addition to emotional pain, I had to regard feelings of low self-worth, powerlessness and even depression as characteristic of people having to cope with the challenge of living with HIV&AIDS. People living with HIV&AIDS might further experience mental health problems and display suicidal behaviour or thoughts, in an attempt to cope with the idea of facing death. Apart from worrying about their own illness, about their inability to earn an income, and about what will happen to them and their families, HIV infected parents also worry about their children. They are usually concerned about the possibility of their children being discriminated against, the basic survival and future of their children after they have passed away, the possibility of them being exploited and the effect that their illness and possible poverty might have on their children. During later stages of their illness, people with AIDS have to deal with the symptoms and pain of their illness (***physical***

vulnerability). Within the context of my study, I had to be on the look-out for feelings and reactions as mentioned in this paragraph, even for those that were communicated on a non-verbal level (Page *et al.*, 2006; Freeman, 2004; Mallmann, 2002; Gilborn, Nyonyintono & Jagwe-Wadda, 2001). On the other hand, my focus on the asset-based approach guided me in also identifying positive experiences such as spiritual growth, meaning making, support and resourcefulness, as potential responses to vulnerability and the related feelings, such as those described in this paragraph.

In addition to personal experiences and emotions (***personal vulnerability***), I continually had to remain aware of the fact that people living with HIV&AIDS have to cope with the possibility of being stigmatised and having to decide whether or not to disclose their status and to whom (***social vulnerability***). Based on stigmatisation, I had to respect the decision not to disclose and rather hide an HIV positive status, resulting in the possibility of people living with HIV&AIDS not accessing emotional and practical support (like treatment), thereby intensifying their own ***physical vulnerability***. I acknowledge the possibility of even family members stigmatising relatives and discriminating against them, rejecting or isolating them. In the case of people deciding not to disclose their status to family members, they might be rejected at later stages of their illness when they require care and support, based on their initial decision to keep a secret from the family (Barolsky, 2003; Strode, Grant, Clacherty & Associates, 2001). With regard to disclosure, I support McDonald (1998), who takes disclosure back even one step further by regarding the first level of disclosure as the decision to be tested for HIV – so-called *disclosing to the self.*

I regard stigmatisation and discrimination as central challenges related to HIV&AIDS, which add to the ***social vulnerability*** of people who are already vulnerable. Not only does stigmatisation result in people being judged, blamed and discriminated against, it also prevents intervention initiatives from being effective. Stigmatisation might, for example, prevent people from accessing care and support, seeking information or protecting themselves and others by preventing further infections. In extreme cases, I believe that infected people might even avoid accessing the government disability grant (which might bring financial relief) and as a result increase their ***physical vulnerability***, based on their fear for discrimination and isolation. I support the view

that, due to stigmatisation, people living with HIV&AIDS do not only have to cope with their status or illness, but also with discrimination and rejection by others (Holzener & Uys, 2004; Akintola & Quinlan, 2003).

Numerous calls have been made to address stigmatisation and discrimination, in order to encourage people with AIDS to disclose their status (see for example Brouard *et al.*, 2005; Monson, 2005a; Department of Social Development, 2002; Gilborn *et al.*, 2001; UNICEF, 2001; Van Dyk, 2001). In response, the study for *Save the Children* (Clacherty & Associates, 2002) revealed that the levels of stigmatisation seem to be decreasing (Strode *et al*., 2001). Yet on the other hand, a study by Kelly (2000a) in the Eastern Cape, KwaZulu-Natal and the Western Cape revealed contradictory findings, where selected adolescents and young adults (15-30 years old) displayed more positive attitudes towards people living with HIV&AIDS, whilst participants in rural areas still displayed intolerance. As such, there seems to be a decline in the tendency to blame people living with HIV&AIDS, as well as a tendency to accept them as '*normal*' community members in certain areas. However, in rural areas (specifically in the Eastern Cape) stigmatisation still appears to be evident. Results like these emphasise the fact that different regions display different tendencies with regard to stigmatisation and discrimination against people living with HIV&AIDS. My study might contribute to the existing body of knowledge by providing insight into the levels of stigmatisation within the selected informal settlement community where I conducted my study.

In addition, my awareness of the possibility of the Eastern Cape being characterised by high levels of stigmatisation (***social vulnerability***) could guide me in approaching the research field, as I faced the challenge of exploring a phenomenon which is more often than not regarded as a *taboo* subject. My awareness of the possibility that participants might not have been willing to share their perceptions enabled me to carefully plan my data collection activities and adapt them where necessary. In addition, my realisation that stigmatisation and discrimination are still a harsh reality, allowed me to, at times, understand the responses and reactions of the participants.

Cloete (2003) relates stigmatisation to the lack of access to treatment and is of the opinion that it could start diminishing once treatment is freely available. I do not fully

agree with this statement, as I believe that stigma strongly relates to fear. As such, enhancing treatment possibilities might help in combating stigmatisation, but cannot necessarily be accepted as the primary factor in breaking down stigma. Whatever the case may be, at present stigmatisation is still a relevant challenge faced by those who are living with HIV&AIDS, that needs to be addressed as a prerequisite for enhancing their quality of life (Department of Economic and Social Affairs of the United Nations, 2005a; UNAIDS/WHO, 2005; Browde, 2003; Masindi, 2003; Siyam'kela project, 2003; Van Dyk, 2001; International HIV/AIDS Alliance, 2000). In addition to purposefully addressing the stressor of stigmatisation, Strebel (2004) suggests that stigmatisation needs to be acknowledged in revising and planning future community-based interventions. Strebel's (2004) suggestion resulted in me acknowledging stigmatisation whilst planning and conducting my field work.

Stigma related to HIV&AIDS can take on many forms and result in various reactions by the person living with HIV&AIDS or by other people of the community. In my study, I adhered to the Siyam'kela Project's (2003) differentiation between stigma on an external and an internal level. On an external level, I regard reactions such as avoidance, rejection and moral judgement as often experienced by people living with HIV& AIDS. In addition, people living with HIV&AIDS might be stigmatised by association, by an unwillingness to invest in them, or by being discriminated against or abused by others. ***Avoidance*** is related to the fear of casual transmission of the virus and takes on the form of others not being willing to touch or share the same objects of those living with HIV&AIDS, as well as the tendency to gossip, resulting in people living with HIV&AIDS feeling isolated. ***Rejection*** can reach extremes, as people who are living with HIV&AIDS might be rejected by their partners (upon disclosing their status), other family members, the wider community and even members of their church or faith-based organisations. With regard to ***moral judgement***, HIV&AIDS is often linked to at-risk sexual behaviour, resulting in people being judged or labelled as immoral. ***Stigmatising*** people ***by association*** refers to tendencies such as assuming that people who are loosing weight are suffering from HIV&AIDS, or in cases where the cause of death is not stated, that they had died of AIDS. Furthermore, relatives or children might be stigmatised due to the HIV status of a family member, resulting in parents being secretive about their status and not disclosing it to their children. In the same manner, people working as care workers

or volunteers within the context of HIV&AIDS might be stigmatised (Siyam'kela Project, 2003; Clacherty & Associates, 2002; Strode *et al.*, 2001).

An ***unwillingness to invest in people living with HIV&AIDS*** relates to people fearing disclosure, based on their fear of being marginalised due to their status within an organisation by, for example, not being included in training, development and promotion possibilities. In terms of ***discrimination***, people living with HIV&AIDS are often not able to access services such as funeral coverage, medical schemes and blood transfusions. Furthermore, they sometimes do not receive the same health services, care and courtesy as other people. Finally, people living with HIV&AIDS might be ***abused***, for example physically abused after disclosing, or verbally abused as immoral or a threat to the community (Siyam'kela Project, 2003; Clacherty & Associates, 2002; Strode *et al.*, 2001; Antle, Wells, Goldie, DeMatteo & King, 2001).

Concerning internal stigma, people living with HIV&AIDS often fear disclosure, withdraw themselves socially, perceive themselves in a negative manner and exclude themselves from certain services and opportunities. I regard reactions like these as coping behaviour and strategies, employed by people living with HIV&AIDS, in an attempt to address the challenge of their illness. People who are infected with HIV or who have AIDS usually ***fear disclosure***, based on their fear of being judged or rejected by their partners, family members or the wider community. In addition, they might fear discrimination against their family members and children, or not being promoted at work. Even caregivers looking after people living with HIV&AIDS sometimes avoid disclosure in fear of being stigmatised and discriminated against. ***Excluding themselves from services and opportunities*** such as support groups can be linked to people's fear of stigmatisation. In the same manner, people living with HIV&AIDS might ***withdraw themselves socially***, in order to protect themselves against stigmatisation and discrimination, or due to their fear of being judged or rejected. It is, however, common practice for people living with HIV&AIDS to spend time with other people who are HIV infected or who have AIDS. With regard to their ***perceptions of themselves***, people living with HIV&AIDS might experience themselves as less valuable, and that they had disappointed others. In an attempt to protect themselves from discrimination, or due to internal stigma, they might ***overcompensate*** in their behaviour. They might also tend to prove to others (for

example the church) that they are good people (Siyam'kela Project, 2003; Strode *et al.*, 2001; Mkwelo, 1997).

Within the context of my study, I relate potential reactions and behaviour that are associated with stigma on an internal level, to the coping strategies employed by people living with HIV&AIDS. I further regard the coping reactions and behaviour described in the previous paragraphs as defence mechanisms and potential ways of denying an HIV positive status. Concerning stigma on an external level, I propose that the reactions as identified by the Siyam'kela Project (2003) also be regarded as coping strategies, but as the strategies employed by people **not** living with HIV&AIDS, in response to community members who are infected or who have AIDS. As such, I viewed any such reactions (on both an external and an internal level) against the background of stigmatisation and as potential coping strategies employed by the participants. Figure 2.1 provides a summary of potential coping responses to HIV&AIDS against the background and reality of stigmatisation. Within the context of my study, insight into the ways in which community members employ these potential reactions as coping strategies might elaborate and build on the basic theory provided by the Siyam'kela Project (2003).

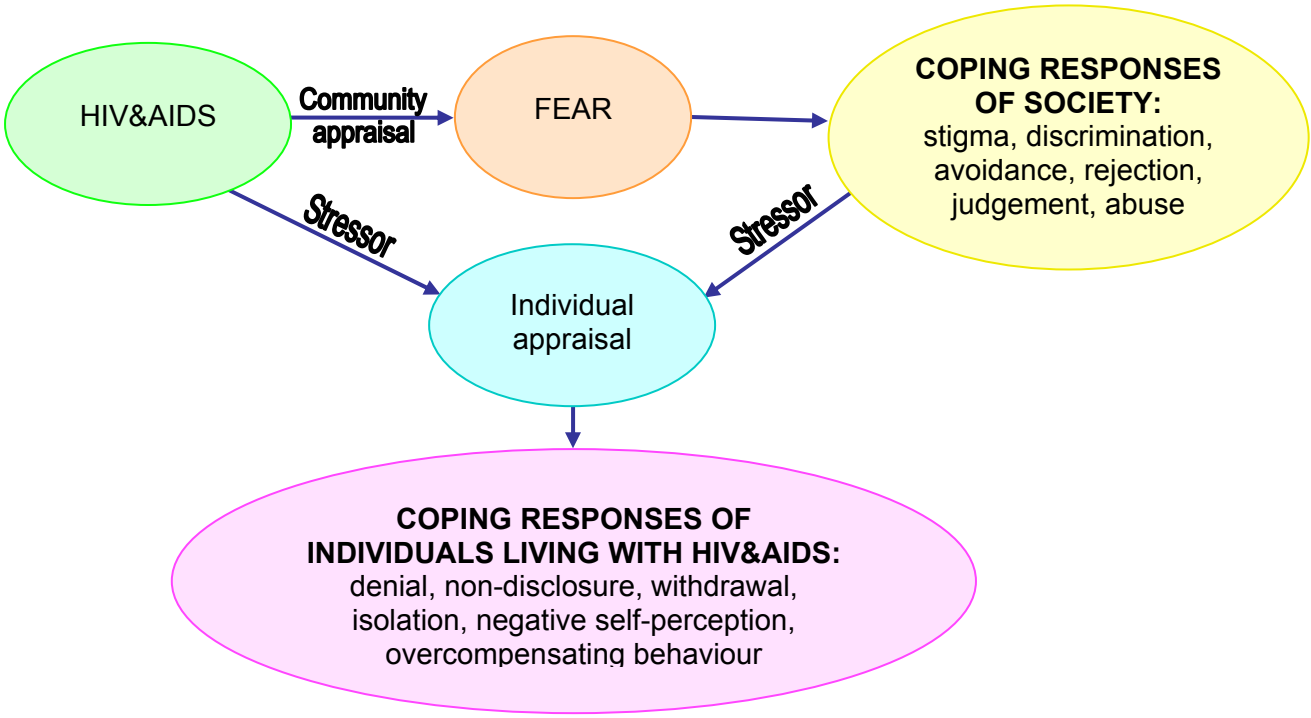


FIGURE 2.1: POTENTIAL COPING RESPONSES TO HIV&AIDS AGAINST THE BACKGROUND OF STIGMATISATION

2.2.3.2 The challenge of supporting people living with HIV&AIDS

Relatives of those living with HIV&AIDS face many challenges themselves, as the pandemic impacts on the whole family and requires of them to cope with a relative becoming ill and ultimately dying. The psychosocial feelings experienced by significant others (both family members and other loved ones) correspond with the feelings of a person being infected with HIV or having AIDS. Family members typically display reactions of disbelief, confusion and shock. Other feelings that are commonly experienced include uncertainty, anger, emotional numbness, despair, stress and depression. Relatives may further fear infection themselves or even be angry with the infected family member for bringing the stigma onto the family (Richter *et al.*, 2004; Van Dyk, 2001; Mkwelo, 1997). During my study, the knowledge of such potential feelings and reactions to a relative living with HIV&AIDS provided background against which I could interpret certain reactions and responses obtained during data collection. As such, my knowledge of typical feelings and experiences of relatives impacted on my exploration of their way of coping.

As in the case of people who are HIV infected or who have AIDS, family members have to cope with the possibility of stigmatisation and discrimination. They may experience stress due to their loved ones being stigmatised and discriminated against, or they may experience psychological distress if they themselves tend to stigmatise others who are infected with and affected by HIV&AIDS, and are now faced with a family member falling into this category. In addition, HIV&AIDS might overwhelm families whose coping capacities have already been stretched to their limits by poverty, as family members usually have to take over the responsibility of income generation, household tasks, caring for the children and supporting or even caring for the relative upon becoming ill. These experiences might add to the vulnerability of the whole family, as well as the levels of psychological stress experienced by family members in coping with both poverty and the challenges imposed by a family member living with HIV&AIDS (Freeman, 2004; Richter *et al.*, 2004; Tindyebwa *et al.*, 2004; Bennell, 2003; Sayson & Meya, 2001; Mkwelo, 1997; Geballe *et al.*, 1995).

In the case of a child who is HIV positive, initial reactions include shock, denial, disbelief, anger, fear and sadness. In addition, family members might lose their hope for the future. During times of illness parents often feel guilty, helpless, lonely and even depressed. Parents also have to cope with their own diagnoses in such difficult times (Tindyebwa *et al.*, 2004; Van Dyk, 2001; Mkwelo, 1997). In undertaking my field work and exploring participants' way of coping with HIV&AIDS (which might have implied coping with a relative living with HIV&AIDS), I continually considered the possibility of the participants in my study having to cope with the feelings and experiences as described in this section. However, by describing positive support initiatives, as practiced by the community members of the selected community, I aimed to provide a counter discourse for the range of stressors and challenges often associated with supporting others living with HIV&AIDS.

2.2.4 RESPONDING TO THE PANDEMIC

I support the generally agreed upon idea that the challenges posed by HIV&AIDS require a multi-sectoral, integrated (coping) response, involving international, national and regional role-players from as many sectors of society as possible, including local communities. The government, NGOs, public sector, private sector and people living with HIV&AIDS could complement each other's initiatives, establish partnerships and operate in a consolidated way, whilst protecting the human rights of the people involved. HIV&AIDS programmes might be mainstreamed into broader programmes in an attempt to address the causal and underlying factors related to people's vulnerability to HIV infection, as well as to the consequences of HIV&AIDS. Managing such an integrated approach includes components of research, formulation of goals, development of strategies and resources, provision of community support, evaluation of activities and refining of initial goals and outputs (Brouard *et al.*, 2005; Department of Economic and Social Affairs of the United Nations, 2005b; UNAIDS/WHO, 2005; Cabassi, 2004; Lucas, 2004; Strebel, 2004; Department of Social Development, 2002; Kelly, 2001a; Sayson & Meya, 2001; International HIV/AIDS Alliance, 2000; Marais, 2000; Parker, Dalrymple & Durden, 2000).

I hold the view that such an integrated approach could indeed address the challenges of HIV&AIDS faced by communities worldwide. However, despite numerous efforts employed since the outbreak of the pandemic (as reported on in the following paragraphs), I still find the extent of the pandemic to be vast and overwhelming. I inevitably ask myself the question as to whether or not the various areas of importance (as identified in the previous paragraph) are indeed being addressed, and, if not, which areas need to be addressed more rigorously. In an attempt to find an answer to this question, I explore current responses to the question in the paragraphs to follow. To me, a central intrigue is whether or not an intervention study, following PRA principles, could permit me insight into aspects that might facilitate change (or not) in terms of coping with HIV&AIDS.

In response to the vast impact of HIV&AIDS, action has been taken on a worldwide level, aiming at self-sufficient coping by communities. The first global response was seen in 1994, when the Economic and Social Council of the United Nations established the *Joint United Nations Programme on HIV/AIDS* (UNAIDS), in order to support a coordinated response from the United Nations. Examples of other global responses include the establishment of the *Commission on HIV/AIDS and Governance in Africa* in 2003 by the United Nations, upon becoming aware of the vast impact of the disease on Africa, as well as the approval of the *Declaration of Commitment on HIV/AIDS* in 2001. Furthermore, the *Strategic plan for intensifying action against AIDS in Africa*, the World Health Organisation's *3 to 5 Initiative*, the *Global Fund for AIDS, TB and Malaria*, and the United States of America's *Presidential Emergency Plan for AIDS Relief* have been developed. In Africa every Ministry of Education is required to implement an *AIDS in the Workplace Strategy*, in order to prevent further infections and create a caring environment for staff members (Department of Economic and Social Affairs of the United Nations, 2005a; Department of Economic and Social Affairs of the United Nations, 2005b; Tindyebwa *et al.*, 2004; Bennell, 2003; World Bank, 1999).

In support of orphaned and vulnerable children, a *Framework for the protection, Care, and Support of Orphans and Vulnerable Children living in a World with HIV and AIDS* was endorsed by USAID, UNICEF and UNAIDS in 2003 – as part of the *Children on the Brink* series. The framework identified five strategies in support of

children infected with and affected by HIV&AIDS, which have been adopted internationally, nationally and locally (USAID, 2005; Richter *et al.*, 2004; Tindyebwa *et al.*, 2004; UNAIDS, UNICEF & USAID, 2002). The first strategy involves ***strengthening and supporting the capacity of families to protect and care for orphaned and vulnerable children***. Supporting this primary safety net (often extended family members) for orphaned and vulnerable children might take on the form of economic strengthening and psychosocial support, improving access to basic services and education, increasing agricultural productivity, improving access to employment and markets, and providing additional ways of generating income. In addition, support might take the form of basic care for those with AIDS, or assistance to parents in drawing up wills, planning for the future of their children and discussing it with them. Secondly, ***community-based responses need to be mobilised and supported***. Communities are regarded as the second safety net for orphaned and vulnerable children and for vulnerable households, as community members might identify vulnerable children and families, assist them first-hand or direct them to local or outside resources. Strengthening community-based responses can take the form of developing community gardens, organising youth groups and recreational activities, or encouraging schools to exempt children from school fees. The third identified strategy centres on the ***strengthening of the capacity of children and young people to address their own needs, by ensuring access to essential services***. Support initiatives aim at keeping vulnerable children in school, preparing them for the future and enabling them to provide for their own needs. Interventions focus on school attendance, access to basic health and nutrition services, safe water and sanitation, protection of vulnerable children, and placement where needed.

In the fourth place, responses in support of orphaned and vulnerable children need to focus on ***ensuring that government develops policies (including legal and programmatic frameworks) and essential services to protect the most vulnerable children***. Governments are required to take action and ensure that children, families and communities are able to cope, by, for example, further developing, implementing and enforcing laws to protect vulnerable children, and by making sure that those who do not have the support of family or community members are provided with essential social services. Strategies include the development of national action plans to guide programming, the development of

Children's Acts and protection services, as well as the delivery of education, health and other essential services, by collaborating with international organisations, NGOs, religious groups, donors and the private sector. The last identified strategy involves ***raising awareness at the various levels of society, in order to establish an environment that enables support for children affected by HIV&AIDS***. An awareness of the impact of the pandemic needs to be encouraged among community leaders, policy makers, organisations and the general public, in order to establish a shared sense of responsibility. Initiatives can focus on aspects such as stigma, discrimination and social mobilisation, involving the media, faith-based groups and other stakeholders (USAID, 2005; Richter *et al.*, 2004; Tindyebwa *et al.*, 2004; UNAIDS, UNICEF & USAID, 2002).

I regard these five strategies as broad by nature and possessing the potential of addressing the challenges associated with HIV&AIDS on various levels. In my opinion, and within the context of my study, the focus on community-based responses is of particular value, as I adhere to the perception that any response to HIV&AIDS lies in the community facing the challenge. Secondly, I support the emphasis placed on enhancing the capacity of individuals facing the challenge, as I am of the opinion that individuals might take agency in coping with the challenges they face. I further propose that strategies focusing on capacity building could be related to the asset-based approach, as they propagate the idea of community members relying on themselves in order to address the challenges they face. Finally, I support the fact that the five strategies include responses on a government level and propagate an awareness at the various levels of society, as I regard the HIV&AIDS challenge as one that is faced by community members on various levels, requiring responses on the different levels, including government level. However, I wonder to what extent the five proposed strategies are at present being addressed within the South African context, and propose that further research on the evaluation of such implementations is needed in our country. I regard the intervention research that I undertook in the selected informal settlement community as addressing the second strategy, resulting in the possibility of my study making a contribution to research in this area.

Based on the suggested strategies, most governments have responded in terms of policy and law reform, national strategies, integrated development plans and models of intervention. On a worldwide level, emphasis is placed on the protection of the rights of children, as well as on quality education. Poverty is combated by striving to achieve adequate standards of living for all, in terms of adequate nutrition, clothing, housing and basic living conditions. Throughout, the goal is to enhance human capabilities and social well-being by, amongst other initiatives, facilitating access to health and social services for citizens. Countries worldwide have developed HIV&AIDS strategic plans, focusing on access to HIV prevention, basic care and support (including psychosocial support and counselling), as well as treatment. Throughout, existing capacities of communities are supported, in an attempt to enhance sustainability (Birdsall & Kelly, 2005; Miamidian *et al.*, 2004; Strebel, 2004; Smart, 2003a; Smart, 2003b; Centre for Policy Studies, 2001; UNICEF, 2001; Marais, 2000; UNICEF, 2000b; Cook, 1998). Although most community- and home-based intervention programmes focus on strengthening community capacity in order to support orphaned and vulnerable children, I believe the support initiatives can be applied to community's coping in general, thereby enhancing community members' coping by strengthening their belief in themselves and their ability to cope.

In South Africa, legal and policy frameworks have been put into place over the past few decades. A few examples of responses on local ground include the *HIV/AIDS and STD strategic plan for South Africa 2000-2005*, the *Comprehensive Plan for Care, Management, Treatment and Support*, and our *National Integrated Plan for Children Infected and Affected by HIV/AIDS*. In addition, *National Guidelines for Social Services to HIV&AIDS Infected and Affected Children* were developed by the Department of Social Development, which might be implemented by any role-player, such as volunteers, NGOs, community-based organisations and family members. HIV&AIDS has been made part of the school curriculum and an integrated *Nutrition Programme for Schools* was put into place, as well as a *Food Security Programme* (Birdsall & Kelly, 2005; Giese, Meintjes, Croke & Chamberlain, 2003; Smart, 2003a; Gow & Desmond, 2002; South Africa Department of Social Development, 2002).

Furthermore, regulations of the *Social Assistance Act* were put into operation in 1998, to make government grants more accessible to people supporting children

infected with and affected by HIV&AIDS. In 2003, a new draft *Social Assistance Bill* was dispersed and in 2002 the *child-related laws* were reviewed by the South African Law Commission. The *Child Support Grant* and *Foster Care Grant* were revised and a *Top-up Grant for Children with Special Needs* proposed. It was also recommended that children receiving social security be *exempted from school fees*. Other examples of local initiatives include the *Children's Bill*, the *National Social Security Agency Bill*, the *National Health Bill* and the *Child Justice Bill* (Smart, 2003a). However, despite such initiatives and policies being put in place, it seems that intervention has not yet reached all South African communities. Examples of communities that occasionally do not benefit from the programmes being put into place include informal settlement communities, such as the one where I conducted my study. For example, concerning government grants, people often seem to be ignorant regarding the procedures that ought to be followed in accessing financial grants[5]. In my opinion, and based on the hardships still experienced in numerous communities, continued research needs to be undertaken in order to investigate to what extent the policies that have been put in place are indeed positively impacting on South African communities, specifically those characterised by poverty and limited service provision.

Although national leadership is important in responding to the challenge of HIV&AIDS, I support the idea that actions also need to be planned and initiated at regional and ground level (complying with basic PRA principles). Numerous groups and organisations are currently involved in South Africa in community level responses to HIV&AIDS, such as faith-based organisations, civil society organisations (NGOs, community-based organisations, non-profit organisations and others, like women's or political organisations) and government institutions or departments. Activities target the spectrum of age groups and focus on prevention, care and support – often in an integrated manner, mutually reinforcing one another and thereby enhancing the impact, sustainability and credibility of the activities. *Prevention* initiatives include educational and awareness activities as well as specialised interventions, such as mother-to-child transmission, abstinence, condom

[5] *Ebersöhn, L., Ferreira, R. & Blankenship, K. Teachers' perceptions of a disability grant. Presentation at the American Educational Research Association (AERA) Conference 2006, San Francisco, 7 April 2006.*

use and life skills. *Care and support* initiatives focus on emotional care and support, counselling services, the promotion of community care, support groups, programmes on nutrition, home-based care, income generating possibilities and support to vulnerable and orphaned children by providing free education, free health care, protection against abuse and children's homes, crèches and places of safety. In addition, aspects like financial assistance (for example government grants), shelter and placement, as well as legal assistance, are covered. *Treatment* initiatives refer to clinical treatment interventions, as well as treatment-related education (Birdsall & Kelly, 2005; Amoateng, Richter, Makiwane & Rama, 2004; Richter *et al.*, 2004; Kelly, Ntlabati, Oyosi, Van der Riet & Parker, 2002; Mugabe *et al.*, 2002; UNICEF, 2001; International HIV/AIDS Alliance, 2000; UNICEF, 2000a).

Despite the fact that numerous initiatives are undertaken in various areas of South Africa, targeting various communities, I am of the opinion that more extensive research might be undertaken on the outcome of initiatives. As a secondary outcome of my study, knowledge might be generated on the impact that such participatory intervention initiatives have in the community in which my study is located, specifically within the context of coping with HIV&AIDS. I further propose a more holistic approach to intervention initiatives, as many projects seem to be undertaken in isolation and not in support of other initiatives. By following a holistic approach, lessons might be learned from one another and unnecessary reproduction reduced.

I regard organisations involved in projects as potential resources in addressing the challenge of HIV&AIDS, which might become involved in intervention initiatives such as training programmes, provision of services, capacity building initiatives, as well as initiatives focusing on obtaining funding and networking with other organisations and people on community level (Birdsall & Kelly, 2005). However, communities with limited resources (such as rural or informal settlement communities) are often not the focus of such organisations (Mugabe *et al.*, 2002). As such, I propagate community-based responses to the HIV&AIDS pandemic, in response to the social reality and challenges faced by South African communities (especially poverty-stricken communities). Despite the intention to provide external help, the impact of the pandemic is so vast that the external resources are not always able to meet the needs. I therefore support others (Smart, 2003b; UNAIDS, UNICEF & USAID, 2002),

by proposing that the various levels of society need to be strengthened and mobilised to increase their own capacity to cope with the challenge, thereby meeting their own needs.

In terms of treatment, the South African government decided to provide anti-retroviral treatment to people with AIDS in 2003. Despite the decision, the roll-out plan has not yet been developed in detail, resulting in the situation that by mid-2005 an estimated 870 000 South Africans in need of treatment were not receiving it – mostly people in under-resourced communities, such as informal settlements (Marais, 2005). This situation does not solely prevail in our country, as only one in ten people in Africa in need of anti-retroviral therapy was receiving it by mid-2005. However, as a result of the provision of anti-retroviral treatment having tripled since the end of 2001, over one million people in low and middle income countries now benefit by indeed living longer. In addition, between 250 000 and 350 000 deaths were prevented in 2005, due to the treatment scale-up (UNAIDS/WHO, 2005). In my opinion and against the background of statistics like these, the South African government needs to address the challenge of streamlining the roll-out plan on anti-retroviral medication, in order to provide treatment to as many people as possible .

Despite numerous responses to the HIV&AIDS pandemic, the need for rapid responses remains, in particular developmental interventions and preventative responses. The need for research is continuously emphasised, especially with regard to monitoring and evaluating existing intervention initiatives, in order to determine the sustainability of programmes and in order to plan ahead. Continuous research on multidimensional levels is required, as the various disciplines might add to the understanding of the phenomenon and its implied challenges (UNAIDS/WHO, 2005; USAID, 2005; Freeman, 2004; Richter *et al.*, 2004; Strebel, 2004; Akintola & Quinlan, 2003; Kelly, 2001a). I planned and undertook my study against this backdrop of a pandemic impacting on various levels and requiring community-based responses and continued research initiatives, according to which economically disadvantaged communities cope with the challenges they face by relying on the resources available in their immediate environment. Closely related, I regard research on the outcomes of programmes and initiatives to be important, as current initiatives might influence future planning – not only during individual and isolated

projects but on a wider level, for example by impacting on future policies. As such, the study I undertook might add to the body of knowledge on potential intervention initiatives that might be applied in informal settlement communities in South Africa, as well as the outcomes thereof.

2.3 UNDERLYING THEORY: COPING

In the following section, I explore coping as the underlying theory to my study. After providing the necessary background in terms of an overview of existing coping theories, I investigate coping with HIV&AIDS in terms of the general quest for community-based coping, implying empowerment as a central concept. I discuss possible ways of coping with being infected with HIV or living with AIDS, coping with others living with HIV&AIDS, and coping with orphaned and vulnerable children.

Although coping refers to adjustments in order to address demands, the concept of coping implies more than mere adjustment within the context of my study. To me, coping entails a process that inevitably implies growth, well-being and differentiation, whereby people and the community where I conducted my study could experience certain changes. By coping with the challenges implied by HIV&AIDS, feelings of well-being, self-worth, a sense of accomplishment and hope for the future could be facilitated amongst participants (refer to Matthews & Zeidner, 2003; Ebersöhn & Eloff, 2002; Zeidner & Saklofske, 1996). I support the idea of the contextual nature of stress and coping, thereby acknowledging coping as a dynamic process that differs under different cultural, political, social, historical and economic conditions. As such, I believe that contextual factors determine the manner in which individuals cope and that different ways of coping (for example as found in my study) cannot merely be applied to situations and contexts in the same manner (Donnelly, 2002; Snyder & Pulvers, 2001; Lazarus, 1993).

Matthews and Zeidner (2003) identify two main factors influencing individuals' ways of coping with challenges. Firstly, the attributes of people facing challenges determine their ways of coping, including aspects like available resources, the individuals' sense of efficacy, their commitment, beliefs and values. Secondly,

knowledge relating to possible ways of coping and personal beliefs concerning the efficiency of the options determine the ways in which people deal with challenges. The effectiveness of coping in turn relates to the internal-external requirements of the given situation. Exploring coping with HIV&AIDS within an informal settlement community against the background as described by Matthews and Zeidner (2003) implied that I investigated participants' (community members') ways of coping by considering individuals' personal attributes, resources, beliefs and values, as well as their personal experiences of potential ways of coping with challenges.

Aldwin (1994:107) regards coping as '*the use of strategies for dealing with actual or anticipated problems and their attendant negative emotions*'. I concur with the author's emphasis on the importance of both social and cultural factors influencing the way that people experience stressful situations, as well as the coping strategies they employ in dealing with challenges or difficulties. Four factors might influence the way in which individuals cope, namely their appraisal of stress; the coping resources available; resources provided by the culture; and the reaction of other people. Culture, in turn, might have an influence on the kind of stress experienced by individuals, on individuals' evaluation of challenging situations, as well as on possible coping strategies that might be employed when coping with difficult situations (Aldwin, 1994). I regard all four of these factors to be important within the context of my study and in determining the selected community's way of coping with HIV&AIDS.

2.3.1 Overview of Coping Theories

Literature provides various theoretical frameworks and philosophical perspectives on coping. For the purpose of this chapter, I do not intend including all such perspectives, but merely focus on the ones that I regard as relevant in providing the necessary background to my conceptualisation of coping, as applied during my study.

Lazarus (1993) distinguishes between two main approaches to coping – the so-called traditional approach and the approach according to which coping is viewed as a process. The traditional approach to coping emphasises personality characteristics by regarding coping as a trait or style, and valuing strategies that reduce tension as

effective coping strategies. The hierarchical style or trait approach places emphasis on inner dynamics rather than on external environmental influences and forces, focusing on characteristic types of coping. This approach assumes that change cannot be related to time – an idea that does not comply with more recent theories of coping and that I do not agree with (Frydenberg, 1999). As such, and for the purpose of my study, I explored coping with HIV&AIDS not as a fixed trait or mode of behaviour, but as a process that is influenced by context and time.

The process approach, on the other hand, regards coping as an '*effort to manage stress that changes over time and is shaped by the adaptational context from which it is generated*' (Lazarus, 1993:234). In support of this approach, Ridder (1997:418) regards coping '*not as an enduring personality trait, but rather as a constellation of certain cognitions and behaviours that occur in reaction to specific stressful situations*'. As such, an individual who has to cope with a challenge relies on available personal and social resources as well as on the context in which the stressors occur. The fact that stressors and difficult situations vary, results in the idea that coping is a continuous and dynamic process that changes, due to external environmental factors, an individual's capacity to cope, as well as the interrelationship between the environment and the individual. Therefore, I regard coping as the (continuously changing) processes (including both cognitive and behavioural efforts) of adapting to and managing internal and external demands (Buchwald, 2003; Donnelly, 2002; Snyder & Pulvers, 2001; Muldoon & Cairns, 1999; Ridder, 1997; Lazarus, 1993). In applying this view to the field work that I conducted, I view coping with HIV&AIDS by the informal settlement community I selected as a process whereby community members are continually required to manage the challenges related to the pandemic – both the challenges experienced internally (such as feelings and perceptions) and those on an external level (like stigmatisation by other community members).

Relatively recent perspectives on coping build on the work of Lazarus, classifying coping theories into contextual, dispositional or integrative frameworks. Contextual approaches emphasise the role of situation-based factors, whereas dispositional approaches relate coping behaviours to person-based characteristics. These two approaches are combined in integrative frameworks such as Folkman and Lazarus'

person-environment interaction model, according to which coping implies the use of both situation-based factors and person-centred characteristics in dealing with challenges (Buchwald, 2003; Frydenberg, 2002; Frydenberg, 1999; Holahan, Moos & Schaefer, 1996). Within the context of my study, I support the view that coping implies an interactive link between environmental influences (situational factors) and personality traits. In addition, I acknowledge the influence of culture on the ways of coping employed by people when faced with challenges.

Coping entails a multidimensional process and a combination of events that continue through individuals' lives, and on which a variety of determinants have an influence. It implies a process of dynamic interaction between people and their environments, referred to as transactional coping. After experiencing demands in the environment, the individual needs to make a decision on how to manage the experienced stress. This process of cognitive appraisal of a situation is followed by certain responses and emotional reactions, in terms of coping behaviour aiming to restore equilibrium. The ultimate outcome of the decision making process is then reappraisal or a coping response, which will in turn impact on the individual's environment (Ebersöhn & Eloff, 2002; Frydenberg, 2002).

Restoring equilibrium does not necessarily imply a sense of total control, it merely aims at minimising the distress caused by a specific situation. Snyder and Pulvers (2001:4) summarise this view as follows: '*coping reflects thinking, feeling, or acting so as to preserve a satisfied psychological state when it is threatened*'. Besides these determinants (emotion, cognition and behaviour), the unique personality and personality traits of the individual coping with a challenging situation also influence the way of coping, as well as the personal and environmental resources that are available. During any coping effort, the meaning that is attached to a specific stressor (HIV&AIDS and the related challenges within the context of my study) will influence the appraisal of the stressor as being severe or not. This meaning is often based on prior experiences, memories and belief systems (such as experienced stigmatisation, discrimination and isolation) (Dirkzwager, Bramsen & Van der Ploeg, 2003; Frydenberg, 2002; Gibson *et al.*, 2002; Frydenberg, 1999).

Lazarus determined two main categories of coping, namely problem-focused coping (environment-directed strategies) and emotion-focused coping (self-directed strategies). In problem-focused coping, the individual facing a challenge actively attempts to change the challenging situation by, for example, seeking external assistance or advice on effective coping strategies. Emotional-focused coping, on the other hand, implies that the individual facing the challenging situation relies on thoughts and behaviours in order to manage the negative emotions that are often experienced during difficult times. As such, the individual attempts to accept the challenging situation as a reality and make the best of it (Whitty, 2003; Snyder & Pulvers, 2001; Williamson & Dooley, 2001). Within the context of coping with HIV&AIDS, I support Lazarus' distinction, as different people respond differently to the challenges implied by HIV&AIDS. For example, problem-focused coping might be employed by a person actively seeking information on HIV&AIDS upon becoming aware of an HIV positive status. On the other hand, emotional-focused coping might be employed when an individual relies on positive thoughts to cope with the positive outcome of an HIV test.

Whitty (2003) suggests that coping strategies be viewed in relation to defence mechanisms, as people facing difficult situations often rely on both defence mechanisms and coping strategies to overcome the challenge they face. I relate this idea to Snyder and Pulvers' (2001) description of the *avoidance-approach* way of coping, whereby an individual experiencing stress or a challenging situation will either *avoid* coping (defence mechanism of denial) or *approach* the situation, thereby relying on coping strategies. Denial might be regarded as adaptive in the short-term, as it allows the individual to come to terms with the impact of the stressor and to gradually start working on a more long-term way of coping. Within the context of my study, denial might enable an individual living with HIV&AIDS to overcome initial fear of stigmatisation and isolation, whilst accepting the fact of being HIV positive.

During *avoidance coping*, an individual will firstly analyse an experienced stressor in terms of seriousness and possible consequences (Lazarus' concept of *primary appraisal*). In the case of the stressor being experienced as having personal relevance and particularly when experienced as threatening, the individual will react with so-called *denial numbness*, denying the situation and avoiding coping. I assume

that, within the context of HIV&AIDS, where the stressor is mostly experienced as life-threatening, denial numbness might often be implemented by people living with HIV&AIDS. In the case of the stressor not being perceived as too threatening, the individual will start appraising possible responses to the stressor as it is perceived (so-called *secondary appraisal*). This will result in the perception that the stressor is overwhelming and that the resources available will not enable the individual to cope effectively, leading to the individual submitting to avoidance strategies. This in turn might result in the individual being even more aware of the stressor, experiencing intensified self-focus or disruptive thoughts and emotions, due to the fact that coping did not take place (Snyder & Pulvers, 2001; Frydenberg, 1999).

On the other hand, *approach coping* also implies an analysis of the stressor, but with the aim of lessening its threatening qualities. This is followed by an appraisal of potential responses, resulting in the individual selecting one or more suitable coping strategies and implementing either emotion-focused or problem-focused coping. Emotion-focused coping strategies (such as avoidance, wishful thinking and accepting responsibility) are often used when a stressor is perceived as uncontrollable, whilst problem-focused coping strategies (like planned problem solving strategies) are usually employed when a stressor is perceived as controllable. Within the context of my study, denial, concealment, isolation and crying are examples of emotion-focused strategies often employed by people that are infected with HIV. Denying one's status can be ascribed to the individual's refusal to accept the HIV status, whilst concealment is associated with the fear of being abandoned, or avoiding a situation whereby additional stressors could be added to uninfected family members (Brandt, 2005; Dirkzwager *et al.*, 2003; Snyder & Pulvers, 2001; Hackl, Somlai, Kelly & Kalichman, 1997).

Social support is a key concept in coping, as people facing challenging situations often rely on the support of others to cope with the challenge at hand. Social support implies three main areas of support, namely concrete, tangible and practical support; instrumental or informational support in the form of advice; and lastly emotional support (Dirkzwager *et al.*, 2003; Greenglas, 2002; Dillon & Brassard, 1999). Concerning social support, research indicates a specific strong link between coping and support by women. As opposed to men, women tend to rely on interpersonal

relationships and talking to people in their support networks, in order to cope with challenges. They access social support more easily and are more sensitive to the needs of others, as specified by traditional gender-role expectations. As women are more communally oriented, they seem to rely on colleagues as source of social support more often than men. Besides these external coping options, individuals rely on internal coping options when facing challenges, such as self-efficacy, a positive self-esteem, adaptive skills and optimistic self-beliefs (Gibson *et al.*, 2002). Within the context of my study and an informal settlement community coping with HIV&AIDS, I wonder about the levels of importance that might be placed on social support as a possible coping strategy.

Johnson and Johnson (2002) base their view of coping on such social interdependence between people. According to the *interdependent-self approach to coping*, individuals are involved in networks of interdependent relationships with family members, friends, other community members, people at church and in other walks of life. When faced with stress, people therefore rely on their social networks for support and the provision of resources. In this manner, coping is regarded as a joint process of problem-solving and social support, where individuals experience challenges within established networks that might assist them in coping, by implication employing communal coping. As opposed to interdependent coping, the independent-self approach to coping emphasises the individual as an isolated and independent unit who deals with stress independently, by relying on personal resources only. Community-based coping inevitably implies an interdependent-self approach to coping. Furthermore, I propose that an interdependent-self approach to coping might relate to the asset-based approach, which is discussed in section 2.4 (Johnson & Johnson, 2002; Muldoon & Cairns, 1999).

Lately, research has been focusing on *proactive coping,* whereby the quality of life is improved in preparation of challenges and difficult situations. As such, general resources are built up in order to promote personal growth and the achievement of goals. In addition, *preventive coping* (building resources in order to reduce the consequences of stress) and *anticipatory coping* (anticipating a challenge and dealing with it) are often the focus of research in the field of coping (Ebersöhn, 2006; Greenglas, 2002). In addition, religious coping is often mentioned, referring to the

tendency to rely on religion as the primary source of coping with difficult situations or challenges, such as life crises. The basis for religious coping lies in the fact that religion provides specific methods for people to cope with life stressors and obtain meaning and significance in difficult situations. Methods of religious coping include, amongst other strategies, *deferring religious coping* (submissively waiting for God to control the difficult situation), *pleading religious coping* (seeking help from God), *seeking spiritual support* (relying on God's love and care to obtain comfort and reassurance), and *seeking congregational support* (relying on the love and care of congregation members) (Pargament, Poloma & Tarakeshwar, 2001). Within the context of my study, I ponder upon the thought whether or not religiosity and faith might be employed as coping strategies by informal settlement community members in coping with HIV&AIDS. As I assume the selected community to be coping with the resources available to them, I propose that they might rely on religion and faith in addressing the challenges they face, such as HIV&AIDS.

2.3.2 COPING WITH HIV&AIDS

I commence this section by discussing coping as being community-based by nature and implying empowerment as central concept. Next, I discuss coping in terms of coping with being infected with HIV or living with AIDS, coping by means of providing care and support to others living with HIV&AIDS, and coping with children orphaned due to HIV&AIDS. These discussions provide the necessary background against which I approached the empirical part of my study, focusing on an informal settlement community coping with HIV&AIDS.

2.3.2.1 General quest for community-based coping

It is widely documented (refer to Lucas, 2004; Mallmann, 2002; Van Dyk, 2001; Child Protection Society of Zimbabwe, 1999; Geballe *et al.*, 1995 as examples) that communities are supposed to have control over their own well-being and that any response to HIV&AIDS might be guided by the experiences of community members on ground level, as they are the people who feel the impact of the pandemic and who must find ways of facing the challenge. I adhere to Mallmann's (2002:20) emphasis on the importance of fellow community members in coping with challenges such as

the HIV&AIDS pandemic, as the '*impact of disasters is shared rather than experienced alone*'. I further support Kretzmann, McKnight, Sheehan, Green and Puntenney (1997:1), emphasising the importance of coping being embedded in the community, by stating that '*communities are made stronger when residents use their full potential by directing their capacities toward the well-being of the neighborhood*'. Community-based coping supports the *Ubuntu* principle, a philosophy characteristic of South African indigenous communities.

Loots (2005) defines community-based coping as the ability of a community to effectively deal with challenges within the community, within the specific, dynamic and multi-functional social system. In coping with challenges, community members strive towards a mutual goal, share responsibility and respect the well-being of the group. To my mind, the well-being and health of communities imply their ability to cope with challenges like HIV&AIDS, as coping often results in well-being and health. Community-level responses are steered by community members themselves, becoming aware of their own capabilities and responding to the concerns and needs of community members by relying on the resources, skills, knowledge and talents available in the community. As community involvement is encouraged for the different phases of HIV&AIDS intervention initiatives, people on community level could be involved in planning, implementing and assessing HIV&AIDS programmes. Community responses range from informal care for orphaned children by relatives and neighbours, to planned intervention by outside organisations, facilitating change in communities by involving community members (often volunteers) (Cabassi, 2004; Lucas, 2004; Browde, 2003; Cloete, 2003; Goudge, Gilson & Msimango, 2003; Smart, 2003a; Department of Social Development, 2002; Kelly *et al.*, 2002; Foster, 2001; Sayson & Meya, 2001; Smith, Littlejohns & Thompson, 2001; Van Dyk, 2001; Child Protection Society of Zimbabwe, 1999; Geballe *et al.*, 1995). I propose that this focus on well-being and community health, as well as the basic approach of relying on existing resources in order to address challenges, links with the asset-based approach, which I discuss in detail in section 2.4.

Outside intervention implies participatory research and intervention – as I implemented in my study. As I facilitated certain actions in the community (per definition doing intervention) while conducting research, I conducted community-

based activist intervention research. During the process I focused on a community instead of individuals, and worked in partnership with the community members without interfering in their performance of the usual daily activities. My actions ultimately aimed at participants being empowered and social change being facilitated within the community, in order to promote its well-being and health (Blumenthal & Yancey, 2004; Minkler & Hancock, 2003; Minkler & Wallerstein, 2003b). As such, I employed the self-help model of community development (Bender, 2004), based on my belief that community development concerns helping community members to help themselves. I merely acted as facilitator, guiding the participants to set goals and plan action steps.

In line with the basic principles of the asset-based approach (as discussed in section 2.4), pioneers in community capacity building (or *asset-based community development*) propose that outsiders (such as the government, NGOs or other volunteers) merely act as facilitators in guiding community members to firstly identify the community's challenges, needs and strengths, and secondly, to formulate and implement plans and ways of utilising the existing strengths to address the identified challenges and improve the community (Snow, 2001b; Kretzmann & McKnight, 1993). During this process, outsiders need to guard against imposing their cultural values or ideas on community members, as they might not fit into the local system. During my involvement in the selected community I adhered to the following suggestions by Mokwena (1997:67), which do not only support effective community development initiatives, but are also in compliance with the basic principles of PRA:

> *Communities need professional guidance and support in initiating the process of empowerment but the professionals must appreciate the need for the community to stand on its own as soon as possible. The community must be allowed enough space to be able to make their own decisions regarding issues that affect them and to employ strategies that are in accordance with their own norms with the professional being available to help when requested or needed.*

By building community members' capacity to work together in addressing communities' challenges, community development inevitably occurs, resulting in so-called *community competence*. Community mobilisation, on the other hand, refers to the guidance of community members to accept responsibility and take action with regard to existing challenges, thereby taking ownership and regarding it as their own

priority to address (Smith *et al.*, 2001; Snow, 2001b; Kretzmann & McKnight, 1993). External agencies might facilitate this process of mobilisation, thereby assisting community members in helping themselves by, for example, increasing their decision-making powers, encouraging their ability to support other vulnerable community members, and providing training and support where needed (Richter *et al.*, 2004; Smart, 2003a; Department of Social Development, 2002; Sewpaul, 2001; Khmer HIV/AIDS NGO Alliance, 2000; Kretzmann *et al.*, 1997). As existing literature does not provide distinct guidelines in terms of the level of involvement required from external agencies, my study might contribute to this body of knowledge. As I fulfilled the role of outside facilitator during my study, I was able to explore this area of interest.

In describing community mobilisation as part of a community-based HIV&AIDS prevention and care programme implemented in Malawi, Hunter (2002) emphasises the link between the *sustainability* of social change on the one hand, and community members owning the process and the communication involved on the other, thereby *building capacity* and making communities the *agents of their own change*. Communication could strengthen relationships in the community, empower community members and build their confidence. In my opinion, self-worth and feelings of pride can in turn be relied on as assets, assisting community members in coping with HIV&AIDS. Emphasis might, however, rather be placed on debate and negotiation, instead of the transferral of information. As such, I emphasise the importance of moving away from a so-called *welfarist* approach to a long-term *development approach* (Strebel, 2004; Mugabe *et al.*, 2002; Subbarao *et al.*, 2001; Broughton, 1999; Child Protection Society of Zimbabwe, 1999). In my field work, I supported the development approach to community-based coping with HIV&AIDS, as I regard the answers to questions and the responses to challenges as being situated within the communities involved, thereby propagating the asset-based approach.

Community development initiatives imply intervention and involve role-players on various levels and from different sectors. According to this people-centred approach the focus, amongst other objectives, falls on developing the potential of individuals, families and communities. Facilitating community-based change implies certain principles, for example trusting people with their own development and believing that

the local community is the most sustainable basis for development, as people possess knowledge and wisdom that might impact on their development. Empowerment within the context of HIV&AIDS might result in community members acting responsibly and being self-reliant, in an attempt to decrease community members' vulnerability to HIV&AIDS and promote the community's health. Apart from being child-centred, family- and community focused, any intervention initiative are required to respect the basic rights of those involved (Bender, 2004; Cabassi, 2004; Green & Haines, 2002; Smith *et al.*, 2001; Karnpisit, 2000; Broughton, 1999; Buysse, Wesley & Skinner, 1999). Based on striking similarities with PRA, I summarise the human capacity development approach in terms of the following four key elements, as identified by Lucas (2004): local response, organisational change, policy and the transfer of knowledge acquired through local action and experience. I trust that the latter component will be a potential outcome of my study, where other communities can learn from the experiences of the selected community and participants in my study.

In planning and conducting my study I considered the eight core principles of effective community building initiatives, as identified by the National Community Building Network and formulated by Snow (2001a). The first principle requires that *community development and human service strategies be integrated*. Although my study mainly focused on the enhancement of human capital in terms of the community members' ability to cope with HIV&AIDS, it included the development of a vegetable garden at the school through which I entered the community, thereby integrating community development and human service strategies. In an attempt to *maintain racial equity* I approached my study with an *equity-for-all-groups* attitude, respecting role-players and their contributions as of equal importance. I *valued cultural strengths*, by respecting the cultural assets and strengths of the participants as well as other community members throughout my study. Although my study mainly involved selected educator-participants, *broad community participation was encouraged*, by extending participation to other community members as part of the projects initiated by the educators. I strived to *build partnerships by means of collaboration,* by encouraging educator-participants to form networks and build partnerships with stakeholders in the community, which they did when planning and implementing the three projects. I *started from local conditions* by starting from and

continuously working with the challenges and potential strengths of the community. Furthermore, I aimed at *supporting families and children* during my study. In regard to this principle, a direct outcome of my study was that families and children were indeed supported in the community, guided and facilitated to be able to help themselves, thereby resulting in a stronger community, in a position to address the challenges it faces. Lastly, I *built on community strengths* by employing the asset-based approach, thereby emphasising the value of assets, as well as the importance of relying on local resources and capacities in overcoming challenges.

Community level responses to HIV&AIDS are often mediated by *social capital,* which refers to the characteristics of community members that enhance cohesion and a sense of belonging, thereby encouraging community members to participate in activities that might promote the community. Within the context of my study, it entails networks that community members might rely on in order to work together towards a shared goal (such as initiating school-based projects), thereby strengthening the community. In this manner, social capital facilitates people and institutions to work together for the purpose of mutual social benefit (coping with HIV&AIDS as a community). Therefore, communities with a high level of social capital might be able to more easily cope with social challenges (Lucas, 2004; Kelly *et al.*, 2002; Ngcobo, 2001).

As families are the building blocks of communities, community-based coping implies family-based coping. The opposite also applies, as family-based coping implies community-based coping. I regard family as the *heart of the social context.* It is ironic that, on the one hand, the family is one of the most important social resources in coping with HIV&AIDS, due to the care and support provided within this context, but on the other hand, the impact of HIV&AIDS on the family is so immense. It is within the family that loss is experienced, fears faced, decisions made and alternatives evaluated. However, many functions of the family might be performed by institutions in society, such as schools, churches and social service departments, once again emphasising the importance of community-based responses to a challenge such as the HIV&AIDS pandemic (Amoateng *et al.*, 2004; Barolsky, 2003). As I respect the potential value of the relevant role-players in coping with HIV&AIDS, I explored these as both assets and potential assets during my study.

2.3.2.2 Empowerment as central concept of community-based coping

I support Leach's (2003b:21) definition of empowerment as '*the process or processes whereby people become aware of their own interests and the power dynamics that constrain them, and are then able to develop the capacity and the means to take greater control of their lives*'. To me, empowerment implies specific outcomes, centred on the well-being of those who are involved, in terms of an improvement of their life situations. It implies participation and agency, with the aim of actualising strengths and mobilising community resources. This might result in an increase in personal, interpersonal and economic power (Saidi, Rosenzweig & Karuri, 2003; Bartle, Couchonnal, Canda & Staker, 2002; Karnpisit, 2000; Mokwena, 1997; Sewpaul, 1993).

I adhere to the idea of empowerment implying that people who seemingly do not have access to resources, can take the primary responsibility to develop strategies whereby they can increase their power, gain control and accept agency over their own lives, by making changes where necessary. This dynamic process of capacity building usually results in individual development and growth, which in turn could add to social change on a broader level. Within the context of HIV&AIDS, empowering people implies that individuals or groups of people (such as informal settlement communities) are involved in projects, and are encouraged to address their own health concerns by finding their own solutions and accepting agency with regard to the HIV&AIDS-related challenges they face. By being empowered, the self-esteem and self-confidence of individuals is enhanced, as well as feelings of efficacy and self-reliance, building on relationships and working collectively, as opposed to relying on external resources when facing challenges. Although *outside role-players might facilitate* empowerment by providing suitable resources, ideas and experiences, I believe that the process of *assuming power* and *accepting agency lies within the person participating in the process of empowerment*. By being involved, community members' commitment is encouraged, as well as their co-operation, local ownership and the possibility of development being sustainable (Kabiru, Njenga & Swadener, 2003; Saidi *et al.*, 2003; Bartle *et al.*, 2002; Sims, 2002; Foster, 2001; Van Dyk, 2001; DeGraft Agyarko, 1998; Mokwena, 1997; Archer & Cottingham, 1996; Nelson & Wright, 1995; Slocum & Thomas-Slayter, 1995; Sewpaul, 1993). Within the

context of my study, I propose that community members that are implementing the asset-based approach could accept agency and be empowered during the process of intervention research, thereby being able to cope with the challenge of HIV&AIDS.

According to the *Cornell Empowerment Group* (Sims, 2002), empowerment rests on ten assumptions, to which I adhere and in accordance with which I entered the research field. I assume that people possess strengths. I value differences between individuals and their backgrounds, and view the needs of individuals within their wider contexts. I recognise the ability of individuals to make choices, and do not regard the deficit approach as suitable for empowerment efforts. I value an understanding of culture and culture-related roles and expectations as essential, as well as an understanding of patriarchy and how it influences roles and expectations. I assume power to be the centre of accessing resources and as something that needs to be understood, functioning both directly or indirectly. Finally, I assume that empowerment is directed at the reallocation of power and resources.

Mokwena (1997) provides specific strategies to empower communities, which I adhered to during my study. Firstly, I facilitated community members (participants) to realise, appreciate and utilise their assets and talents, in order for them to become aware of the fact that they are capable of helping themselves. I challenged their feelings of powerlessness, and encouraged them to take control over their lives, in order to enhance their participation in decision-making and community-based action plans. In order to support them, I supplied information that they did not have easy access to and established social support networks. I encouraged participants to participate in community issues, thereby developing ownership and evoking feelings that they are obligated to ensure success of initiatives. Lastly, I guided them to develop local leadership skills, as this can enhance sustainability of development initiatives.

2.3.2.3 Coping with being HIV infected or living with AIDS

I believe that people living with HIV&AIDS have to cope with their illness in order to be able to live positively and plan for the future. Coping with HIV&AIDS implies various challenges. It often implies coping with the loss of loved ones, as well as the

physical and psychosocial symptoms implied by the disease, including the possibility of stigmatisation and discrimination. Furthermore, families living with HIV&AIDS have to cope with additional financial burdens placed upon them when individuals can no longer earn an income, and have higher expenses due to treatment and basic health care. Families often do not even have money for transport to health care facilities, resulting in them relying on home-based care. In addition, people have to disclose their status in order to access such services – something that is not always done (Swanepoel, 2005; Richter *et al.*, 2004; Nnko *et al.*, 2000).

In reaction to confirmation of their HIV positive status, and that they are faced with a life threatening, chronic illness, people often employ one of two main coping strategies, namely vigilance and avoidance. People will apply *vigilance* as coping mechanism in an attempt to reduce their levels of uncertainty and stress by, for example, actively seeking knowledge in order to use such newly acquired knowledge to cope with their illness. These individuals therefore usually disclose their status, in order to access the help and support that are available. On the other hand, people infected with HIV might rely on *avoidance* in an attempt to cope with their illness. These individuals will avoid disclosing their status, in an attempt to protect themselves (McDonald, 1998). Besides denial, isolation and crying, other coping strategies that might be employed include religion, strategies that focus on family unity and, in rare cases, a positive future perspective (Rehm & Franck, 2000). With relation to these potential ways of coping with HIV&AIDS, I hypothesise that members of the community where I conducted my study might employ a combination of these strategies, depending on the individual as well as the context.

2.3.2.4 Coping as being related to providing care and support to others living with HIV&AIDS

People with AIDS usually rely on the support of social systems such as extended family members, traditional support systems or other community members in order to cope with the challenge they face. In this manner, they rely on so-called coping resources, in other words, reasonably stable characteristics in themselves and their environments. Besides family members, support groups or self-help groups may play a significant role in the life of a person living with HIV&AIDS, by providing emotional

and social support, as well as the opportunity to learn from one another. Other potential resources include the mass media, which may convey HIV&AIDS-related information, but might not reach the spectrum of communities easily; the possibility of community home-based care; facilities such as clinics, hospitals and hospices; as well as support systems like women's and religious groups (McCausland & Pakenham, 2003; Parker *et al.*, 2000; Van Dyk, 2001; Zimba, 2000).

A strong sense of community can be identified as prerequisite for not isolating those living with HIV&AIDS, as collaboration and a sense of cohesion might result in a community sharing resources in order to support community members living with the disease (McCausland & Pakenham, 2003; Mallmann, 2002; Mkwelo, 1997). Within the context of my study, knowledge of the potential social systems guided me in exploring the ways in which participants cope with HIV&AIDS, by implication coping with being infected, coping by providing care and support to others living with HIV&AIDS, or coping with children that are orphaned due to HIV&AIDS.

2.3.2.5 Coping with orphaned and vulnerable children

Although caregivers of orphaned and vulnerable children differ across regions, these children are mostly cared for by the surviving parent or alternatively by a relative (Miamidian *et al.*, 2004; Gilborn *et al.*, 2001). Various authors (such as Brouard *et al.*, 2005; the International Social Service & UNICEF, 2004; Nyambedha, Wandibba & Aagaard-Hansen, 2003; Van Dyk, 2001; Cook, 1998) are, however, of the opinion that extended family systems are overburdened, especially in communities with limited resources, and suggest that programmes be developed to support families' ability to cope with these children. Yet, despite ongoing debates, the extended family still seems to form the primary basis of coping with orphaned and vulnerable children, with women (for example aunts and grandmothers) seemingly being the primary role-players (Amoateng *et al*., 2004; Monasch & Boerma, 2004; Winkler, Modise & Dawber, 2004; Barolsky, 2003; Lachman, Poblete, Ebigbo, Nyandiya-Bundy, Bundy, Killian & Doek, 2002; Sayson & Meya, 2001; Boxer, Burke, Cohen, Cook, Weber, Shekarloo & Lubin; 1998). Against the background of these seemingly contradicting opinions, my study might contribute by providing insight into the selected community's way of coping with children that are orphaned due to

HIV&AIDS, situated within the broader context of coping with HIV&AIDS. In addition, based on the fact that I selected an indigenous community in which to conduct my field work, the possibility of culture and women forming components of coping exists. By exploring this as part of my study, contributions might be made in terms of the significance of culture and (African) women in coping with vulnerable and orphaned children.

Grandparents and relatives caring for orphaned and vulnerable children are, however, often old and/or impoverished. Besides the financial challenges placed on family members taking care of orphaned children, these children typically display the need for medical care, love and support within a family context, as well as the need for education. In such cases, extended families might turn to other community members for support. In the rare case of relatives or community members not being available or able to take orphaned children into their care, children might end up living in child-headed households, placed in institutions (the last resort) or end up as homeless children on the street (Monson, 2005b; International Social Service & UNICEF, 2004; Linsk & Mason, 2004; Richter *et al.*, 2004; Nyambedha *et al*., 2003; Ramsden, 2002; Berns, 2001; Gilborn *et al.*, 2001; Ratsaka-Mothokoa, 2001; Sayson & Meya, 2001; Subbarao *et al*., 2001; Townsend, 2001; Zimba, 2000; Geballe *et al.*, 1995).

In addition to relatives and other community members, I regard the South African government as fulfilling a role with regard to orphaned children and families taking care of them by, for example, offering financial assistance in the form of a variety of government grants, food support for impoverished families, free health care for children under six, exemption from school fees and free vocational training for young people (Richter *et al.*, 2004; Meintjes, Budlender, Giese & Johnson, 2003; Ramsden, 2002; Centre for Policy Studies, 2001; Ngcobo, 2001; UNICEF, 2001). Finally, schools seem to play a role in supporting communities coping with children infected with and affected by HIV&AIDS, by collaborating with role-players on other levels and providing assistance to the families of children infected with and affected by HIV&AIDS. Despite the fact that South African legislation requires of schools to have an HIV&AIDS policy in place, and provide for free education for children who cannot afford to pay, this is not always adhered to, as schools need the money to manage

day-to-day expenses. School-based support further includes the early identification of children infected with and affected by HIV&AIDS, addressing their special educational needs, referral and monitoring of vulnerable children, teaching learners life skills, providing school-based nutrition programmes, providing pastoral care and counselling, financially assisting children who need it, involving caregivers and guardians, and supporting children living with HIV&AIDS (Marais, 2005; Amoateng *et al*., 2004; Brookes *et al.*, 2004; Bennell, 2003; Giese *et al.*, 2003; Smart, 2003a; World Bank, 2002; UNICEF, 2001; UNICEF, 2000b).

2.4 UNDERLYING APPROACH: THE ASSET-BASED APPROACH

I now turn my discussion to the asset-based approach, being the underlying approach on the basis of which I planned and undertook my empirical study. Page-Adams and Sherraden (1997:431) summarise the emerging nature of the approach: '*Although asset-based community development is in the early stages of formation and little guidance exists about how to proceed in terms of models and implementation, the concept invites innovation, creativity and adaptation to many populations and purposes.*' Du Preez (2005), as well as Lubbe and Eloff (2004), add to this by emphasising the emerging nature of research and practice relating to the asset-based approach, leaving the field open for my study in terms of contributing to the existing base of knowledge. In addition to a range of studies by Ebersöhn and Eloff (2006; 2002; 2001), various small-scale studies are (and have been in recent years) ongoing, to build on the emerging theory of the asset-based approach, for example the studies by Coetzee (2005), Ferreira-Prévost (2005), Griessel-Roux (2005), Smuts (2005), Viljoen (2005), De Wet (2004), Briedenhann (2003) and Kriek (2002).

The asset-based approach was initially introduced in the early 1990s by Kretzmann and McKnight (1993), within the context of community development and empowerment. I support these authors by propagating that the asset-based approach might be regarded as a change in perspective rather than a comprehensive and complete approach, as it shifts the focus from external help and services being provided to a community, to empowerment and developing a

community from the inside out. In support of this line of thinking, I subscribe to Eloff and Ebersöhn's (2001) view that the asset-based approach is more than just an intervention approach, but concerns attitudes towards people, as well as strategies of intervention. As such, I regard the asset-based approach as not only implying a theory, but also relating to dynamic strategies for intervention (Ebersöhn & Mbetse, 2003). Within the context of my study, I decided on exploring the manner in which an informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources, based on the reality that communities currently have to cope with the challenges implied by HIV&AIDS, and secondly on the possibility of relying on the asset-based approach in doing so.

Although the asset-based approach was initially introduced within the context of community development, it has since been applied with success in other contexts, thereby highlighting the suitability thereof for individuals or groups of people, such as families, schools and (informal settlement) communities facing (HIV&AIDS-related) challenges on various levels (Lubbe, 2004; Lubbe & Eloff, 2004). In accordance with the underlying framework of the asset-based approach, I view individuals (and their assets) on the following four levels: the individual, the local community (families, schools and peer groups), the wider community and the whole social system. Furthermore, I continually keep in mind that the various levels are constantly developing and interacting with one another (Eloff, 2006b).

Eloff (2006b) identifies various potential role-players within the context of the asset-based approach, which also applies to my study. Besides the potential assets and strengths of individuals themselves, family members, the school, classroom and members of the peer group are regarded as potential assets. In addition, community members' associations, local institutions and the broader social community can be explored. Prior to my study, these potential role-players appeared to be relevant within the context of my study, namely a community coping with the challenges related to HIV&AIDS. The various levels of contributions by the individual agents were to be explored during my field work.

I henceforth deal with the asset-based approach in terms of it being an alternative to the needs-based approach, the core of the approach and the main components or

phases of the approach. Thereafter, I elaborate on possible advantages and, lastly, the role of the facilitator.

2.4.1 AN ALTERNATIVE TO THE NEEDS-BASED APPROACH

The asset-based (also referred to as *capacity-based*) approach was introduced as an alternative to the needs-based approach (so-called deficit model), which is (and has been) often applied during intervention with individuals or groups of people. I support Du Preez's (2005) suggestion that these two approaches ought not to be regarded as opposites but rather as two approaches on the same continuum, yet at different levels, of the spectrum. Whilst the needs-based approach focuses on problems, needs and deficits, I view the asset-based approach as an approach shifting the focus to that of actively discovering resources and capacities, establishing links and initiating programmes, in order to address existing challenges, such as HIV&AIDS (Eloff, 2006a; Saidi *et al.*, 2003; Sims, 2002; Fuller & Brockie, *s.a.*).

I prefer the use of the concept *challenges* as opposed to *problems*, as I support Minkler and Wallerstein's (2003a) view of a *problem* as a concept implying that something is *wrong* (for example with a community) and needs to be fixed. I do, however, not support the use of the term *issue*, as proposed by these authors, as, according to my view, the term *challenge* implies something that is experienced by an individual or within a community (such as vulnerability within the context of *HIV&AIDS*) that needs to be *coped* with – another concept central to my study. Concerning the concept *needs*, Fuller and Brockie (*s.a.*) are of the opinion that *needs* refer to resources that have not been utilised yet, therefore *threatened assets*. As such, any perceived threats might be addressed by relying on available resources – in my opinion by implementing the asset-based approach.

By focusing on challenges (problems) that need to be solved (often with the assistance of outside expert help), I regard the needs-based approach as sustaining disempowerment, dependence and the tendency to rely on outsiders during decision-making processes. In this manner, outsiders are regarded as experts who provide information and *rescue* the people facing a challenge, often being labelled as powerless and in need of guidance (Ebersöhn & Eloff, 2006; Saidi *et al.*, 2003; Sims,

2002). As a result, individuals (in my case community members) are prevented from working collaboratively in addressing a challenge by relying on the skills and capacities amongst themselves. In this regard I support Fuller and Brockie (*s.a.*:3), summarising this idea as follows: '*Needs divide us – assets combine us*' and further stating that '*Asset-building connects people to a common cause. It brings us together, focuses our attention, and points us in the same direction*'.

Within the context of my study, the asset-based approach (as alternative to the needs-based approach) seems appropriate for viewing existing and facilitating broadened coping repertoires in an informal settlement community. Based on the current social context and reality of South African communities being characterised by poverty and a lack of external resources, I propose that communities will increasingly rely on their own available resources, in order to address the challenges associated with the pandemic. As stated earlier, despite numerous HIV&AIDS outreach projects and campaigns launched countrywide on a regular basis, poverty-stricken communities are often exposed to such initiatives on an *ad hoc* and once-off basis. I doubt if such once-off initiatives will indeed positively impact on the targeted community. As external support and assistance are therefore not likely to provide in their existing needs, I suggest that the HIV&AIDS challenge requires an approach working from the inside out, such as the asset-based approach.

2.4.2 ESSENCE OF THE ASSET-BASED APPROACH

The asset-based approach is based on three principles, namely [1]assets (the skills, knowledge, talents, resources and other assets existing in the community), [2]an internal focus (regarding the community to be capable) and being [3]relationship driven (emphasising the constant building and rebuilding of relationships within the community). The approach does not deny the existence of needs, deficiencies or problems – it merely shifts the focus from constantly emphasising such challenges (which are a reality in communities) to the capacities, strengths, ***assets*** and resources that are available in the community and might be utilised to overcome difficulties or address challenges. *Assets* imply the gifts, talents, skills, resources and capacities of individuals, families, associations and institutions that might be utilised to address existing challenges. Closely related, *strengths* entail behavioural

and emotional abilities, competencies and attributes that lead to feelings of personal achievement and attribute to successful relationships (Eloff, 2006a; Bouwer, 2005; Lubbe & Eloff, 2004; Eloff & Ebersöhn, 2001; Rhee, Furlong, Turner & Harari, 2001; Snow, 2001b; Rudolph & Epstein, 2000; Child Protection Society of Zimbabwe, 1999; Kretzmann & McKnight, 1993). Within the context of community development a community asset can be defined as '*anything that can be used to improve the quality of community life*', including community members and their connections, knowledge and experience within the community, physical resources and local businesses (Saidi *et al.*, 2003). By choosing to explore the use of the asset-based approach in coping with HIV&AIDS, I am emphasising assets, and following an internal focus and relationship-driven approach.

As the asset-based approach is ***internally focused***, I continually emphasise the selected community's interests, challenges, priorities, creativity, strengths, hopes and power, as identified and defined by community members (participants) themselves. As such, I adhere to the idea that the challenge of HIV&AIDS be addressed within context (an informal settlement community), by re-assessing and evaluating resources and potential resources in the immediate environment in terms of the possible (and sometimes new) ways that they might be utilised in overcoming difficulties. In addition, and in accordance with the asset-based approach, I recognise the potential value of external agencies and resources, but also believe that external resources might be utilised more effectively when internal resources have been mobilised and the aim of obtaining additional (external) resources has been determined by the community (Eloff, 2006a; Bouwer, 2005; Lubbe & Eloff, 2004; Minkler & Hancock, 2003; Kriek, 2002; Sims, 2002; Eloff, 2001; Eloff & Ebersöhn, 2001; Smith *et al.*, 2001; Snow, 2001b; Emmett, 2000; Ammerman & Parks, 1998; Mokwena, 1997; Trivette, Dunst & Deal, 1997; Kretzmann & McKnight, 1993).

I regard ***relationships*** as central to asset-based community development. As such, and for the purpose of my study, I do not merely focus on the assets in the selected informal settlement community, but also on establishing and maintaining relationships between the assets, namely individuals, local associations and institutions. As individuals form part of various circles (such as families, friends,

colleagues, peers and fellow community members), community development can be facilitated when the relationships between the various role-players are enhanced. To me, this idea of community development based on relationships emphasises the applicability of the asset-based approach to traditionally rural communities (and which can be applied to informal settlement communities), which are usually characterised by close relationships between community members, and support for one another, as well as the tendency to rely on what is available when facing challenges (Ebersöhn & Eloff, 2006; Eloff & Ebersöhn, 2001; Snow, 2001b; Kretzmann & McKnight, 1993).

2.4.3 MAIN COMPONENTS OF THE ASSET-BASED APPROACH

I support Saidi *et al.*'s (2003) identification of three main components of the asset-based approach, namely asset mapping, asset mobilisation and asset management. As I believe that successful implementation of the asset-based approach is based on the people involved, focusing on assets that can be utilised to address challenges, my view is that they firstly need to acquire knowledge of the accessible resources and assets available within the environment (community). As such, I regard the assessment of (community) assets and resources, with the aim of obtaining an overview of the available assets, as the first component of the asset-based approach (Minkler & Hancock, 2003; Kretzmann & McKnight, 1993).

2.4.3.1 Asset mapping

Community development (with the potential of effectively coping with a challenge like HIV&AIDS) is only possible once local members of the community become involved and committed to actively look for ways and resources that can be used to cope with the challenge at hand. To me, this implies insight by community members into the capacities, assets and abilities of the community, referring to both an individual and institutional level. Local community members therefore have the responsibility of identifying potential resources and connecting them with one another, thereby increasing their power and levels of effectiveness (Kretzmann & McKnight, 1993). Within the context of my study, such insight into available capacities and assets

seems to be the first step that needs to be actualised when implementing the asset-based approach.

My decision to facilitate participants in completing *community capacity inventories* or *community asset maps* rests on the purpose of listing the so-called *building blocks* of a community. In the first place, participants in my study had to compile individual capacity inventories, in order to obtain an overview of the knowledge, skills, abilities, talents, capacities, signature strengths, interests and experiences of community members (***individuals***), thereby relying on people and their relationships or associations as assets that might be mobilised. Secondly, I facilitated participants to compile an inventory of the repertoire of resources in the selected community, in terms of local organisations and ***associations*** (per definition *a group of local people working together towards a common goal*). In this manner, both formal and informal resources that might assist in addressing the challenges of coping with HIV&AIDS could be identified, for example community-based support groups, local churches and church groups, businesses, sport and political organisations, and youth and women's groups. Finally, an inventory of private, public and non-profit local ***institutions*** (mostly formal in nature) that might provide materials, financial assistance or other services was to be compiled, including such institutions as libraries, schools, hospitals, banks, human service agencies, parks and community centres. Although it does not usually form part of the mapping activities, I also included *risk mapping*, facilitating community members to identify the challenges faced by the community and then having discussions on how to address them, by formulating action plans (Eloff, 2006a; Bouwer, 2005; Minkler & Hancock, 2003; Snow, 2001a; Snow, 2001b; Kretzmann, 2000; Ammerman & Parks, 1998; Kretzmann *et al.*, 1997; Kretzmann & McKnight, 1993).

Concerning *personal strengths* as potential resource for coping with challenges (such as HIV&AIDS), I support Bouwer's (2005) description of three types of personal characteristics implied by the concept. Firstly, I acknowledge personal strengths as implying a positive disposition, which includes attributes like interest, being motivated, taking initiative, engaging, maintaining attention and being open and willing to identify various options and to make choices. Secondly, I view personal strengths as implying ecological resources, which refer to individuals' levels of

development, implicating their existing knowledge bases, experiences and acquired skills. In the third instance, I regard demand characteristics as part of personal strengths, as the manner in which people express themselves and respond to others, impact on the feedback they receive, as well as on the way of interpreting and perceiving experiences.

My decision to employ asset mapping was partially based on the advantages of identifying community assets, as formulated by Saidi *et al.* (2003). Firstly, in identifying assets I could obtain a holistic overview of the available resources and assets in the community. Within the context of my study, such an overview as well as an understanding of the informal settlement community enabled me to plan how to facilitate change, by setting priorities and initiating programmes. In addition, I was able to identify and eventually facilitate the utilisation of potential assets that might have been overlooked or not mobilised to their full potential. In the process, I experienced the possibility of facilitating community members to take ownership and invest in promoting the well-being of the community, which might have resulted in more effective and sustainable development. Furthermore, based on my insight into the community's assets, potential partnerships and interaction between community members, associations and institutions could be identified, as well as potential outside resources that might be contacted to complement existing resources.

Bouwer (2005) describes the asset-based approach within the framework of supporting learners that are facing barriers to learning. Applying her discussion of asset-mapping to my context results in my conclusion that a community facing the challenge of HIV&AIDS might be able to accept agency, take ownership and cope with the challenge, provided that community members are guided and facilitated to recognise and gain insight into the assets that are available to them in the community; and secondly, provided that they are steered in the direction of not merely recognising these assets, but planning how to utilise them. In this manner, I put forward that the identification of potential assets might be expanded upon to include an exploration of *how* to access them, resulting in a dynamic system of assets being utilised in overcoming a challenge (asset mobilisation).

2.4.3.2 Asset mobilisation

The identification of assets is followed by action. I adhere to the suggestion that the process of *mobilising assets* implies two components: the *agency component* (referring to the realisation and appreciation of available assets) and secondly a *mutual willingness component* (concerning potential partners and supporters who might be of assistance). As such, within the context of my study, the mobilisation of assets entails the processes of forming, accessing and utilising partnerships that might be beneficial in addressing the challenge of coping with HIV&AIDS (Bouwer, 2005; Lubbe, 2004; Ebersöhn & Eloff, 2006).

Therefore, after becoming aware of and identifying assets, networks can be established and relationships initiated between individuals, institutions and associations. In this manner, a capacity inventory is not only a list of skills, it is a way of identifying potential connections and connecting capacity information, in order to put the identified skills to work when facing a challenge. This process refers to the utilisation of asset maps, thereby mobilising (releasing) the *power of the community* (Bouwer, 2005; Ebersöhn & Mbetse, 2003; Snow, 2001b; Emmett, 2000; Kretzmann *et al*., 1997; Kretzmann & McKnight, 1993). Coetzee (2005:13) summarises this process effectively by stating that, '*for a skill, talent, gift, resource, capacity or strength to be recognised as an asset, it should be accessible, attainable and functional*'. In my study, an existing support group could only be regarded as an asset for a community member that is infected with HIV once the person has become aware of the support group and has been facilitated to start participating in the group's activities. By not accessing such a group, it would merely remain a potential resource for coping with the illness of AIDS. Yet, by accessing such a group, the group itself, as well as the members' collaborative relationships, the knowledge shared and support provided could become assets to the individual.

2.4.3.3 Asset management

The third main component of the asset-based approach concerns asset management, which implies that individuals take ownership and responsibility to sustain the actions that had been initiated, such as growth that has taken place. In

my study, employing the asset-based approach might have guided community members in taking certain actions with regard to the *critical issue of* coping with HIV&AIDS. Secondly, *relationships and social capital* could be developed amongst community members, and *community-building activities and projects* initiated. Apart from *tangible* results such as these, community members experienced feelings of belief in their own abilities, as well as those of the community (so-called *intangible* results) (Saidi *et al.*, 2003; Snow, 2001b). After initiating these actions and achieving such outcomes, the challenge is now to sustain initiated actions, especially after having terminated my involvement in the community.

Sustainability is regarded as a central concept of the asset-based approach and it may be enhanced by promoting enablement and creativity. After implementing the asset-based approach, towards the end of the process, result mapping (for example in the form of photographs or verbal accounts) may provide insight into possible changes that might have occurred, as well as into the likelihood of sustainability (Eloff, 2006b; Saidi *et al.*, 2003; Snow, 2001b; Kretzmann *et al*., 1997; Kretzmann & McKnight, 1993). I propose that the sustainability of my intervention research might only be determined a few months (or even longer) after termination of my involvement in the field. As the participants indeed accepted agency and took responsibility for identified initiatives, I predict that the projects that were initiated will probably be sustained. This is, however, a mere prediction that needs to be explored further in order to be able to reach viable conclusions.

2.4.3.4 Synthesis in terms of eight basic steps

Eloff (2006b) refines these three broad stages of the asset-based approach in terms of eight interdependent and interlinked steps, and applies them in the context of learning support and life skills facilitation. They can also be applied to community-based intervention – as employed during my study. These steps might vary from situation to situation and be followed in a linear or non-linear manner. In my study, I implemented these steps during facilitation of the asset-based approach. Table 2.1 provides an overview of the eight stages, as proposed by Eloff (2006b).

TABLE 2.1: BASIC STAGES OF THE ASSET-BASED APPROACH (Eloff, 2006b)

STEP	PROCESS	IMPLIED ACTIVITIES
1	Becoming aware of the asset-based approach	Gathering information on the approach. Becoming enabled to apply the approach.
2	Learning to focus on capacities and assets	Intentionally and constantly focusing on assets and capacities.
3	Identifying and mapping key assets	Activities such as asset-mapping, compiling capacity inventories, collaborating and participating in relationship building initiatives. Improved understanding of the context, interrelationships between systems and the potential of identified capacities and assets.
4	Asset access mapping, including relationships and power relationships	Evaluating identified assets in terms of their usefulness. Indicating access to assets, relationships between assets and power relations on asset maps.
5	Mobilising assets, in order to build strong partnerships in the immediate system	Relying on asset map information, to build strong, mutually beneficial partnerships and relationships in the community.
6	Mobilising assets, to build strong partnerships outside the immediate system	Relying on asset map information, to build strong, mutually beneficial partnerships and relationships outside the community.
7	Sustaining asset mobilisation and development	Insiders (community members) enabled to continue with collaborative efforts. Promoting empowerment and collective action.
8	Continuous revisiting, reflection, reconsidering and revising	Continuously revisiting and reflecting on the various stages. Revising steps where necessary.

2.4.4 POTENTIAL ADVANTAGES OF THE ASSET-BASED APPROACH

As the asset-based approach regards people as active mediators of change, well-being and coping, individuals or groups of people are usually enabled to effectively and confidently cope with the challenges they face by means of asset-based intervention (Ebersöhn & Eloff, 2006). Focusing on the competencies of individual community members in turn contributes to the strength of the broader community. Kretzmann and McKnight (1993:13) summarise this advantage of the asset-based approach as follows: '*Each time a person uses his or her capacity, the community is stronger and the person more powerful. That is why strong communities are basically places where the capacities of local residents are identified, valued and used*'. To me, and within the context of my study, a *strong* community refers to one where community members are able to cope with the challenges related to

HIV&AIDS, thereby enhancing the general well-being of the community. My exploration of and findings on possible changes in the general health of a community, growth and quality of life, as well as the ability to cope with HIV&AIDS by relying on existing assets and local resources, could add to the knowledge base on potential advantages of the asset-based approach.

In siding with Page-Adams and Sherraden (1997), I regard asset building as a *community revitalising strategy*, based on my view of assets having various positive effects on people's (communities') well-being. Smith *et al.* (2001) elaborate even further and regard communities with a strong capacity as healthy communities, often characterised by community members being determined to address the challenges they face, caring and trusting social relationships, a sound sense of purpose and control over life – both on an individual and communal level. In addition, community members tend to be supportive of one another and display high levels of competence and self-confidence. As such, I view community members as *co-producers of health*, cooperating with one another and working together towards a positive impact on individuals' relationships, behaviour and policies (Smith *et al.*, 2001; Kretzmann, 2000; Fuller & Brockie, *s.a.*). I therefore believe that capacity building initiatives often form part of health promotion practice. Within the context of my study, I aimed at exploring a possible connection between relying on the asset-based approach and coping with the challenges implied by HIV&AIDS.

Besides individual capacity building and strengthening of the community, other advantages of the asset-based approach (as actualised during my study) include shared responsibility and agency by community members, immediacy, relevant and practical solutions, flexibility and a warm, caring environment. In this manner, community members took responsibility for addressing the challenges they face, within the context of HIV&AIDS (Eloff, 2006a; Minkler & Hancock, 2003).

2.4.5 Role of the Outsider/Professional when employing the Asset-Based Approach

Applying the asset-based approach within the context of community development, as was done in my study, emphasises my role as an outsider and as one of

continuously exploring, assessing and focusing on individual and community-based assets, as well as guiding community members to improve by utilising what they have. In fulfilling the roles of interventionist/researcher and facilitator, I adhered to the basic principles of PRA. I (the outsider or professional) therefore had to assist the community in becoming aware of, appreciating and utilising the assets and talents available within the community, thereby encouraging local leadership. In addition, I had to network, connect and collaborate with community members and stakeholders who might fulfil a role in the community. Besides establishing social support and networks, I could provide helpful information not readily available to community members and enable them to gain access to external funding, where possible (Eloff, 2006a; Kriek & Eloff, 2004; Ebersöhn & Mbetse, 2003; Eloff & Ebersöhn, 2001; Mokwena, 1997).

My role as outsider had to shift from professional dominance to a role of facilitation and collaborating with community members. Efficient facilitation had to in turn result in community members being enabled to identify assets, even in cases where they appear not to exist. In addition, the processes of identifying and mobilising assets might have resulted in the discovery of more assets, by relying on local members of the community. Being involved in the discovery of assets and being busy with information and new skills, in turn resulted in the individuals (participants) and inevitably the community being empowered (Kriek & Eloff, 2004; Mokwena, 1997).

2.5 CONCEPTUAL FRAMEWORK FOR THE STUDY

Within the context of my study, the extensive literature on the HIV&AIDS pandemic, its impact and extent, provided me with the necessary background to the community that I selected. Characteristic of informal settlement communities in South Africa and in line with available literature, the community that I selected is characterised by poverty, limited resources, a high rate of unemployment and a high rate of HIV infections. By relying on existing literature relating to HIV&AIDS, I qualify the selected community as highly vulnerable to the impact of HIV&AIDS. As poverty and HIV&AIDS intensify one another, I regard the selected community as vulnerable, due to the high levels of poverty that community members face, intensified by the

challenges implied by HIV&AIDS, such as an inability to earn an income on becoming sick, an increase in expenses and high levels of vulnerability due to emotional and psychosocial challenges. In addition, community members typically need to cope with changes in the family, where both parents and children face the challenges of coping with family members infected with HIV or who have AIDS. Furthermore, they seem to face the challenge of coping with increased household responsibilities.

Based on the statistics available, I consider the challenge posed by HIV&AIDS as serious and relevant within the South African context, in terms of challenges like an increase in HIV infections, AIDS-related deaths, the number of orphaned and vulnerable children, child-headed households, crime and poverty. As South Africa is regarded as one of the countries most severely impacted upon by the pandemic, I support the worldwide request for rapid responses on the different levels, as well as ongoing research and monitoring of intervention initiates. I believe that prevention, treatment, care and support ought to be the focus of initiatives, but further propose that coping initiatives on ground level might be emphasised, as South Africans at present have no other option than to cope with the challenges imposed by the pandemic.

Although I highly value the important (supportive) role of the government (for example by providing financial assistance, educational support and health services), NGOs, faith-based organisations and other community-based organisations, I regard the core of coping with HIV&AIDS as being situated within the relevant South African communities. As community members experience the impact and affects of HIV&AIDS on a primary level, I put forward that they are the people that need to address the related challenges in their own unique manner and in such a way that responses fit into their unique contexts and daily lives.

In conceptualising *coping with HIV&AIDS*, I rely on existing literature on both coping theory and the HIV&AIDS pandemic. I regard coping with the challenge of HIV&AIDS as crucial, in order for individuals to be able to face the future positively. To my mind, *coping with HIV&AIDS* implies various nuances and entails different aspects. I relate *coping with HIV&AIDS* to *coping with vulnerability* – vulnerability to the possibility of

being stigmatised, vulnerability due to poverty and basic needs not being met, vulnerability to being HIV infected, vulnerability due to having AIDS, or vulnerability due to a parent, a child or family members being HIV infected or having AIDS. I view *coping with HIV&AIDS* as the dynamic process of making adjustments in reply to the various levels of vulnerability implied by the pandemic. I support Johnson and Johnson's (2002) *interdependent-self approach* to coping, according to which individuals experience challenges within specific contexts and networks available to them, within which they then employ strategies to overcome the challenges they face. I presume that there are linkages between this way of addressing difficulties and the *asset-based approach*.

In conceptualising the *asset-based approach* within the context of my study, I propagate that communities cope with the challenges implied by HIV&AIDS by relying on the assets and strengths of community members themselves, as well as on the assets and resources existing in local organisations, associations and institutions. As such, I propose that community members follow an internal approach by relying on available social support when facing challenges. In addition, I suggest that they identify resources in the external environment that might be of assistance and could be mobilised to enhance their coping.

Although I regard the ideal situation to be that people and organisations on the relevant levels become involved in responding to the HIV&AIDS pandemic, I am fully aware of the reality of South African rural and informal settlement communities more often than not being under-resourced and not the focus of external intervention initiatives. Therefore, I support the idea of *community-based responses* to the challenges implied by the pandemic, where community members themselves take the responsibility to address the challenges, by relying on their own capabilities, skills, knowledge and competencies. As such, I propose the implementation of the asset-based approach as a viable possibility of community-based coping with HIV&AIDS. In this manner, I conceptualise the asset-based approach within community-based development.

My assumption is that, by implementing the asset-based approach during community-based responses to HIV&AIDS, communities may take up agency, whilst

capacity might be built and change facilitated. I conjecture that agency and capacity building may consequently contribute to personal growth and the well-being of communities – thereby illustrating that communities are most probably coping.

In undertaking a study on the application of the asset-based approach in career facilitation, Coetzee (2005) identified certain asset-based principles, defining them as the basic beliefs valued by the asset-based (career) facilitator. Adapting these principles within the context of my study results in the following assumptions related to *coping with HIV&AIDS, within the theoretical framework of the asset-based approach*, as tenets of my conceptual framework:

- Community members take ownership of the process of coping with HIV&AIDS.
- Community members share the responsibility of identifying assets and possible strategies for coping with the challenges implied by HIV&AIDS. Whilst in the field, the facilitator (researcher) might guide and assist '*them*', but not provide advice or address challenges on behalf of the community.
- Community members can take up agency to cope with HIV&AIDS by being involved in the processes of identifying and mobilising available assets (PRA activities).
- Coping with HIV&AIDS in the community requires a collaborative effort of the relevant stakeholders.

I conclude this section with Figure 2.1, summarising my conceptual framework in the form of a metaphor. In using a tree, I regard the asset-based approach as the trunk of the tree – relying on the roots and allowing growth of the leaves. In this manner, I view the asset-based approach as a basic approach that is embedded in community-based development and that informs community-based coping. I view community-based development as the foundation of coping, thereby comparing it to the roots of a tree. By relying on the principles of community-based development and by implementing the asset-based approach during coping, communities experience growth and well-being (the leaves of a tree). Growth and well-being in turn indicate the ability to cope with challenges such as HIV&AIDS.

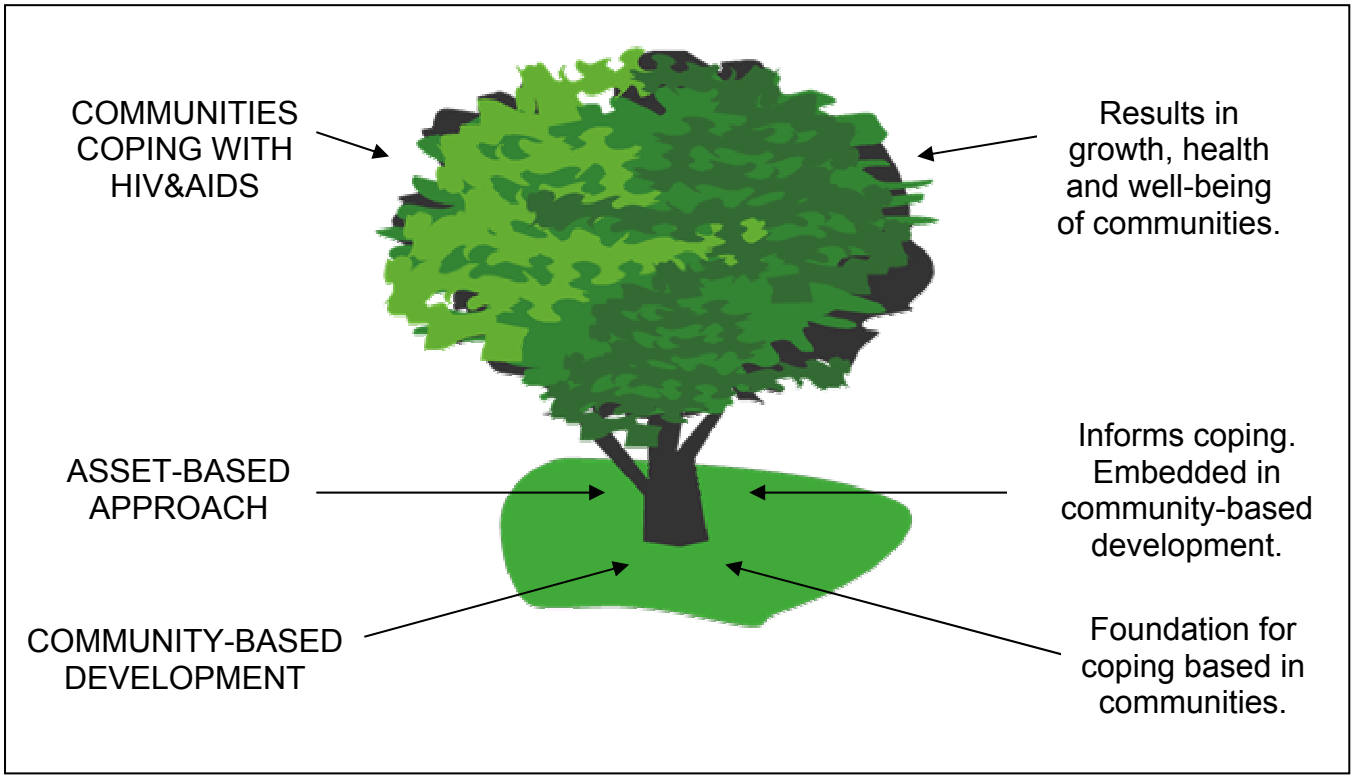


FIGURE 2.2: CONCEPTUAL FRAMEWORK FOR THE STUDY

2.6 CONCLUSION

In this chapter I situated my study within the framework of existing literature. I commenced the chapter by describing the context of HIV&AIDS, in terms of the extent of the pandemic, its impact, related challenges and required responses. Thereafter, I discussed the theory of coping, followed by an investigation of the asset-based approach. In concluding with the conceptual framework of my study, I linked community-based coping within the context of HIV&AIDS to the asset-based approach.

In the next chapter, I describe the empirical study that I conducted, based on the theoretical background provided in this chapter. I explain the methodological choices that I made within the context of my study, and in terms of my research questions, as formulated in chapter one.