

**THE SENSE OF COHERENCE AND COPING RESOURCES OF ADULT FAMILY
CAREGIVERS OF HIV/AIDS PATIENTS IN THE KWAZAKHELE AREA OF PORT
ELIZABETH**

by

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Dedication

This treatise is dedicated to all the family caregivers of HIV/AIDS patients who so freely and unselfishly give of themselves in improving the quality of life of these patients.

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Summary

Human Immune Deficiency Virus (HIV), which results in Acquired Immune Deficiency Syndrome (AIDS), has many manifestations. Literature reveals that some of these manifestations may compromise the infected individual's sense of well-being and negatively impact on health related quality of life. As the number of people living with HIV/AIDS disease grows, so does the need for their care. In the early days of the AIDS epidemic, care was primarily handled by special agencies, hospitals and clinics. These agencies have been inundated with the demands of people living with HIV/AIDS, while their resources are shrinking. As it stands now, the total assistance given to people living with HIV/AIDS is provided by relatives and this responsibility of caregiving will more increasingly rest with families. This situation is particularly salient for the rural community in South Africa, which has been disproportionately affected by the AIDS epidemic. AIDS has a tremendous impact on the entire family system, particularly on the individual who has primary responsibility for caregiving. The caregiver must cope with many circumstances that are frustrating and often beyond their control. Caring for a Person Living with HIV/AIDS (PLWHA) appears to be a major stressor in the lives of caregivers, and can be very demanding, impacting on carers financially, physically, emotionally and socially. Given the lack of research on HIV/AIDS family caregiving from a salutogenic approach, this study aimed to explore and describe the sense of coherence and coping of family caregivers of HIV/AIDS patients in the Kwazakhele area in Port Elizabeth.

The sample consisted of 50 participants aged between 21 and 65 years, recruited via the Kwazakhele Masizakhe Project. An exploratory-descriptive design was employed. Data was obtained by a biographical questionnaire, the Coping Resources Inventory (CRI) and the Sense of Coherence (SOC-29) Questionnaire. A non-probability convenience sample of adult male and female family caregivers were sampled. Descriptive statistics and correlation coefficients were utilized to describe and explore the coping and sense of coherence of the family caregivers and the correlation between these constructs, respectively. The data obtained from the biographical questionnaire was analysed by using descriptive statistics and frequency counts. Key findings include the following: Results from the coping resources measure indicated that this sample perceived themselves as having an average level of coping resources. The sample tended to rely more readily on spiritual resources and less on cognitive resources. Results from the SOC-29

revealed fairly high mean scores. There is no positive relationship between the SOC-29 and the CRI for the current sample. No significant relationship existed between the SOC and the subscales of the CRI. Suggestions are made for future research, the limitations and value of research were outlined.

Key Words: HIV/AIDS, coping, coping resources, sense of coherence, caregivers, stress, salutogenesis

Chapter 1

Introduction and Problem Statement

1.1 Chapter Overview

In this chapter, an overview of the theoretical foundation of the study is provided. A brief literature review against which the study can be reviewed is presented and the motivation for the study is outlined. The aims of the study and an outline of the chapters that are to follow conclude this chapter.

1.2 Theoretical Overview

The development of the field of health psychology indicated a move away from the pathogenic orientation of the Western medical model to a salutogenic one. This resulted as a consequence of a growing body of research and related literature which urged a reassessment of the existing models in health science. In this pathogenic model, much attention was given to sickness and dysfunction, and as a result valuable resources were committed to remediation of problems (Strumpher, 1995). Prevention of specific diseases, particularly among high-risk individuals or groups, has been primarily emphasized (Antonovsky, 1987).

Health is not merely perceived as the absence of disease but rather as the presence of positive well-being (Schlebusch, 1996). The salutogenic paradigm in psychology arose as an alternative response to dealing with illness in individuals, and the paradigm as a whole suggests that instead of focusing on illness and disease there should be a focus on that which promotes wellness. The salutogenic construct proposes that what should be investigated are the origins of health, not those of disease. The salutogenic paradigm is a preventative model as opposed to being a disease model (Antonovsky, 1987).

Antonovsky (1979) argued that microbiological, chemical, physical, psychological, social and cultural pathogens are everywhere, and because individuals are confronted with them everyday, he commented that it would seem natural if everyone succumbed to them and died. Given the fact that this does not happen, Antonovsky (1987) sought to identify the sources of health and to ascertain how individuals cope with stress and remain well. Antonovsky's (1979; 1987) theory on salutogenesis is related to the sense of coherence concept which explains why some individuals become ill following a stressful situation while others, after having experienced the same stressful situation, manage to stay well (Geyer, 1997; Hutchinson, 2005). Antonovsky (1987) coined the term salutogenesis which moved away from focusing on treating a specific disease and instead looked to the broader realm of well-being where it is hoped that healthcare professionals can utilize social, psychological, and cultural

resources to promote health and resist illness. It is a given that everybody experiences multiple stressors throughout their lives, yet some people who experience a high stress load not only survive but even prosper. Tension is created when stressors are faced. The way in which stressors are confronted and how tension is managed determines whether the outcome will be pathological, neutral or salutogenic (Antonovsky, 1985).

One of the main focus areas of the salutogenic approach and health psychology in which it is couched is stress management for wellness. Stress and stressful reactions have been viewed as resulting from an imbalance in both coping resources and appraisal demands (Matheny, Aycock, Curlette & Junker, 1993). According to Hobfoll (1989), the measurement of coping resources is more predictive of stressful reactions than the measurement of appraised demands. In line with this salutogenic framework, this study focuses on investigating salutogenic concepts like sense of coherence and coping resources, specifically the sense of coherence and coping resources of adult family caregivers of HIV/AIDS patients in the Kwazakhele area of Port Elizabeth. In the subsequent section, the relevance and need for this research is highlighted.

1.3 Problem Statement

HIV/AIDS has increasingly become a health problem; and as its chronicity continues, the importance of informal systems of care becomes commensurately greater. The advent of highly active antiretroviral therapy (HAART) has extended the lives of many and is one of the principal factors responsible for moving HIV/AIDS from an acute to a chronic illness, an illness that requires vigilant and ongoing home care (Orner, 2006). In response to the inability for the public health care system to accommodate all patients requiring affordable medium-to-long term care; hospices have been designed to take care of those that are infected with as well as affected by, HIV-related illness. Although these facilities are available, hospices can only offer care for a period of two weeks (Avert.org, 2006). As a result, home care has been suggested as a viable solution. The basic tenet of home-care is that individuals who would otherwise require extensive and expensive institutional care are looked after in their own homes by community members specifically trained to do so. These community members are referred to as community based carers (Orner, 2006). Once properly trained, these community-based carers usually work on a voluntary basis, but receive an allowance for food and transport. Home care has already proven to be successful.

The public health system, as well as various non-governmental organizations in this country such as the South African Red Cross Society and South Coast Hospice, has taken up the challenge of providing training in the area of home-care. Members of the community are given training on the basic skills required in order to nurse a person at home. Specific input on HIV/AIDS is given in order to ensure

that community based carers are fully equipped to handle the physical and emotional needs of their families and households. Home-carers are then allocated to patients who may have different AIDS-related conditions. These patients are visited on a regular basis, with the frequency of visits and intensity of care depending on the needs of patients. Each community-based carer is allocated a limited number of clients to be visited (Brennon & Moore, 2000).

Community-based carers fill what was previously a sorely felt gap in the public health system. Not only do they attend to the physical and emotional needs of their patients, they also address their patients' spiritual needs by encouraging them in their religious beliefs where this is deemed appropriate (Cameron & Uys, 2003). Community-based carers visiting the HIV/AIDS patient are able to educate their patients and members of their families and households about the disease, addressing fears and misconceptions and dispelling myths. These community based carers are from the same community as their patients; speaking the same language and having a similar background makes it easier for them to establish an informal relationship of trust with their patients in which the patients' needs can be met.

Although the service of community-based carers is available, it is the adult family caregivers who provide most of the care for the sufferers. These adult family caregivers live with the HIV/AIDS patient and are responsible for caring for the HIV/AIDS patient on a daily basis and are subjected to many negative factors that emerge as a result of their ill family member's condition. These adult family caregivers are typically the lovers, spouses, children or family of someone diagnosed with HIV/AIDS. They usually have little or no training in the home-based care which is offered to them by the community-based carers during their visits, which would enable them to cope on their own (O'Neil & McKinney, 2003).

Caring for a chronically ill loved one is often an emotionally intense and physically demanding experience, one that is characterized by persistent, stressful demands. These adult family caregivers provide practical support (i.e., shopping, housekeeping, bathing, feeding, etc.) and as symptoms worsen they are likely to take on more clinical roles such as keeping track of medication, giving injections, inserting catheters and cleaning wounds (Folkman, Chesney & Christopher-Richards, 1994). Turner, Catania and Gagnon (1994) have argued that, whilst adult family caregiving for HIV/AIDS patients reduces costs to the formal sector, the costs of such care to caregivers themselves should also be considered. The needs of caregivers are more often than not forgotten, dismissed, ignored or trivialised in favour of the more visible and often more pressing needs of patients. Carers' needs are put aside both by patients and institutions on the one hand, as well as by the caregivers themselves on the other (Cameron & Uys, 2003).

As can be surmised from the above argument, adult family caregivers present an invaluable resource in the care of the family members that are diagnosed with HIV/AIDS. Over time, caregiver stress and strain accelerate while physical and mental well-being are heavily taxing. Often stress symptoms result. However, people caught up in difficult circumstances do not necessarily go through the same stress and coping process, and people react differently to the role of caregiving.

At present, there is a paucity of research on stress, coping and sense of coherence in adult family caregivers working in the field of HIV/AIDS in South Africa. Research has addressed the burden of caring and the coping strategies of these family caregivers, thus leaving room for the kind of research undertaken in this treatise. These studies identified difficulties associated with caregiving in HIV/AIDS (Shebi, 2006; Simpson, 2006), but to date the sense of coherence and coping resources of caregiving by an adult family member has not been looked at with specific reference to South Africa.

1.4 Primary Objectives of the Research

The primary objective of this study is to investigate the sense of coherence and coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area of Port Elizabeth. There were three main aims in this regard:

- (a) To explore and describe the sense of coherence of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area of Port Elizabeth.
- (b) To explore and describe the coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area of Port Elizabeth.
- (c) To explore and describe the correlation between sense of coherence and coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area of Port Elizabeth.

1.5 Delineation of the Research

Chapter 1 served as an introduction to the research and provided an overview of the theoretical foundations relevant to the present study. The chapter also included a motivation for the study and the operationalised aims were outlined.

Chapter 2 narrows the focus to the specific topic of HIV/AIDS and caregiving and outlines the nature and dynamics of HIV/AIDS. This is followed by a general description of the caregiver. Finally, caring for an HIV/AIDS family member and the stress related to this role is discussed. This is done in an effort to contextualise the key concepts pertaining to this research.

Chapter 3 explains and defines the central concepts and theories on which the study is based, i.e., sense of coherence and coping resources, as well as the salutogenic paradigm from which these terms arise. The initial section of this chapter provides a foundation for these concepts by exploring the

general concepts of stress and coping as well as the link between stress, coping and health. The relationship between stress and how it relates to the caregiving of HIV/AIDS patients as well as the concept of coping, with reference to specific coping resources that are utilised by HIV/AIDS caregivers, is discussed.

Chapter 4 provides a description of the methodology employed, outlines the aims of the study, offers a discussion of the research design, a description of the participants, and an explanation of the sampling method that was employed. A brief explanation of the measures utilized in the research is included to provide a better understanding of the data collection. Outlines of the procedures, the process of the research, and the ethical considerations are given. Lastly, the data analysis employed in the study is explained.

Chapter 5 encompasses the results of the research. These results are discussed in relation to the literature outlined in chapters 2 and 3.

Chapter 6 provides conclusions based on the results of this study. A discussion of the limitations of the study is provided. The chapter ends with recommendations for future research in this area based on the results obtained.

1.6 Conclusion

This chapter introduced the concept of salutogenesis and provided the motivation for the present study. The aims were defined. The chapter concluded with a delineation of the current research. The following chapter discusses HIV/AIDS and caregiving.

Chapter 2

HIV/AIDS and Caregiving

2.1 Chapter Preview

The previous chapter provided a theoretical outline, which aimed to offer a context for understanding the broader theoretical framework on which this study is based. This chapter narrows down the focus to the specific topic of HIV/AIDS and caregiving and outlines the nature and dynamics of HIV/AIDS. This is followed by a general description of the caregiver. Finally, caring for an HIV/AIDS family member and the stress related to this role is discussed. This is done in an effort to contextualise the key concepts pertaining to this research.

2.2 HIV/AIDS

AIDS is the acronym for Acquired Immune Deficiency Syndrome and represents the most serious manifestation of chronic HIV infection. AIDS is an acquired disease and is caused by HIV, which enters the body from the outside (Bennett, 2000). Although AIDS is referred to as a disease, it is more commonly known as a syndrome. AIDS is a collection of many different conditions that are the result of a compromised immune system. HIV/AIDS is one of the most threatening syndromes known to mankind (Whiteside & Sunter, 2000).

Once a person has been infected with the virus, s/he can remain or appear to be healthy for some time depending on the state of the immune system. Eventually HIV attacks the immune system and once this is compromised it is weakened and other diseases are thus able to invade the body. Reeves and Doms (2002) termed these diseases opportunistic diseases. A person is described as having AIDS when the immune deficiency caused by HIV is so severe that various life-threatening infections occur (Bennett, 2000).

2.3 Epidemiology

In this section, the global, national and local epidemiology of HIV/AIDS is discussed. This discussion provides a perspective regarding the extent of the HIV problem internationally, nationally and locally.

2.3.1 The Global Epidemic

More than twenty years after its outbreak, there is still no cure for AIDS. Since the first cases of Acquired Immune Deficiency Syndrome (AIDS) were reported in 1981, infection with human immunodeficiency virus (HIV) has grown to pandemic proportions, resulting in an estimated 65 million infections and 25 million deaths worldwide. During 2006 alone, an estimated 2.9 million persons died from AIDS, 4.3 million were newly infected with HIV (400 000 more than 2004), and

39.5 million were living with HIV worldwide (2.6 million more than in 2004) (UNAIDS/WHO, 2006). That total number breaks down into 37.2 million adults, 17.2 million women, and 2.3 million children younger than 15 years of age. It is further reported that, throughout the year 2006, 4.3 million new infections and 2.9 million deaths occurred (UNAIDS, 2006). The spread of the HIV/AIDS epidemic seems to vary from one country to the next, owing to different risk behaviours, demographic and geographic variables, and socioeconomic conditions (Gilbert, 2002). While slowing down in some industrial countries, thanks to education campaigns and available social and economical resources, the epidemic is less restrained in other regions.

The United States Centres for Disease Control and Prevention (CDC, 2006) estimated that 1.2 million people were living with the virus at the end of 2006 and in 2006 another 65,000 people became infected in the USA alone (CDC, 2006). The number of people living with HIV/AIDS (PLWHA) in Eastern Europe and Central Asia continued to rise in 2006. An estimated 270 000 people were newly infected with the virus, bringing to 1.7 million the number of people living with AIDS in 2006. (UNAIDS/WHO, 2006). In South and South East Asia, 8.5 million people are now living with HIV. The growth of the epidemic in this region is largely due to the growing epidemic in China, where a million people are now living with HIV, and where official estimates foresee a manifold increase in that number over the coming decade. There remains considerable potential for growth in India, too, where almost 5.2 million people are living with HIV (UNAIDS, 2006a). The regional HIV/AIDS statistics for 2006 are published in the Worldwide HIV and AIDS Statistics Summary (2006) yearly AIDS epidemic update and are presented in Table 1.

Table 1
Regional Statistics for HIV/AIDS in 2006

Region	Adults and children living with HIV/AIDS	Adults and children newly infected with HIV	Adult prevalence rate	Deaths of adults and children
Sub-Saharan Africa	24.7 million	2.8 million	5.9%	2.1 million
North Africa & Middle East	460, 000	68, 000	0.2%	36, 000
South & South East Asia	7.8 million +	860, 000+	0.6%+	590, 000
East Asia	750, 000	1000, 000	0.1%	43, 000
Oceania	81, 000	7, 100	0.4%	4, 000
Latin America	1.7 million	140, 000	0.5%	65, 000
Caribbean	250, 000	27, 000	1.2%	19, 000
Eastern Europe & Central Asia	1.7 million	270, 000	0.9%	84, 000
Western & Central Europe	740, 000	22, 000	0.3%	12, 000
North America	1.4 million	43, 000	0.8%	18, 000
Total	39.4 million	4,3 million	1.0%	2.9 million

UNAIDS, (2006)

Table 1 depicts important patterns regarding HIV infection rates. The most visible aspect that emerges, is the clear distinction between poor and rich regions. It seems that the spread of the epidemic is more rapid in developing countries, a fact that highlights the social and economic imbalances around the world. The above statistical data further indicates that, at present, more than 62.6% of the global HIV-positive population lives in Africa, and in particular, in sub-Saharan Africa. It is also noticeable that the number of infected women in these regions far exceeds the number of infected men. While rich and creative support systems and resources are available to 25% of the HIV-positive population, simply because of their geographical position, the rest of the population finds itself with a bigger problem and less available financial and social resources (UNAIDS/WHO, 2006).

2.3.2 HIV/AIDS in Sub-Saharan Africa

Almost two thirds (63%) of all people living with HIV/AIDS globally live in Sub-Saharan Africa with an estimated total of 24.7 million adults and children (UNAIDS/WHO, 2006). Some 2.8 million adults and children became infected with HIV in 2006, more than in all other regions of the world combined, while the epidemic claimed the lives of an estimated 2.1 million Africans in the same year (International AIDS Economics Network, 2002). Ten million young people (aged 15-24) and almost 2 million children under the age of 15 are living with HIV (UNAIDS, 2006a). This is the part of the world which has the highest rates of infection, the lowest resource availability, and the least adequate socio-economic systems (UNAIDS, 2006a).

Across the region, 40 countries have completed national strategic AIDS plans. This fact stands as evidence to the commitment to fighting HIV/AIDS. Community involvement has also increased, and many private organizations take an active part in the war against the virus. This is being done not only through economic contributions and support, but also through education for prevention, which is becoming more available to all levels of the population (UNAIDS, 2006a). Offering treatment and care for the millions who are infected poses a challenge. Although the efforts that are made at present are valuable ones, when measured against the extent of need, they are plainly inadequate (UNAIDS, 2006b).

2.3.3 HIV/AIDS in South Africa

South Africa has a population of 47.4 million of which 51% are women (Knight, 2006). The HIV prevalence rate for adults is 18.2%. Research has indicated that 5.5 million people are HIV positive, making South Africa the country with the largest number of people living with HIV/AIDS in the world (Avert.org, 2006; Department of Health, 2006). The epidemic in South Africa is one of the fastest growing in the world, with an estimated 1000 new infections daily (Department of Health South Africa, 2005; Shisana, 2005; UNAIDS, 2006). Regional statistics are escalating with the Eastern Cape having the 3rd highest infected population in South Africa (Province of the Eastern Cape Department of Social Development, 2003).

The high rate of infection in South Africa causes substantial disruptions in social interactions and economic structures in the country. Societies can only deal with a certain amount of disruption before they collapse, and the South African society at present is at enormous risk (Geffen, 2006). The epidemic in South Africa is much younger than in other African countries, and is estimated to be up to nine years behind countries such as Uganda or Kenya. However, despite the lower levels of HIV infection rates in the early 1990's, South Africa rapidly caught up with other Sub-Saharan countries in the previous decade, when over 50% of all southern African new infections occurred in this country

(UNAIDS, 2006). An estimated 6 461 372 individuals were reported as infected with HIV (Dorrington, Bradshaw & Budlender, 2004). The total number of adult South Africans (18-64 years) infected with HIV was estimated to be 6 141 578, while 3 125 498 of the overall infected adult population were women (Dorrington, et al., 2004). The total number of infected children (below 15 years) was reported to be 205 134, while the number of infected youth (15-24) was reported to be 1 210 749 (Dorrington, et al., 2004).

Based on the National HIV Survey, the researchers estimate that 10.8% of all South Africans over the age of 2 were living with HIV in 2005. Among those between 15 and 49 years old, the estimated HIV prevalence was 16.2% in 2005. The implications of these statistics are far-reaching. To begin with, South Africa currently supports more HIV-infected individuals than any country in the world, while the economic condition of the country suffers, and the availability of resources is lower (Fredriksson & Berry, 2002; Gilbert, 2002). Hours are lost in different workplaces, because more workers are taking increasing sick leave; there is increasing expenditure on health services, which places additional strain on the national budget; and taxes are high. Economically active groups in the population carry the burden of paying high premiums that help to cover all these costs; and the resources needed in order to care for those affected by the epidemic, such as orphans, are being overused and drained (Fredriksson & Berry, 2002; Gilbert, 2002). The rapidly increasing infant, child, and young adult mortality rates leaves South Africa with no fresh future labour resources, and its government thus faces the enormous task of providing financial aid to the surviving members of families, such as orphans and the elderly (Dorrington, et al., 2004; UNAIDS, 2006). As in other areas in sub-Saharan Africa, the number of infected women exceeds the number of infected men (Fredriksson & Berry, 2002; UNAIDS, 2006).

2.3.4 HIV/AIDS in the Eastern Cape Province of South Africa

According to Dorrington, Johnson, Bradshaw and Danel (2006), the Eastern Cape has a total of 666 822 PLWHA. This province accounts for 12.1% of infections among adults, but the third highest proportion (16.4%) of infections in youth. There are 590 805 adults infected of which 237 299 are adult men and 352 507 are women. The infection rates in the rural areas of the Eastern Cape were found to be higher than the rates of infection in the urban areas (Dorrington et al., 2006). The provincial HIV/AIDS statistics for 2006 are presented in Table 2.

Table 2

Eastern Cape statistics for HIV/AIDS, end 2006

	Infections among adults	Infections among women	Infections among men
Eastern Cape	590 805	352 507	237 299

Dorrington, Johnson, Bradshaw & Danel, 2006

2.4 Transmission

The origins of AIDS have been surrounded by controversy, debates and stigmatization. The origin of the disease is still unknown but there are various theories about it. According to Catalan, Green and Thorley (2001), the virus crossed over from a species of monkey in South Africa in the early 1990's. HIV is thought to have spread from chimpanzees to humans in central Africa (Thorley, 2006). The spread of viruses happens with various strains of flu where viruses are passed on through an animal host or reservoir to humans. The conclusion that this is the origin of AIDS is based on the similarities between the human and monkey forms of the virus as well as the common geography shared by both the monkeys and the human viral strains (Usdin, 2003).

According to Pope and Haase (2003), HIV is difficult to transmit. In order for a person to be infected, the virus has to enter the body in sufficient quantities. Whilst HIV/AIDS is spread predominantly through unprotected sexual intercourse, other modes of infection remain important and are summarized below.

1. Mother to child HIV transmission: HIV is transmitted to approximately one third of babies of HIV positive mothers if there is no medical intervention. Use of antiretroviral drugs, obstetric practices including caesarean delivery, and safe infant feeding practices can reduce transmission to very low levels (Brocklehurst & Volmink, 2002).
2. Blood transfusion: The risk of HIV transmission via infected donor blood is very high. However, donor and biological screening procedures allow for risk of HIV transmission through blood donation to be contained. Such procedures are followed rigorously in South Africa and risk is estimated to be very low (Heyns & Swanevelder, 2005).
3. Exposure to blood: In health care settings HIV can be transmitted between patients and health care workers in both directions via blood on sharp instruments, and may also be transmitted between patients through re-use of contaminated instruments. A number of studies have highlighted the importance of infection control measures in such settings as well as post-exposure prophylaxis in the case of sharp instrument injuries (Colvin, 2005). Exposure to blood can also occur in a wide range of institutional settings and in emergency situations where

people are injured. Universal precaution practices including use of gloves and other protective measures are recommended.

4. Intravenous drug use (IDU): IDU has long been recognized as a high-risk practice for HIV transmission, as needles and syringes may be shared between users. The extent of intravenous drug use in South Africa is under-researched, mainly because of the legal environment and stigma associated with this behaviour. In regions where HIV occurs amongst intravenous drug users, prevalence is very high (UNAIDS, 2006).
5. HIV is transmitted through the blood or body fluids (semen, vaginal and cervical fluids and breast milk) of an infected person (Varghese, Maher, Peterman, Branson & Steketee, 2002). The virus is also found in all body fluids including saliva, tears, sweat, but the quantities are minute and the risk of transmission is minimal (Whiteside & Sunter, 2000).

2.5 Stages of HIV Infection

Evian (2000) has identified six stages of HIV infection. The first stage is the initial infection with HIV. Stage two is called the window period. It is during this period that the person is asymptomatic and there are no antibodies. An HIV antibody test at this stage will be negative although the virus is present. This stage is usually 2 – 12 weeks, but may last several months or occasionally even longer. Sero conversion is stage three where the antibodies begin to develop. This stage may be accompanied by a few days of flu like symptoms. Some people experience no illness at this stage. Stage 4 is called asymptomatic HIV infection where antibody tests are positive, but there are no apparent signs or symptoms of illness. This period may last from a few months to many years. The fifth stage highlights the emergence of HIV/AIDS related illnesses when symptoms increase, because HIV is damaging the immune system (e.g. diarrhea, swollen glands and night sweats), but these are not life threatening. This may continue for months or years. Infections gradually become more persistent and serious until the last stage of full blown AIDS is reached. It is at this stage that life threatening infections/diseases and cancers occur because the immune system is severely weakened. The patient will eventually die when an untreatable life threatening condition develops. Life expectancy depends on a number of conditions such as care, nutrition and available treatment.

2.6 Treatment

There is no cure for HIV and treatment differs depending on the individual. Whiteside and Sunter (2000) maintained that there are three stages in the treatment of HIV positive people. The first is when they are infected, but CD4 cell counts are still high. At this point the emphasis is on ‘positive living’” staying healthy, eating the correct food and so on. The second stage occurs when the CD4 cell count begins to drop. At this stage treatment with prophylactics to prevent Tuberculosis (TB) and other

common diseases are normally begun. The third stage is the use of antiretroviral drugs to fight HIV directly. Concurrently with the above, counseling and support for the individual are offered (UNAIDS, 2006). Treatment used to be costly but with the government rollout of the antiretrovirals at hospitals, it is beginning to be affordable for many people. However, due to the poverty in South Africa, many infected individuals still find it financially difficult to be treated with these antiretrovirals (UNAIDS, 2006).

Until 2003, treatment, care and support, except for those on medical aid or with private sponsorship, was usually limited to treatment for ongoing opportunistic infections, palliative care and deathbed care. The prospect of life-prolonging treatment as opposed to treatment to relieve symptoms is still remote for the majority of those infected and as a result there will be huge numbers of people dying from AIDS given the paucity of treatment options offered to many with AIDS (UNAIDS, 2006). Most care will need to be community based – in homes and clinics – as opposed to hospital and hospice based.

2.7 Factors Fuelling and Impacting the Epidemic in South Africa

South Africa is considered to be one of the countries worst affected by HIV/AIDS. The reasons for this are complex, nevertheless, certain sociocultural factors have been identified as responsible for the rapid spread of the disease. These factors are now explained.

2.7.1 Social/Contextual Factors responsible for the rapid spread of HIV/AIDS

2.7.1.1 Poverty

People who carry the heaviest burden as a result of HIV/AIDS are the poor. AIDS increases poverty and families are the first to feel the economic effects of HIV and AIDS. Families lose income if an earner is sick (Steinberg, 2002). Often another one of the family members stays at home to look after the sick person and further income is lost. Families also have increased costs as they have to spend money on caring for the sick or paying for funerals. Poverty does not operate on its own as a risk factor for infection with HIV. Its effect needs to be understood within a socio-epidemiological context (Steinberg, 2002). It works through a myriad of interrelations, including unequal income distribution, economic inequalities between men and women which promote transactional sex, relatively poor public health education and inadequate public health systems (Halperin & Allen, 2001). Poverty-related stressors arising from aspects of poverty in townships such as poor and dense housing, and inadequate transportation, sanitation and food, unemployment, poor education, violence, and crime, have also been shown to be associated with increased risk of HIV transmission (Kalichman, Simbayi, Kagee, Toefy & Jooste, 2006).

2.7.1.2 Gender and Gender-Based Violence

Violence against women is a major problem in South Africa and is linked to its male dominated culture. Men often use violence in an attempt to maintain their status in society and prove that they are real men by keeping women under their control (Innes, 2006). Physically abusive relationships limit women's ability to negotiate safer sex and many men still do not want to use condoms, and some become violent if women insist on safer sex. Women may not even raise the issue of safer sex for fear of a violent response. South Africa, where a woman has about a one in three chance of being raped in her lifetime, has among the highest sexual violence statistics in the world, with obvious implications for the spread of HIV/AIDS (Steinberg, 2002). The genital injuries that result from forced sex increase the likelihood of HIV infection; when virgins and children are raped, the trauma is more severe, and risk of infection even higher (Kalipeni, Craddock, Oppong & Ghosh (2004).

2.7.1.3 Cultural Attitudes and Practices

Certain prevalent cultural attitudes and practices related to sexuality contribute to the risk of HIV infection. First, there may be negative attitudes towards condoms, as well as difficulties negotiating and following through with their use. Men in South Africa regularly do not want to use condoms, because of certain and because sex is equated with masculinity and is seen as necessary for male health. Condoms also have strong associations of unfaithfulness, lack of trust and love and disease. Secondly, in cultures where virginity is a condition for marriage, girls may protect their virginity by engaging in unprotected anal sex. Thirdly, the importance of fertility in African communities may hinder the practice of safer sex. Young women under pressure to prove their fertility prior to marriage may try to fall pregnant, and therefore do not use condoms or abstain from sex. Fathering many children is also seen as a sign of virile masculinity (Kalipeni, Craddock, Oppong & Ghosh (2004). Polygamy is practiced in some parts of southern Africa. Even where traditional polygamy is no longer the norm, men tend to have more sexual partners and to use the services of sex workers. This is condoned by the widespread belief that males are biologically programmed to need sex with more than one women (Innes, 2006). HIV infection is also believed to occur during some of the traditional health practices conducted by traditional healers when they use unsterilised sharp instruments such as knives, blades, spears, animal horns and thorns during some of the healing practices and/or recommend sex with a virgin as part of their treatment of patients (Innes, 2006).

2.7.1.4 Stigma, Denial and Discrimination

HIV and AIDS is perhaps one of the most stigmatized medical conditions in the world. Stigma interferes with HIV prevention, diagnosis, and treatment and can become internalized by people living with HIV and AIDS (UNAIDS, 2006). Stigma is largely due to lack of knowledge (Crawford, 1996;

Gilbert, 2002; Poindexter, & Linsk, 1999). It influences the manner in which many respond to people living with HIV, and often results in discrimination. Discrimination is the way that people actively identify and act against others because they are infected or affected by HIV and AIDS. Often people living with HIV/AIDS are treated with indignity. Their human rights may be violated. The direct consequence of this is that people are scared to be open about their status, forcing the disease underground. This often prevents them from seeking the help they need, and also makes it very difficult to control the further spread of HIV (Gilbert, 2002). The stigma attached to HIV seriously hinders prevention efforts, and makes HIV-positive people wary to seek care and support for fear of discrimination. People who are infected may also be reluctant to adopt behaviour that might signal their HIV-positive status to others (Poindexter, 2005).

Another consequence is denial. Both silence and denial about HIV/AIDS are lethal because they prevent people from accurately assessing their own personal infection risk (Poindexter, 2005).

2.7.1.5 Labour and Migration

The migrant labour system has been particularly important as a vehicle for HIV transmission. Labourers were prevented from settling where they worked in the urban areas, but maintained links with their families in rural parts, and moved between the two. This to-and-fro migration has been a major factor in the spread of HIV and other STIs (which in turn, increase the risk of HIV infection). Migrant labour patterns persist because of uneven development and employment opportunities, both within the country and in neighbouring African countries (Innes, 2006).

People separated for long periods tend to seek sex outside their stable relationships, which in the single sex hostels accommodating migrant labourers, has often been in the form of unsafe male-to-male sex, and making use of the sex-work industry that developed in the vicinity. Men frequently become HIV-infected at their place of work, and then carry the infection back home and pass it on to their wives and unborn children (Innes, 2006).

2.8 The Impact of HIV/AIDS in South Africa

In South Africa, HIV/AIDS has had far-reaching implications. The most obvious effect of this crisis has been illness and death, but the impact of the epidemic has certainly not been confined to the health sector; households, education, workplaces and economies have been significantly affected, along with other areas of society. (UNAIDS, 2006). AIDS is erasing decades of progress made in extending life expectancy. The HIV/AIDS epidemic is putting strain on the health sector and schools are heavily affected as well. HIV/AIDS dramatically affects labour and through its impacts on the labour force, households and enterprises, HIV/AIDS can act as a significant brake on economic growth and development. HIV/AIDS is already having a major affect on South Africa's economic

development, and in turn, this affects South Africa's ability to cope with the epidemic (UNAIDS, 2006c).

As a result of the increase in HIV/AIDS statistics and the lack of resources in the health sector, the pressure of providing care for those PLWHA is increasing (UNAIDS, 2006c). The impact on the health sector specifically the effect on hospitals is discussed next. This discussion is followed by a depiction of the impact of HIV/AIDS on households specifically relating to household income, basic necessities, healthcare expenses and funeral costs. Lastly, the impact on enterprises and workplaces is discussed in this section.

2.8.1 The Impact on the Health Sector

As the epidemic grows, the demand for care for those living with HIV rises, as does the toll on health workers. The results of the annual antenatal surveys conducted in South Africa from 1990 until 2000, have indicated a steady increase in the number of new infections in the country from year to year (Tshabalala-Msimang, 2000). We can expect that the public health care system will be stretched to beyond its capacity in years to come (UNAIDS, 2006c). South Africa is experiencing the impact of the HIV/AIDS pandemic in the public health system.

2.8.2 The Effect on Hospitals

As the HIV prevalence rises, the strain placed on its hospitals will increase. In South Africa, people with HIV-related diseases occupy more than half of all hospital beds. Reports indicate that public hospitals, particularly in parts of the country with high infection rates and few resources (notably those in rural areas), cannot cope with the large numbers of patients presenting with AIDS-related illnesses. Due to ever-increasing patient numbers in the midst of staff shortages, budget cuts and the patient's medical needs apart from HIV/AIDS, patients presenting with AIDS-related conditions often have to make do with minimal care before being sent home (UNAIDS, 2006b). Due to the nature of the disease, it is inevitable that within a period of time, patients who may have been sent home a short while before will present with another opportunistic infection, only for the cycle of minimal care and early discharge from hospital to be repeated (UNAIDS, 2006b). Government-funded research in South Africa has suggested that, on average, HIV-positive patients stay in hospital four times longer than other patients. It is predicted that patients affected by HIV and AIDS will soon account for 60-70% of hospital expenditure in South Africa resulting in a shortage of hospital beds. This shortage results in people being admitted only in the later stages of illness, reducing their chances of recovery. As the epidemic worsens, more complex cases of HIV and AIDS are likely to arise, taking up more hospital time and further reducing the standard of care provided (UNAIDS, 2006c).

This epidemic is taking place and will continue to grow within a context of already massively overstretched public health care resources, which are unable to cope with the growing burden of HIV-related infections (Orner, 2006). Ideally this lack of resources would call for greater collaboration between state and community in achieving cost-effective health care for PLWHA. However, in practice, what has been seen in South Africa is that families and communities are increasingly taking responsibility for providing care. As a result these patients are often expected to be cared for by a family member who is seen as their primary caregiver (Akintola, 2004).

2.8.3 The Impact on Households

As the number of people living with HIV/AIDS syndrome grows, so does the need for provision of their care (Held, & Brann, 2007). In the early days of the AIDS epidemic, care was primarily handled by special agencies, hospitals, hospices and clinics. These agencies have been inundated with the demands of people living with HIV/AIDS, while their resources are shrinking (Orner, 2006; Tolliver, 2001). As it stands now, approximately two-thirds of the total assistance given to PLWHA is provided by family members (Brennan & Moore, 2000; Steinberg, 2002). AIDS has a tremendous impact on the entire family system, particularly on the individual who has primary responsibility for caregiving (Steinberg, 2002). Van Dyk (2001, p. 338) referred to the family caregiver as the “hidden victim” of AIDS. Care in the context of HIV/AIDS is likely to place additional and unique strain on the caregiver, especially if the need to provide care was unexpected and the person being cared for had previously lived on their own (Turner, Catania & Gagnon, 1997; Wight et. al., 2003).

The toll of HIV and AIDS on households can be very severe. Although no part of the population is unaffected by HIV, it is often the poorest sectors of society that are most vulnerable to the epidemic and for whom the consequences are most severe. A study of rural South Africa suggested that households where an adult had died from AIDS were four times more likely to dissolve than those where no deaths had occurred (Hosegood & McGrath, 2004). Much happens before this dissolution takes place; AIDS strips families of their assets and income-earners, further impoverishing the poor.

2.8.3.1 Household Income, Basic Necessities and Healthcare Expenses and Funeral Costs

In Africa it is estimated that, on average, every income earner is likely to acquire one additional dependent over the next ten years due to the AIDS epidemic. A dramatic increase in destitute households, those with no income earners, is also expected. Many countries in Africa are experiencing the same problem, as individuals who would otherwise provide a household with income are prevented from working by HIV and AIDS, either because they are ill themselves or because they are caring for another family member who is. Such a situation is likely to have repercussions for every member of the family (Hosegood & McGrath, 2004; Steinberg, 2002).

A study in South Africa found that already poor households coping with members who are sick from HIV or AIDS were reducing spending on necessities even further. The most likely expenses to be cut were clothing (21%), electricity (16%) and other services (9%). Falling incomes forced about 6% of households to reduce the amount they spent on food and almost half of households reported having insufficient food at times (Steinberg, 2002).

Taking care of a person sick with AIDS is not only an emotional strain for household members, but also a major strain on household resources. Loss of income, additional care-related expenses, the reduced ability of caregivers to work, and mounting medical fees push affected households deeper into poverty. It is estimated that, on average, HIV-related care can absorb one-third of a household's monthly income. The financial burden of death can also be considerable, with some families in South Africa spending three times their total household monthly income on a funeral (Steinberg, 2002). Now that an understanding of the epidemic has been provided and the need for care at household level has been explained, the topic of the caregiver and the description of a caregiver is discussed in the following chapter.

2.9. Description of a Caregiver

There are two types of caregivers that provide clinical care and supportive services to PLWHA. Formal caregivers include health professionals, behavioural health specialists, and social workers, who are trained and compensated for their caregiving activities. The trained volunteers and spiritual counselors associated with AIDS service organizations, AIDS care teams, and hospice programs also fall in this definition category (Carson, 2001). Informal caregivers include relatives, spouses/partners, and friends who provide in-home care, usually on an unpaid basis. These caregivers vary in the types of tasks performed, the amount of time devoted to caregiving, and living arrangements.

For the purpose of this study, the caregiver is an adult family member who lives with the PLWHA and provides constant care. These individuals provide practical help and nursing to PLWHA at home and are on call twenty-four hours a day. This is in contrast to nurses who are shift workers, thus having time off from other patients. Typically these individuals are parents, siblings, or a member of the extended family.

To aid in understanding the many diverse roles and social tasks caregivers face, in addition to their caregiving role, it is valuable to place the typical caregiver in the context of their personal and social development. One of the most comprehensive theories of human development is that of Erik Erickson. Erickson's theory proposes that humans develop in eight psychosocial stages. At critical points in an individual's life, they are faced with certain social conflicts. These conflicts necessitate adjustment

both in the social environment and in the person, themselves. These adjustments can be altered later in life if a satisfactory result was not achieved initially (Craig, 2005).

Caregivers are those individuals who provide practical help and nursing to PLWHA at home. Research has shown that most HIV/AIDS family caregivers are the spouses of the ailing person, with the next most likely caregiver being the child or sibling of the sufferer (Tolliver, 2001). Extended family members also intervene and assist as the primary caregiver if the former family members are not available to fulfill the caregiving role (Orner, 2006). It stands to reason that these typical family caregivers would be in their mid – or late adulthood years.

Erickson's stages of psychosocial development span the entire lifetime from birth to death. Two stages that correspond with middle and late adulthood are stage seven, or what Erickson refers to as adulthood, and stage eight, which Erickson calls maturity (Erickson, 1982).

Stage seven corresponds with ages 25 to 64 (Niolon, 2003). The psychosocial conflict at this age centers on generativity versus self-obsession as it poses the question "What can I offer succeeding generations?" The ideal resolution of this psychosocial crisis results in the ego strength of caring (Hoare, 2005). Successful resolution of this conflict results in a feeling of purposefulness and productivity, while a maladjustment resolution ends in feelings of regression and a lack of enrichment (Hoare, 2005). It is at this stage of life that one is typically building a career and raising children. Many people of this age are also involved in social issues and community service ventures. This is also most commonly the age at which one becomes frail and needs support.

Stage eight starts around 60 to 65 and continues until death. This final stage of Erickson's theory involves the psychosocial conflict of finding contentment and satisfaction in one's life's work and play (Craig, 2005). The overall ego strength accomplished in the ideal resolution of this conflict is wisdom. An adjusted individual will have a sense of ego-integrity characterized by feelings of unity, direction and a sense of closure (Niolon, 2003). However, the maladjusted individual at this stage experiences despair, hopelessness and dissatisfaction with life. This person often feels a lack of completeness. This is also the stage of life where one is confronted with slowing down, physically and perhaps even mentally, in addition to coping with the loss of friends and loved ones. Many people lose their career at this stage, as they reach the age of retirement. This is often a severe blow to one's self-image (Niolon, 2003).

Majority of the adult family caregivers who participated in this study found themselves in stage seven or eight of Erikson's psychosocial development. It is within these stages that individuals are establishing intimacy, gearing towards a career, looking after their families and households, and securing their future financially (Hoare, 2005). Many a times these caregivers are pushed into the

caregiver role and have to make many sacrifices to care for the family member living with HIV/AIDS. These social conditions are sometimes compromised as a result of these individuals taking on the role of adult family caregiver and the intense, hard work and time spent in these roles. As a result these individuals do not have much time for themselves and could possibly find themselves in a situation where they feel loneliness, ostracism, lack of enrichment, regression, lack of completeness and dissatisfaction (Niolon, 2003).

Another important social characteristic to examine when discussing caregivers is that of gender. Research has shown a high prevalence of female caregivers, particularly in HIV/AIDS (Kipp, Nkosi, Laing & Jhangri, 2006). This is due in part to the societal view that women are better carers than men, and thus the expectation that daughters or females are best equipped to care for ailing family members. The gender of the carer also seems to affect the ability to cope with caregiving stressors, with female caregivers feeling more stress and role strain than their male counterparts (Ogden, Esim, & Gowen, 2004). It is with these psychosocial conflicts, age specific tasks, and gender differences in mind that the actual role of caregivers is discussed in the next session.

2.10 Caring for an HIV/AIDS Patient

As mentioned above, most HIV/AIDS patients are cared for in the community by members of their family. It has been found that these adult family caregivers of patients with HIV/AIDS commonly have high levels of psychological distress (Carlisle, 2000). Much research has focused on the stress experienced by these caregivers and it has repeatedly been found that they have elevated levels of depression; with some research showing that this depression persists even after the patient's death (Land & Hudson, 2004).

These caregivers have been actively concerned with issues surrounding the quality of life and care for their patients. Caring for an individual with HIV/AIDS is usually time-consuming, burdensome and stressful (Akintola, 2004; Flaskerud & Tabora, 1998). They assist with the patient's physical needs, diet, exercise, rest, recreation, personal habits, dressing, washing, feeding, toileting, continence, and home layout (Sidwaba, 2004). However, in focusing on the patient's needs, their own needs have at times been neglected (Sidwaba, 2004). Van Dyk (2001) stated that much of the stress experienced by caregivers is inherent in the nature of the work itself – the fact that they are dealing with an incurable disease that eventually destroys people and that in the process causes suffering to the patient, the family members and the family caregiver to the HIV/AIDS patient. According to Van Dyk (2001), few things can be more stressful and draining on the caregiver's resources than caring for or counseling patients with HIV infection or AIDS. Caregivers as well as patients are faced with existential issues such as continuous physical and psychological deterioration, their own mortality, as

well as the fear of contagion and death (Lane, McKenna, Ryan & Flemming, 2003). Granich and Mermin (2000) put forward that people who care for very ill people with HIV/AIDS sometimes become sad and tired. Stress or burnout may result if carers do not have sufficient time to rest and talk about their own sense of frustration and loss (Hagedoorn et al., 2002; McCausland & Pakenham, 2003;).

Living arrangements, financial status, employment status, health problems and emotional distress are often affected by the nature of HIV/AIDS caregiving responsibilities (Strydom & Wessels, 2006). The resulting disruption in the life of the caregiver can be burdensome (Mullan, 1998). The caregivers are also responsible for educating the ill about the disease and addressing fears and misconceptions. In addition, because they are part of the same family, they speak the same language and have the same background; it is easier for them to establish an informal relationship of trust with their ill family or community member in which the patient's needs can best be met. Caregivers are often overwhelmed in their attempts to care for the relative who has AIDS, hold together the family and maintain their own health. Consequently, they are at risk for negative stress outcomes (Pakenham, Dadds & Lennon, 2000).

Studies have shown that chronic stress can affect both immune system functioning, as well as physical and psychological health in HIV/AIDS caregivers. In addition to this, HIV/AIDS caregivers often experience emotions of anxiety, depression, anger, guilt and resentment connected to their caregiving role (Richards, Folkman, & Acree, 2001). In a study by Martin, Wolters, Klaas, Perez and Wood (2004), it was shown that some of these emotions were more heavily related to specific coping mechanisms than others. This study found that the use of fantasy and other emotion-focused coping mechanisms were more highly related to higher levels of anxiety and depression than more problem-focused coping.

Lack of resources such as social support and locus of control were also found to negatively influence emotions, such as anger and anxiety, in HIV/AIDS caregivers (Wight, LeBlanc, & Aneshensel, 1998). The intense demand of the caregiving role often takes over the recreational and even occupational life of the HIV/AIDS caregiver and the loss of these contacts often results in loneliness. Caregiving and attempting to fulfill one's other responsibilities often leads to role strain and role conflict for the HIV/AIDS caregiver (Lane, McKenna, Ryan & Fleming, 2003).

As HIV/AIDS is degenerative, symptoms worsen over time and stressors are constantly changing, necessitating changes in coping resources and mechanisms. What transpires between the stages of initial diagnosis and eventual death is a series of events that require continuous adjustment regardless of how long one has been a caregiver (McCausland & Pakenham, 2003). Initially, the new role of

caregiver adds its own stressors and burdens; yet as the disease progresses, coping and adjustment must continue, as the patient needs help with more and more activities (Gumede, 2003).

Subjective stress and grief are often continuous in HIV/AIDS caregiving as the caregiver mourns the loss of cognitive ability and relationship with the patient (Gumede, 2003). The tasks and time needed in the caregiving role are greatly dictated by the severity of the patient's impairment, both cognitively and behaviourally, at that time. One study has found that family caregivers in the United States spend an average of 6 hours and 28 minutes a day in caregiving duties (Sherman, 2000). Many of these caregiving activities are instrumental in nature, such as helping move and dress, helping with personal hygiene, doing household chores, taking care of the financial responsibilities of the patient, doing the shopping, and dispensing medication. This can prove a problem with caregivers who are themselves often elderly.

In cases where a caregiver's life is greatly disrupted, emotional consequences such as anger, depression and fatigue are common. Studies have shown that caregivers find the sleep disturbances, loss of relationship with the patient and loss of their own freedom to be the most stressful events in their caregiving experiences (Sidwaba, 2004). The constant need for decision making, particularly when the entire family needs to be consulted, has also proved to be a major stressor on the primary caregiver.

Caregivers of patients with HIV/AIDS face a long path of pain and deterioration between the first appearance of symptoms and the eventual death of the patient. The primary caregiver often faces a barrage of conflicting emotions that threaten to overwhelm them and their ability to cope (Parks & Novielli, 2000; O'Brien, 2000). The stress associated with having to care for a person with HIV/AIDS is very often enormous (Van Wyk, 2002).

Family caregivers are on call twenty-four hours a day. This is in contrast to nurses who are shift workers, thus having time off from patients. This in itself places great demands on the well being of the family caregiver.

2.11 Research on HIV/AIDS Caregiving

Little research has been conducted on family caregivers of PLWHA. This is particularly needed with regards to family caregivers since these people spend most of the time with the HIV sufferers. Formal training in caring for the terminally ill is minimal. Home-based carers who are themselves trained at a minimal level give this training. For this reason, training usually focuses only on assistance with practical care. According to Mullan (1998), caregivers experience a lot of difficulties that have to do with patients' comfort; especially when patients are acutely ill or cognitively impaired. Secondary to that is interpersonal strain resulting from imbalances within the relationship when

dealing with issues of autonomy, independence or reciprocity. The fear of the death of those they care for is a constant threat. These may result in feelings of overload, of loss, of being a captive to caregiving demands, of guilt and of incompetence (Mullan, 1998).

According to Edelman (2000), caregivers also experience feelings of poor self-esteem, stress, low morale, fatigue, anxiety and hopelessness about the future. Past psychiatric status, personality, social support, and the relationship of the carer and recipient, together with the nature of the illness and the degree of impairment, all are factors that aggravate the emotional experiences of caregivers (Edelman, 2000). These experiences might also be noted with carers who are uninformed about the development of the disease. Due to a lack of information, caregivers might think that the sufferers develop extensive pressure sores as a result of being bedridden, or become incontinent, confused or forgetful, or experience persistent nausea and vomiting. These conditions might bring feelings of uncertainty that in turn will exacerbate feelings of stress among the caregivers (Shebi, 2005).

It is also noted that poverty increases the worries of caregivers, as they might not have enough money for a balanced diet and regular medical check-ups, especially when the person is bedridden as there is a need for transportation to medical facilities (Brouwer, Wolffers & Sebagals, 2000). Leblanc, London and Aneshensel (1997) studied potential adverse impacts of caregiving on the physical health of informal HIV/AIDS caregivers. These researchers found that symptoms of poor physical health were markedly present among HIV/AIDS caregivers and were significantly associated with related demands and stressors. It was noted that the caregivers' poor physical health was increased by the PLWHA's depression, financial worry and assistance with various activities of daily living i.e. bathing, dressing and feeding.

2.12 Conclusion

This chapter established the context of the study with regard to HIV/AIDS and adult family caregivers of PLWHA. Chapter 3 explores specific psychosocial concomitants in greater depth, namely stress, coping resources and sense of coherence. After laying a brief theoretical foundation on these three concepts, the discussion turns to explore how these are operant in HIV/AIDS adult family caregivers.

Chapter 3

A Conceptual Model of Understanding Stress and Coping: The Sense of Coherence and Coping Resources

3.1 Chapter Preview

This study focused on the exploration and description of the sense of coherence and coping resources of adult family caregivers of patients living with HIV/AIDS. This study focused on health and attempted to explain healthy outcomes via a salutogenic paradigm. This chapter aims to explain and define the central concepts and theories on which the study is based, i.e., sense of coherence and coping resources, as well as the salutogenic paradigm from which these terms arise. The initial section of this chapter provides a foundation for these concepts by exploring the general concepts of stress and coping as well as the link between stress, coping and health. The relationship between stress and how it relates to the caregiving of HIV/AIDS patients as well as the concept of coping, with reference to specific coping resources that are utilised by HIV/AIDS caregivers, are discussed.

3.2 The Concept of Stress

There is a wealth of literature that reflects the belief that stress is a major factor affecting people's lives, is intimately tied with mental health, and is possibly linked to many physical health problems. Although there is much debate as to a precise definition of stress, most theorists agree that stress is neither only an external situation nor an internal state, but a complex interaction of the environment and the perceived ability to cope (Neufield, 1989; Weinstein, 2004). However, Cohen (2000) and Cohen, McChargue and Collins (2003) stated that numerous definitions of stress vary in the extent to which they emphasize stressful events, responses, or individual appraisals of situations as the central characteristic of stress. The meaning of stress thus remains contentious (Cohen, 2000; Greenberg, 1999).

Despite the fact that this term is contentious, Cohen (1997) nevertheless concluded that researchers seem to utilize a process definition of stress. This definition focuses on how an individual perceives or responds to various events. Stress is therefore defined as a transaction between the person and the environment, in which the person appraises situations, along with available resources for coping with the given situation(s). The person is said to be experiencing stress when the situation is perceived to demand more by way of coping than the person believes is available (Bester & Swanepoel, 2000). To put it plainly, individuals experience stress when events disrupt their usual level of functioning such that they require to put an extra effort in, in order to re-establish their equilibrium.

Vlisides, Eddy and Mozie (1994) identified four different types of stress symptoms, namely behavioural, emotive, cognitive and physical. Behavioural symptoms of stress include procrastination and avoidance, withdrawal from friends and family, loss of appetite and energy, emotional outbursts and aggression, changes in sleep patterns and neglect of responsibilities (Michie & Abraham, 2004). The most common emotive symptoms of stress include anxiety, irritability, depression, denial, fear, a sense of frustration, and feelings of loss of control. Among the cognitive symptoms of stress are loss of motivation and concentration as well as excessive worry, loss of recall, confusion, poor problem-solving and loss of hope. Common physical symptoms include fatigue and physical weakness, migraine, tension headaches and backaches, including lower back pain and muscle tension (Michie & Abraham, 2004). Stress has a major impact on the general functioning of an individual. Powell and Enright (1990) and Aldwin (2007) stated that an estimated 80% of all modern diseases have their origin in stress.

Current models of stress and coping emphasize the importance of subjective evaluations of events in determining whether or not demands will be experienced as stressors (Hobfoll, 1989; McCarthy, Lambert & Brack, 1997). Although the term “stress” is difficult to define, a number of theories pertaining to stress have been formulated in an attempt to understand this popular concept (Brown, 2002). Weinstein (2004) outlined three basic ways in which stress can be defined. This author posited a stimulus definition, a response definition and an appraisal or transactional definition of stress, which can be regarded as theories or models to explain this phenomenon. These three models and the conservation-of-resources model proposed by Hobfoll (1989), are briefly discussed in the section that follows.

3.2.1 Models of Stress

The stimulus-event model argues that stress involves a stimulus event (e.g., illness or death in the family) that presents difficult demands to the individual concerned (Holmes, 1979). Bishop (1994) pointed out that this model assumes that different individuals respond similarly to events, which means that the amount of stress experienced can be measured by assessing the events that have occurred. However, according to Monat and Lazarus (1977), stimulus-based definitions are incomplete in that any situation may or may not be stressful, depending on the characteristics of the individual and the meaning the individual ascribes to the situation.

Based on the response model, Selye (1976) defined stress as the predictable response or physiological arousal elicited by troublesome events. These included a release of hormones, changes in heart rate, blood pressure, respiration, and gastrointestinal activity (Aldwin, 2007; Bishop, 1994; Friedman, 2002). Monat and Lazarus (1977) also criticized this model by pointing out that the same

response pattern may arise from entirely different stimulus conditions. These could include heavy exercise or extreme fright (Monat & Lazarus, 1977).

According to the appraisal/transactional model, the experience of feeling threatened depends on what events the individual notices and how he/she chooses to appraise and interpret them (Wieten, Lloyd & Lashley, 1991). According to Lazarus and Folkman (1984), two types of appraisals or interpretations occur in response to stress. The first (primary appraisal) involves the initial evaluation of an event as irrelevant, relevant but not threatening, or stressful. The second (secondary appraisal) involves the evaluation of the coping resources and options for dealing with the stressful event and its impact on the individual. This is activated when the individual has primarily appraised an event as stressful. Lazarus and Folkman (1984) viewed a stress outcome as a dynamic relationship between individuals and the environment. Stress results when the environment is appraised as taxing or exceeding their resources such as coping skills and social support, thus endangering their well-being (Aldwin, 2007). Although the transactional model of stress continues to evolve and mature (Brown, 2002), Hobfoll (1989) criticized it as being “tautological, overly complex, and not given to rejection” (p. 515). This author proposed the conservation-of-resources model of stress in place of the transactional model and argued that demand and coping capacity are not defined separately in the latter model. This theorist was of the opinion that whether an event is demanding or not depends on coping capacity, and whether coping capacity is adequate or not is dependant on demand. Hobfoll’s (1989) model proposed that individuals possess resources that are important to them and that they wish to conserve and protect these resources. These include object resources (e.g., home and business), condition resources (e.g., seniority, power, and marriage), personal characteristics (e.g., self-efficacy and self esteem) and energies (e.g., time and knowledge). Psychological stress thus occurs when resources are threatened, when there is a real or perceived loss of resources, or when there is a lack of anticipated gain upon investment of resources (Hobfoll, 1989).

When looking at the aforementioned models that were discussed, it is evident that the more modern views of stress emphasize the role of appraisal in determining whether demands become stressors (Lazarus, 2000). In terms of this view, it can be said that stress is the result of an imbalance between appraised demands and appraised resources (Lazarus & Folkman, 1984). Although the literature has indicated that much emphasis has been placed on the measurement of perceived demands (Holmes & Rahe, 1967; Matheny et. al., 1993), Hobfoll (1989) maintained that the focus of stress models should be directed mainly to the resource side of the equation. Hobfoll (1989) argued that resources are the single unit necessary for understanding stress, and that the measurement of coping resources will be more predictive of stressful reactions than will the measurement of demands. Hammer and Marting’s

(1988) Coping Resources Inventory (CRI) is one of the measures that examine the resource end of the demand-resource imbalance (Matheny et al., 1993). The CRI was used as one of the two measuring instruments in the present study. This measure is discussed in greater detail in Chapter 4.

This model further suggests that people possess resources that are valuable to them, which they constantly strive to protect and conserve. These resources include physical, psychological, social and material assets. According to Sanderson (2004), resources are of utmost importance to individuals, as available resources influence coping outcomes. Individuals who possess sufficient resources to meet perceived demands are able to cope more effectively than those individuals who are faced with demands that exceed resources and who experience stress as a result of this discrepancy. A close relationship exists between available resources and coping outcomes (Crossley, 2000). Lazarus would use his theory to explain why some HIV/AIDS caregivers seem to cope with their stressful life experiences while others reach exhaustion and burnout. For this reason the concept of stress is inherently linked to that of coping.

3.3 The Concept of Coping

It is widely recognized that the negative health consequences of stressors depend to a large extent on the individual's ability to cope with these stressors (Aldwin, 2007; Olf, Brosschot & Godaert, 1993). Just as there are many theories and definitions of stress, so there are various opinions about the definition and process of coping (Hobfoll, Schwarzer & Chon, 1998). Coping is the most widely studied topic in all of contemporary psychology (Weiten & Lloyd, 2003). The starting point for much of this research is the conceptual analysis of stress and coping offered by Lazarus and Folkman (1984). According to these writers, the term coping can be defined as the "constantly changing, cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). According to Kleinke (1998) this definition has three key features:

1. an implication that coping involves some effort and planning and is influenced by the person's appraisal
2. an assumption that the outcome of the response will not always be positive
3. an emphasis on the fact that coping is a process that takes place over time.

The cognitive and behavioural efforts that were mentioned above are directed at mastering, tolerating, reducing and/or minimizing environmental and internal demands and conflicts that strain an individual's resources (Schafer, 2000). Furthermore, Lazarus and Folkman (1984) emphasized that although coping efforts can and should be aimed at correcting or mastering the problem, it may also simply help the person alter his/her perception of a discrepancy, tolerate or accept the harm or threat,

and escape or avoid the situation. Their model of stress emphasized the role of appraisal in determining whether demands become stressors. This model became widely accepted by researchers (Hobfoll, 1989; Matheny, Aycock, Pugh, Curlette & Canella, 1986). In gaining an understanding of coping and the coping process, it is essential that the process of appraisal be discussed. In the subsequent section two theories relevant to coping are discussed, namely Lazarus and Folkman's (1984) model of coping and Antonovsky's (1987) model of coping.

3.3.1 Lazarus and Folkman's Model of Coping

Lazarus and Folkman (1984) outlined two processes that occur when the individual experiences a stressor, namely cognitive appraisal and coping. The appraisal phase can be subdivided into primary and secondary appraisal. Primary appraisal is the process of perceiving a threat to oneself and it entails the individual evaluating whether the situation may bring harm or negative consequences. If it is decided that the stressor does not imply any danger, the coping process is stopped. In the event that danger or threat is perceived, the individual moves into the process of secondary appraisal. In secondary appraisal, the individual evaluates whether anything can be done about the perceived danger or threat. If something can be done about the stressor, the individual assesses what form of action can be taken. Secondary appraisal also includes individuals' evaluations of their coping resources and the options available for dealing with the perceived challenge or threat. Coping is the third phase and could include actions, a change in thinking, redefining the situation, or any other appropriate subjective solution, or anything else deemed appropriate after the individual's primary and secondary appraisal (Lazarus & Folkman, 1984). The strategy which the individual chooses may not always be the most useful one in such a situation. The activities or efforts chosen in this final phase depend on the variety of personal and environmental resources that the individual has at his/her disposal (Schafer, 2000).

According to Lazarus and Folkman (1984), coping has two widely recognized major functions. The first function, termed problem-focused coping, is aimed at problem solving or doing something to alter the source of the stress. The second function, which is termed emotion-focused coping, is aimed at reducing or managing the emotional distress that is associated with the particular stressor facing the individual (Schafer, 2000). Although most stressors elicit both types of coping, problem-focused coping tends to predominate when people feel that something constructive can be done, whereas emotion-focused coping tends to predominate when people feel that the stressor is something that must be endured (Folkman & Lazarus, 1980). Coping is contextual, as it changes over time and across different stressful situations (Lazarus, 1993).

In terms of coping, Folkman and Moskowitz (2000) reviewed evidence from their studies of AIDS caregivers which helped to explain how individuals under chronic stress and those under essentially

uncontrollable chronic stress sustain and create positive affect. The individuals under study employed the meaning-based coping processes of positive reappraisal, problem-focused coping, and the infusion of ordinary life events with positive meaning.

3.3.2 Antonovsky's Model of Coping

Antonovsky (1987) expanded on Lazarus and Folkman's (1984) description of the coping process. This author offered a further distinction between primary appraisal I, primary appraisal II, primary appraisal III, secondary appraisal, and tertiary appraisal. Like Lazarus and Folkman (1984), Antonovsky (1987) argued that the coping process initiates with a definition of an event as either a stressor or a non-stressor (i.e., primary appraisal I). Primary appraisal II is referred to as the judgment of the nature of the stimulus as benign, threatening, or positive, and primary appraisal III refers to the extent to which one is emotionally and cognitively capable of dealing with the stressor. The secondary appraisal withholds the selection of the most appropriate coping strategy, and the tertiary appraisal refers to the further assessment of different resources if the first option fails or turns out to be unavailable (Antonovsky, 1987). The following section outlines the pathogenic paradigm and the salutogenic paradigm.

3.4 Salutogenic Paradigm and Positive Psychology

Before the discussion of the theoretical constructs of the sense of coherence and coping resources, a brief description is given of the salutogenic paradigm from which these constructs have arisen. The traditional pathogenic paradigm, which contrasts the salutogenic paradigm, is also discussed.

3.4.1 The Pathogenic Paradigm

In the past, the field of psychology firmly aligned itself with the pathogenic orientation of the Western medical model. This emphasis was on disease, investigations of the abnormal, and prevention of specific diseases (Strumpher, 1993). The pathogenic orientation is generally directed at finding out why people fall ill and why they may develop a particular disease. The orientation steered researchers, practitioners and policy makers to concentrate on the specific disease diagnosed, or on prevention of specific diseases, particularly among high-risk individuals or groups (Antonovsky, 1987; 1996; Wissing & Van Eeden, 1997; Witmer & Sweeney, 1992).

At the heart of the pathogenic paradigm is the assumption that diseases are caused by physical, biochemical, microbiological and psychosocial agents (Strumpher, 1993). More recently, the emphasis has been on multifactorial causes of illnesses, usually in terms of risk factors (Bester, 2003). Primary attention has been given to 'sickness' and 'dysfunction' and resources have been committed almost exclusively to remediating problems (Witmer & Sweeney, 1992). This trend can be seen in much of the research on stress and health.

3.4.2 The Salutogenic Paradigm

While the pathogenic paradigm produced valuable insights into the causes of illness as well as illness prevention, the exclusive emphasis on the nature of disease obscured other relevant and insightful conclusions about the nature of health. As early as 1947 for example, the World Health Organisation defined health not just as the absence of disease or infirmity but as the physical, mental, and social well-being of the individual (World Health Organisation, 1958). Recently, spiritual well-being was added to this definition. Researchers have utilized the salutogenic paradigm increasingly in the last decade as an alternative paradigm that facilitates understanding of health, rather than disease or illness. As its name suggests, salutogenesis emphasizes the origins of health or wellness (from Latin: *salus*=health; Greek: *genesis*=origins) (Antonovsky, 1979).

Strumpher (1993) traced the origins of the salutogenic paradigm in psychological literature to Super's (1955) distinction between hygiology and psychopathology. Super viewed hygiology as the concern of counseling psychology as opposed to that of clinical psychology which is concerned with psychopathology. Hygiology referred to "the normalities even of abnormal persons, with locating and developing personal and social resources and adaptive tendencies so that the individual can be assisted in making more effective use of them" (Super, 1955, p. 5). Other personality theorists such as Maslow (1954; 1973) raised similar ideas with his emphasis on the need for self-actualization and humanistic psychology, as well as Rogers' (1959) concepts of actualizing tendency and the fully functioning personality. At the core of these ideas was an examination of what human beings are capable of, in spite of the odds that may be against them.

3.4.3 The Salutogenic View of Stress

Antonovsky's research in the field of health and stress has reviewed many of the conceptualizations of stress. For the most part, both lay people and professionals were inclined to equate stress with rather unusual and extreme circumstances. Antonovsky's research contradicted this perception. One of the core assumptions of the salutogenic paradigm advanced by Antonovsky (1987) was that the most typical characteristic of the living organism was "heterostasis, disorder, and pressure toward increasing entropy" (1987, p. 2). This view of chaos as the "norm" challenged the concept of homeostasis first introduced by Canon (1939).

Antonovsky argued that stressors, rather than isolated negative events, were an unavoidable part of daily living. Besides the extreme forms of oppression and consequent stress suffered by some of the populations which Antonovsky studied, it became evident that even people in comfortable, benign, sheltered environments are fairly continuously exposed to reasonably serious stressors (e.g., accidents, physical trauma and psychosocial stressors).

Whether the source of the stressors is the internal or external environment, whether they are daily hassles, acute or chronic and endemic, whether they are imposed on us or freely chosen, our lives are replete with stimuli to which we have no automatic, adequate response and in the face of which we must respond (Antonovsky, 1987, p. 130).

Antonovsky (1979) concluded that “stressors are omnipotent in human existence” and in fact, “the human condition is stressful” (p. 10). With this in mind, the question then became about how individuals survived this continual bombardment of pathogens. It became clear that individuals obtained strength from inner resources to cope with these continuous challenges – and that some coped better than others. In both research and practice, this line of thinking led researchers to attend to the range of what Antonovsky labeled, generalized resistance resources which people use for coping with a diversity of pathogens and stressors (Bester, 2003).

While the view that stressors are ever-present lies at the heart of the salutogenic orientation, stressors are not viewed as necessarily deleterious in effect. Antonovsky (1987) quoted Selye’s suggestion about eustressors when he discussed the fact that stressors are not all inherently negative and that certain stressors may produce positive outcomes. Attention is drawn to the distinction between tension and stress. While all stressors cause psychological and physiological arousal or tension in the individual, the translation of that tension into stress is mediated by the individual’s internal reactions and responses to the event (Antonovsky, 1987). Antonovsky (1996) thus indicated the importance of focusing on the complexity of the individual, rather than on pathology. This researcher advocated for his theory to form the basis of the field of health promotion. More significantly, this theory also produced ideas such as the construct of sense of coherence which is now discussed.

3.5 The Sense of Coherence (SOC)

As discussed in previous sections, stress can produce salutary consequences (Antonovsky, 1979). What determines whether one has the ability to respond to stressful or traumatic events not with despair, depression and purposelessness but with resilience and a sense of reward or purpose? To explain how the human system copes with the introduction of stressors of daily living, Antonovsky (1979; 1987) developed the sense of coherence (SOC) construct, which explains successful coping with stressors and movement towards health. In this section, the sense of coherence concept is discussed with specific reference to theory and research that exists on this construct. Attention is given to the description of the sense of coherence and the dimensions as well as the development of the sense of coherence. These constructs are now elaborated on.

3.5.1 Description of the Sense of Coherence Concept and Dimensions

In Antonovsky's (1987) view, all GRRs have in common that they facilitate "making sense out of the countless stressors with which we are constantly bombarded" (p. xiii). In providing these experiences repeatedly, they generate over time, a strong sense of coherence. A formal definition (Antonovsky, 1979) was put forward in 1987:

The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (a) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (b) the resources are available to one to meet the demands posed by these stimuli; and (c) these demands are challenges, worthy of investment and engagement (Antonovsky, 1987, p. 19).

The three core components of the definition, as indicated above, were expanded on and described by Antonovsky (1987) as follows:

1. Comprehensibility refers to the extent to which the person understands the stimuli both from within and without as clear, ordered, structured and consistent information. In other words the person feels that his/her perceptions make cognitive sense. There is also an assurance that stimuli encountered in the future will also be predictable, or at least ordered and explicable.
2. Manageability refers to the extent to which the person perceives that the resources needed to meet the stimuli-imposed demands are available to them. The resources referred to may include one's own resources (GRRs) or those resources controlled by legitimate others. Someone high on manageability will not feel victimized by events and will approach situations with the belief that the resources needed to cope are available to him/her.
3. Meaningfulness refers to the extent to which the person feels that life makes sense emotionally rather than cognitively. At least some of the problems and demands of living are felt to welcome challenges motivating one to invest energy.

Antonovsky (1987) proposed that the three components be inextricably intertwined with high inter-correlation among the components. However, the inter-correlation was found to be imperfect. Antonovsky (1987) stated that the three components of the SOC are of unequal centrality, though all necessary. It was found that the motivational component of meaningfulness seems to be most crucial and important in terms of successfully handling events. Without meaningfulness, the person high on comprehensibility or manageability or even both, soon falls behind (Antonovsky, 1987).

In general, a person with a strong SOC confronted with a stressor will according to Antonovsky (1987; 1996):

1. wish to be motivated to cope (meaningfulness). This represents the emotional dimension of the SOC.
2. believe that the challenge is understood (comprehensibility). This represents the cognitive component of the SOC.
3. believe that resources to cope are available (manageability). This represents the instrumental dimension of the SOC.

Hence, the three components of the SOC represent different dimensions or components of coping with stimuli, stressors, or challenges.

In order to measure the SOC in terms of the three components, Antonovsky (1983; 1993a) developed a questionnaire namely, The Orientation to Life Questionnaire (Sense of Coherence Scale, SOC-29). Numerous researchers have found the SOC Scale to be consistently feasible, reliable, and valid, in determining a person's sense of coherence (Antonovsky, 1993b; 1996; McSherry & Holm, 1994). This scale was therefore used as one of the measuring instruments in the present study. The SOC-29 is discussed in more detail in chapter 4.

3.5.2 Development of the Sense of Coherence

Throughout adolescence and early adulthood, the individual's SOC develops as a function of their experiences and the extent to which these are comprehensible, manageable and meaningful. The strength of the individual's SOC is dependent on their ability to bring into play the GRRs available to them (Antonovsky, 1987). GRRs refer to a property of a person, a collective or a situation, which facilitate successful coping with the inherent stressors of human existence, as evidence or logic has indicated (Antonovsky, 1996). The relationship between GRRs and SOC is described as dynamic and reciprocal. In the development of the SOC, an individual's perception of available GRRs strengthens their SOC (Wolff & Ratner, 1999). On the other hand, if there are deficits in the person's GRRs (which is also known as generalized resistance deficits (or GRDs) the person may cope ineffectively with life's stressors and develop disease (Antonovsky, 1987). The strength of an individual's SOC is not only influenced by GRRs or GRDs. Antonovsky (1979; 1987) stated that the strength of the sense of coherence is predominantly shaped by three major life experiences. These experiences include the following:

1. Consistency refers to an individual's need for consistent, stable, predictable, and structured behaviours in different contexts. Consistency thus forms the basis of the comprehensibility (i.e., cognitive) component of the SOC.

2. Load Balance refers to the perceived availability of resources to meet the demands placed on an individual. Someone with overload will feel that the available resources are inadequate to meet the demands placed on them. Someone with under load on the other hand, experiences a lack of opportunity to actualize his or her potential or capabilities. Load balance thus represents the basis of the manageability (i.e. instrumental) component of the SOC.
3. Participation in socially valued decision-making involves choosing to undergo an experience, judging whether the rules of the game are legitimate, and solving the problems and tasks posed by the experience (Antonovsky, 1987). Participation is the third type of life experience that contributes to the meaningfulness (i.e., emotional and motivational) component of the SOC concept.

The individual's culture, historical antecedents, and position in social structures such as work and family shape the extent of these three life experiences. However, factors such as gender, ethnicity, genetics and constitution also shape life experiences. Antonovsky (1996) stated that "what matters is that one has had the life experiences which lead to a strong SOC, this in turn, allows one to 'reach out' in any given situation, and apply the resources appropriate to that stressor" (p. 15). Antonovsky (1987) described the development of the SOC through experiences from infancy and childhood, adolescence and adulthood. Taking into account that the sample under study are adults, the next paragraph briefly describes the development of the SOC across the life span.

Family experiences play a significant role in shaping an individual's SOC during the infancy and childhood life stage. Comprehensibility develops over time as children become aware of the consistency and regularity of their social environment, thereby realizing that their social world can be counted on to be familiar and structured (Antonovsky, 1987). Antonovsky (1987) noted that the manageability component develops as children become increasingly physiologically able to comply with the demands placed on them by the environment. Children's sense of meaningfulness develop and is influenced by their perception that they matter and are valued by significant others (Antonovsky, 1987).

The development of the SOC in adolescence is influenced by the cultural and social environments in which they spend most of their time (Antonovsky, 1987). According to Antonovsky (1987), there are four environments in which adolescents grow up and are raised, which may foster life experiences that shape SOC. According to Antonovsky (1987), the different environments include (1) the complex open society which provides the adolescent with a wide variety of legitimate, realistic options, including drugs, religion, sex and education; (2) the homogenous and isolated subcultures that rigidly define legitimate adolescent behaviour; (3) the socio-economically devastated and confusing

subculture that challenges adolescents to develop in a state of socio-economic deprivation; and (4) the fundamentalist culture which is linked to power and destruction.

Antonovsky (1987) indicated that adolescents have a strong SOC which may be useful for short range prediction about coping with stressors and the resulting health status. However, as the individual moves into early adulthood, these many factors contribute to shaping their SOC. During adulthood the individual's location on the SOC continuum becomes more or less fixed. These adulthood demands of the individual's commitments include commitment to one's spouse or children, social roles, and work. It is especially the experience gained from work as a life role that reinforces or reverses the strength of the SOC that developed during adolescence (Antonovsky, 1987). According to Sagy, Antonovsky and Adler (1990), the SOC is crystallized around the age of 30 and becomes relatively stable over time. This, however, seems only to apply to individuals with a strong SOC at the beginning of adulthood (Carstens, 1995). When individuals with a strong SOC are confronted with challenges, one could expect their SOC to return or even surpass premorbid levels once the crisis is over (Jacobs, 2005; Otto, 2002). On the contrary, individuals with a weak SOC tend to take on the challenge as a burden, which results in a downward spiraling circle (Antonovsky, 1987). When individuals with a weak SOC are in crisis, one could expect their SOC to weaken even further and when the crisis is resolved, it is likely that these individuals' SOC will not return to premorbid levels (Otto, 2002).

The SOC could be directly related to other aspects of successful living, like effective performance at work and career effectiveness, and effective marital, parental and other interpersonal relationships (Strumpher, 1995). Antonovsky (1979) viewed the sense of coherence as stable and fundamental to an individual's make-up. However, more recently Antonovsky (1987) has recognized the dynamic nature of life experiences in shaping one's sense of coherence. It could therefore be argued that life experiences such as having to deal with illness, suffering and death on a regular basis, impacts on the existential issues of death, as well as on an individual's feelings, and their immediate personal relations (Antonovsky, 1987). In addition, he stated that such adverse conditions could have a significant negative impact on the individual's experience of consistency, load balance, and participation in socially valued decision-making. It could therefore be suggested that life events such as those with which adult family caregivers have to deal with on a daily basis could alter the strength of the SOC in either direction (Antonovsky, 1987). This assumption is further considered when the results of the current study are discussed. The sense of coherence and the setting of personal boundaries are discussed in the following section.

3.5.3 Sense of Coherence and Boundaries

Having a strong SOC does not mean that individuals view their entire world as comprehensible, manageable and meaningful (Antonovsky, 1983). People set boundaries with reference to certain areas of interest and involvement (Cairns, 2001). Some people might have little interest in politics, little interest in cognitive skills, and demonstrate little concern for trade union activities, and so on, and yet have a strong SOC (Antonovsky, 1983). Antonovsky (1987) stated that there are four spheres that cannot be excluded if a person is to maintain a strong SOC, namely their own feelings, immediate interpersonal relations, the major sphere or activity (usually work), and the existential issues of death, inevitable failures, shortcomings, conflict, and isolation. Antonovsky (1987) was of the opinion that flexibility of those life areas included within boundaries may be an effective way of maintaining a coherent view of one's world. In the section that follows, the relationship between the sense of coherence and coping is discussed.

3.5.4 Sense of Coherence and Coping

Taking into account the above components, a person with a weak SOC would perceive internal and external stimuli as noise, as inexplicable disorder and chaos and as unpredictable in terms of the future rather than as meaningful information (Strumpher, 1993). Individuals would feel that they are being victimized unfairly by the unfortunate events of life. Furthermore, they would feel that nothing in life matters much, or worse, that life consists of unwelcome demands and wearisome burdens (Antonovsky, 1987).

Research by McSherry and Holm (1994) supported Antonovsky's claim that the SOC construct is related to how individuals assess and cope with stressful events. The results of their study indicated that not only are low SOC individuals more psychologically distressed before a stressful situation, but they maintain these greater levels of distress subsequent to the stressful experience as well. On the other hand, an individual with a high SOC appears to enjoy a generally more positive outlook and this appeared to assist them in meeting life's challenges successfully. These results support the premise that SOC significantly affects cognitive appraisal, specifically secondary appraisal as described by Lazarus and Folkman (1984).

The SOC conceptualization of the coping process is unique in that it combines the cognitive, emotional, behavioural, and motivational aspects of coping (Antonovsky, 1996). The combination of these facts of coping is clearly seen in Antonovsky's (1987) description of coping as "the extent to which one is capable of cognitively and emotionally ordering one's perception of the stressor and accepting a willingness to confront it" (p. 137). According to the SOC construct, the individual who is coping successfully approaches the world with the generalized expectation that stressors are

meaningful and comprehensible. Antonovsky (1987) stated that this forms the motivational and cognitive basis for managing and preventing the transformation of tension to stress.

The strength of an individual's SOC is thus central to the regulation of the ongoing tension generated by ever-present stressors. The person with a strong SOC is more likely to define stimuli as nonstressors and to assume that he or she can adapt automatically to the demand, as compared to an individual with a weak SOC (Antonovsky, 1987). Even if the strong person appraises the stimulus as a stressor, they are more likely to see it as being irrelevant or harmless. Individuals with a strong SOC would thus prevent the transformation of tension to stress. As a result of the tension being managed well, the outcome is either neutral or salutary. Consequently, SOC is the major determinant of the location and movement of an individual's state of wellness along the health-ease/dis-ease continuum (Wolff & Ratner, 1999).

The SOC is a dispositional orientation, not a state or trait (Antonovsky, 1987). The SOC is not a specific coping style. Life poses many stressors; they are varied and continuous, therefore, one cannot adopt one pattern of coping because the individual will fail to respond to the nature of the stressor and so to decrease the chances of successful coping. A person with a strong SOC selects a particular coping strategy that seems most appropriate to deal with the stressor being confronted. Consequently, a person with a strong SOC is able to choose an appropriate combination of resources from their existing generalized and specific resistance resources. Having chosen these resources, the strong SOC person would be in a better position to cope with the stressor that they are experiencing (Sheridan & Radmacher, 1992).

A further distinction was made by Antonovsky (1996) between a resistant resource as a potential asset, and the actual mobilization and utilization of a resource. The actual mobilization of what seems to be the most appropriate resource or combination of resources in the face of the given stressor is the real strength of the person with a high SOC. SOC could also be understood as a readiness to coordinate and take advantage of resources. This readiness can be regarded as being independent of the level and type of resources at the individual's disposal (Suominen, Blomberg, Helenius & Koskenvuo, 1999).

Antonovsky (1987) developed a 29-item Sense of Coherence Questionnaire to measure the concept. Several hundred studies including Bishop (1993), Frenz, Carey and Jorgensen (1993), McSherry and Holm (1994), Smith and Meyers (1997), Suominen, et al. (1999), and Wolff and Ratner (1999) utilising the SOC measure and has been conducted around the world. These studies documented that the sense of coherence heightens the chances of distress-resistance and of good mental and physical health (Schafer, 1996). Several South African studies confirmed these findings for South African

populations. These include Bester (2003), Cairns (2001), Carstens (1995) and Wissing and Van Eeden (1997). Due to the fact that coping behaviour forms one of the coping cornerstones of the present research, brief attention is now given to coping styles that are also referred to as stress-resistant personality patterns.

3.5.5 Sense of Coherence and Related Concepts

Much of the research on stress and coping is pathogenic in orientation as the need to explain pathology is emphasized. However, a number of researchers and theorists have emerged in this field who have developed similar concepts to the SOC. This is an attempt to understand individual differences in coping and to conceptualise coping styles that have come to be known as stress-resistant personality patterns (Schafer, 1996). These salutogenesis-related constructs have stimulated further insights by their attempts to explain health rather than disease. Table 3 presents a brief summary of a few of these concepts.

Table 3

Sense of Coherence and Related Concepts

Concept	Researcher	Definition
Hardiness	Kobasa (1979)	Hardiness is a personality style which has three constituent components namely; (a) a liking of challenge (comprehensibility), (b) a sense of commitment (meaningfulness), and (c) a sense of control (manageability).
The Survivor Personality	Siebert (1993)	People characterized by this personality are those who have survived a significant crisis through personal effort, finding previously unknown strengths through the experience and afterwards finding value in their struggle.
Learned Optimism	Seligman (1970)	Learned optimism is a coping style and a personality pattern whereby the individual ascribes good events to internal, permanent and pervasive factors. Bad events are ascribed to factors that are external, temporary and limited in scope.
Self-Efficacy	Bandura (1982)	Self-efficacy is a coping style whereby a person, when confronted by a situation that is threatening or induces tension, believes that they have the ability to behave in the way required for a desired outcome.
Type C Behaviour Pattern	Kriegel and Kriegel (1984)	The Type C personality pattern describes how people manage to thrive and produce peak performance under pressure. The Type C pattern draws some of the best attributes from the Type A and Type B patterns and adds new elements to form a cluster of ingredients for meeting challenges head on with success and vitality. The “C” in this model stands for the three Cs in the Type C pattern: challenge, confidence and control.
Fortigenesis	Strumpher (1995)	This concept is more encompassing than salutogenesis because it looks beyond just physical health to the sources of strength in general.

The conceptualizations of coping listed in Table 1 tend to explain and characterize the coping process as the result of either a personality pattern of a cognitive appraisal or an emotive and behavioural style. On close examination, threads of the three components of the SOC – comprehensibility, manageability and meaningfulness – may be found in all of the listed theories. A study by Smith and Meyers (1997) that examined correlations between the measure of SOC and measures of learned optimism, self efficacy, hardiness and locus of control found that all the variables seemed to be measuring the same core construct. The results of a South African study by Wissing and Van Eeden (1997) also supported Antonovsky's (1993a) findings of positive correlations of the SOC with indices of psychological well-being such as internal locus of control, self esteem, hardiness, general well-being, quality of life, problem focused coping and stamina. Further research has compared Antonovsky's SOC scale with other scales designed to measure the same or similar constructs, and has found Antonovsky's instrument to be more accurate (Dana, Hoffman, Armstrong & Wilson, 1985).

The uniqueness of the SOC concept lies in its particular combination of the cognitive, behavioural and emotional aspects of coping (Antonovsky, 1996). Moreover, unlike concepts such as internal locus of control, mastery, empowerment, problem-solving coping, and the like, the SOC is not a culture-bound construct. The sources of the three components may vary greatly from culture to culture or situation to situation (Antonovsky, 1996). The following section focuses on cultural issues and the South African context in relation to the sense of coherence concept.

3.5.6. Cultural Considerations and the South African Context

All individuals are born into a particular set of life experiences based on a specific culture and history. This section investigates potential differences in culture with regards to sense of coherence. Sense of coherence and certain cultural factors are examined as well as cultural concerns related to the sense of coherence construct.

One of the things that determine the position of the individual on the sense of coherence continuum are the patterns of experience created by the historical and social conditions that make certain generalized resistance resources available (Antonovsky, 1987). Antonovsky (1979) acknowledges the fact that genes and predispositions may influence sense of coherence, but states that every individual is born into a particular class and is considered to be a certain culture, gender, religion and other social categories that determine particular patterns of life experiences for individuals. These social categories may facilitate either a stronger or weaker sense of coherence.

The Sense of Coherence Questionnaire (Antonovsky, 1987) comprises items that have been found to be universally understandable and meaningful across gender, social class and region (Carstens &

Spangenberg, 1997), and has been administered in 14 languages including English, Afrikaans, Dutch, Finish, German, Hebrew, Norwegian, Rumanian, Russian, Serbian, Spanish and Swedish which is indicative of its applicability across cultures (Bowen, 1996; 1997; Carstens & Spangenberg, 1997; Edwards & Besseling, 2001). Antonovsky (1987) and Bowman (1996; 1997) postulate that many different cultural paths will result in similar levels of sense of coherence, and that differences in pathways are more likely due to differing life experiences and not to cognitive, motivational or motivational factors. Antonovsky (1993b) argued that individual experiences must receive social valuation; this may be from family and friends and not from society at large, as long as there is some type of social valuation to reinforce meaningfulness. Not all cultures are naturally conducive to a strong sense of coherence, and similarly many cultures facilitate a strong sense of coherence. Antonovsky (1987) used the example of the contrast between sense of coherence in individuals living in London's privileged Kensington area and those poverty-stricken individuals living in Johannesburg's Soweto Township. This theorist stated that the difference hypothesized may result from the contrast between the amount of stressors inhibiting the sense of coherence, and the availability of GRRs enhancing the sense of coherence. The historical, political and social conditions of South Africa differ significantly from those in first world countries. The following section focuses on the coping resources construct. Attention is given to Antonovsky (1979), Lazarus and Folkman (1984) and Hammer and Marting's (1988) conceptualizations of the coping resources construct.

3.6 Coping Resources

While Antonovsky's SOC is one of the constructs utilized in the present study, the second area of investigation is that of coping resources. Like the SOC, coping resources may be viewed as a salutogenic construct. There are a number of coping resources available to an individual in the coping process. Different researchers have explored and defined these coping resources in various ways.

Various mediating factors are capable of affecting the process of coping and play an influential role with regard to the manner in which individuals are able to cope with stressful demands. Among these are psychological resources (i.e. personal characteristics that individuals draw upon, such as self-esteem, hardiness and an internal locus of control) and social support (Gouws, 2004, Smith, 2006; Stanley, 2000). Weiten, Lloyd and Lashley (1991) are of the opinion that constructive coping involves the effort to deal with events and situations that are deemed or judged to be relatively healthy. McCrae and Costa (1986) concluded that the most effective coping resources include seeking help, communicating feelings, taking rational action, drawing strength from adversity, using humour, and maintaining faith, self confidence and feelings of control. According to these authors, the least effective coping resources include indecisiveness, hostility, self-blame, as well as attempting to escape

or withdraw from the situation. For the purpose of the present study, Antonovsky's (1979), Lazarus and Folkman's (1984) and Hammer and Marting's (1988) conceptualizations of coping resources are examined and explored.

3.6.1 Antonovsky on Coping Resources - Generalized Resistance Resources (GRRs)

The term GRR refers to “a property of a person, a collective or a situation which, as evidence or logic has indicated, facilitated successful coping with the inherent stressors of human existence” (Antonovsky, 1996, p. 15). In Antonovsky's (1987) view, all GRRs facilitate “making sense out of the countless stressors with which we are constantly bombarded” (p. xiii). In providing these experiences repeatedly, they generate, over time, a strong sense of coherence. Antonovsky (1979) described a range of GRRs including:

1. Physical and biochemical GRRs such as immunosuppressors
2. Artefactual-material GRRs, particularly wealth, that can buy, for example food and clothing, but also power, status and services
3. Cognitive GRRs, particularly knowledge and intelligence, contingent on education
4. The emotional GRR of ego identity
5. Coping strategies, as overall plans or action for overcoming stressors
6. Interpersonal-relational GRRs, like social support and commitment
7. The macrosociocultural GRRs which include religion and other beliefs, rituals or norms.

In summary, it could be stated that Antonovsky (1979) found that the extent to which one possesses GRRs is a primary determinant of the extent to which one comes to have a generalized, pervasive orientation towards life. The orientation will enable an individual to “make sense” of life in a cognitive, instrumental and emotional manner (Antonovsky, 1987; 1996). This led to the development of the sense of coherence construct, which can be explained as a generalized orientation towards the world which perceives the world on a continuum as comprehensible, manageable, and meaningful (Antonovsky, 1996). This forms the motivational and cognitive basis for managing and preventing the transformation of tension and stress.

3.6.2 Lazarus and Folkman on Coping Resources

According to Lazarus and Folkman (1984), the manner in which people cope is heavily dependent on the resources available to them and the constraints they face. Coping resources are concerned with the resources one draws on in order to cope. According to Lazarus and Folkman (1984), these may be grouped into major categories such as:

1. health and energy are the most pervasive and relevant resources to all people and are refer to physical well-being. Healthy people are able to manage external and internal demands much better than frail, sick or tired people.
2. positive beliefs – perceiving oneself positively can be regarded as a very important psychological resource. When people believe that they can successfully bring about desired consequences, their ability to cope with stress is enhanced.
3. problem solving skills refers to the ability to search for information, analyse situations, and generate alternative solutions to the problem at hand. These skills are drawn from other resources that include experience, knowledge, cognitive ability and the capacity for self-control.
4. social skills are an important source of stress management and include the ability to get other people to cooperate. This involves the capacity to communicate with other in a socially appropriate manner.
5. social support refers to interpersonal relationships that involve information giving, tangible support involving direct assistance, and emotional support that contributes to the feeling that one is loved and cared about.
6. material resources refer to monetary resources, including money and the resources that money can acquire, such as easier and sometimes more effective access to professional assistance, such as legal, medical and financial help.

Current literature suggests that the coping resources needed by caregivers include financial resources, social support and physical health. In addition to this, psychological characteristics such as internal locus of control and psychological well-being are also needed (Connell, Janevic, & Gallant, 2001; Haley, Roth, Coleton, Ford, West, Collins & Isobe, 1996).

3.6.3 Hammer and Marting on Coping Resources

Hammer and Marting (1988) are of the opinion that individuals make use of coping resources to enable them to deal with stressors more effectively. These authors further advocated that coping resources are inherent in individuals and facilitated the experience of fewer or less intense symptoms on exposure to a stressor, or to faster recovery from exposure to stressors. Similarly, individuals with low resources can be described as “vulnerable and constitutionally fragile” (Kessler & Essex, 1992, p. 487), while those with high resources have been characterized as resilient and hardy (Kobasa, 1979).

From this definition it becomes clear that exploring coping resources concurs with the salutogenic premise of attempting to explain health and healthy behaviour, rather than disease. Hammer and Marting (1988) examined coping resources in five domains, namely: cognitive, social, emotional,

spiritual/philosophical, and physical. Brown (2002) pointed out the extent to which these domains corresponded with Antonovsky's (1979) explanation of coping resources (referred to as Generalised Resistance Resources), as Antonovsky (1979) also described cognitive, social, emotional, and physical characteristics in his definition of coping resources.

The following is a description of these five domains:

1. The cognitive domain focuses on the extent to which individuals maintain a positive sense of self-worth, a positive outlook towards others, and optimism about life in general.
2. The social domain is concerned with the degree to which individuals are embedded in social networks that are able to provide support in times of stress.
3. The emotional domain questions the degree to which individuals are able to accept and express a range of affect, based on the proposition that a range of emotional responses help in relieving relieving the long-term negative consequences of stress.
4. The spiritual/philosophical domain examines the degree to which actions of individuals are guided by stable and consistent values derived from religious, familial, or cultural tradition or from personal philosophy. These values might serve to define the meaning of potentially stressful events and to prescribe strategies for responding effectively.
5. The physical domain questions the degree to which individuals enact health-promoting behaviours, which is believed to contribute to increased physical well-being. Physical well-being is thought to decrease the level of negative responses to stress and to enable faster recovery from stressful events.

From the preceding discussion of the concept of coping and related topics, it is evident that the literature indicates that life stressors are associated with a wide range of psychological and physiological disorders. However, coping resources act as compensatory factors that help maintain health and contribute to overall coping in the face of stressful conditions. The next section briefly describes research that was conducted relating to coping resources and the sense of coherence.

3.7 Research on Coping Resources and Sense of Coherence

McSherry and Holm (1994) provided results indicating that low SOC subjects show more distress. They also appraise and cope with stressful situations in ways less likely to resolve or eliminate their distress. Smith and Meyers (1997) referred to research findings that indicate that people with a strong sense of coherence appear to experience less anxiety (Frenz, Carey & Jorgensen, 1993; McSherry & Holm, 1994), less depression (McSherry & Holm, 1994), less stress (Bishop, 1994; Frenz et al., 1993), less anger (McSherry & Holm, 1994), and fewer physical health symptoms of illness (Bishop, 1993; McSherry & Holm, 1994). Likewise, Suominen, Helenius, Blomberg, Uutela and Koskenvuo (2001)

found a strong SOC to be predictive of good health in men and women. Antonovsky and Sagy (2001) found that a poor sense of coherence related to anxiety and psychological distress. Physiological symptoms including neck and back pain (Petrie & Azariah, 1990), and absence due to sickness (Kivimaki, Vahtera, Thomson, Griffiths, Cox & Pentti, 1997) positively correlated with a poor SOC. Smith and Meyers (1997) concluded that it appears that greater psychological and physical health are realized, depending on the degree to which individuals with a strong sense of coherence can effectively negate the harmful effects of stress.

Wolff and Ratner's (1999) study focused on explaining the effects of stress, social support, and life events on SOC. Analysis of the data indicated that one third of the variability in SOC can account for chronic illness, childhood stress, recent life events, and social support. Unsuccessful development of one's SOC may result in negative health effects in adulthood. However, social support for adults can buffer the effects of traumatic events. Their findings indirectly supported Antonovsky's premise that the SOC is a major variable in determining the health of an individual.

3.8 Conclusion

The salutogenic orientation is useful in providing direction and focus in the field of health psychology. It allows the field to be committed and concerned with the entire spectrum of health ease/dis-ease, to focus on salutary rather than risk factors and to always view the entire person rather than the disease. With this salutogenic framework, many rich and useful insights have been gained into how individuals manage stress and stay well. For the purpose of this study, two constructs from this paradigm have been discussed as a comprehensive source and guide for research and action in health promotion namely, sense of coherence and coping resources. The following chapter focuses on the research design and methodology of the current study.

Chapter 4

Research Design and Methodology

4.1 Chapter Preview

This chapter provides an overview and description of the methodology employed in this research study. The aims of the present study are outlined. A discussion of the research design will be followed by a description of the participants and an explanation of the sampling method that was employed. A brief explanation of the measures utilized in the research is included to provide a better understanding of the data collection. Outlines of the procedures, and the process of the research, as well as the ethical considerations are given. Lastly, the data analysis of the study is explained.

4.2 Aims of the Research

The aims of this study are as follows:

1. To explore and describe the sense of coherence of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area.
2. To explore and describe the coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area.
3. To explore and describe the correlation between caregivers' sense of coherence and coping resources.

4.3 Research Design and Methodology

This study falls within the sphere of quantitative research. An exploratory-descriptive research design was employed in which participants were asked to complete self-report paper and pencil survey type questionnaires (Babbie, 1998; De Vos, 2000; Salkind, 1997). This method was chosen to gather descriptive data to meet the aims of the study. Exploratory descriptive studies attempt to gain familiarity and insight, while accurately depicting the characteristics of the phenomenon under scrutiny. The goal of exploratory research is the formulation of more precise questions for future research to answer (Neuman, 2000), while descriptive studies aim to describe situations and events in order to accurately portray the characteristics of a particular individual, group, situation or event (De Vos, 2000). Various descriptive methods can be employed (Creswell, 2003; May, 2001). These include field observation (i.e., making observations in a particular natural setting); systematic observation (i.e., observation of one or more specific behaviours in a particular setting); case studies (i.e., descriptions of individuals); survey research (i.e., the use of self-report measures given to a group of people in order to measure their attitudes, behaviours, beliefs, values or tendencies to act); and

archival research (i.e. using already existing information to answer research questions) (Goodwin, 2002). Survey research is one of the best methods available to social scientists interested in collecting original data for describing a population too large to observe directly (Corbetta, 2003).

Of the various descriptive methods that a researcher can employ, the survey method is viewed as the most applicable for this research as the study aims to utilize self-report paper and pencil questionnaires and to gather information to describe the sense of coherence and coping resources of HIV/AIDS adult family caregivers (May, 2001). This survey research included a biographical questionnaire as well as standardized paper-and-pencil measures to collect data. Survey research is a way of collecting information from people and is an important way of studying the relationship between variables. This does not necessarily mean that a causal relationship can be established, however, the existence of a relationship and the strength and direction of a relationship can be inferred.

There are a number of advantages and disadvantages when conducting survey type research. The advantages include considerable savings in terms of time, the quality of information, cost effectiveness, and the ease of distribution to large numbers of people (Creswell, 2003). Dane (1990) and Salkind (1997) noted other advantages, such as obtaining accurate results and better generalization of the results. Participants also have the added advantage of greater assurance and autonomy as well as removing interviewer bias (Rosnow & Rosenthal, 2005). A survey has instructions on how to complete the questionnaires, and presents a number of questions or items that may have forced response choices or open-ended questions (Fowler, 2002). Regardless of the type of questions used, these measures are easy to use, score and code, and provide all participants with the same options, therefore enhancing reliability and validity (Rosnow & Rosenthal, 2005). Some disadvantages include a low response rate, dishonesty in answering, as well as an increased risk of a biased sample (Flick, 2002; Mitchell & Jolley, 1992) or subjective responses (Nardi, 2003). Omitting questions and the researcher's lack of control over the environment, unpredictable return dates of questionnaires, as well as unpredictable response rates, an increase in the likelihood of misunderstood items, and incomplete responses (Bailey, 1997), add to the disadvantages of survey methods. In addition, Sullivan (2001) stated that the survey method is rigid, with limited variation in responses. In the present study, these disadvantages will be minimized, as the researcher will distribute and collect the questionnaires by hand, as well as verbally explain the procedure for completing the questionnaires. The participants will complete questionnaires in a controlled environment under the supervision of a trained test administrator.

The study can also be described as correlative in nature, since the relationship among variables will be explored (Cozby, 2004). Correlation designs are identified by their ability to demonstrate

relationships between variables (Davidshofer & Murphy, 1998). In other words, as explained by Howell (1995), when dealing with the relationship between two variables, the research is concerned with correlation, which implies the measurement of the degree or the strength of the relationship between these variables. This relationship is represented by a correlation coefficient (Howell, 1995). In the section that follows, the sampling procedures are explained.

4.4 Participants and Sampling Procedure

Sampling methods are divided into two categories, namely probability and non-probability sampling (Creswell, 2003). A probability sample is selected by an objective method and it is possible to calculate each person's chances of selection. Non-probability samples are convenient, involving selection of only those participants who are willing and available to be part of the study (Fink & Kosecoff, 1998). Since the aim of the study was to describe the sense of coherence and coping resources of the adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area, non-probability convenience sampling was utilised. Non-probability sampling means that the researcher has no way of knowing the probability that a particular person will be selected for the sample (Harris, 1998). It involves the participants being willing and available to take part in the study. This implies that the sample is not randomly selected (Babbie & Mouton, 2001). While it is difficult to determine how representative the sample will be, generalization can be assessed through replication (Babbie & Mouton, 2001; Barker, Pistrang & Elliot, 1994; Mertens, 1998). This shortcoming should not have an effect on this particular study, because the aim of the study is not to generalize the results, but to explore and describe the sample. All adult family caregivers who are registered with the Masizakhe Community Project were considered for inclusion in the sample. The inclusion of participants took place irrespective of age and gender. It was required that the participants be able to read and understand English in order to complete the questionnaires.

The advantage of this sampling technique is that it saves time and money and is less complicated than probability sampling methods, since the population of participants is accessible to the researcher (Harris, 1998). Despite the considerable number of disadvantages attached to non-probability convenience sampling, Strydom and De Vos (1998) have pointed out that this is one of the most commonly employed sampling strategies because it is relatively easy and inexpensive. Since the aims of the study were exploratory and descriptive in nature, these limitations did not impact significantly on the study.

The rationale for recruiting the sample from the Masizakhe HIV/AIDS community project, which is coordinated and funded by the iThemba AIDS foundation, was a request from the Management team at the community project. Management of the organization who form part of the Masizakhe community

project identified the research participants. Taking part in the proposed study was beneficial to the sample and to the Masizakhe community project as the results gathered were utilised to foster a greater understanding regarding the caregiver's psychological mechanisms, which assisted the organization in future support program development and intervention. The researcher together with the Masizakhe community project team informed the participants about the nature and aims of the study. The participants received the administration times and dates. Thereafter, the participants who were willing to participate in the study were included. According to Grinnell and Williams (1990), 30 subjects are considered a minimum in terms of sample size for an exploratory descriptive study; at least 50 are required for a correlation study (Creswell, 2003). The research population consisted of 50 Xhosa speaking adult family members who are the primary adult family caregivers of an HIV/AIDS patient regardless of their marital status, gender or age. It was essential that these caregivers were caregiving for an ill family member for longer than six months. The questionnaires are only available in English; therefore it was imperative that the participants had a fairly good command of the English language. More detailed information regarding the participants will be provided in chapter 5. Now that a description of the sample has been provided, a brief discussion of the biographical and standardized questionnaires utilised in the present study follows.

4.5 Measures

Three measures were utilized to collect the data for the study. These measures included a Biographical Questionnaire that was developed by the researcher based on a literature review, the Sense of Coherence Questionnaire (SOC-29) that was developed by Antonovsky (1983), and Hammer and Marting's Coping Resources Inventory (CRI). Each of the above-mentioned questionnaires are discussed in the following paragraphs.

4.5.1 Biographical Questionnaire

A questionnaire that has been designed by the researcher, based on the literature review (Linn, Lewis, Cain & Kimbrough, 1993), was utilized to obtain relevant biographical information about the participants (See Appendix C). The reason for including a biographical questionnaire was to gather contextual demographic and background information pertaining to the participants. This information was used to describe the sample group. The variables included in the biographical questionnaire are age, gender, marital status, number of people living in the household where the patient is being cared for, economic status, daily responsibilities, role of the caregiver, the caregiver's relationship to the patient, number of hours spent caregiving, and caregiving stressors (See Appendix C). This questionnaire assisted in describing and extending the research (Tolliver, 2001).

4.5.2 Sense of Coherence Questionnaire (SOC-29)

The Sense of Coherence Scale was developed by Antonovsky (1987) to operationalise this concept and to provide a way of measuring it (Antonovsky, 1993a). Antonovsky (1993a) stated that “on the basis of a comprehensive theoretical model, a systematic questionnaire was developed, usable for both interview and self-completion purposes” (p. 726). The SOC scale comprises of 29 items, and participants were asked to select an appropriate response from a seven-point semantic scale, which has two anchoring phrases at each end of its continuum. For example, in response to the item “when you talk to people, do you have the feeling that they don’t understand you?” participants can choose any response from 1 (never have this feeling) to 7 (always have this feeling) (Smith & Meyer, 1997). Reversed scoring is used for negatively formulated items. Antonovsky (1987) indicated that the concept of SOC refers to the global orientation to one’s inner and outer environment, which is hypothesized to be a significant determinant of location and movement on the health ease/disease continuum.

Antonovsky's (1987) sense of coherence ought to explain why some people manage stress and stay well while others break down. According to Antonovsky's formulation, SOC is strongly developed if a person sees the world as comprehensible (i.e. rational, understandable, consistent and predictable), as manageable (i.e. extent to which the person perceives that the resources needed to meet the stimuli-imposed demands are available to them), and as meaningful (i.e. challenges and demands that are worth making commitments for). Sense of coherence has gained widespread attention and has been used as an explanatory variable in many studies. It is important to note that the scale was developed to measure the Sense of Coherence construct as a global life orientation, rather than consisting of explicit components. Other studies have confirmed that the SOC scale is a unidimensional instrument with a single global factor that measures SOC (Frenz, Carey & Jorgensen, 1993; Holm, Ehde, Lamberty, Dix & Thompson, 1988).

For the purposes of this research, the English SOC-29 was the only form of the measure used. Antonovsky (1993) mentioned that more than 10,000 people in 14 different languages have completed the Sense of Coherence questionnaire. These languages include Afrikaans, Czech, Dutch, English, Hebrew, Norwegian, Romanian, Serbian, Spanish, Swedish, Xhosa and Tswana. These participants were representative in terms of gender, age, social class and culture.

The questionnaire has thus been exposed to scrutiny in various countries and has been found to be valid and reliable in many studies. Antonovsky (1993) stated that in 26 studies the Cronbach’s alpha has been used to determine the internal consistency of the scale. Consistently high Cronbach’s alphas, ranging from 0.83 to 0.95, were found across a variety of populations (Antonovsky, 1993; Frenz,

1990). The few test-retest correlation studies have also shown stability over time (Antonovsky, 1993; Holm et al., 1988). There is also substantial evidence that confirms content validity and face validity with further indications of good construct validity and criterion validity (Antonovsky, 1993). Criterion validity correlations were found to be statistically significant.

In a later article, Antonovsky (1996) reiterated these findings by stating that the 29-item SOC scale had been found to be consistently feasible, reliable and valid across cultures, social classes and ethnic groups and for men and women of all ages. The SOC scale has been found to bear a strong correlation to a variety of measures of well-being and health, as well as distress and maladaptation (Smith & Meyers, 1997). Recent South African studies that have used the SOC-29 include Madhoo (1999) who investigated the SOC in patients participating in cardiac rehabilitation programmes; Cairns (2001) who investigated the SOC in patients suffering from cancer; Otto (2002) who investigated the SOC in adults with depressed mood; Katalan (2003) who investigated the SOC in HIV-positive adult females attending a support group; Kayal (2003) who investigated the SOC of male police officers in the South African Police Services; and Jacobs (2005) who investigated the SOC of teachers educating learners with intellectual disabilities. Wissing and Van Eeden (1997) investigated the validity and cross-cultural applicability of this measure in the South Africa context, and once again the scale was found to have adequate validity. The South African research also confirmed the universal applicability and validity of the construct across culture, gender and age barriers. For this reason, it was deemed appropriate for the present study. At present, specific norms for the population under study does not exist for this country and this is one of the reasons a description of the findings in this specific group of HIV/AIDS adult family caregivers were undertaken. Antonovsky (1993) was of the opinion that the Sense of Coherence construct is universally meaningful and cuts across lines of gender, social class and culture. This questionnaire has been used in a variety of different countries and has been found reliable and valid in numerous studies. The latter is credited to the fact that the Sense of Coherence Scale does not refer to a specific type of coping strategy, but to factors, which in all cultures are always the basis for successful coping. It is evident that the scale has been used extensively locally and internationally and was found to be very useful. The following section outlines the procedures that were followed when conducting the research.

4.5.3 The Coping Resources Inventory (CRI)

Much clinical theory and practice focuses largely on people's deficits as opposed to their resources. The CRI was constructed to facilitate an emphasis on resources rather than deficits and was developed to provide a tool for identifying resources that are currently available to individuals for managing stress (Hammer & Marting, 1988). Hammer and Marting (1988) were of the opinion that identifying

and acknowledging the individual's resources and competencies as well as their deficits and impairments might be useful in developing interventions and in improving their self-concept. Such increased knowledge of the role of resources in the coping process may also assist in the design of prevention programs and allow researchers to specify more comprehensive models of coping that take into account both deficits and resources (Hammer & Marting, 1988).

The Coping Resources Inventory measures five basic ways that individuals handle stress. This measure was developed to be administered to individuals ranging in age from fourteen to eighty-three (Hammer & Marting, 1988). Hammer and Marting stated that the CRI can be used in a variety of applications such as,

1. treatment planning for stress-related problems of individuals in counseling;
2. treatment planning for specific rehabilitation programs such as those for cardiac patients;
3. as a tool for designing stress workshops tailored for specific groups;
4. as a tool for identifying individuals who might be at risk, in need of counseling or in need of medical intervention;
5. as a tool for programme evaluation;
6. as an educational planning and assessment device in high school health classes;
7. as a research instrument to investigate coping resources in various populations and to provide a standardised measure in coping research.

The resource domains of the CRI were devised by the test developers based on their experience in conducting stress programmes, as well as a thorough literature review. All the resources that fell into the counseling domain were then incorporated into the measure. This resulted in the 60-item measure that examines resources in five domains, namely cognitive, social, emotional, spiritual/philosophical and physical (Hammer & Marting, 1988). The 60 items measuring resources in the five domains are as follows:

1. Cognitive: the extent to which individuals maintain a sense of self-worth, a positive outlook towards others, and optimism about life in general. An example of an item from this domain is: "I feel as worthwhile as anyone else".
2. Social: the degree to which individuals are embedded in social networks that are able to provide support in times of stress. An example of an item from this domain is: "I am part of a group other than my family, that cares about me".
3. Emotional: the degree to which individuals are able to accept and express a range of affect, based on the premise that a range of emotional response aids in ameliorating long term negative consequences of stress. An example of an item from this domain is: "I can cry

when sad”.

4. Spiritual/Philosophical: the degree to which actions of individuals are guided by stable and consistent values derived from religious, familial, or cultural tradition or from personal philosophy. Such values might serve to define the meaning of potentially stressful events and to prescribe strategies for responding effectively. The content domain for this scale is broader than traditional western religious definitions or spirituality. An example of an item from this domain is: “I know what is important in life”.
5. Physical: the degree to which individuals enact health-promoting behaviours believed to contribute to increased physical well-being, which serves to decrease the level of negative response to stress and enables faster recovery from stressful events. An example of an item from this domain is: “I am in good physical shape”.

The 60-item questionnaire is answered on a separate answer sheet. For each of the 60 items, participants are asked to use a four-point rating scale to indicate how often they have engaged in the item over the past six months (Hammer & Marting, 1988). The sums of the item responses for each scale constitute the scale scores. Six items with negative wording are reversed scored, before adding their points to the total score for that particular scale. The total Resource score is computed by adding the five individual scale scores. The higher the scale score, the higher the resources of that person (Hammer & Marting, 1988).

The CRI was selected for the study, as it is a short questionnaire, and has good reliability and validity. Although this measure was developed and standardized by Hammer and Marting (1988) in the United States of America, a number of South African based studies have indicated the CRI’s suitability in its implementation in the South African context. These studies include Madhoo (1999), who investigated the coping resources of patients in cardiac rehabilitation programmes; Cairns (2001) who investigated the coping resources in cancer patients; Brown (2002) who investigated the biopsychosocial coping and adjustment of medical professional women; Otto (2002) who investigated the coping resources and orientation of patients with the diagnosis of major depression; Katalan (2003) who investigated the sense of coherence and coping resources of HIV-positive adult females attending a support group; Gouws (2004) who investigated the biopsychosocial coping and adjustment of adult female irritable bowel syndrome patients; and Jacobs (2005) who investigated the coping orientation and resources of teachers educating learners with intellectual disabilities.

Internal consistency reliabilities of the CRI were estimated using Cronbach’s alpha. Cronbach’s alpha refers to an internal-consistency reliability coefficient appropriate for tests comprised of dichotomous or multipoint items (Aiken, 2000). According to Murphy and Davidshofer (1994), the

levels of reliability typically reported for rating scales is .70. This indicates low to moderate reliability. However, research conducted by Brown (2002) reported a reliability coefficient of .93 indicating a moderate to high reliability for the sample in that study. Madhoo's (1999) study resulted in means and standard deviations that were similar to the results of Hammer and Marting's cardiac rehabilitation sample. A reliability co-efficient of .85 was computed for the present study indicating a moderate to high reliability.

The reliability and validity of the CRI were tested on a variety of subjects. The item to scale reliability correlations were shown to possess fairly good homogeneity in terms of item content per scale. Similarly, the internal consistency, which was measured using Cronbach's alpha, possessed a range and pattern that suggests that the constructs in the CRI are fairly homogenous and reliable (Aiken, 2000). As regards validity, the CRI was found to possess evidence of predictive, convergent, divergent, discriminant and concurrent validity (Hammer & Marting, 1988).

The intercorrelations of the CRI scales reveal some overlap among resource constructs for the cognitive, social, and emotional scales. Despite this overlap, Hammer and Marting (1988) cautioned that their separations seem justified until further data are available. The relationship among these scales suggests that individuals with a positive outlook also have a supportive social network, and are aware of, and can express their emotions. The strongest test of validity of a coping measure is its ability to predict symptoms of stress over time. In theory, higher resources should be associated with fewer symptoms (Hammer & Marting, 1988). In addition, the CRI total resource score as found to be a significant predictor of stress symptoms (Hammer & Marting, 1988).

4.6 Procedure

The HIV/AIDS unit at the Nelson Mandela Metropolitan University was requested by iThemba AIDS Foundation to conduct research into their community project. Formal contact was established with the representative of the iThemba AIDS Foundation in the Eastern Cape and a meeting was arranged with the management team of the Masizakhe Community Project in Kwazakhele, Port Elizabeth to establish their research needs. Once all stakeholders agreed upon the research needs, verbal consent was obtained from the director of the organization. Before fieldwork commenced, a proposal was submitted to the iThemba Trust as they funded the research. The ethical standards of the Ethics Committee (Human) of the Nelson Mandela Metropolitan University were met. Once written permission was obtained to proceed, the management team was contacted to obtain a database of possible participants. The dates of administration were arranged and interested participants were informed of the nature and purpose of the study in the form of an information letter (See Appendix 1). As stated previously, it was imperative that the participants had a fairly good command of the English

language. Included in the letter was a clear description of the confidentiality and voluntary nature of the research, as well as a consent form that was attached for the participant to sign. For this reason, all the questionnaires that were completed and any correspondence thereafter was available only in English.

The administration of the tests took place individually at the caregiver's homes as well as in a group context at the Masizakhe Community Project office. The members of the management team who form part of the organization were trained by the researcher in administering the questionnaires, and were available to assist participants with any queries. The participants were expected to be literate in English with a grade ten level of education. They were asked to sign a form to ensure confidentiality of all information gathered. They were informed that their participation would remain confidential, and that all research results would remain anonymous. The researcher was responsible for inputting the data on a database that was set up by the statistician. Once the database was complete the data was ready for analysis. The Masizakhe Community Project management team received a written feedback report after the final treatise was completed. This report outlined the aims of the study, the findings, and possible recommendations. The participant's right to confidentiality was upheld, as no identifying details were disclosed in this report. With the procedures stated above, the following section focuses on the ethical considerations pertaining to the present study.

4.7 Ethical Considerations

According to Leedy and Ormrod (2001), research procedures must be carefully considered because these projects require the participation of human beings. Struwig and Stead (2001) postulated that ethical principles are concerned with the rights, dignity, welfare, respect and courtesy of research participants. According to Jackson (2003) and Russel and Roberts (2001), there are various guidelines that exist in order to ensure that the researcher respects the rights and dignity of the research participant at all times. The main ethical considerations taken into account whilst conducting the present study were: informed consent, voluntary participation, confidentiality, minimizing harm to the participants and release of findings. In conjunction with consent obtained from the relevant authorities and stipulations of the Nelson Mandela Metropolitan University Ethics Committee (Human), the ethical considerations taken into account whilst conducting the present research are outlined in detail.

4.7.1 Informed Consent

According to De Vos (2000), informed consent implies that adequate information of the goal of the research, the procedures that will be followed during the study, and the possible advantages or disadvantages will be rendered to the participant. Emphasis must be placed on accurate and complete information so that the participant will fully comprehend the study, and consequently, be able to make

an informed decision about his or her possible participation. The issue of informed consent may be the most important ethical consideration in research due in part to how much it is emphasized in the psychology profession's code of ethics. Informed consent involves providing participants with an accurate perception of the process; possible risks of participation and what the information gained will be used for (McBurney & White, 2004). Participants should be informed that they have the right to withdraw from the study at any time as well as possible risks and discomfort (Russel & Roberts, 2001). Leedy and Ormrod (2001) stated that all research conducted involving human beings as participants must have informed consent forms signed by the participants. In the present study, the participants each received a covering letter (see Appendix 1) in which the nature as well as the aims of the study were described. They also each signed a consent form so as to ensure that they understood their voluntary participation in the research project (see Appendix 2). Participants were provided with a contact number for the researcher in case of any queries or any questions that might have arose.

4.7.2 Voluntary Participation

Coercion in terms of ethical research refers to forcing and pressurizing a member of the population under study to take part in the research study (Pelham & Blanton, 2007). This is in direct contradiction to the freedom to participate and withdraw at any point in the research process. This ethical guideline was adhered to in the present study, as the participants in the study were assured in the information letter that participation was voluntary (Appendix 1). As a result, only those participants who showed an interest in the study completed the questionnaires. All participants were treated with respect and value; they were thanked for their interest and time.

4.7.3 Confidentiality

Confidentiality of information and participant details is of the utmost importance, particularly considering the nature of the information provided. Confidentiality implies that only the researcher should be aware of the identity of the participants, and he or she should therefore make a commitment to safeguard their right to confidentiality (Jackson, 2003). This research study adhered to the principle of confidentiality, as no identifying detail was revealed in the dissemination of the results. The data was kept safely, where others had no access to it, and the data was used solely for the purposes of the study (De Vos, 2000).

4.7.4 Minimizing Harm to Participants

It is important when conducting research to ensure that the participants are protected from any physical or psychological discomfort that might arise during their participation in the study (Jackson, 2003). The potential risks that could have been incurred during participation in the study were relatively low. A trained volunteer was available during the administration of the questionnaires and

the contact number of the researcher was made available to the participants should they have felt any discomfort whilst completing the questionnaires.

4.7.5 Release of Findings

De Vos (2000) argued that the final written report must be accurate, objective, clear and unambiguous, and contain all essential information. The research findings of this study were compiled in as accurate and objective a manner as possible, so that the report writing met the afore-mentioned criteria. A feedback report including the findings and recommendations was given to the management team at the Masizakhe community project in Kwazakhele. A copy of the research was also made available to the iThemba AIDS foundation, as they are involved in funding and assisting with the programmes that are conducted at the Masizakhe community project. The following section provides an overview of the data analysis conducted in the present study.

4.8 Data Analysis

The researcher scored the questionnaires that were utilized. The research consultant/statistician conducted the analysis and the interpretation of the research results. The data was analysed in terms of the three aims of the research study. Both descriptive and correlational analysis were utilized.

4.8.1 Descriptive Statistics

The data were analysed in terms of the two aims of this research. The first two aims were to explore and describe the sense of coherence and coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area. This information was collected through a biographical questionnaire and objective measures. The quantitative data collected from the objective measures were analysed using descriptive statistics, which seek to describe the distribution, variety and trends in responses for the sample as a whole and for selected biographical variables (Vernoy & Kyle, 2002). This typically included the computation of the means, standard deviations, medians, ranges and percentages for each of the measures administered (Bordens & Abbott, 2002). Using the mean, central tendency is measured and numerical values that refer to the center of the distribution are provided (Gravetter & Forzano, 2002). The advantage of using the mean is that it estimates a population mean better than other measures that assess central tendency such as median and mode (Gravetter & Wallau, 2002). However, while describing the mean it is important to consider that extreme scores influence it and this must be considered as a substantial disadvantage (Gravetter & Wallau, 2002). The standard deviation is a measure of variability (or spread of scores) and measures distance of scores from the mean (Vernoy & Kyle, 2002). This was important in the research, as norms for this specific group did not exist. Hence data in this regard needed to be described in terms of its mean and distribution. Describing the data in that way can be an important step towards the understanding of the sense of

coherence and coping resources of the research group. The data that was obtained from the biographical questionnaire was analysed with the help of descriptive statistics and frequency counts.

4.8.2 Correlational Analysis

According to Spata (2003), correlation studies aim to examine the relationship between two or more variables in order to identify whether they co-vary, correlate, or are associated with each other. Once a correlation has been established, it is important to assess the significance of the relationship (Spata, 2003). It is important to note in this regard, that although two variables may be related to one another causation is not necessarily implied (Aiken, 2000). In terms of the third aim, which was to examine the interrelationship between the participants' sense of coherence and their coping resource scores, the Pearson product-moment correlation coefficient was utilised. It is difficult to assess the strength of a relationship between two variables on the basis of a scatter diagram (Willemse, 1990). With regard to the specific correlations examined, the mean of the SOC scores were compared with the mean of the total CRI scores, as well as with the means of the five individual components of the CRI (cognitive, social, emotional, spiritual/philosophical and physical). Finally, the means of the five components of the CRI were compared to one another to see if for this particular sample significant relationships existed between the various components. According to Rosnow and Rosenthal (2005), the value of r is that it gives information about the strength and the direction of the relationship between the two variables. Rosnow and Rosenthal (2005) indicated that the value of r ranges from -1.0 through 0 to $+1.0$. A value of 0 means that there is no relation between the variables being correlated. A value of $+1.0$ means that there is a positive relation between the variables, and a value of -1.0 means that there is a negative relation between the variables. A positive relationship means that, as scores on the one variable increase, so scores on the other variable decrease (Spata, 2003). However, once a correlation between variables has been established, it becomes important to determine the significance of such a relationship. Spata (2003) stated that a p -value of 0.5 is the standard for most psychological reports in order to assess the significance of the correlation coefficients.

Rosnow and Rosenthal (2005) indicated that the value of r provides information about both the strength and direction of the relationship between variables. The Pearson r ranges from -0.1 through 0 to $+0.1$ (Rosnow & Rosenthal, 2005). A value of 0 indicates that there is no relationship between the variables being correlated. A value of -1.0 indicates that there is a perfect negatives relationship between the variables. This means that as scores on the one variable increases, so scores on the other variable decrease (Spata, 2003). A value of $+1.0$ means that there is a perfect positive relationship between variables, indicating that as scores on the one variable increase, so scores on the other variable also increase (Spata, 2003).

Once a correlation between variables have been established, it is important to assess the significance of the relationship. In order to assess the significance of the correlation coefficients computed for the third aim, a standard p -value of 0.5 was utilized, as this is the standard for most psychological research reports (Harris, 1998). Harris (1998) maintains that although a p -value of .05 is regarded as being statistically significant, a p -value of .01 or .001 is considered to be more significant, as these p -values are representative of more stringent and rigorous significance levels. With regard to the interpretation of significant correlations, the following well established set of guidelines suggested by Guilford (1946) was used for the interpretation of the magnitude of the relationships:

- Less than .20 slight; almost negligible relationship
- .20 - .40 low correlation; definite but small relationship
- .40 - .70 moderate correlation, substantial relationship
- .70 - .90 high correlation; marked relationship
- .90 – 1.00 very high correlation; very dependable relationship

4.9 Conclusion

The research design and methodology utilised in the present research were chosen based on the aims of the study. An exploratory, descriptive research design was used in the research. A biographical questionnaire, which was developed by the researcher, the Sense of Coherence Questionnaire (SOC-29), and the Coping Resources Inventory (CRI) was used to gather data. A non-probability convenience sample of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area completed the questionnaires. The questionnaires were hand delivered and explained to the volunteers who were trained to administer the questionnaires. The questionnaires were personally collected and scored, and the data was statistically analysed by using descriptive and correlation statistics. Ethical considerations were adhered to while the research project was undertaken. The results obtained from the statistical analysis are outlined and discussed in the following chapter.

Chapter 5

Results and Discussion

5.1 Chapter Preview

In this chapter, the results obtained from the data analysis of the two measures utilized to investigate the three aims are discussed. In order to gain a comprehensive picture of the sample, the biographical details of the research participants obtained from the biographical questionnaire are described first. Thereafter the results of the two measures, namely the Sense of Coherence Questionnaire (SOC-29) and the Coping Resources Inventory (CRI) are presented individually in response to the aims of the study. Finally, the correlation between the participants' sense of coherence and coping resources is discussed.

5.2 Review of the Aims

Before discussing the results obtained from the data collection and analysis of the two measures utilized in this study, it is important to review the aims of the research. The first aim was to explore and describe the sense of coherence of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area. The second aim was to explore and describe the coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area. The third aim was to explore and describe the correlation between caregivers' sense of coherence and coping resources.

5.3 Biographical Description of the Sample

In this section, the biographical variables that are discussed pertain to the information obtained from the biographical questionnaire (Appendix C) completed by the participants. These variables include age, gender, marital status and economic status. Also included in the biographical questionnaire were items pertaining to the caregiver role that previous research (Tolliver, 2001) has found to be related to HIV/AIDS caregiving. These factors include the number of people living in the household where the patient is being cared for, daily responsibilities, role of the caregiver, the caregiver's relationship to the patient, number of hours spent caregiving, and caregiving stressors (See Appendix C). In order to ensure that the sampled group was kept as homogenous as possible, the extraneous variable of age was controlled for. Gender was not controlled for, as gender was not one of the inclusion criteria.

5.3.1 Biographical Description of the Caregivers

5.3.1.1 Age

The ages of the participants ranged from 20 to 60 years. This puts all the participants in the middle and late adulthood years according to Erickson's theory (Erikson, 1963). The age distribution of the sample is presented in Table 4.

Table 4

Age Distribution of the Caregivers

Age in completed years	<u>N</u>	Percentage
20 –29	15	30%
30 - 39	16	32%
40 - 49	14	28%
50 - 59	4	8%
60 +	1	2%
Total	50	100%

Thirty-two percent of the sample fell in Erikson's middle adulthood stage, where the main task is that of generativity versus self-absorption or helping younger generations and feeling productive (Erikson, 1959). Having to care for a terminally ill family member at the same time as often having to care for one's own children can add to an already stressful role and lead to caregiver role strain (Hargreaves, 2002). During this life stage, men and women who have resolved earlier conflicts are free to direct their attention more fully to the assistance of others. However, failure to resolve earlier conflicts often leads to a preoccupation with oneself, one's health, psychological needs, and comfort, and may subsequently result in psychological stress (Erikson, 1959). The task of late adulthood is that of ego-integrity versus despair or obtaining a sense of closure, and feelings of satisfaction and contentment (Erikson, 1982). Only two percent of the sample fell in this category. Some studies have shown that having to care for an ill family member especially when diagnosed with a terminal illness, can disrupt this stage and cause feelings of isolation and despair (Connell et al., 2001).

In chapter 3 it was noted that many factors contribute to shaping the individual's SOC. By the age of 30 individuals have been exposed to a pattern of life experiences for some years and their SOC begins to crystallize (Antonovsky, 1979). While examining the age of the current participants, with the exception of some who are younger than 30 years of age, it is clear that the majority should have an established SOC. While some transformation in SOC can occur later in life, Antonovsky (1987)

suggested that no major changes in a person's SOC will take place after the age of 30. When viewing the age distribution of the sample, it is clear that thirty percent of the sample is still in the process of shaping their SOC up to a point where it would crystallize. However, the rest of the sample should have a well-established, deeply rooted SOC or coping orientation. It could therefore be expected that the SOC of the younger participants would be more prone to fluctuations from the mean of the general population, while the older participants would present with a stable dispositional orientation, that for the most part, would not change dramatically when compared with the mean.

5.3.1.2 Gender

Eighty-eight percent of the participants were female with only twelve percent were male participants. The gender distribution of the sample is depicted in Table 5.

Table 5

Gender Distribution of the Caregivers

Gender	<u>n</u>	Percentage
Male	6	12%
Female	44	88%
Total	50	100%

The high prevalence of female caregivers has also been found in other research (Kipp, et al., 2006; Strydom & Wessels, 2006; Tolliver, 2001). As mentioned previously, this has ramifications for the caregivers' ability to cope with their role, with female caregivers typically feeling more stress and role strain than their male counterparts (Kipp, et al., 2006; Strydom & Wessels, 2006; Tolliver, 2001).

5.3.1.3 Marital Status

Social relationships and social support play a significant role in the formulation of a coping orientation and in coping with life's demands and challenges. The marital status of the sample is presented in Table 6.

Table 6

Marital Status Distribution of the Sample

Marital status	<u>n</u>	Percentage
Single	38	76%
Married	11	22%
Separated	0	0%
Divorced	0	0%
Widowed	1	2%
Total	50	100%

The marital status of the participants in the sample varied between being single, married, and widowed. Seventy-six percent of the participants were single, 22% married and two percent were widowed. This could have repercussions for the ease of obtaining the coping resource of social support. None of the sample indicated that they were separated or divorced.

It is important to consider the significant others in the caregiver's life as they tend to provide social support. Social support plays a vital role in helping the caregiver deal with their role, and those who receive higher levels of positive social support show better adjustment to a loved one or family member being diagnosed and living with a terminal illness (Kipp et al., 2006; Strydom & Wessels, 2006).

Involvement in social relationships is at the heart of what is measured in the CRI's Social Resource subscale. In terms of Antonovsky's (1987) SOC concept, the SOC should be viewed in a social context. As such, the SOC is a personal perspective that develops through social learning and is reinforced by social circumstances. Hence, in attempting to maintain health and well-being, the focus should not only be on the individual, but also on the social environment (Antonovsky, 1994).

5.3.1.4 Employment Status

Employment status was varied, with 78% of the participants being unemployed, 10% were employed on a part-time basis, 10% were employed on a full-time basis and 2% were retired. The employment distribution of the sample is presented in Table 7.

Table 7

Employment Status of the Sample

Employment	<u>n</u>	Percentage
Unemployed	39	78%
Part-time employed	5	10%
Full-time employed	5	10%
Retired	1	2%
Total	50	100%

Literature states that many caregivers have difficulty in fulfilling both the caregiver and the employee role (Connell, et al., 2001; & Tolliver, 2001). The caregivers in this sample are situated in a rural area where the majority of the community is unemployed due to lack of employment opportunities and the inability to work due to their social commitment to caring for a terminally ill family member. The caregivers reside in households where there is no source of income, a lack of food, insufficient shelter, electricity and basic necessities of life. This finding is consistent with previous research that indicates that caregivers report poverty to be a major concern in these communities (Sidwaba, 2004).

5.3.1.5 Number of People Living in the Caregiver's Home

All the caregivers had to care for people other than the HIV/AIDS patient. Three (6.38%) of the sample had two people living in their home; nine (19.14%) had three people living in their home; fourteen (29.78%) had four people living in their home; five (10.63%) had five living in their home; five (10.63%) had six living in their home; seven (14.89%) had seven living in their home; three (6.38%) had eight living in their home; and one (2.12%) had more than ten living in their home. The distribution of the number of people living in the home is displayed in Table 5.

Table 8

Distribution of the Number of People Living in the Home

Number of people	<u>n</u>	Percentage
1	0	0%
2	3	6.38%
3	9	19.14%
4	14	29.78%
5	5	10.63%
6	5	10.63%
7	7	14.89%
8	3	6.38%
9	0	0%
10	0	0%
>10	1	2.12%

Note: All percentages are rounded to two decimal points.

These numbers included the patient. Having to care for other people besides the patient tends to add to the caregiver's responsibilities and stress load (Connell et al., 2001; Strydom & Wessels, 2006; & Tolliver, 2001).

5.3.1.6 Relationship to HIV/AIDS Patient

Ten percent of the participants were the spouses of the patient. Twenty-two percent of the participants indicated that they were the parent of the HIV/AIDS patient. Seven stated that they were the children of the HIV/AIDS patient and twenty-seven stated that they were related to the patient in another way. This information is summarised in Table 9.

Table 9

Distribution of Relationship to Patients

Relationship to patient	<u>n</u>	Percentage
Spouse	5	10%
Parent	11	22%
Child	7	14%
Other	27	54%
Total	50	100%

The distribution of relationship to patient for participants in this study did not seem to reflect the general caregiver population as described in the literature. Spouses are the most common primary caregivers of people with HIV/AIDS, followed by adult children (Connell et al., 2001; Tolliver, 2001). However, results of this finding could be skewed due to the small sample size. However, it is not uncommon to see that there is another member of the extended family that cares for the terminally ill patient.

5.3.2 Patient Information

5.3.2.1 Gender

The majority of the patients were female totaling thirty-six (72%), with only fourteen (28%) male patients. The gender distribution of the sample is depicted in Table 10.

Table 10

Gender Distribution of the Patient

Gender	<u>n</u>	Percentage
Male	14	28%
Female	36	72%
Total	50	100%

According to UNAIDS (2006a), statistics indicate that the gender distribution of HIV infection around the world tends to be unequal. Although HIV infection was initially attributed mainly to gay men, with time the virus spread to both genders, and at present, many men and women around the world are infected with HIV/AIDS. In Sub-Saharan African countries and South Africa, the number of infected women exceeds the number of infected men (Avert.org, 2006a; 2006b).

5.3.3 Personal Caregiver Information

5.3.3.1 Health

Health is another area of concern when discussing caregiving, as research has shown that a caregiver's health can be negatively impacted upon by their caregiving role (Shebi, 2006). The caregiver's own health can also have implications for coping with the stressors associated with caregiving (Simpson, 2006). Participants were asked to rate their own health as good, average or poor. Fifty-eight percent of the participants described their health as being good; twenty-four percent indicated that their health was average, while the remaining eighteen percent indicated that their health was poor. Participants' rating of their health is presented in Table 11.

Table 11

Distribution of Caregiver's Subjective Rating of Health

Rating	<u>n</u>	Percentage
Good	29	58%
Average	12	24%
Poor	9	18%
Total	50	100%

5.3.3.2 Medical Condition

Studies have shown that caregiving stressors affect the caregiver's overall well-being. However coping resources can mediate the effects of these stressors (Simpson, 2006). The caregiver's health has been found to impact the effect of caregiver stress (Cameron & Uys, 2003). The frequency counts of medical conditions among caregivers is presented in Table 12.

Table 12

Frequency Count of Medical Conditions of Caregivers

Condition	<u>n</u>	Percentage
None	35	70%
Hypertension	6	12%
Diabetes	3	6%
Epilepsy	2	4%
Tuberculosis	4	8%
Total	50	100%

Thirty percent of the participants indicated having a medical condition while 70% of the participants indicated no medical condition.

5.3.4 Caregiving Role Information

This section explores the role of the caregiver by describing the length of time the participant has been caring for the patient, the number of hours spent caregiving, the daily responsibilities of the caregiver, the stressors related to the caregiving role, and the ways in which the caregiver copes during times of stress. This information was gathered in the biographical questionnaire through a number of close-ended questions.

5.3.4.1 Duration of Being the Primary Caregiver

The average length of time participants in this study were the primary caregivers was 34.26 months (2.86 years) with a minimum of 5 months to a maximum of 134 months. This has relevance, as a requirement for this study was that the caregiver had been in this role for a minimum of six months. This time period of six months was selected to ensure that the caregiver had had time to adjust to the new role. The distribution of the time of caregiving is depicted in Table 13.

Table 13

Distribution of Length of Time Caregiving

Time in months	<u>n</u>	Percentage
5 - 40	28	56%
41 – 76	12	24%
77 – 112	14	28%
113 – 147	1	2%
Missing data	5	10%
Total	50	100%

The majority of the participants in the study had been caregiving between five and forty months. The minority had been caregiving between one hundred and thirteen months and one hundred and forty-seven months. It should be noted that five participants (10% of the sample) did not complete this question in their biographical questionnaire.

5.3.4.2 Hours Spent Per Day in the Caregiving Role

In order to ascertain how much of their day caregivers spent in active caregiving, participants were asked how many hours a day they spent performing caregiver duties. The results are presented in Table 14.

Table 14

Distribution of Number of Hours per day Spent Caregiving

Hours	<u>n</u>	Percentage
2 hours or less	6	12%
3 – 4 hours	19	38%
5 – 8 hours	3	6%
9 – 12 hours	5	10%
13 hours or more	17	34%
Total	50	100%

Table fourteen indicates that most caregivers in this sample spend between three and four hours in caregiving activities. Thirty four percent of the sample spends 13 hours or more fulfilling their daily duties.

5.3.4.3 Daily Responsibilities

Caregivers were asked to indicate their daily responsibilities with reference to their caregiving role. Table 15 provides a frequency count of these daily responsibilities.

Table 15

Frequency Count of Daily Responsibilities Related to Caregiver Role

Responsibility	<u>n</u>	Percentage
Food preparation and feeding	25	50%
Outings (e.g. taking for walks)	35	70%
Medication distribution	48	76%
Personal hygiene (e.g. bathing)	31	62%
Overseeing financial responsibilities	27	54%
Shopping and household chores	13	26%

Common caregiver activities and responsibilities according to other studies include assisting with medication, personal hygiene, household chores and shopping (Cameron & Uys, 2003; Hargreaves, 2002; Simpson, 2006). The caregivers in this sample can thus be seen to be carrying out the responsibilities expected of someone caring for an HIV/AIDS patient.

5.3.4.4 Stress Related to the Caregiving Role

The stressors listed in the biographical questionnaire were extracted from literature pertaining to caregiver stressors (Tolliver, 2001). The results of this study indicate that caregivers have numerous responsibilities connected to their caregiving role and spend many hours a day carrying out these responsibilities. Caregivers were also asked to indicate what they find most stressful about their caregiving role. Frequencies of these responses are indicated in Table 16 according to how often or seldom they experience the stressor.

Table 16

Frequency Count of Stressors in Caregiving

Stressor	<u>Never</u> n	Seldom n	Monthly n	Weekly n	Daily n
Lack of freedom	4	19	7	6	14
Helping with personal hygiene	3	9	0	1	36
Assisting with sleep disturbance	5	18	3	1	23
Explaining disease, course and treatment	5	9	5	0	30
Answering questions regarding death and dying	13	19	4	1	13

5.3.4.5 Coping Behaviours in Response to Stress

Due to the fact that research has found a link between HIV/AIDS caregiving, stress and ineffective coping responses, the researcher was interested in determining whether findings pertaining to ineffective coping strategies would be similar in the current study. The participants were requested to indicate how they usually cope during times of stress. A number of coping behaviours were stipulated and a distribution of responses to this item is presented in Table 17. These coping behaviours were deduced from previous research on caregivers' coping behaviours (Hargreaves, 2002). Note that the participants were able to indicate more than one response to this item. They also indicated their behaviour as either never, seldom, monthly, weekly or daily.

Table 17

Distribution of Coping Behaviours in Response to Stress

Coping Behaviours	<u>Never</u> (n)	Seldom (n)	Monthly (n)	Weekly (n)	Daily (n)
Ignore the stress	8	15	3	4	18
Avoidance (sleep)	7	18	1	0	24
Use of substances (alcohol)	33	14	0	2	0
Medication (pain killers)	3	9	6	8	22
Exercise/meditation	13	16	4	5	11
Seek social support	9	4	10	9	18

As discussed in Chapter 3, emotion-focused coping is directed towards managing emotional distress (Lazarus & Folkman, 1984). Kleinke (1991) maintained that individuals are more likely to engage in emotion-focused coping when a challenge or problem is perceived as beyond their control. Examples of this type of coping strategy include physical exercise, relation procedures and meditation, and the expression of feelings. From Table 17 it is evident that the coping behaviour most frequently employed in the current study is that of avoidance and medication. These are considered to be less effective and self-destructive coping behaviours. There is not a very large discrepancy between the more adaptive coping strategies (i.e., seeking social support) and those that are less effective, particularly ignoring the stress. Due to the fact that this study focused on coping resources as a primary variable, the data obtained from the biographical questionnaire as it pertains to coping should be given adequate attention. Based on the findings of the present sample, the majority of the participants indicated that they engaged in avoidance behaviour and ignoring the stressor(s). According to Lazarus and Folkman (1984), individuals use this type of coping style to maintain hope and optimism, to deny both fact and implication, to refuse to acknowledge the worst, and to act as if what happened did not matter. This lends itself to an interpretation of self-deception or reality distortion (Lazarus & Folkman, 1984). This type of coping is designed to make life more bearable by avoiding realities, which might prove to be overwhelming if directly confronted (Goldstein, 1980). Although adaptive coping responses of seeking social support and exercise/meditation is evidently indicated in the current sample to some extent, it remains evident that the largest percentage of responses indicated the less effective coping responses of avoidance, ignoring the stress and medication.

5.3.4.6 Well-being of the Caregiver

The participants were requested to rate their general well-being. Table 18 indicates the subjective ratings of the participants as either excellent, good, average, below average or poor. A person's subjective well-being might be contributing to the individual factors (i.e., hardiness, commitment, control and challenge) which play an important role in the experiencing of stress (Kobasa et al., 1982). The importance of individual factors cannot be overestimated in the experience of stress as they determine an individual's vulnerability to a particular stressor (Simpson, 2006).

Table 18

Subjective Ratings of Well-Being of the Sample over the past 6 months

Rating	<u>n</u>	Percentage
Excellent	6	12%
Good	0	0%
Average	13	26%
Below Average	18	36%
Poor	13	26%
Total	50	100%

The majority of participants indicated that they subjectively viewed their general well-being as below average. No participants rated their well-being as good and six participants rated their well-being as excellent.

5.4 Results of the Measures

5.4.1 Sense of Coherence Questionnaire

This section focuses on exploring and describing the sense of coherence (SOC) of HIV/AIDS adult family caregivers in the Kwazakhele area of Port Elizabeth. The SOC was defined as a global orientation towards life and coping that develops over the life span and crystallises in early adulthood, around the age of 30 years (Antonovsky, 1979). The core components of the SOC, namely comprehensibility, manageability and meaningfulness, work together as a whole to shape the strength and effectiveness of an individual's coping orientation (Antonovsky, 1987).

A person with a strong SOC will be more successful in choosing the most effective coping strategies, whereas a person with a weaker SOC will be overwhelmed when confronted with life stressors and therefore will employ less successful coping strategies (Antonovsky, 1987). According to Anotonovsky (1987), the strength of individuals with a strong SOC lies in their ability to mobilize

and utilize a combination of effective resources to confront the stressor. These individuals will perceive situations and life experiences as comprehensible, manageable and meaningful, are flexible in their approach to situations, and are able to prevent tension aroused by the event from turning into stress (Antonovsky, 1987; Fouche, 1999). The means and standard deviations for the current sample are reflected in Table 19, and thus provide information regarding the coping orientation of this group.

Table 19

Means and Standard Deviations of the SOC-29

Variable	<u>X</u>	Minimum	Maximum	<u>SD</u>	Range
Sense of Coherence (N=50)	124.18	100.00	161.00	14.53	61

Note: X = Mean SD = Standard Deviation

Normative data for the SOC-29 was not provided by Antonovsky (1987). However, a number of internationally published studies which provide normative data for a variety of samples exist (Antonovsky, 1987). In order to place the findings of the current study into perspective, this normative data is presented in Table 20.

Table 20

Normative Data from Internationally Published Studies Using the SOC-29.

Sample	<u>N</u>	<u>M</u>	<u>SD</u>
Swedish high-risk children	148	152.6	22.0
Kibbutz fathers	67	152.5	14.5
Israeli retired men (aged 65)	428	152.2	22.8
Kibbutz men (aged 65)	130	152.2	22.8
Kibbutz mothers	67	151.0	15.3
Israeli medical students at entry	93	150.2	16.5
Finnish adult male sample	340	150.2	21.9
Kibbutz fathers, disabled children	67	146.3	19.4
Finnish adult female sample	329	146.1	22.7
Kibbutz women (60 years)	130	145.7	20.2
Israeli retired women (age 60)	368	145.0	23.4
Czech controls in cancer study	153	145.0	–
Kibbutz mothers, disabled children	67	140.1	22.6
USA male patients at VA clinics (aged +55 years)	240	139.6	36.4
Finnish university students (52% women)	117	138.6	23.1
New Zealand, chronic pain (78% women)	107	138.6	14.9
Israeli Jewish national sample	297	136.5	19.8
USA production workers (76% women)	111	133.0	26.5
Israeli cerebral palsy (aged 18-33)	34	131.1	0.8
USA undergraduates (68% women)	307	129.5	24.5
Czech cancer patients	17	117.0	–

(Adapted from: Antonovsky, 1993a)

The highest mean score obtained in the studies outlined in Table 20 was 152.6 in a study on Swedish high-risk children and the lowest mean score obtained in the studies was for a sample of Czech cancer patients who obtained a mean score of 117.0. When examining the means and standard deviations that are presented in Table 20, it can be noted that the results obtained are lower than most of the worldwide studies.

On a national level, a number of recent South African studies have explored the SOC of individuals (Bester, 2003; Cairns, 2001; Carstens, 1995; Jacobs; 2005; Katalan, 2003; Madhoo, 1999; Otto, 2002;

Smith; 2006; Wissing, De Vall & De Beer, 1992; Wissing & Van Eeden, 1997). Some of the samples in the studies mentioned above consisted of healthy men and women who were not facing a particular stressor as well as individuals diagnosed with a chronic illness or general medical condition and those in a working environment. The mean scores of these studies are summarised in Table 21.

Table 21

Normative Data from South African Studies Using the SOC-29

Sample	<u>N</u>	<u>M</u>	Reference
Nurses at a Psychiatric Hospital	67	140.69	Bester (2003)
Cancer patients	34	151.71	Cairns (2001)
Patients with Major Depressive Disorder	50	100.56	Carstens (1995)
Teachers of learners with disabilities	59	144.95	Jacobs (2005)
HIV-positive adult females attending a support group	83	116.65	Katalan (2003)
Patients in cardiac rehabilitation	35	159.00	Madhoo (1999)
Adult patients with depressive mood	54	99.10	Otto (2002)
Post graduate learners	60	145.47	Smith (2006)
Group of rural university students	249	140.21	Wissing et al. (1992)
Mixed group sample of Psychology students	550	136.52	Wissing & Van Eeden (1997)

Table 21 indicates that the highest mean score obtained in these studies was for a sample of patients in cardiac rehabilitation ($X = 159.00$) (Madhoo, 1999). The lowest mean obtained in these studies was for a sample of adult patients with depressed mood who obtained a mean of 99.10 (Otto, 2002). A review of both South African and international literature revealed that no studies exist that address the SOC of HIV/AIDS caregivers. Hence, no specific norms for the SOC of HIV/AIDS caregivers have been established. When comparing the scores of the current study with the mean scores of the studies presented in Table 21, the results of the current study are fairly low.

The mean ($\bar{X} = 124.18$) of the current sample is higher than that obtained in the study by Carstens (1995) of patients with Major Depressive Disorder ($X = 100.56$), Katalan (2003) of HIV-positive adult females attending a support group ($X = 116.65$) and Otto (2002) of adult patients with depressive mood ($X = 99.10$). In South Africa, Wissing and Van Eeden (1997) in their study with a mixed sample group, reported a mean of 136.52 and a standard deviation of 21.68. However, Wissing and Van Eeden (1997) used a larger sample size ($N = 550$). As a result, an attempt to compare the SOC of the

current sample to the above-mentioned findings must be done carefully while considering these differences.

In the absence of any other comparative sample in general, and specifically with regard to adult family caregivers, the present study can only provide tentative speculative reasons for any differences in mean scores apparent in the research results already discussed. Antonovsky (1993) postulated that it is important to examine the sample in context, since a valid scale should produce different mean scores among samples that would be assumed to vary, based on theoretical knowledge. It appears that the mean score obtained from the sample is relatively low. These results suggest that individuals in the current study have a fairly low SOC. Numerous studies have highlighted that individuals with a weak SOC report worse levels of physical and mental health and are less able to cope effectively with life stressors than those with a strong SOC. The majority of the participants described their health as being good and 70% of them reported no medical condition.

While addressing the assumption that the SOC results obtained from the current sample are the reflection of their responsibility of caring for a family member diagnosed with a chronic illness, it is further necessary to address the question of whether the SOC can be changed during life. This issue was discussed in Chapter 3, where it was mentioned that, although the SOC initially formulates and crystallises by the age of 30, this does not negate the possibility of it being influenced by changes in patterns of life experiences. Another suggested explanation for the low SOC mean score of the current sample is the age group in which the sample is clustered. The majority of the sample falls between the ages of 20-29 and therefore the combination of a young age and having the responsibility of caring for a patient with a chronic illness can influence the SOC of these participants. Yet another possible explanation for the low mean score of the current sample relates to the fact that individuals who present a weaker SOC after an exposure to a stressful life event had a weaker SOC even prior to that exposure. According to McSherry and Holm (1994), individuals with a weaker SOC were found to be psychologically distressed prior to an exposure to a stressful life event, but in addition demonstrated and maintained a greater level of distress after exposure to a stressful life experience.

In conclusion, the current sample obtained a low mean SOC score. While some research suggests that significant alterations in a person's SOC are not likely to take place easily, other studies suggest that caregiving for someone with a chronic illness can negatively contribute to a person's coping orientation. Finally, it should be mentioned that the SOC mean score which is depicted in Table 21 may have been lower even before exposure to the stressor because of other variables and circumstances such as low levels of education, low socio-economic status, marital status and so on. The following

section focuses on exploring and describing the coping resource data that was obtained utilising the CRI.

5.4.2 Coping Resource Inventory

Before embarking on a discussion of the findings as they relate to the CRI, the definition of coping resources and its place in the coping process is revisited. Chapter 3 detailed the coping process and the role that coping resources play. To conceptualise the current results, these aspects are briefly reviewed. According to the developers of the CRI, individuals make use of coping resources to enable them to deal with stressors more effectively. Coping resources are inherent in individuals and enable them to experience fewer or less intense symptoms on exposure to a stressor, or to recover faster after exposure to a stressor (Hammer & Marting, 1988).

In order to understand how the presence of coping resources results in more effective handling of stressors, it is important to consider how the presence of coping resources fits into the coping process. In terms of the appraisal processes outlined by Lazarus and Folkman (1984), coping resources come into play in both the primary and secondary appraisal stages of the coping process. During primary appraisal, the individual assesses whether a stressor or challenge can be perceived as irrelevant, relevant but not threatening, or stressful. During primary appraisal, an individual with high levels of coping resources would be less likely to make the initial appraisal that a stressor or challenge is in fact threatening. However, should a demand be perceived as stressful, the process of secondary appraisal is activated. During this stage of the coping process, the individual will assess whether anything can be done about the perceived threat. Secondary appraisal also involves an individual's evaluation of his/her coping resources and options for dealing with the perceived threat or challenge (Lazarus & Folkman, 1984). It is thus reasonable to deduce that a perception of higher levels of coping resources would facilitate better coping and that individuals high in coping resources are likely to respond to stressors more effectively. According to Billings, Folkman, Acree and Moskowitz (2000), the most effective coping responses include seeking help, taking rational action, communicating feelings, drawing strength from adversity, using humour, and maintaining faith, self-confidence and feelings of control.

The five scales of the CRI have different numbers of items attributed to them. Due to this fact, direct comparisons amongst the scales based on raw scores are not possible. Standard scores are thus indicated and presented in Table 16 in order to facilitate comparisons between the various subscales of the CRI. The mean raw score for the total coping resources scale and the five subscales obtained by the sample were thus converted into standard scores. These standard scores have a mean of 50 and a standard deviation of 10 points. Hammer and Marting (1988) maintained that approximately 95% of

individuals will have standard scores that fall between 30 and 70. It can therefore be assumed that scores below 30 are considered to be below average while scores above 70 can be regarded as being above average.

The current sample's results are now discussed. The descriptive statistics in terms of the means (\bar{X}) and standard deviations (SD) obtained on the CRI for both the total score and the subscale scores are presented in Table 22.

Table 22

Means and Standard Deviations of the Coping Resources Inventory

<u>Variable</u>	<u>\bar{X}*</u>	<u>Minimum*</u>	<u>Maximum*</u>	<u>SD</u>	<u>Range</u>
Coping Resource Total Score (N=50)	52.36	27.00	69.00	8.86	42
Cognitive Resource Scale	54.72	32.00	68.00	9.44	36
Social Resource Scale	47.42	25.00	61.00	7.61	36
Emotional Resource Scale	53.74	29.00	73.00	8.81	44
Spiritual/Philosophical Resource Scale	51.80	33.00	69.00	9.43	36
Physical Resource Scale	51.08	40.00	73.00	7.87	33

Note: * All scores indicated in these columns are standard scores

Hammer and Marting (1988) suggested that coping resources which are used in order to manage stressors more effectively, are inherent in the personality, allow both faster recovery from an exposure to stress, and lower symptom intensity. According to Lazarus and Folkman (1984), coping resources play an important role both in the initial stage of the coping process while interpreting an event as stressful or not, and in the secondary stage after an event is perceived as stressful. These authors proposed that during primary appraisal, higher levels of coping resources can lead to perception of an event as not stressing at all, and therefore lead to the ending of the coping process. At the same time, if secondary appraisal is initiated, higher perceived availability of coping resources will result in a better and more successful coping process.

The current sample reported a total resources mean score of 52.36. This is higher than the mean of 50, which is the mean score that was established by Hammer and Marting (1988). The means of the subscales of the CRI, namely cognitive, emotional, spiritual and physical subscales were clustered above the mean of 50 and the social resource subscale was below the mean of 50 (see Table 22). These results indicate that the research participants perceived their coping resources as average.

The highest mean score obtained by the current sample (54.72) was on the cognitive resource subscale, which measures amongst other things the extent to which individuals maintain a positive sense of self worth (Hammer & Marting, 1988). According to Shebi (2006), caregivers in the Western Cape were able to face life optimistically despite adversities due to their caregiving roles. Other research findings indicated that frequently used strategies adopted by HIV/AIDS caregivers include applying positive self-talk, believing in one's self, maintaining a positive self-image, feeling motivated and developing a positive outlook (Koopman, 2001).

The second highest score was obtained for the emotional resource subscale. This subscale measures the degree to which individuals are able to cope and express a range of affect (Hammer & Marting, 1988). This finding is supported by Simpson (2006) where participants (caregivers) stated that they are able to express their emotions and that by expressing emotions it assisted them in dealing with the stressors that they experience.

The third lowest mean score obtained by the current sample was for the physical resource subscale, which measures the degree to which individuals enact health-promoting behaviours believed to contribute to increased physical well-being (Hammer & Marting, 1988). The biographical questionnaire highlights that 22% of the participants' utilized exercise as a means to cope with the stress that they experience during their caregiving roles. Another variable that could have been influential in lowering the physical resources of the sample is that of the numerous hours spent in the caregiver role. Thirty-four percent of the sample reported that they spend 9-13 hours in their caregiving role.

The second lowest mean score obtained by the sample was for the spiritual/philosophical resource subscale. This subscale measures the degree to which actions of individuals are guided by stable and consistent values derived from religious, familial, or cultural tradition or from personal philosophy. These values may serve the function of defining the meaning of potentially stressful events and may prescribe strategies for responding to these events effectively (Hammer & Marting, 1988). It was not noted in the biographical questionnaire that the participants viewed their religion as a coping behaviour in response to stress. This information does not support Cairns (2001) or Gouws' (2004) claims that religion could be viewed as playing an integral part in the coping process.

The lowest score obtained by the current sample was for the social resource subscale, which measures the degree to which individuals are embedded in social networks that are able to provide support in times of stress (Hammer & Marting, 1988). According to the information gathered from the biographical questionnaire, the participants do not often utilise the coping behaviour of social support. Finally, the literature indicated that receiving support from one's spouse is an important factor in

psychological and physical well-being (Wight, Aneshensel & Eblanc, 2003). As the majority (77%) of the participants in the current sample are not in a marital relationship, one would expect the mean score of this sample to be low, possibly due to the absence of effective social support systems.

In conclusion, the current sample obtained average mean scores for both the total coping resources scale as well as for the five coping resources subscales. It appears that the participants in the current study perceive the availability of their coping resources to be average, and therefore demonstrated generally average coping resource scores throughout the different domains. The following section focuses on exploring and describing the relationship between the SOC-29 and the CRI result obtained by the sample.

5.4.3. The Relationship Between the SOC-29 and the CRI

In order to meet the third aim of the study, the correlation between the two measures was examined by generating correlation coefficients. The Pearson Product-Moment Correlation Coefficient, or Pearson r , was used to achieve this. Before discussing the results reported in the correlation matrix, it is important to recapitulate the function of the data analysis technique and the rationale for utilizing it. The Pearson r provides an objective measure of the direction and strength of the relationship between the variables, which in this case were coping resources and sense of coherence as reflected in the frequency distributions. According to Rosnow and Rosenthal (1993), the Pearson r ranges from -0.1 through 0 to $+1.0$. A value of $+1.0$ indicates that there is a perfect positive relationship between the variables while a value of -1.0 indicates that there is a negative relationship between the variables. Rosnow and Rosenthal (1993) explained that a positive relationship means that as scores on the one variable increase, so scores on the other variable increase. A negative relationship means that as scores on the one variable increase, so scores on the other variable decrease. Again, it needs to be emphasized that while correlation implies prediction, it does not imply causation. It should therefore be noted that although two variables may be related, it does not mean that either is necessarily a cause of the other (Aiken, 2000).

In order to discuss the results reported in the correlation matrix, it is important to also recapitulate the significance of various p -values. P -values assess the significance of the correlation coefficients. Although a p -value of 0.05 is the standard for most psychological reports and is considered to be statistically significant, an r that also reaches a p -value of 0.01 or 0.001 is considered to be more statistically significant as these p -values are representative of more stringent and rigorous significance levels (Harris, 1998). While it is important to note that a causal or explanatory link cannot be established in terms of the current study, significant positive relationships were found between some of the variables correlated. These correlations are discussed according to Guilford's (1946) guidelines

which enabled the researcher to interpret the magnitude of the relationship between these variables. Guilford's (1946) guidelines are presented in Table 23.

Table 23

Guilford's (1946) Correlation Guidelines

Correlation	Degree of correlation	Magnitude of relationship
Less than 0.20	Slight correlation	Almost negligible relationship
0.20 – 0.40	Low correlation	Definite but small relationship
0.40 – 0.70	Moderate correlation	Substantial relationship
0.70 – 0.90	High correlation	Marked relationship
0.90 – 1.00	Very High correlation	Very dependable relationship

Table 24 presents the correlation matrix, which is indicative of the interrelationship between the two measures, namely the CRI and SOC-29 utilised in the study.

Table 24

Correlation Matrix: SOC-29 and CRI (n=50)

Variable	SOC and Total CRI	SOC and Cognitive Subscale	SOC and Social Subscale	SOC and Emotional Subscale	SOC and Spiritual/ Philosophical Subscale	SOC and Physical Subscale
Correlation	.16	0.27	.171	.14	.05	.20
<i>p</i> -value	.07	.00	.02	.00	.18	.34

Note: Results are significant, * $p < 0.05$

Several interesting findings become evident from the correlation matrix presented in Table 24, and these are discussed individually. To begin with, according to the correlation coefficient, it is clear that for a critical *p*-value of 0.05, no significant correlation exists between the SOC mean score and the total CRI mean score. In terms of the magnitude of the relationship, according to guidelines suggested by Guilford (1946), it can be described as a slight correlation which indicates an almost negligible relationship between the two measures. This relationship suggests that, in the current sample of HIV/AIDS adult family caregivers, those participants that reported higher on their SOC were also likely to report higher levels of coping resources while the participants who scored lower on their SOC were likely to report lower levels of coping resources. The theory concerning Antonovsky's (1987) Generalised Resistance Resources (GRRs) and the concept of coping resources discussed in Chapter 3

is fairly consistent with the results found above. GRRs were defined as any properties of a person that facilitates successful coping with the inherent stressors of daily living (Antonovsky, 1987). These GRRs comprise cognitive, emotional, social and physical and meaning characteristics. This definition is very similar to Hammer and Marting's (1988) definition of coping resources, which is defined as "those resources inherent in individuals that enable them to handle stressors, or to recover faster from exposure" (p. 2). Hammer and Marting (1988) divided coping resources into five domains, namely cognitive, social, emotional, spiritual/philosophical and physical. From the above discussion, it becomes evident that the definition of GRRs and coping resources clearly overlap, and hence one would expect a significant positive correlation to exist between the two measures however, this is not evident in this study.

Furthermore, the findings in this study do not confirm the findings of other research studies conducted in South Africa. For example, Cairns (2001) in her study found a positive relationship between the coping resources and the SOC among a group of cancer patients. Jacobs (2005) also found a positive relationship between the coping resources and SOC among teachers educating learners with intellectual disabilities.

The results in this study revealed that the participants had a low SOC score. This result supports Antonovsky's (1987) opinion that individuals with a low SOC are less likely to mobilize and take advantage of the resources available to them when confronted with a stressful situation (Antonovsky, 1987). As a result they are more likely to define stimuli as threatening during primary appraisal, leading them to believe that are not able to adapt to the demands using the resources available to them during secondary appraisal (Jacobs, 2005). Relating to this, Antonovsky (1987) explained that coping resources (termed GRRs) interplay with the coping process to build a strong SOC in individuals who experience success in their coping efforts.

Although no significant relationship was evident between the SOC-29 and the total score of the CRI, a further investigation of the correlation matrix presented in Table 24 revealed positive relationships between the SOC and the cognitive, social and emotional subscales of the CRI. The magnitude of the relationship between the SOC and the cognitive, social and emotional subscales may be described as negligible. Furthermore it is evident that no significant relationship existed between the SOC and the spiritual/philosophical and physical subscale. Possible explanations for these findings are now considered.

As discussed in Chapters 3 and 4, the spiritual/philosophical subscale of the CRI measures the extent to which actions of individuals are guided by stable and consistent values derived from religious, familial, or cultural tradition or from personal philosophy (Hammer & Marting, 1988). Such

values might serve to define the meaning of potentially stressful events and prescribe strategies for responding effectively. In contrast, the SOC-29 does not directly address the spiritual dimension. Although this explains the lack of a significant relationship between the two variables, it does not mean that spirituality is completely excluded from the SOC concept.

Another important finding is the lack of a significant relationship between the SOC and the physical subscale. One suggested explanation for this finding is the fact that the sample group indicated on the biographical questionnaire that they seldom or never participated in any form of exercise or meditation. Due to the many hours that these caregivers attend to their family patients, they do not have time to care for their own health. Therefore, regardless of their coping orientation, and regardless of their perception of the physical resources as contributing to the overall coping process or not, those who might usually choose physical resources as a coping mechanism, might not find it applicable any more, and therefore try to utilize and mobilize other resources that are available to them.

Overall the relationship between the measures of sense of coherence and coping resources found in this study, does not point to a link between the participants' perceptions of stress and stressors and their perceived availability of coping resources. Antonovsky (1979, 1987) postulated that inadequate resources and a weak SOC lead to an increase of negatively experienced stress, and that this in turn will have a negative effect on an individual's coping ability. While the spiritual/philosophical and physical subscales were not found to be significantly correlated to the SOC of the sample; the cognitive, social and emotional subscales of the CRI was found to be significantly correlated to the SOC. However, these correlations were negligible indicating only a slight correlation.

5.5 Conclusion

The results of this study as they relate to the three aims of the research have been discussed in this chapter. Where possible, the findings of this study have been linked to previous studies and previously researched literature. Some of the findings in this study confirm findings of earlier studies and literature and some of the findings appear to be unique to this particular sample. This is an expected consequence of using a small sample size for the study. The conclusions based on the results of this study, the limitations of the study, as well as recommendations for future research are outlined in the next and final chapter.

Chapter 6

Conclusions, Limitations and Recommendations

6.1 Introduction

Due to psychological factors playing a role in HIV/AIDS caregiving, there has been a need to explore and better understand the psychological variables that may be involved. This chapter provides a summary of the main findings and a discussion of the value and limitations of the study. The chapter concludes with a number of recommendations for future research.

6.2 Aims of the Study Revisited

In order to draw conclusions based on the results of this study, the ensuing discussion will be structured according to the aims of the study. The primary objective of this study was to investigate the sense of coherence and coping resources of adult family caregivers of HIV/AIDS patients in the Kwazakhele area of Port Elizabeth. The three aims were:

1. to explore and describe the sense of coherence of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area of Port Elizabeth.
2. to explore and describe the coping resources of adult family caregivers of patients living with HIV/AIDS in the Kwazakhele area of Port Elizabeth.
3. to explore and describe the correlation between caregivers' sense of coherence and coping resources.

6.2.1 Description of the Sense of Coherence of the Sample

The current sample of HIV/AIDS caregivers obtained a low mean score on the SOC-29. As there are no established norms for the SOC of HIV/AIDS caregivers in South Africa, it is difficult to assess whether the mean score for this sample is significantly higher or lower than that of other studies. However, when compared to a variety of South African studies that measure SOC, the mean score for the current sample was one of the lowest obtained.

Literature stated in chapter 3 has revealed that stressful life events may have either salutary or negative psychological consequences (Antonovsky, 1987). Thus, it appears that for the current sample, a stressful life event such as continued exposure to routine work stress, which is the case among HIV/AIDS caregivers, brings about negative psychological change and weakens the SOC. A central factor determining whether stressful life events produce desirable outcomes appears to be whether or not the individuals are able to find meaning and purpose within their circumstances (Antonovsky, 1987). It was speculated that the above findings might be true for the sample under

investigation, and that their overall SOC may have decreased due to the nature of caregiving in HIV/AIDS.

Additional explanations for the low SOC mean score that was reported in the current study might have resulted from the biographical variables that characterized the sample. Some of the biographical variables that were considered included participants' age and the length that the caregiver has been caregiving. Literature indicates that the SOC develops throughout the life-span and stabilizes around the age of 30 years (Antonovsky, 1987). As the majority of the participants were 30 years or older, they may have crystallized SOC's based on previous patterns of life experiences.

6.2.2 Description of the Coping Resources of the Sample

The second aim of this study was to explore and describe the coping resources of a sample of adult family HIV/AIDS caregivers. The results of the CRI obtained for this sample indicated that participants themselves have an average level of coping resources at their disposal. This conclusion is based on the fact that the mean score for the total coping resources scale obtained for the current sample was between 30 and 70 as stipulated by Hammer and Marting (1988), thus indicating that the participants' coping resources were considered to be within the average range.

The highest mean score obtained by the current sample (54.72) was on the cognitive resource subscale, which measures amongst other things the extent to which individuals maintain a positive sense of self worth (Hammer & Marting, 1988). It was speculated that this could be understood in terms of previous research findings which indicated that some of the frequently used strategies adopted by HIV/AIDS caregivers involve applying positive self-talk, believing in one's self, maintaining a positive self-image, feeling motivated and developing a positive outlook (Koopman, 2001).

The second highest score was obtained for the emotional resource subscale. This subscale measures the degree to which individuals are able to cope and express a range of affect (Hammer & Marting, 1989). This result indicates that participants may not have an adequate ability to accept and express a range of affect (Hammer and Marting, 1989) which suggests that the sample has an inability to communicate their emotions verbally.

The third lowest mean score obtained by the current sample was for the physical resource subscale, which measures the degree to which individuals enact health-promoting behaviours believed to contribute to increased physical well-being (Hammer & Marting, 1988). The biographical questionnaire highlights that 22% of the participants utilized exercise as a means to cope with the stress that they experience during their caregiving roles. Another variable that could have been influential in lowering the physical resources of the sample is that of the numerous hours spent in the

caregiver role. Thirty-four percent of the sample reported that they spend 9-13 hours in their caregiving role.

The second lowest mean score obtained by the sample was for the spiritual/philosophical resource subscale. It was not noted in the biographical questionnaire that the participants viewed their religion as a coping behaviour in response to stress. This information does not support Cairns (2001) or Gouws' (2004) opinion that religion could be viewed as playing an integral part in the coping process.

The lowest score obtained by the current sample was for the social resource subscale. According to the information gathered from the biographical questionnaire, the participants do not often utilise the coping behaviour of social support. Finally, the literature indicated that receiving support from one's spouse is an important factor in psychological and physical well-being (Wight, Aneshensel & Eblanc, 2003). As the majority (77%) of the participants in the current sample are not in a marital relationship, one would expect the mean score of this sample to be low, possibly due to the absence of effective social support systems.

6.2.3 The Correlation between the Sense of Coherence and Coping Resources of the Sample

In terms of correlations that were conducted, no significant relationship was found between the SOC and the total CRI scores obtained from the sample. The results in the current study support the similarity between Antonovsky's (1987) concept of GRRs and the concept of coping resources. It can be concluded that the theory of SOC (specifically that of GRRs) and that of coping resources does overlap. The findings of a negligible relationship also appear to support the premise that SOC affects cognitive appraisal processes, which was outlined by Lazarus and Marting (1984). Specifically, individuals with low SOC are less likely to define stimuli as non-stressors during primary appraisal or to perceive that they have the resources to cope with stressors during secondary appraisal.

With regard to the individual subscales of the CRI, results indicated that there were significant relationships between the SOC and the cognitive, social and emotional subscales of the CRI. However, no significant relationship existed between the SOC and the spiritual/philosophical and physical subscale. The lack of a significant relationship between the SOC and the spiritual/philosophical subscale of the CRI may be due to the fact that spirituality is not directly addressed in the SOC-29 as it is in the CRI.

6.3 The Value of the Research

The current study contributes to the body of emerging research that prefers a focus on the promotion and study of health, as opposed to a focus only on illness per se. The study of the relationships between stress, coping, and health or illness, forms the basis of the field of health

psychology. The researcher chose specifically to investigate the sense of coherence and coping resources of adult family caregivers of HIV/AIDS patients in the Kwazakhele area of Port Elizabeth. The decision was rooted in evidence generated from a literature survey. Moreover, personal communication with the Community Project and their sponsors revealed that these caregivers are experiencing stress within their homes and as a result of their duties as caregivers. Thus, stress is a given for a caregiver of a patient suffering from a terminal illness, and the researcher wanted to investigate the ways in which these caregivers cope and the resources which they use to manage their stress. In conjunction with this, the strength of a person's sense of coherence came forth as a buffering factor for handling and coping with stress. The relationship between the coping resources and sense of coherence was of interest, and therefore the possible relationship between the two concepts were investigated. This was motivated by a need to focus on positive health outcomes in response to stress experiences. The need to focus on positive health outcomes has been highlighted by Sommerfield and McCrae (2000), who stated that the field of study that focuses on human adaptational processes is in crisis. Folkman and Moskowitz (2000) added that psychologists need to understand more clearly the adaptational significance of positive affect in the midst of stress, and they need to learn how people generate and sustain positive affect under stressful or challenging conditions. According to Cairns (2001), it is concepts such as coping resources that provide productive theories for research into these issues.

With regards to the large body of research conducted on health on a broader scale, it was pointed out that studies on HIV/AIDS caregivers' health have received little research attention. This author continued by stating that with regards to health issues concerning the patient and the caregiver, most research has been limited to the patients, thus leaving a "gap" in knowledge concerning HIV/AIDS caregivers' health. Due to the fact that this study investigated the coping resources and sense of coherence of adult family caregivers exclusively, it can be said that this focus addressed, to some extent, the need for knowledge concerning caregivers' health in the field of health psychology.

The study furthermore contributes to the limited South African research data on the coping resources and sense of coherence in African cultures. The feedback report to the manager of the Masizakhe community project where the caregivers are registered, which included the aims of the study, the findings and possible recommendations, could also serve as valuable information to the management of the Masizakhe community project.

Of value to those individuals who chose to participate in the study was that they receive feedback based on the general findings of the research. Based on this they were made cognizant of the positive findings in terms of the coping and sense of coherence, as well as those areas where coping resources

may be lacking. Being aware of less effective coping behaviours may contribute to participants' motivation to enhance those coping resources on which they may be low and thus improve their sense of coherence, be it for future challenges and stressors, or in their caregiving role itself.

6.4 Limitations of the Research

A number of limitations to this research can be identified. These limitations relate to the research design, the participants and sampling method, and the measures utilized in the study.

The design of this study posed particular limitations. Lazarus (2000) postulated that certain research methods are essential in the study of stress, emotion and coping. These methods are described as longitudinal, since they repeat measurements on the same sample across time and circumstances (Lazarus, 2000). The current study adopted a cross-sectional design and therefore measured the participants' SOC and coping resources at one point in time, rather than across various points in time. Consequently, no account can be given of premorbid levels, or changes in these levels.

Another limitation in the design of the current research is the absence of qualitative information. Elmes, Kantowitz and Roediger (2003) postulated that qualitative research is based on the participants' subjective view of a changing reality, and seeks to understand the individual's world. In other words, a disadvantage of using quantitative data only, stems from the fact that the individual's story gets lost among the forced-choice questions (Elmes, et. al., 2003). Combining both quantitative and qualitative data in triangulation would have enriched the data and contributed to a deeper understanding of the sample under investigation.

Another shortcoming of this study is related to the sampling method and sample size. The sampling method employed in this study was non-probability convenience sampling. With convenience sampling, the sample is not randomly selected, and is therefore not representative of the general population. There might also be significant differences between the individuals that volunteered and those that chose not to. This has the potential to influence the results obtained in the study, as it is possible that the individuals who volunteered might be biased towards those who perceived their coping resources to be sufficient and efficient. In conjunction with the limitation mentioned above, the sample obtained was not representative of HIV/AIDS adult family caregivers in South Africa, because the study was conducted at only one specific community project where caregivers are affiliated.

Furthermore, the small sample size and unequal groupings of the current study render it non-representative of the wider population. Hence, the findings of this study are only applicable to the sample under investigation, and cannot be generalized to the general population of adult family caregivers. Additionally, the small sample size and unequal groupings prevented the utilization of additional parametric procedures, which could be used to identify the relationship among variables of

the sample (Harris, 1998). Such an analysis would have been useful in exploring the significance of the biographical information in relation to the results of the measures.

As mentioned in Chapter 4, a further possible limitation is that the biographical questionnaire and the two measures (SOC-29 and CRI) were available in English only. Consequently it was a requirement that the participants be able to read and write in English. However, it must be noted that the sample under investigation were Xhosa speaking and English is not their first language. This could have contributed to the inability to understand and answer the questions with much insight and understanding.

A shortcoming associated with the Coping Resources Inventory stems from the fact that it was developed and standardised in the United States of America by Hammer and Marting (1988). The norms and standard deviations used for the interpretations of the participants' response are therefore not necessarily valid in a South African context. In addition, no previous South African studies, which explore the coping resources of HIV/AIDS adult family caregivers, have been completed thus far. Hence, there is no previous study with which to compare the findings of the current study.

Finally, no causal relationship could be deduced from the results obtained from the study, despite the fact that a positive correlation was indicated between the SOC and the Coping Resources Inventory. The mere existence of such a relationship does not account for the reason(s) for, and direction of, the relationships between these two variables. However, the aim of the study was to explore and describe both variables, as well as to investigate the possibility of a relationship between the variables with an HIV/AIDS adult family caregiver population. The exploratory and descriptive nature of this study therefore does not allow for a causal explanation to be made.

6.5 Recommendations

Based on the limitations of the current study, the following recommendations for future research are suggested. Firstly, it is recommended that a replication of the present study be undertaken at other HIV/AIDS community projects, to obtain a more representative and larger sample, and to generate more South African data on the measures as well as to identify the differences and similarities in the findings across these community projects. This recommendation is made based on the fact that much of the research cited in the study comes from international sources. This indicates the need for more South African research in the field of coping resources and sense of coherence of HIV/AIDS adult family caregivers. The questionnaire should be available in more than one language, with larger and more representative samples, so that the results can be more generalisable to the larger population of HIV/AIDS adult family caregivers. Related to the fact that the participants in the study were African, it is recommended that a similar study be conducted in a between-cultures comparison, as this could

establish whether the present results is culture-specific or culture-free. South Africa, with its rich cultural diversity and need for more efficient and cost-effective health care, is fertile ground for such a study.

Longitudinal research is suggested and could be used to investigate the consistency of coping resources and sense of coherence over time, with regard to age and developmental differences. This is especially relevant to the ever-changing and transforming South African context, with regards to the health system in South Africa and especially those individuals forced to care as a result of the resources on a provincial level.

It is also recommended that the research include qualitative information into the data collection. This will serve to confirm and enrich the quantitative data. Qualitative research focuses on specific personal experiences, and could assist in developing a better understanding of the sense of coherence and coping resources of HIV/AIDS adult family caregivers.

6.6 Conclusion

This study was an attempt to explore and describe the sense of coherence and coping resources of adult family caregivers of HIV/AIDS patients in the Kwazakhele area of Port Elizabeth. The study also examined whether a relationship exists between the sense of coherence and coping resources measures used in the research. Although the present study represents a tentative, descriptive picture that requires further verification, the important contributions of the study cannot be ignored. The mean scores and the positive relationship between the sense of coherence and coping resources provide important information regarding the sample under investigation. This could pave the way towards intervention approaches aimed at improving the individuals' capacity to cope with stress, which could play an important role in the long-term management of coping with the stress and difficulties that they face being a caregiver. In addition, this study paves the way for future research involving stress, coping and sense of coherence of adult family caregivers of HIV/AIDS patients, and recommends that these future studies use larger sample groups and employ experimental designs. This could enable the generalisability of the results and the establishment of causal relationships between variables. Furthermore, the results of this study can contribute to the larger body of research in health psychology that focuses on the origins of health as opposed to the stress experience of individuals. This research has contributed towards a more holistic approach in the understanding of HIV/AIDS caregivers towards which health psychology increasingly aspires. It is hoped that through this contribution, the present treatise provides the groundwork for future research in the South African context.

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**THE SENSE OF COHERENCE AND COPING RESOURCES OF ADULT FAMILY
CAREGIVERS OF HIV/AIDS PATIENTS IN THE KWAZAKHELE AREA OF PORT
ELIZABETH**

Research has shown that care giving of a patient of HIV/AIDS can be a highly stressful experience. People cope in many different ways and with varying levels of satisfaction in their coping response. More research is needed to explore how South African family caregivers of HIV/AIDS patients cope with their role as caregiver in order to better understand and provide assistance.

I am an Intern Clinical Psychologist in the Psychology Department at the Nelson Mandela Metropolitan University who is undertaking a study regarding the sense of Coherence and Coping of adult family caregivers of HIV/AIDS patients in the Kwazakhele area of Port Elizabeth. The aims of the study are to explore and describe the sense of coherence and coping resources of adult family caregivers.

This study would contribute to the body of research on the coping mechanisms of HIV/AIDS caregivers. Results would identify the general trends of coping that would be of benefit to psychological intervention as well as guide the committee at the Masizakhe Community Project to assist the family caregivers with healthier ways of coping with the stresses which they are experiencing.

I am appealing to adult family caregivers, who have been considered to be the primary caregiver for the past six months and longer, to consider participating in this research study. You should be 21 years of age and older.

Your participation will be strictly voluntary and all results and information would be treated with the utmost privacy and strict confidentiality. Results will be used purely for research purposes and to assist the community project to improve their programme to help the family caregivers.

This study would require the completion of two questionnaires and a biographical questionnaire and should take about half an hour of your time. A member from the organization will be seated with you when you complete the questionnaire on an individual basis. Alternatively, a group administration of the measures could be arranged at a time convenient to the participants.

If you are willing to participate kindly complete the attached consent form.

If you would like further information or assistance, please do not hesitate to contact me on 084 476 8370.

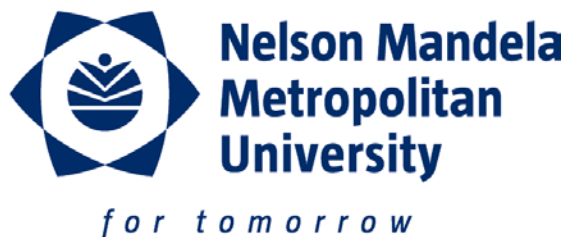
Your assistance is much appreciated.

Yours faithfully

Ms. Sherina Naidoo
(Researcher)

Dr. D. Elkonin
(Clinical Psychologist and Research Supervisor)

Ms. O Brown
(Clinical Psychologist and Research Co-supervisor)



NELSON MANDELA METROPOLITAN UNIVERSITY

INFORMATION AND INFORMED CONSENT FORM

Title of the research project	The Sense of Coherence and Coping Resources of HIV/AIDS adult family caregivers in the Kwazakhele area of Port Elizabeth
Reference number	
Principal investigator	Sherina Naidoo
Address	PO Box 1600 Psychology Department Nelson Mandela Metropolitan University Port Elizabeth 6000
Postal Code	
Contact telephone number (private numbers not advisable)	

A. DECLARATION BY OR ON BEHALF OF PARTICIPANT (Person legally competent to give consent on behalf of the participant)		Initial
I, the participant and the undersigned I.D. number OR I, in my capacity as of the participant I.D. number Address (of participant)	<div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div>	
A.1 I HEREBY CONFIRM AS FOLLOWS:		
1. I, the participant, was invited to participate in the above-mentioned research project that is being undertaken by of the Department of in the Faculty of of the Nelson Mandela Metropolitan University.	<div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div> <div style="border: 1px solid black; height: 20px; width: 100%;"></div>	
2. The following aspects have been explained to me, the participant: 2.1 Aim: The investigators are studying: The sense of coherence and coping resources of HIV/AIDS adult family caregivers in the Kwazakhele area of Port Elizabeth The information will be used to contribute to caregiving literature and to highlights resources so in turn to assist the community project		

2.2	Procedures: I understand that I will be completing three paper and pencil questionnaires	
2.3	Risks: N/A	
2.4	Possible benefits: As a result of my participation in this study I will contribute to the knowledge of adult family caregivers in the Kwazakhele area in Port Elizabeth	
2.5	Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigators.	
2.6 will	Access to findings: Any new information/or benefit that develops during the course of the study be shared as follows: In a written report that will be handed to the community project and the iThemba Foundation to assist them with the community resources that they have available and a lack thereof.	
2.7	<p>Voluntary participation/refusal/discontinuation:</p> <p>My participation is voluntary <input checked="" type="checkbox"/> YES <input type="checkbox"/> NO</p> <p>My decision whether or not to participate will in no way affect my present or future care/employment/lifestyle <input checked="" type="checkbox"/> TRUE <input type="checkbox"/> FALSE</p>	
3.	<p>The information above was explained to me/the participant by</p> <p><input type="text" value="Sherina Naidoo"/></p> <p>in <input type="checkbox"/> Afrikaans <input type="checkbox"/> English <input checked="" type="checkbox"/> Xhosa <input type="checkbox"/> Other</p> <p>I was given the opportunity to ask questions and all these questions were answered satisfactorily.</p>	
4.	No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.	
5.	Participation in this study will not result in any additional cost to myself.	

A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT				
Signed/confirmed at		<input type="text"/>	on <input type="text"/>	20
Signature or right thumb print of participant		Signature of witness		
		Full name of witness		

B. STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I, Sherina Naidoo declare that

- I have explained the information given in this document to

and/or his/her representative

- he/she was encouraged and given ample time to ask me any questions;

- this conversation was conducted in

Afrikaans	<input type="checkbox"/>	English	<input checked="" type="checkbox"/>	Xhosa	<input type="checkbox"/>	Other	<input type="checkbox"/>
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and no translator was used

- I have detached Section D and handed it to the participant

<input checked="" type="checkbox"/>	YES	<input type="checkbox"/>	NO
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Signed/confirmed at

<input type="text"/>	on	<input type="text"/>	20
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Signature of interviewer	Signature of witness
	Full name of witness

D. IMPORTANT MESSAGE TO PATIENT/REPRESENTATIVE OF PARTICIPANT

Dear participant/representative of the participant

Thank you for your/the participant's participation in this study. Should, at any time during the study:

- an emergency arise as a result of the research, or
- you require any further information with regard to the study, or
- the following occur

(indicate any circumstances which should be reported to the investigator)

Kindly contact
at telephone number
(it must be a number where help will be available on a 24 hour basis, if the research project warrants it)

Sherina Naidoo
084 476 8370

BIOGRAPHICAL QUESTIONNAIRE

Research Project: The sense of coherence and coping resources of HIV/AIDS adult family caregivers in the Kwazakhele area of Port Elizabeth

Respondent No. (for office use)

--	--

Please complete the questionnaire in full and as accurately as possible. Indicate your responses with an X. You may indicate more than one response if it is applicable.

GENERAL CAREGIVER INFORMATION

1. Age at present

21 – 30	1
31 – 40	2
41 – 50	3
51 – 60	4
61 +	5

2. Gender

Male	1
Female	2

3. Marital status

Single	1
Engaged	2
Married	3
Separated	4
Divorced	5
Widowed	6

4. Employment status

Unemployed	1
Employed	2
Retired	3
Retrenched	4

5. How many people live in your home?

6. What is your relationship to the HIV/AIDS patient?

Spouse	1
Child	2
Other (please specify).....	3

PATIENT INFORMATION

1. Age of HIV/AIDS patient

2. Gender of HIV/AIDS patient

Male	1
Female	2

3. How long has the patient been living with HIV/AIDS?

--

4. Level of patient dependency

Mild	1
Moderate	2
Severe	3

PERSONAL CAREGIVER INFORMATION

1. How would you rate your own health?

Good	1
Average	2
Poor	3

2. Do you suffer from any medical conditions? If yes, please specify.

Yes	1
No	2
Specify	3

INFORMATION ON CAREGIVING ROLE

1. How long has the patient been living with you being the primary caregiver?

--

2. Number of hours a day spent in caregiving role?

2 hours or less	1
3 – 4 hours	2
5 – 8 hours	3
9 – 12 hours	4
13 hours or more	5

3. What are your daily responsibilities regarding your caregiving role?

Food preparation and feeding	1
Outings (e.g., taking walks)	2
Medication distribution	3
Personal Hygiene (e.g., bathing, brushing teeth, etc.)	4
Overseeing financial responsibilities	5
Shopping and household chores	6
Other (please specify)	7

4. What do you find most stressful about your caregiving role?

Lack of freedom, too many responsibilities	1
Helping with personal hygiene	2
Sleep disturbances	3
Lack of co-operation by patient	4
Explaining disease, course and treatment	5
Answering questions regarding death and dying	6
Other	7

5. How do you usually cope during times of stress?

Ignore the stress	1
Avoidance (e.g., sleeping)	2
Use of substances (e.g., alcohol)	3
Medication (e.g., pain killers)	4
Exercise	5
Seek social support	6
Other	7

6. How would you describe your general well-being over the last 6 months?

Excellent	1
Good	2
Average	3
Below Average	4

THANK YOU FOR YOUR PARTICIPATION IN COMPLETING THE
QUESTIONNAIRE!

Appendix A
Research Cover Letter

Appendix B
Consent Form

Appendix C
Biographical Questionnaire