

**SOCIAL WORKERS' PERSPECTIVES ON SOCIAL  
SUPPORT NEEDED BY PEOPLE LIVING WITH HIV/AIDS**

**by**

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Thesis presented in fulfilment of the requirements for the degree of  
Master of Social Work in the Faculty of Arts and Social Sciences at  
Stellenbosch University

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**Cr t ki2014**

## **DECLARATION**

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March 2014

## ACKNOWLEDGEMENTS

I would like to acknowledge the following persons and institutions by expressing my sincere thanks and appreciation for their respective roles in the completion of my thesis.

- The Lord Almighty for the strength He gave me, I will always be grateful to Him.
- My family for the interest they have shown in my studies especially my father, General RZK Kulu for all kinds of support that he provided, friends, my former colleagues and work supervisor, Ms Yolanda Fransman.
- Professor Sulina Green for her patient supervision, guidance, encouragement and support.
- Staff members of the Department of Social Work at Stellenbosch University, Prof Lambert Engelbrecht and Mrs Rochelle Williams for their support and encouragement.
- The social workers at Child Welfare: South Africa and Hospice in Stellenbosch, Somerset West and the greater Helderberg for their willingness to participate in this study.
- Mrs Suzette Winckler for the technical care of this study. Her thoroughness is commended.
- The Language Centre for the language editing of this study.

## ABSTRACT

The South African government has laws and policies that forbid discrimination against individuals. These policies protect people from being discriminated against in the workplace due to sickness, race and many other factors. Discrimination against people living with HIV/AIDS has caused many people who suffer from this disease not to come forward with their illness because they fear being discriminated against and stigmatised; some even lose their jobs because they are infected with HIV. People infected with HIV are discriminated against not only in the workplace but also in their communities and families. This implies that people living with HIV/AIDS need support from all levels of society in order to live positive lives, which may lead infected people to live longer.

This study explored HIV/AIDS as terminal illness and the stressors experienced by people infected with the virus. This was done by examining the support available to people living with HIV/AIDS, as well as identifying the support needed by these people. By adopting an ecological approach to the study, the need for support could be investigated on multiple levels.

A combination of a quantitative and qualitative research design was used in the study. Data were gathered by means of a semi-structured interview schedule that was administered during individual interviews with service providers. This allowed for data that were both measurable as well as rich in description to be collected. The questions in the semi-structured questionnaire were based on the information retrieved from the literature review.

The findings from the empirical investigation revealed that people living with HIV/AIDS receive limited support from their families, the South African government and society at large. The findings further indicated that informal sources of support such as family, friends and partners are relatively supportive of people living with HIV/AIDS. However, the relationships between people living with HIV/AIDS and their families and partners are often strained, especially when a person first discovers his or her status as HIV positive. Furthermore, people living with HIV/AIDS are stigmatised on multiple levels because of

their status. There is stigmatisation from family, friends, in the workplace and in the community.

The most important recommendations resulting from the study are that services such as counselling are needed for people living with HIV/AIDS together with their families. This is of particular significance to the South African government, especially the health sector, which needs to improve the health care system.

In addition, recommendations emphasise the importance of promoting education and awareness, which could have great value for people living with HIV/AIDS, their families and communities. Knowledge about HIV/AIDS would empower people at all levels to support those who live with the disease and would also be of great value in helping those living with the disease to contribute something of value towards their health condition.

## OPSOMMING

Die Suid-Afrikaanse regering beskik oor wette en beleide wat diskriminasie teen individue verbied. Hierdie wette en beleide beskerm mense teen diskriminasie in die werkplek, diskriminasie op grond van siekte, gestremdheid, ras en vele ander redes. Diskriminasie teen mense wat met MIV/vigs leef, laat baie van hulle hul MIV/vigs-status geheim hou omdat hulle diskriminasie en stigmatisasie vrees. Sommige verloor selfs hulle werk wanneer dit rugbaar word dat hulle aan MIV/vigs ly. Diegene met MIV/vigs ervaar egter nie net in die werkplek diskriminasie nie, maar ook in hul gemeenskappe en families. Dít impliseer dat mense met MIV/vigs op alle vlakke ondersteuning nodig het om 'n positiewe lewe te lei en daarmee hul lewensverwagting so ver moontlik te verleng.

Hierdie studie het die stresfaktore van terminale MIV/vigs-lyers ondersoek. Daar is voorts ondersoek ingestel na die ondersteuning wat mense met MIV/vigs ontvang, sowel as die ondersteuning wat hulle nodig het. MIV/vigs-lyers se ondersteuningsbehoefte op etlike vlakke is deur middel van 'n ekologiese navorsingsbenadering bepaal.

'n Kombinasie van 'n kwantitatiewe en kwalitatiewe navorsingsmetodologie is vir die studie gebruik. Data is met behulp van 'n semigestruktureerde vraelys ingesamel, wat gedurende individuele onderhoude met diensverskaffers afgeneem is. Sodoende kon meetbare sowel as hoogs beskrywende data ingesamel word. Die vrae in die semigestruktureerde vraelys was gegrond op die inligting uit die literatuuroorsig.

Die bevindinge van die empiriese ondersoek toon dat mense wat met MIV/vigs leef beperkte ondersteuning van hul familie, die Suid-Afrikaanse regering en die groter samelewing ontvang.

Die bevindinge dui voorts daarop dat informele ondersteuningsbronne, soos familie, vriende en lewensmaats, betreklik ondersteunend is teenoor diegene met MIV/vigs. Tog is die verhouding tussen MIV/vigs-lyers en hul families en lewensmaats ook dikwels onder druk, veral net nadat die persoon ontdek dat hy/sy MIV-positief is.

Daarbenewens word mense met MIV/vigs op verskeie vlakke gestigmatiseer – deur hul familie, vriende, in die werkplek en die gemeenskap.

Die belangrikste aanbeveling uit die studie handel oor die behoefte aan dienste soos berading vir mense wat met die virus leef, sowel as vir hul familie. Die aanbeveling behoort veral van belang te wees vir die Suid-Afrikaanse regering, en in die besonder die gesondheidssektor, wat hierdie behoefte in gedagte moet hou om die gesondheidsorgstelsel te verbeter.

Ander aanbevelings beklemtoon die belang van meer opvoeding en bewusmaking, aangesien dit uiters waardevol kan wees vir mense met MIV/vigs, hul familie en gemeenskappe. Kennis oor MIV/vigs sal mense op alle vlakke bemagtig om diegene met die virus te ondersteun, terwyl dit MIV/vigs-lyers self ook sal help om hul eie gesondheidstoestand beter te bestuur.

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## **CHAPTER 1**

### **INTRODUCTION**

#### **1.1 PRELIMINARY STUDY AND RATIONALE**

People living with HIV/AIDS suffer a great deal due to several factors, such as chronic illness, stigma and isolation. The stigma attached to HIV/AIDS causes people to become discriminated against by their families, communities, peers, workplaces and churches. HIV/AIDS is a fatal disease that cannot be cured. There is no clear explanation for the mechanism of AIDS infection. People living with HIV/AIDS are seen as people living with a fatal, mysterious disease that will eventually cause their death, and these perceptions turn people living with HIV/AIDS into “the others”, causing discrimination and stigmatisation in society (Chikanda & Mokgatle, 2006).

South Africa is one of the countries where people living with HIV/AIDS still live on the level of fear, stigma, isolation and rejection, while many other countries, such as Uganda, have moved to the level of tolerance, solidarity and acceptance (Chikanda & Mokgatle, 2006).

In the work experience of the researcher, people living with HIV/AIDS are suffering due to stress-related sicknesses because they fear disclosing their status. They highlight the disadvantages of disclosure, for instance that if they disclose, they will be discriminated against, stigmatised or isolated as no one will want to be associated with them. They fear that they will lose their family members, jobs, friends and sexual partners. In their families, people living with HIV/AIDS are given their own room to separate them from others, and they do not share articles such as utensils with other family members. They are abandoned by their sexual partners, and many have lost their marriages due to HIV/AIDS.

Some people living with HIV/AIDS end up losing their jobs because employers become intolerant of them due to their sickness. Sickness has an effect on their jobs as it affects their performance and they may also be frequently absent from work because of sickness. They may also feel isolated as there is no one at work who wants to be associated with them.

In 2000 the South African government introduced the disability grant to people who live with HIV/AIDS, and antiretroviral treatment (ART) started in 2003/4. The question is that if people living with HIV/AIDS do receive this kind of support, is it enough and effective, or do they need another kind of support? The pressure to provide these government grants became worse when the roll-out of ART started on the 1<sup>st</sup> of May 2003 because one could not take the medication on an empty stomach. The treatment demanded that people disclose their status because if they were to be on treatment, they would need to have a “treatment supporter” who would always remind them of the treatment so that they would adhere to the treatment and not default.

The Nelson Mandela/HSRC study (2002) confirms that South Africa is faced with problems such as an increasing number of orphans, child- and grandparent-headed households, single parents, shorter life expectancy of the population, poverty and vulnerability of women and children due to HIV/AIDS. This poses challenges to social welfare services to strategise on new policies and interventions that can address these problems. On the same note, the Nelson Mandela/HSRC study (2002) shows that poverty plays a pivotal role in increasing vulnerability to HIV infection in sub-Saharan African countries, including South Africa.

The opinion of the researcher is that people living with HIV/AIDS need more support as the disease is chronic and it may cause one to suffer from severe stress. Lack of support may lead to stressors such as depression, suicidal thinking and many others. Support is needed from all institutions that are available in our society, starting from the primary institution, the family. As a social worker, the researcher has recognised the need for social support. As Maguire (1991) states, social support serves to protect people from the effects of stress and to help them to cope better. The basic unit of support for most people (adults and children) is their families because families can provide the strong, intimate bonds that people need (Maguire, 1991). Caplan (cited in Maguire, 1991) identified major forms of assistance that operate as social support systems. The first one is the significance of others who help the individual to utilise his or her own psychological resources and overcome difficulties, empowering the person thus supported to deal with the causes of the stress. Another form of assistance is providing extra resources such as guidance, money, material or skills to help the individual to handle difficult situations.

Social support systems serve three purposes, according to House (cited in Maguire, 1991). Firstly, less desirable influences are crowded out as supportiveness increases, so negative and stressful situations and stimuli become less dominating. Secondly, health improves as individuals begin to take better care of themselves under the influence of caring support or become more aware of their own roles in solving their problems. Lastly, social support serves as a buffer against the effects of stress, therefore protecting people from such common psychological overreactions as self-blame and guilt and from physical reactions such as sleeping disorders related to depression, or abuse of alcohol or drugs.

A study done by Knowlton, Hua, & Latkin (2005) on HIV-positive men and women showed patterns of selective disclosure. Most participants disclosed their status to some people close to them and not to others. The rate of disclosure was associated with social support. Friends were disclosed to most often and were perceived as more supportive than family members, and mothers and sisters were disclosed to more often than other family members. Analyses done by Path (cited in Knowlton, et al 2005) who tested a model of HIV showed that stress was associated with disclosure of HIV status and that disclosure was related to social support. Disclosure and its association with social support varied for different relationships, and these differences had implications for mental health and coping “interventions”.

A study done by Jia, Uphold, Wu, Reid, Findley & Duncan (2003) explored the experiences of social support of a number of HIV-positive gay men. The study highlighted the links between social support and the health and well-being of people with chronic illness. The findings highlighted patterns of support among members of this marginalised community. At that time, treatment was extending the life expectancy of people infected with HIV and in the United Kingdom at least there were major changes in the funding of HIV services. The study raised pertinent questions about the impact of social support on people suffering from this illness and about the development of appropriate services. Social support networks were seen as having played a major role in the lives of 30 HIV-positive gay men. Although the study was limited to the gay community, social support is vital to all people who are chronically ill. The study caused

a growing interest in the nature and significance of the link between chronic illness and social support and social networks.

Family caregivers experience a lack of welfare and family/emotional support in their care of HIV/AIDS orphans. The study recommended that health care workers, including social workers and home-based caregivers, be trained in available social support from government and nongovernmental organisations for caregivers of HIV/AIDS orphans.

Serovich, Kimberley, Mosack and Lewis (2010) are also of the opinion that social support is an important factor in coping with HIV infection. Their study identified a lack of certainty regarding the extent to which others were perceived as supportive and who was perceived as supportive.

Another expected finding, as the researchers call it, is the lack of relationship between the length of time that HIV-positive individuals have known their status and their perception of social support. According to Kimberley and Serovich (1996), the possible explanation may be that perceptions of available support providers change over the course of the illness. Macklin (cited in Kimberley & Serovich, 1996) mentions the disclosure of one's status to many family members as a barrier to receiving the necessary support. According to Macklin, if HIV-positive persons tell more family members, this may actually inhibit the availability of social support because it is common for families to reject or abandon an HIV-positive member.

## **1.2 PROBLEM STATEMENT AND FOCUS**

HIV/AIDS is a chronic illness that has an impact on the life of an individual, family, friends and the community at large. The disease has also an impact on the availability of support from the mentioned structures. The need for support is caused by the fact that when one is diagnosed, the diagnosis is followed by anger, despair, fear of rejection or stigma, suicidal thinking and other negative thoughts and feelings. People living with HIV/AIDS have many fears as they are uncertain of their future and are afraid of dying alone and in pain (Van Dyk, 2005).

Social workers work directly with people living with HIV/AIDS, their families, social groups and communities. The purpose of this research was to obtain the perspective of social workers on the support needed by people living with HIV/AIDS. Regarding what has been mentioned about these people's feelings in the previous paragraph, the literature only shows the feelings that these particular researchers have come across. Social workers' perspectives would provide information on the other kinds of support that people living with HIV/AIDS need.

### **1.3 AIM OF THE RESEARCH AND THEORETICAL POINTS OF DEPARTURE**

The aim of the study was to gain an understanding of social workers' perceptions of the nature of social support needed by HIV-positive people. The study had the following objectives:

- To explain HIV/AIDS as terminal illness.
- To describe the psychosocial stressors experienced by people infected with HIV and affected by HIV/AIDS.
- To discuss the relevance of the ecological perspective to people living with HIV/AIDS.
- To investigate the perspectives of social workers on the nature of the support needed by HIV-positive people.

According to Specht (cited in Payne, 2005), social support applies to a wide range of social relationships and organisations whereas social networks refer to a specific set of interrelated people. It is stated that people with a good social support system believe that they are cared for and loved, esteemed and valued and belong to a network of communication where others can be counted on to help. Those who lack support from family, friends and community, however, show more symptoms of physical and psychological ill-health than those with support,

HIV/AIDS is a chronic illness because there is no cure for the disease yet. People living with this disease may perceive themselves as in a state of crisis and feel afraid that they may die. They try hard to cope with the new situation in their lives. The crisis intervention model states that individuals are presumed to be in a state of crisis when they react to a threatening situational

event or developmental change by trying out old coping mechanisms that do not work and then experience upset as they search for new ways of coping (Nelson, cited in McKendrick, 1991).

HIV-positive people feel threatened by death, and their condition deteriorates as they find it difficult to cope with the new situation. McKendrick (1991) states that health problems, physical and mental, frequently represent serious stress for both the patient and the family.

The ecological or adaptational model described by Germain (cited in McKendrick, 1991) views human development and functioning, including health and illness, as outcomes of continuous exchanges between the individual and the social environment, the physical setting and the cultural context. In this model there are three core concepts that are pertinent to social work practice: adaptedness, stress and coping. According to McKendrick (1991), people must learn to adapt to all changes that either they or their environment have induced; adaptation is a constant, continual process. It is a concern of researchers to find out whether HIV-positive people do receive enough social support.

Being in contact with HIV-positive people almost daily shows one that they are really stressed by their situation and the challenges that they come across, for instance abandonment by their sexual partners and their marriages ending in divorce. As McKendrick (1991) states, the stress of the disease may lead to stress in other areas of life, especially the family, workplace and community, interfering with recovery or with the management of the health problem. For these patients and their families to cope, appropriate support must be provided.

Living a satisfactory life depends on the support systems in one's environment, as Pincus and Minaham (cited in Payne, 2005) put it. Pincus and Minaham suggest three kinds of system that may help people: informal or natural systems such as family, friends and co-workers, formal systems such as community groups and trade unions, and societal systems such as hospitals and schools. It is in the interest of the researcher to find out whether this theory is relevant to those who live with HIV.

The research questions were as follows:

1. Why is HIV/AIDS a terminal illness?
2. Are ecological perspective theories relevant to people living with HIV/AIDS?
3. What are the psychosocial stressors experienced by people living with HIV/AIDS?
4. Do people living with HIV/AIDS receive enough support?

## **1.4 RESEARCH DESIGN AND METHODS**

### **1.4.1 Research approach**

The researcher used both quantitative and qualitative approaches. Quantitative research relies upon measurement and uses various scales (Bless & Higson-Smith, 2005). The numbers form a coding system so that different cases and different variables may be compared. Systematic changes in scores are interpreted or given meaning in terms of the actual world that they represent. The advantage in this type of research is that the numbers are exact (Bless & Higson-Smith, 2005). Another advantage of quantitative research is that numbers can be analysed using descriptive and inferential statistics.

Rubin and Babbie (2001) describe qualitative studies as likely to refer to a more intensive examination of their deeper meanings, which means that they lead to a more thorough description, whereas quantitative studies typically refer to the characteristics of a population and a survey design.

### **1.4.2 Research design**

#### ***1.4.2.1 Exploratory research***

The study explored social workers' perspectives on the support needed by HIV-positive people. The study was to assist the researcher in gaining insight into a situation, phenomenon, community and individual (Bless & Higson-Smith, cited in De Vos, Strydom, Fouché and Delpont, 2005). As indicated by De Vos et al. (2005), the need for such a study arises out of a lack of basic information on a new area of interest or a desire to become acquainted with a

situation so as to formulate a problem or hypothesis. Since this study had certain goals, exploratory research was useful.

The study was conducted to explore the support of the psychosocial needs of HIV-positive people, the kind of support that they needed and whether the support that they received was sufficient or not. The researcher views exploratory studies as important. As Babbie and Mouton (2001) state, exploratory studies serve to satisfy the researcher's curiosity and desire for a better understanding, to test the feasibility of undertaking a more extensive study, to develop the methods to be employed in any subsequent study, to explicate the central concepts and constructs of a study, to determine priorities for future research and to develop new hypotheses about an existing phenomenon.

#### ***1.4.2.2 Descriptive research***

According to Neuman (cited in De Vos et al., 2005) descriptive research presents a picture of the specific details of a social situation, social setting or relationship and focuses on "how" and "why" questions. It can have a basic or applied research goal and can be either qualitative or quantitative in nature. It is one of the major purposes of social scientific studies to describe situations and events (Babbie & Mouton, 2001).

#### **1.4.3 Sampling**

The unit of analysis was 20 social workers (male and female) who were working with people living with HIV/AIDS. They worked in various sectors such as the Department of Social Development and nongovernmental organisations that were specifically dealing with people living with HIV/AIDS.

The sampling method that was used was non-probability sampling. Bless and Higson-Smith (2005) refers to non-probability sampling as a case where the probability of including each element of the population in a sample is unknown. Purposive sampling was used because it is based entirely on the judgement of the researcher and it is composed of elements that contain the

most characteristic, representative or typical attributes of the population (Singleton et al., cited in De Vos et al., 2005).

#### **1.4.4 Method of data collection**

The data were collected by making use of semistructured interviews. According to Bless and Higson-Smith (2005), semistructured interviews are very helpful in exploratory research as well as when the pilot survey is conducted. This method helps to clarify concepts and problems and allows for the establishment of a list of possible answers or solutions (Bless & Higson-Smith, 2005).

#### **1.4.5 Ethics considerations**

Before the interview process can take place, ethics clarification should be done with the respondents. According to Kvale (cited in Henning, Van Rensburg & Smit, 2009) when the interview plan has been finalised, the ethics clarification can begin. This was done in the following manner in this study:

- Research process: Respondents were fully informed about the research process, meaning how the interviews would be used.
- Privacy and sensitivity: The researcher explained to the respondents that after the information had been recorded it would be protected and also explained how the interviews were going to be used (Henning et al., 2009).
- Letter of consent: The letter was drafted by the researcher at a time when the interviews were planned. Respondents had to consent to participate in the study. Another letter of consent was taken to their organisations: Child Welfare South Africa (Stellenbosch and Somerset West child welfare societies), Stellenbosch Hospice, Prevention and Treatment of Child Abuse in Helderberg (PATCH) and the Afrikaanse Christelike Vrouevereniging (ACVV). The purpose was to obtain consent for their respondents to participate in the study.
- Anonymity: Respondents were assured of anonymity by the use of pseudonyms.

- Confidentiality: Respondents were assured that no one would have access to the data that would be collected from the respondents except those who were going to work on the data, like the researcher.
- Right to privacy and voluntary participation: Participation in the study was voluntary and the respondents could refuse to divulge certain information about themselves.
- No harm to the respondents: The issue of no harm being done to them was emphasised to the respondents.

## **1.5 TIME FRAME AND CHAPTER LAYOUT**

This research report includes six chapters. Chapter 1 is an introduction to the study and presents an outline of how the research was undertaken. Chapter 2 discusses HIV/AIDS as terminal illness, modes of transmission, stages that people living with HIV/AIDS experience and ART. Chapter 3 focuses on the ecological perspective in relation to support needed by people living with HIV/AIDS. Chapter 4 discusses the consequences of living with HIV/AIDS, and the stressors experienced by infected and affected people are described. In Chapter 5 the data concerning the empirical study are presented, indicating the perspectives of social workers on the support needed by people living with HIV/AIDS. Chapter 6 presents conclusions and recommendations based on the findings of the empirical study.

The investigation took place from 8 February 2010 to 31 March 2012. The final proposal was concluded by June 2010. The literature chapters were completed in August 2011. The data were gathered by means of a questionnaire administered during interviews with the respondents, from 14 October to 25 October 2011.

## **CHAPTER 2**

### **HIV/AIDS AS TERMINAL ILLNESS**

#### **2.1 INTRODUCTION**

HIV is a cause of terminal illness but is also different from other chronic illnesses because of its psychological burden. Hoffman (1996) states that HIV affects a person's entire life, emotionally and physically, a person's family relations as well as a person's ability to perform duties. People living with HIV/AIDS have to confront major social issues as the disease progresses, which is when they learn about the infection. There is a relatively long period during which they are free from symptoms, then they experience nonspecific symptoms and eventually they experience certain AIDS-related conditions. HIV-positive people may become depressed when they experience physical symptoms associated with advanced stages of HIV infection, as it may evoke considerable stress about what comes next (Temoshok & Baum, 1990, cited in Frans, 2008). The first objective of the study was to describe HIV/AIDS as terminal illness.

The chapter will start by describing the term "HIV/AIDS" as people often confuse the two terms (HIV and AIDS). The key characteristics of the disease will be highlighted. The different stages that people living with HIV/AIDS experience, modes of transmission and various types of ART will be explained.

#### **2.2 PEOPLE LIVING WITH HIV/AIDS**

People living with HIV/AIDS are those who have been infected with HIV. HIV is an abbreviation for "human immunodeficiency virus", which is the virus that causes AIDS, or acquired immunodeficiency syndrome. The virus attacks the body's immune system and makes it weak or deficient (SAMCA, cited in Bezuidenhout, 2004). This virus belongs to a family of viruses called retroviruses, and it causes infected cells to translate the viral genetic material, ribonucleic acid (RNA), into another form, deoxyribonucleic acid (DNA), which it uses to infect new cells (Whiteside, 1998).

HIV attacks mainly white cells in the body, called T lymphocytes, a key part of the immune response. HIV consists of two types: The most common is HIV-1, which is thought to be transmitted about three times more readily than HIV-2, which also causes AIDS and has been seen mainly in West Africa and Mozambique (Whiteside, 1998).

Bartlett and Finkbeiner (2006) define AIDS as follows: AIDS stands for acquired immune deficiency syndrome. Acquired means that AIDS is not inherited as many diseases of the immune deficiency are inherited but is acquired from some substance outside the body. A syndrome is not so much a disease as a collection of symptoms. In this case AIDS is evidence of infection with HIV and either a complication that results from immune deficiency or a test of immune function that indicates susceptibility to such conditions.

Most often people confuse HIV with AIDS and they cannot differentiate between the virus and the disease. It is also mentioned by Bartlett and Finkbeiner (2006) that “AIDS” is used incorrectly as a catch-all term for infection with the AIDS virus. Human immunodeficiency virus is the name of the virus that causes AIDS as HIV infects the immune system and weakens it. People with HIV infection do not necessarily have AIDS; if they take drugs against HIV, they may never contract AIDS.

Due to the destruction of the immune system cells, the body becomes increasingly unable to resist all types of infection, giving rise to the opportunistic infections characteristic of AIDS. As the body's defence system becomes weak, the following symptoms appear, separately or simultaneously: chronic fatigue or weakness, diarrhoea, minor skin infections, respiratory problems, sustained weight loss, persistent swelling of the lymph nodes and deterioration of the central nervous system (Whiteside, 1998). More severe diseases manifest themselves as the immune system weakens: cryptococcal meningitis, tuberculosis, pneumonia and cancers, such as Kaposi's sarcoma. This severe phase can continue for up to two years before death; there are progressively longer periods of illness that may be interspersed with periods of remission.

The key characteristics of HIV/AIDS are stated as follows by Whiteside (1998):

- AIDS has a long incubation period. Persons who are infected with HIV may have many years of normal, productive life, although they can infect others during this period.
- The prognosis for people infected with HIV currently is bleak or depressing.
- The scale of the epidemic is different from that of other diseases. In some clinics more than 30% of antenatal clinic attendees are infected.
- The disease is found mainly in two specific age groups: infants and adults aged between 20 and 40 years. In developing countries, more women than men are infected and women develop the disease at a younger age than men.
- HIV interacts with other diseases; for instance, other sexually transmitted diseases increase the rate of HIV transmission tenfold and significant increases in tuberculosis (TB) cases are directly related to HIV.
- The epidemic is still spreading. In some southern African countries it may have peaked in urban centres but it continues to spread in the rural areas.

People living with HIV/AIDS may live many fruitful years although they may spread the virus by infecting other people. The diagnosis brings depression and devastation to them. The disease spreads more rapidly than other diseases; it has been stated that more than 30% of the attendees at some clinics are infected. The age groups that produce the most victims of the virus are infants and those 20 to 40 years old, and more women than men are infected. Sexually transmitted diseases increase the rate of HIV transmission (Barnett & Whiteside, 2006).

As the immune system is progressively suppressed, other diseases will affect HIV-positive people. Most of these diseases, such as TB and meningitis, are not threatening to HIV-negative or uninfected people, but people with HIV are very likely to develop active TB. The chances of developing TB are low for the uninfected (Barnett & Whiteside, 2006). The estimation is that 40–50% of people with TB in South Africa are co-infected with HIV and that a third of people with HIV are expected to contract TB. It is not TB alone but also other diseases such as malaria that are linked with HIV. It is possible that people with HIV contract malaria more easily, and they certainly have a poorer prognosis.

The following section will look at how the person responds or reacts when discovering that he or she was infected with the virus.

### **2.2.1 Response of people living with HIV/AIDS to the virus**

According to Fanning (1997), the initial response of individuals when learning of a positive HIV test result varies considerably. Some may not be surprised by a positive result because they know that they have engaged in activities that put them at risk of being infected with HIV. Some people may be completely taken aback and shocked by the result. Regardless of whether or not one has expected a positive result, it remains a traumatic experience to first learn of being HIV positive. A person's initial response when learning about a positive HIV test result may be very emotional, especially if the news is unexpected. Some people may be calm at first until the initial shock wears off. Adjustment to this new reality may be a gradual process that may take weeks, months or even years.

People who are infected with HIV face greater emotional strain than most people ever do. What is worse is that most people infected with the virus face it at a young age. People infected with HIV are shocked, angry, depressed, afraid, guilt-ridden or confused or experience any number of these emotions at once. They worry about several issues such as revealing the diagnosis, expressing sexuality, relations with the people they love, increasingly complicated schedules for taking medication, the medication's side effects, the consequences of missing doses and the uncertainty of the future. Questions such as why they are alive are common to HIV-positive people (Bartlett & Finkbeiner, 2006).

Van Dyk (2005) is of the opinion that the only way to stop AIDS is to prevent transmission. Transmission will be discussed in the following section.

## **2.3 MODES OF HIV TRANSMISSION**

According to Almond (1990), HIV is transmitted only in settings of very close and direct human contact. However, it is important to appreciate that the routes of transmission have been proved

by documenting spread in individual cases and through studying populations through epidemiology.

HIV is transmitted by three basic means:

1. Sexual transmission through penetrative intercourse.
2. Transmission by blood, either by transfusion of blood or blood products from HIV-infected people or, increasingly commonly, by injection of drugs using needles and syringes shared with HIV-infected people.
3. Transmission from an infected mother to her unborn child across the placenta and possibly through breast milk.

As regards sexual transmission, there has been a remarkably persistent focus on homosexual transmission, which was the first to become apparent. It has become clear that HIV is simply a sexually transmissible infection and is spread equally effectively by heterosexual contact, passing from man to woman and vice versa (Almond, 1990).

### **2.3.1 Semen, vaginal secretions and cervical secretions during intercourse (anal, vaginal and oral)**

HIV is transmitted from one person to another through the most intimate of contact – sexual intercourse. The virus is found in high quantities in the sexual fluids (semen and vaginal fluid) of people with HIV infection (Evian, 1993). For the virus to gain entry into the body, it needs to attach itself to specific target cells with specific receptors called CD4 receptors, such as macrophages, dendritic cells and T4 lymphocytes. It is these receptors that enable the virus to successfully attach and gain entry into the body's cells. The receptor cells are plentiful in the lining of the genital tract and the ano-rectal area (Evian, 1993).

Frans (2008) is of the opinion that vaginal or anal intercourse results in close contact during penetration and that the transmission risk is high, even when precautions are taken, due to tears, lesions and rips that regularly occur during intercourse. Evian (1993) states that receptive rectal

and vaginal sexual intercourse presents the greatest risk of infection and that condoms that are used often break or come off.

There is a small chance that HIV can be transmitted through oral sex, especially if a person has abrasions, meaning scratches, in the mouth or gum disease (Barnett & Whiteside, 2006). Cunnilingus, in other words oral sex performed on a woman, or fellatio, that is oral sex performed on a man, can transmit HIV infection according to Bartlett and Finkbeiner (2006). The greater risk is fellatio because the semen of an infected man contains more HIV than the vaginal secretions of an infected woman.

### **2.3.2 Blood transmission**

Infection can also occur if HIV-infected blood gains entry into the body. In order for an infection to occur, the blood of HIV-infected persons must bypass the barrier of the skin and enter directly into the body (Evian, 1993). A person can be infected in the following ways: through blood transfusion; via blood-contaminated needles, syringes, razor blades and other sharp instruments; through intravenous drug use (sharing of needles and syringes); and lastly, although it is very rare, when HIV enters the body through an open skin wound or sore.

Use of contaminated blood or blood products is the most effective way of transmitting the virus. It introduces the virus directly into the bloodstream. During the early years of the epidemic, many haemophiliacs were infected because they received unscreened blood products (Barnett & Whiteside, 2006).

### **2.3.3 Mother-to-child transmission**

Mother-to-child transmission is the next most important cause of HIV infection after sexual transmission. The child can be infected with HIV prenatally, during birth or postnatally through breastfeeding. Infection is most common at delivery or birth. This is influenced by a number of factors, particularly that the higher the viral load of the mother at birth, the higher the risk. At the same time a low CD4 count is also associated with increased risk (Bartlett & Finkbeiner, 2006).

The chances of an HIV-positive woman transmitting the virus to her infant are 30%. According to Evian (cited in Bezuidenhout, 2004) transmission may occur during pregnancy, childbirth and breastfeeding. Many pregnant women who are HIV infected are from lower socio-economic backgrounds and are already suffering from socio-economic hardships. HIV infection and the effects thereof add considerably to this burden.

### **2.3.4 Breastfeeding**

Although breastfeeding is an issue that needs further research and clarification, Goldfarb (1993) states that a baby is exposed to HIV from the mother's blood and from breast milk; in other words, breastfeeding doubles the risk of transmission from the mother to the baby. This mode of transmission is viewed as very important, especially in developing countries. In developed countries, women can easily solve the problem of transmitting HIV infection through breastfeeding by simply avoiding breastfeeding whereas in developing countries the issue is more complex (Bartlett & Finkbeiner, 2006).

Seemingly, there are other modes of HIV transmission than the ones discussed above. Other types of contact, although unlikely to transmit HIV, might do so theoretically. Bartlett and Finkbeiner (2006) highlight that HIV has been found in low numbers in saliva, stool and tears.

After one has been infected with the virus, there are stages that one goes through. HIV/AIDS has various clinical stages that occur over a long period of time, usually from five to 12 years. The following section will discuss the stages that people with HIV/AIDS experience.

## **2.4 STAGES THAT PEOPLE LIVING WITH HIV/AIDS EXPERIENCE**

When an acute infection with HIV takes place, the body has not yet produced antibodies to HIV. Antibodies, produced primarily by certain white blood cells called B lymphocytes, attack substances foreign to the body, including viruses. Usually the body takes several days or weeks to recognise a foreign substance such as a virus, and then it produces antibodies to attack the substance. Six to 10 weeks after HIV has entered the body, antibodies to HIV appear in the blood in sufficient concentration to give a positive test (Bartlett & Finkbeiner, 2006). This process of

appearance of antibodies in the blood is called “seroconversion”. All people with HIV infection develop antibodies against HIV. These antibodies along with other immune system mechanisms reduce the concentration of HIV, but they do not eliminate the virus.

A person who becomes infected with HIV usually goes through various clinical stages that occur over a long period of time, usually 5-12 years (Bezuidenhout, 2004). The following stages occur with patients:

- Asymptomatic stage (a stage of being well with no symptoms of disease).
- Mild disease.
- Severe illness (symptomatic stage).
- Death.

HIV slowly damages the immune system, and the appearance and manifestation of disease is usually related to the degree of immune deficiency (Evian, 1993).

Bezuidenhout (2004) agrees with Evian (1993) about the above stages. In the absence of a CD4 cell count, a lymphocyte count can be useful although it is less specific and less accurate. In the absence of these tests, health care workers may rely on the presence of HIV-related signs and symptoms such as thrush, shingles, Kaposi’s sarcoma, and so forth as indicators of advanced immune deficiency.

It is not yet clear whether every HIV-infected person will progress to developing illness and AIDS. Approximately 80% of HIV-infected people develop AIDS within two years of being infected. It takes about eight years, sometimes even 15-20 years, for HIV-infected people to develop severe immune deficiency and symptomatic disease. Some HIV-infected people may be rapid progressors to immune deficiency and AIDS, others may be slow progressors and a very small and lucky proportion is nonprogressors.

Evian (1993) states that there is an early primary infection that occurs in the first 3–6 months after acquiring HIV infection. This infection is characterised by short seroconversion illness that

causes fever, tiredness, rash, sore throat, muscle and joint pains and some swelling of the lymph glands.

### **2.4.1 Asymptomatic phase (Clinical Stage 1)**

Calling this stage asymptomatic means that there are no symptoms. It is called asymptomatic because after several years of seroconversion, people with HIV infection still feel good and experience no symptoms. People may even be unaware of the HIV infection unless a blood test shows antibodies to HIV (Bartlett & Finkbeiner, 2006).

According to Frans (2008), the first clinical stage occurs when a person's HIV status changes from being HIV negative to being HIV positive. Van Dyk (2005) refers to the first stage as the acute phase of HIV infection. A person's functional level of performance is normal, and few newly infected people associate this illness with having acquired HIV (Anderson, 2005).

Both Bezuidenhout (2004) and Evian (1993) state that in this phase, the HIV-infected person usually experiences a period of good health in which the virus remains clinically "silent" or latent. The phase may last between three and seven years (even up to 10 years). Even though the infection is clinically "silent", the virus is active in the body, usually causing progressing damage to the immune system (Bezuidenhout, 2004).

According to Evian (1993), there are minor HIV-related symptoms and signs that may include weight loss, occasional fevers, chronic swelling of the lymph nodes (they are commonly felt in the neck, in the axilla and below the jaw), often called "persistent generalised lymphadenopathy", skin rashes (such as folliculitis, seborrhoeic dermatitis and chronic itchy skin), fungal nail infections, recurrent oral ulcerations, angular stomatitis, cheilitis, herpes zoster and recurrent upper respiratory tract infections.

### **2.4.2 Mild disease (Clinical Stage 2)**

According to Evian (1993), about 5-8 years after HIV infection, the immune system continues to deteriorate and the person becomes more immune deficient. There are signs and symptoms that

are usually due to overgrowth of some of the body's natural flora, with fungal infection and reactivation of old infections (such as TB and herpes). They are also due to uncontrolled multiplication of HIV itself. Previously this stage was called "AIDS-related complex". Evian (1993) mentions the most common signs and symptoms of this stage. These are oral or vaginal candida infection (thrush), usually persistent and recurrent, hairy leukoplakia on the tongue, recurrent herpes simplex infection (cold sores or genital herpes infection), herpes zoster (shingles), acne-like bacterial skin infections, persistent and unexplained fevers and night sweats, skin rashes, generalised lymphadenopathy or shrinking of previously enlarged lymph nodes, persistent diarrhoea and weight loss (more than 10% of the usual body weight). Reactivation of TB may also be associated with this stage of infection, especially in people from low-income communities where TB is endemic.

This phase usually progresses over 18 months into the fully developed AIDS phase of the disease. AIDS is always associated with severe immune deficiency, usually corresponding to CD4 cell counts below 200 cell/mm<sup>3</sup> and to a low lymphocyte count (Evian, 1993). Immune deficiency allows the development of severe opportunistic infection, some cancers and HIV-related organ damage.

### **2.4.3 Severe illness (Clinical Stage 3)**

This stage is the beginning of major symptoms as the immune system continues to deteriorate (Frans, 2008). As the immune system deteriorates, performance or activity levels drop and the HIV-infected person spends most of his or her day in bed. This stage is characterised by symptoms that last for one month or more (Aggleton, Hart & Davies, 1999).

These symptoms include weight loss greater than 10% of body weight, unexplained chronic diarrhoea that lasts for more than a month, unexplained prolonged fever (intermittent or constant) that lasts for one month, oral candidiasis (thrush), vulvo-vaginal candidiasis (chronic) that lasts for one month or is poorly responsive to therapy, oral hairy leukoplakia (thickening of the dorsal surface of the tongue), pulmonary tuberculosis within the past year and severe bacterial infections, such as pneumonia (World Health Organization, cited in Evian, 1993).

#### **2.4.4 Full manifestation of the disease (Clinical Stage 4)**

This stage is described as the full manifestation of the disease. It includes profound immunosuppressant and severe opportunistic infections such as Kaposi's sarcoma and pulmonary tuberculosis (Temoshok & Baum, cited in Frans, 2008). Due to continuous diarrhoea, nausea and vomiting, which may last weeks or even months, the patient becomes thin. This stage is accompanied by symptoms such as severe oral thrush in the mouth, leading to difficulty in eating and swallowing as the thrush progresses to the oesophagus and trachea; vaginal candidiasis, which may lead to cervical cancer in women; enlarged lymph nodes in two or more sites; pain, numbness or pins and needles in the hands and feet; neurological abnormalities such as memory loss, poor concentration, headaches, confusion, loss of vision and seizures; and streptococcal meningitis (fungal infection in the central nervous system), which presents headache, fever, nausea, vomiting, stiffness of the neck and changes in mental status and seizures. Infection of the brain known as "toxomoplasmosis encephalitis", which causes damage to the brain, also occurs.

Further problems include blindness caused by an inflammation of the retina of the eye, Kaposi's sarcoma (skin cancer), characterised by painless reddish brown or bluish purple swelling on the skin and mucus membrane (normally in the mouth but also in the lungs and gastrointestinal tract) and cancer of the lymph nodes. Tuberculosis is one of the serious opportunistic infections that affect people living with HIV/AIDS (Frans, 2008).

HIV/AIDS illness has been discussed above; the following section will discuss ART.

### **2.5 ANTIRETROVIRAL THERAPY**

Anti-HIV medications help people infected with HIV lead longer, healthier lives. The main goal of the HIV treatment is to reduce the amount of virus in a person's body and prevent destruction of the immune system.

Twenty anti-HIV medications have been approved by the United States of America Food and Drug Administration (FDA) for the treatment of HIV. These medications are supposed to be given in combination, and all of the drugs may cause negative side effects. Since some of these medicines come in combinations, they constitute 26 drugs registered with the FDA (Peltzer, Friend-Preez, Ramlagan, & Fomundam, 2008).

The side effects of the drugs may be stressful to people living with HIV/AIDS who are taking the treatment. As Peltzer et al. (2008) states, there are several adverse reactions or side effects that are common and usually self-limiting, such as headache, nausea, vomiting and rash. These side effects need to be noted and reported because they may persist in some individuals and affect adherence to treatment and the patient's quality of life. Severe rash can be life threatening or fatal. These mild to moderate side effects may also be a sign of something more serious and will require a thorough investigation by a health care professional.

The impact of ART-related adverse effects on the population needs to be constantly monitored and carefully considered. This has been confirmed by several studies in the last decade that show that even in countries with very advanced health systems, medicine morbidity and mortality are one of the major health problems faced by several nations (Peltzer et al., 2008). In countries such as the United States of America, adverse drug reactions (ADRs) are the fifth leading cause of death. ADR-related problems are thought to be far worse in Africa due to financial, infrastructural and human resources challenges than in developed countries (WHO report).

Several factors contribute to the high morbidity and mortality of ADR cases in the management of HIV and AIDS. These factors include the following:

- Inadequately trained health care personnel.
- Lack of training in the prevention and management of ADRs.
- Lack of reporting and trending of ADRs for quality assurance improvement.
- High prevalence of medication errors.
- Adherence challenges to prescribed regimens.
- Lack of continuous quality assurance activities.
- Lack of functional and reliable health care systems such as laboratory services.

ART seeks to boost the immune system that has been weakened by HIV, but it is challenging if health care personnel are not adequately trained and if there is a high prevalence of errors in medication, a lack of adherence and a lack of continuous quality assurance activities. This means that more training in the prevention and management of adverse drug reactions is still needed.

The occurrence of ADRs and other drug-related problems differs among practices and countries. Most drugs that are used in Africa are based on clinical trials that were carried out in other parts of the world. There has been a substantial increase in the number of clinical trials taking place in Africa. The following are several factors that are specific to a country or region that may affect the safety of medicines:

- **Traditional and complementary drugs**

According to the World Health Organization (cited in Peltzer et al., 2008), populations throughout Africa, Asia and Latin America use traditional medicines to help meet their primary health care needs. In several countries, most of these products have not been quantified and there is a growing number of sometimes fatal adverse effects and inadequate information on efficacy. Some of these products are known to have severe and sometimes fatal interactions with other medicines (Peltzer et al., 2008).

- **Training of prescribers and prescribing practices**

Prescribers such as doctors and nurses have various levels of keeping abreast with new drugs and new warnings. These differences may have an impact on patient drug safety and drug safety management.

- **Diet and genetics**

Different diets/foods are also known to affect medicine safety outcomes.

- **Disease patterns**

Concomitant diseases are also known to affect the safety outcomes of various drugs.

- **Drug manufacturing, distributing and storage**

Manufacturing processes and how drugs are subsequently handled may also affect the safety of medicines.

The use of traditional medicine in countries such as Africa, Asia and Latin America often results in adverse drug reactions as these medicines may have bad consequences when interacting with other medicine. Prescribers such as doctors and nurses who may have an impact on patient drug safety and drug safety management must be trained. Some diets or foods may affect the safety outcomes of medicine. The way in which drugs are handled and manufactured may also affect the safety of medicines.

According to highly active antiretroviral therapy (HAART), long-term adherence is a real challenge as nonadherence would result in suboptimal viral suppression, which may lead to treatment failure. However, patients with good drug adherence may also be challenged by either transient (diarrhoea and nausea) or longer-lasting (lipodystrophy, dyslipidaemia and neuropathy) side effects. Some of these side effects, though distressing, can be reversible, for example fatigue, insomnia, diarrhoea, nausea and stomach upset. Physical manifestations vary and typically include fat accumulation on the upper back and neck (buffalo hump) and under the muscles of the abdomen. There may also be lipomass, breast enlargement and peripheral fat wasting in the face, legs, arms and buttocks. Drastic changes in physical appearance often cause patients to be in despair and constant fear of exposure of their HIV status (Peltzer et al., 2008).

HAART has received much international publicity in recent years as it uses combinations of drugs and can inhibit the spread of HIV within a person's body (United States Agency for International Development). The following need to be taken into account when considering HAART in the context of developing countries:

- Many HIV-infected persons cannot tolerate the side effects of the drugs; for them the combination therapy treatments are useless. Only about half of prospective users can tolerate the therapy.
- The drugs have to be taken under the strictest conditions, including time of day and either with meals or on an empty stomach. Even small variations from the prescribed pattern can render the treatment ineffective. Patients also need constant access to sophisticated medical laboratories to track viral counts in the body.
- The costs of these treatments are prohibitively high, around US\$8 000 to \$10 000 per patient per year in a developing country setting and even more in industrialised countries.

Through efforts that have been made it is possible that the costs of these drugs could drop to as low as \$350 per patient per year although the infrastructure costs to support this treatment would still be significant.

The new combination drugs are important according to the Policy Project for Bureau for Africa because for the first time a medical treatment has proven effective against HIV and, this creates hope for the future. But for the moment, even in the most developed countries this experiment is highly expensive with an unknown outcome affecting a minority of HIV-infected individuals. First experimental programmes are just beginning in developing countries.

Long-term treatment of the opportunistic infections that develop due to the weakened immune system is possible. The following is the treatment that is given to people living with HIV/AIDS:

### **2.5.1 Zidovudine (AZT, azidothymidine and Retrovir)**

This drug delays the degenerative effects of the virus (Singhal & Rogers, 2003). Zidovudine is a nucleoside analogue that inhibits HIV reverse transcriptase. According to Fanning (1997), it is recommended for people with AIDS or those who are infected with HIV whose CD4 count is less than 200, as well as individuals with CD4 counts between 200 and 500 with symptoms of HIV infection. Zidovudine comes in 100-mg tablets and was originally prescribed as two tablets every four hours around the clock, providing a total dose of 1 200 mg/day but forcing people to wake up in the night every four hours. These dosages are toxic to bone marrow and almost everybody developed a rather significant disease called megaloblastic anaemia. At these dosages almost everyone becomes megaloblastic but very few become significantly anaemic. A variety of other dosages or regimens, such as 200 mg every eight hours or reduced dosages of 100 mg four times a day or 100 mg three times a day, may be prescribed (Fanning, 1997).

Anaemia associated with zidovudine does not respond to supplemental folate or vitamin B<sub>12</sub> administration, although it is more prevalent in patients who had low pre-treatment levels (Fanning, 1997).

It is still unknown whether the myopathy that is reportedly related to zidovudine is not in fact just a natural consequence of HIV infection. Myopathy is an annoying muscular ache or pain with weakness, which may become debilitating and is associated with elevations of CK enzyme. However, for the patient to discontinue the zidovudine may not improve the symptoms (Fanning, 1997). Patients who take zidovudine are seen at least monthly and have general chemistry and hematologic evaluations monthly at first, then every two months, if stable.

### **2.5.2 Didanosine (ddl, dideoxyinosine and Videx)**

According to Fanning (1997), didanosine works by a mechanism similar to that of zidovudine. It has been used in combination with zidovudine. It produces painful chronic peripheral neuropathies that cause a mild stocking-and-glove pattern of discomfort for almost everyone, enough to preclude its use in 20-30% of individuals. It decreases the absorption of ketoconazole, itraconazole and dapsone and must be given two hours before these drugs. Didanosine precludes the concomitant use of tetracyclines because of aluminium and calcium salts in the buffer (defence system).

### **2.5.3 Zalcitabine (ddc, dideoxycytidine and Hivid)**

This drug is approved, according to Fanning (1997), as a combination therapy with zidovudine when CD4 counts are less than 300. Patients should be monitored carefully for pancreatitis if intravenous pentamidine is administered. Other complications include peripheral neuropathy, rash, fever, stomatitis and oesophageal ulceration.

### **2.5.4 Stavudine (d4T and Zerit)**

This is another HIV reverse transcriptase inhibitor that has some activity against zidovudine-resistant strains. It is approved for treatment of individuals intolerant of other nucleoside analogues, those who have disease progression (clinical or CD4 decline) while on other treatments or those who have received prolonged prior zidovudine therapy (Fanning, 1997).

The major toxicity is dose-related peripheral neuropathy, which occurs in 19-24% of patients with advanced disease and 14% of those with less advanced HIV disease (Fanning, 1997).

### **2.5.5 Lamivudine (3TC and Epivir)**

This drug is an HIV reverse transcriptase inhibitor. When used as monotherapy, it develops rapid resistance. It is approved to be used in combination with zidovudine for patients with advanced HIV disease and for previously untreated patients with a CD4 count not greater than 300. Patients in these categories sustained higher increases of CD4 cell counts on AZT-3TC combination than in comparison monotherapy groups. A dosage of 300 mg is generally accepted although it has major effects of nausea, diarrhoea, anaemia, low white blood cell count and pancreatitis, especially in children on prior nucleoside therapy and with neuropathy.

### **2.5.6 Nevirapine**

This is a non-nucleoside reverse transcriptase inhibitor that is approved for use only in combination with a reverse transcriptase inhibitor and possibly a second agent, such as a protease inhibitor. Nevirapine is characterised by rapid emergence of HIV resistance if used as monotherapy.

### **2.5.7 Saquinavir (Invirase)**

Saquinavir falls in a new class of drugs that inhibit HIV protease activity and are effective against viral strains resistant to nucleoside analogues. It is recommended for use with other antiretrovirals for treatment of patients with advanced disease and no prior zidovudine use. Combination therapy with zidovudine is recommended in naïve patients and with Hivid if previous treatment with zidovudine was administered. Adverse events such as diarrhoea, nausea and abdominal discomfort are generally mild.

### **2.5.8 Ritonavir (Norvir)**

This is an HIV protease inhibitor and is approved in combination with nucleoside analogues or monotherapy for the treatment of HIV when therapy is warranted. Treatment in advanced disease has demonstrated a reduction in mortality and disease progression over six months. In less advanced disease, ritonavir led to sustained increases of CD4 count and decreases in viral load. It should be taken twice daily with meals. The escalation of dose may reduce nausea. The side effects of the drug are gastrointestinal (nausea, diarrhoea, vomiting, anorexia, abdominal pain and taste perversion – with the exception of diarrhoea they are amplified by combination with zidovudine) and neurologic (circumoral and peripheral paresthesias). Numerous serious drug interactions occur, and the drug label should be reviewed or a pharmacist should be consulted when prescribing other medications.

### **2.5.9 Indinavir (Crixivan)**

This is also an HIV protease inhibitor approved on the basis of surrogate endpoints for treatment of HIV infection when ART is warranted. The drug (indinavir) alone or in combination led to sustained decrease in viral RNA load and increased CD4 counts compared to zidovudine monotherapy. Unfavourable events that must be noted are nephrolithiasis, which occurs infrequently and should lead to temporary interruption of treatment, maybe for 1 to 3 days. Adequate hydration is recommended for all patients receiving indinavir. If the patient is using ketoconazole, indinavir dosage should be reduced.

### **2.5.10 Acyclovir**

The use of this drug remains controversial but early studies that were presented in Stockholm in 1988 were correct in that high doses (800 mg five times/day) may augment the anti-HIV action of antiretrovirals. This was suggested in 1992 at the Amsterdam conference although the data were unpublished.

## 2.6 CONCLUSION

The chapter has covered HIV/AIDS as terminal illness, defined the terms HIV and AIDS, discussed what happens in the bodies of people living with HIV/AIDS when they are infected with the virus and their response to the virus, and discussed the key characteristics of HIV/AIDS, indicating that the most affected age group is those 20 to 40 years of age.

Different modes of HIV/AIDS transmission, such as sexual transmission through penetrative intercourse, transmission by blood and transmission from an infected mother to her unborn child across the placenta and possibly through breastfeeding, have been covered.

People living with HIV/AIDS experience different stages, such as the asymptomatic stage, which is Clinical Stage 1, in which there are symptoms of HIV and a person may still live many productive years. This stage is followed by Clinical Stage 2 in which an infected person may have mild disease. Clinical Stage 3 is characterised by severe symptoms as the immune system continues to deteriorate. Finally, Clinical Stage 4, the full manifestation of the disease, follows, culminating in death.

The side effects of the treatment, such as vomiting, nausea, headache and rash, may be stressful to people living with HIV/AIDS. The occurrence of ADRs is related to problems such as laboratory services and countries that practice traditional medicine.

The following chapter will discuss the ecological perspective.

## CHAPTER 3

# THE RELEVANCE OF THE ECOLOGICAL PERSPECTIVE TO PEOPLE LIVING WITH HIV/AIDS

### 3.1 INTRODUCTION

HIV/AIDS is a terminal illness that affects an individual's entire life, at the physical, emotional and relational levels. Health, physical and mental problems represent stress for both infected and affected persons, such as family members and friends. AIDS as terminal illness needs to be addressed with the backing of the ecosystemic approach. The approach applies one of the principles of human ecology and systems theory. It has a multiple-level treatment perspective focused on the interaction between individuals and their environment. People living with HIV/AIDS should be understood by social workers by using the ecological perspective as theoretical framework. According to Meyer (1983), the ecosystems perspective provides a framework from which to view, understand and integrate what is occurring. This perspective is meant to provide a way of integrating knowledge and skills. Practitioners such as social workers focus more clearly on the observed situation, highlighting the implications for action and helping to arrive at interventionist decisions that pertain realistically to the problem situation. This perspective emphasises that treatment takes place in the person-environment context as a whole (O'Concor & Lubin, 1984).

The ecological perspective is a form of general systems theory (GST). Ecologists are systems thinkers concerned with the relations among living entities and between them and aspects of their environment. It also gives an insight into the nature and consequences of such transactions for both human beings and for the physical and social environments in which they function (Germain, 1979).

This chapter will address the second objective of the study, namely to discuss GST and the ecological perspective and to explore the relevance of these theories to the situation of people

living with HIV/AIDS and their families. GST as one form of ecology will be discussed in the following section.

## **3.2 GENERAL SYSTEMS THEORY**

The main purpose of GST is to specify the processes of transactions within and among systems, which is of great importance in the view of the ecological imperative. GST is helpful because it provides concepts that organise data in terms of their relatedness. The theory makes use of concepts such as open systems, in which there is a mutual exchange of energy and information between an organism and the environment, and closed systems, in which organisms exist in isolation from the environment (Klir, cited in Meyer, 1983).

GST is a way of thinking as well as of analysis that accommodates knowledge from many sciences, while the system is defined as a set of elements in interaction. These elements exist within both open and closed systems, but the difference is the transaction with the environment of each system (Bertalanffy, cited in Meyer, 1983).

### **3.2.1 Open systems**

An open system functions according to six basic concepts, namely boundaries, structure, hierarchy, transactional patterns, frame of reference and time. Each concept, as applied to the family, will be discussed below:

- Boundaries cause the family to have a discrete system separate from other families. The degree of boundary determines how permeable these boundaries are or how easily information and energy flow in and out. This determines how open or closed the system is. A family has its own boundaries, and they are represented by the rules that have been set within the family. The boundaries also exist between the generations in the family.
- Structure of the system refers to all sets of elements within the boundaries together with the enduring patterns of their relationships. There may be exchange of energy as the system maintains a recognisable sameness in its structural characteristics. The structure of

the family consists of all the members of the family and the way in which they interact with each other.

- Hierarchy means that systems have subsystems within themselves. There are varying statuses of individual members, which form family subsystems. Family members are therefore not of equal status, meaning that there are hierarchical relationships and that members rank themselves when they have some important issues that need consideration.
- Transactional patterns mean that the family interacts with people outside the family, such as friends or neighbours.
- Frame of reference tells the viewer or observer that the area of interest is a family. This concept establishes the nature of the system.
- The family exists in time. It has a past, present and future. It responds to the demands of time so they may be determined of the future course.

When HIV/AIDS attacks one of the family members, it presents a challenge and the observer can see how the above-mentioned elements operate. If a family member has violated the family rules by being infected, it would be reflected by the negative attitude of family members towards the infected member. Interaction of family members outside their system would be shown when an infected member has to disclose his or her HIV status, as encouraged by the health sector. Some members prefer to disclose their HIV status outside the family.

### **3.3 ECOLOGICAL PERSPECTIVE**

The ecological perspective states that human needs cannot be considered apart from the larger systems in which human beings function. Human beings operate in various institutions that are found in society, such as the family, small groups, the community, the school, the church and social agencies. The meaning of these systems is provided by the social systems theory, which is used by social workers to explain and understand these relationships (Johnson & Yanca, 2010).

Different authors have defined the concept “ecology”. This section will start by discussing the term ecology as viewed by different authors.

### 3.3.1 Ecological concept

Germain and Gitterman (1996) refer to the ecological concept as the biological study of relationships among components of the biotic community. The community that they are referring to includes the physical environment such as terrain, climate and natural disturbances. In social work the term symbolises the interdependence of organism and environment as the profession has a historic commitment to the person-in-environment concept. The focus in ecological thinking is on the reciprocity of person-environment exchanges that influence one another over time.

The ecological perspective looks at human development and functioning, including the health and illness of an individual. There are exchanges between the individual and the social environment, the physical setting and the cultural context. These exchanges provide circles of feedback to the individual and the shape of continuing changes (McKendrick, 1991).

Meyer (1983) refers to ecology as the study of complex reciprocal and adaptive transactions among organisms and between organisms and their environment. The main concerns of ecologists are the linkages among systems and how a change in one system may affect another organism. The first part of the definition highlights the relationship. An individual does not survive alone but there is interaction between an individual and the environment. The second part claims that there are exchanges between a person and the environment and that those changes provide feedback to the individual.

An individual is connected to systems such as the family and the environment; the changes that take place in the environment, whether the physical or the social environment, affect the individual and the family. One needs to adapt to these changes. The linkages in the systems are an area of interest because any change that happens to an organism affects the whole system. For instance, if a person is diagnosed as HIV positive, it affects not only the person but also the family and the environment, whether social or physical.

The ecological process has the following three major variables, according to Handler (cited in Meyer, 1983):

- Arrangement and distribution of the species in relation to time and space.
- The manner in which the energy flows.
- The roles of the species involved.

These variables play a major role in the assessment and intervention activities in which both the social worker and the client participate.

The ecological approach has three systems levels, namely micro-, mid- and macro-level, at which interventions take place. Systems range from small to large systems, including the system of social work profession. These systems will be discussed below.

### **3.4 LEVELS OF INTERVENTION IN GENERALIST PRACTICE**

In social work practice, the generalist approach provides an integrated and multileveled approach to the social work profession. Generalist practitioners acknowledge the relationship between personal and collective issues, prompting them to work with a variety of human systems, for instance societies, communities, neighbourhoods, complex organisations, formal groups, families and individuals, to create changes that maximise human system functioning (Miley, O'Media & Du Bois, 2004).

According to this approach, social workers work directly with clients and available resources and intervene in organisations to enhance the responsiveness of resource systems. They work as advocates of just social policies to ensure the equitable distribution of resources and research in all aspects of social work practice (Miley et al., 2004).

#### **3.4.1 Micro-level systems**

At the micro-level, support for HIV-infected people is expected from the family, friends and partners. The family is seen to provide support to people when they are ill. Due to the associated stigma and possible risk of transmission, HIV can have an impact on choice of partners, availability of support, relationships with children and psychological well-being of family and

friends. The virus raises questions about the construct of what the family of origin comprises of parents, grandparents, spouse, children and relatives as well as friends and partners (Bor & Elford, 1998).

The focus of micro-level systems is on work with individuals, families or small groups (support groups). The family is a social system that nurtures and instructs members both directly and indirectly. It also serves as protection against negative forces in the environment. The aim is to foster changes in personal functioning, in social relationships and in the way in which people interact with social and institutional resources. Social workers draw on their knowledge and skills regarding clinical practice, crisis intervention, family therapy, linkage and referral, and the use of group processes. The target of interaction is other systems, including changes in the social and physical environments to facilitate improvement of an individual or a family's social functioning (Maguire, 1991; Miley et al., 2004).

According to Allen-Maeres and Garvin (2000), the family in the ecological view is the most intimate and influential environment where human development takes place. Changes in the family happen regularly and are structurally arranged in a variety of ways to ensure survival of the family. The family is a unique system with structures, norms, recognisable role formations, patterns of behaviour, communication patterns and ways which relates to the larger society. External events such as sickness, for instance HIV/AIDS, or loss cause the family to enter a crisis state. It is during this time that the family would need quick intervention on the cognitive, affective and task levels, such as attaining basic resources, in order to restore the family to at least a pre-crisis level of functioning (Allen-Maeres & Garvin, 2000).

Uys and Cameron (2003) are of the opinion that if there are no supportive structures, discrimination against people with HIV infection can continue. Van Dyk (cited in Uys & Cameron, 2003) describes support groups as a key intervention for people living with illness. They are places where people can meet on a regular basis to talk about their difficulties or simply to relax and enjoy each other's company. This formal structure of support is offered by people from the professional sector, such as community health workers, nurses, doctors, psychologists, traditional leaders, social workers and HIV/AIDS counsellors.

People living with HIV/AIDS might lose the support of family, friends and community members due to discrimination and stigma. A support group environment is described as safe, confidential, blame free, informative, non-discriminating, respectful, understanding and relevant (Uys & Cameron, 2003).

### **3.4.2 Mid-level systems**

These systems intervene by creating changes in task groups, teams, organisations and the network of service delivery. The locus of change is within organisations and formal groups, including their structures, goals or functions. For an effective change in an organisation, there is a need for an understanding of group dynamics, skills in facilitating decision making and proficiency in organisational planning.

Barker (cited in Kirst-Ashman & Hull, 1993) defines a group as a collection of people brought together by mutual interest. These people are capable of consistent and uniform action. There are different ways to categorise the groups that social workers are frequently involved in. Task groups and treatment groups are examples of such groups. Task groups exist specifically to achieve a certain task or objective. Task groups include groups such as a board of directors, task forces, committees and commissions, legislative bodies, staff meetings, multidisciplinary teams, case conferences and staffings, and social action groups. Treatment groups include groups such as growth groups, remedial groups, educational groups, socialisation groups and mutual-aid groups.

Kirst-Ashman and Hull (1993) list the types of group that may be of assistance at the mid-level. People living with HIV/AIDS fit well into treatment groups. Types of treatment group that are relevant to them are growth, remedial, educational and mutual-aid groups.

- Growth groups are designed to support and encourage individuals. Usually the groups for people living with HIV/AIDS meet once a week. A growth group focuses on helping members to explore what they want from their lives.

- Remedial groups help people living with HIV/AIDS to identify their goals. This is important; for instance, many people may lose hope after they have been diagnosed as HIV infected. They may think that because they are infected, life has come to an end. The focus would be on correcting a perceived intrapersonal problem or learning better problem-solving and coping skills.
- Educational groups may also be helpful to people living with HIV/AIDS. As the name indicates, these groups are designed to provide members with information.
- In mutual-aid groups, people share certain characteristics. The aim is to provide one another with advice, emotional support, information or any other help.

The above-mentioned groups are vital to people living with HIV/AIDS because to be diagnosed with the virus may cause one to feel shocked, angry or fearful or have suicidal thoughts. The groups may be helpful as people with HIV/AIDS can meet to give support and advice to one another and receive education on what is happening in their bodies. The social worker may organise different experts from different fields to give the right information to individuals.

### **3.4.3 Macro-level systems**

Activities at this level go beyond individual interventions but are often based on needs, problems, issues and concerns identified in the course of working one-on-one with clients. Practitioners such as social workers are engaged in organisational, community and policy arenas through macro-level activities (Netting & Burnett, 2004). Social workers address the issues within the system of the social work profession. Professional relationships with social work and interdisciplinary colleagues may be helpful to reorient priorities within the social work profession and to reorganise service delivery (Miley et al., 2004).

There is facilitation of social change through work with neighbourhoods, communities and society. For instance, a social worker can work to achieve social change through the neighbourhood, community planning, locality development, public education and social action (Miley et al., 2004). At this level, social workers may find themselves questioning or sometimes

confronting major social issues and global organisational policies. This is because a social worker is working as an advocate of the clients as sometimes client services are not being provided.

According to the generalist approach, social workers work directly with their clients according to the available resources at all three levels. They advocate for the clients by liaising with institutions such as the family, small groups and organisations. The resource that social workers explore at micro-level is the family because it should offer support to its loved one who is infected with HIV. Small groups at the mid-level are important for an infected person to share his or her experience with other people who are infected and to obtain information. At the macro-level, social workers facilitate social change by working with communities and organisations using the available resources.

### **3.5 ECOLOGICAL VIEW**

According to Meyer (1983), ecologists are interested in the linkages among systems and how a change in one system may affect other organisms connected to the system. The term “ecology” derives from biology. Handler (cited in Meyer, 1983) writes that ecologists are trained to focus on the interfaces among systems, on problems that fall between the cracks of basic sciences. In social work, the unit of attention is the person-in-situation, which is embedded in the person’s total setting or ecological environment (Handler, cited in Meyer, 1983), as was discussed in the previous section.

Ecologists view this environment as nested levels of social organisation that are interconnected through feedback structures and have accommodating relationships. Levels of social organisation vary in complexity with the person as the basic building unit. A person adapts to the demands of each new situation that he or she enters. A person constantly creates restructuring and adapts to the new environment as the environment affects the person (Meyer, 1983). For instance, HIV/AIDS makes many demands on the infected person and the family. People need to adapt to this new situation.

The ecological perspective looks at human development and functioning including health and illness. Those are outcomes of continuous exchanges between the individual and the social environment, meaning the physical setting and the cultural context. Ecological thinking explains more complex phenomena that are encountered in social work phenomena. For instance, in the case of a person infected with HIV, a social worker focuses on how to assist the family to maladaptive living of infected and affected person (Germain & Gitterman, 1996; McKendrick, 1991).

There are three core concepts pertaining to the ecological model that are pertinent to social work practice in health care: adaptedness, stress and coping. These ecological concepts help the social worker to maintain the focus on both the person and the environment (Germain & Gitterman, 1996). Each concept will be discussed below.

### **3.5.1 Adaptedness**

Adaptation is a constant, continual process whereby people must adapt to all changes. Adaptedness exists when the environment provides resources and experiences at the appropriate time and in the appropriate form to ensure people's optimum biological, cognitive, sensory, perceptual, emotional and social development and functioning (Dubos, cited in Germain & Gitterman, 1996; McKendrick, 1991).

The role of the social worker within this conceptualisation is to maintain individualised services for people and to effect a better mutual adaptation between a person and society. In other words, a better fit between need and service and also a better ecological balance between personality and environment are effected. It is the responsibility of the social worker to comprehend how systems work (Meyer, 1983).

As the family grows, there are certain circumstances or changes that the family must adapt to, for instance a member who is infected with HIV. Social work values support the profession's preference for person-environment exchanges that release people's potential for further growth

and promote diverse, supportive environments that release human potential (Germain & Gitterman, 1996).

### **3.5.2 Stress**

Germain and Gitterman (1996) state the difference between the two concepts “stressor” and “stress”. A life stressor occurs when life transitions, events and issues disturb the level of person-environment fit or a prior state of relative adaptedness. Stress refers to both physical and emotional responses to a life stressor that exceeds one’s perceived personal and environmental resources to cope.

When a person fails to adapt, stress arises. Stress represents a poor person-environment fit. Stress arises when the individual makes a conscious or an unconscious appraisal of a discrepancy between a demand (stressor) and the personal and environmental resources for meeting the demand (McKendrick, 1991).

Cassel (cited in Meyer, 1983) is also of the opinion that the conception of stress is the manifestation of a lack of fit. This lack of fit derives from the observation that the disease (HIV/AIDS) can occur through factors that disturb the balance between the ever-present disease agent and the host that is harbouring or exposed to it. Psychosocial stressors disturb this homeostatic balance and represent lack of fit.

An illness such as HIV/AIDS can represent perceived demands that exceed resources for its therapy, causing stress. ART is provided by government institutions but it can be difficult for HIV-infected people to access it. In provinces such as the Eastern Cape where the conditions of the roads are poor, there is a high rate of unemployment and people are stricken by poverty, one would find it stressful to obtain treatment.

The stress of a disease such as HIV/AIDS may lead to stress in other areas of life, especially in family, work and community roles, interfering with recovery or with the management of the health problem. Stress affects the ability of an individual to cope. It is necessary for a social

worker working with people living with HIV/AIDS to maintain a dual focus on the individual and the various components of the environment (McKendrick, 1991).

According to Germain and Gitterman (1996), the stress caused by life transitions and traumatic life events is related to the dimensions of the stressor and its meaning to the person. HIV/AIDS is a sickness that causes transition in one's life, and it is a traumatic life event as it causes stressors such as isolation and stigmatisation. The dimensions of the stressor include the following:

- The stressor affects the impact of the disease. If a person has negative feelings towards HIV/AIDS, for instance, there would be chronic conflict and disruption of family relationships.
- A person may be ambivalent about the stressor and its resolution. The family may understand that their loved one is infected, but that may cause the family to be stressed. The stress would be caused by a feeling that the infected member may die, and that could make the family unable to cope.
- An anticipated or unexpected critical event can affect the amount of time available for a person to prepare for the life change.
- Lack of control over a stressor has a profound effect. A diagnosis of a child with HIV infection evokes severe anxiety in the parents. Parents may become hopeless about helping their child.
- The point on the life course at which the stressor strikes is a significant factor in the degree of stress experienced.
- Desired or expected events may not happen, such as a prospective marriage that may be cancelled due to HIV status.

Transitions that take place in people's lives are the main cause of stress. HIV seems to cause a great deal of stress, not only for the infected person but also for those affected. Although the family may understand the situation, it is still stressful and they may be unable to cope because there is always a feeling that the infected member may die.

### 3.5.3 Coping

Coping does the same as adaptedness and expresses person-environment relationships. The effectiveness of coping depends on both personal and environmental resources. Coping responses are evoked by the subjective experience of stress. When special adaptations are called upon to deal with stressful demands, coping may either be effective or ineffective. If coping is effective, it results in stress being reduced or eliminated. If it is ineffective, it results in intensified or unrelieved stress (Germain & Gitterman, cited in McKendrick, 1991). Coping activities fulfil two functions: to modify the stressful person-environment fit and to regulate emotional responses produced by stress (McKendrick, 1990).

Social workers in a health care facility should be aware of patient and family efforts to cope with regard to the abovementioned functions to ensure that appropriate support is provided. In order to maximise these coping efforts by recognising stress-provoking situations in the person-environment fit, health care environments should be humanised, assisting in problem solving and supporting positive adaptation (Rosenberg, cited in McKendrick, 1991).

Coulton (cited in McKendrick, 1991) mentions the following dimensions of the person-environment fit as important to the social worker in health care:

- The physical dimension: Disabled people such as HIV-positive persons differ in their ability to negotiate physical obstacles.
- The psychosocial dimension: Discrepancies in role performance and role expectations, changes in relationships and a need for knowledge and understanding are found.
- The behavioural dimension: Constraints are placed on the individual's ability to meet behavioural demands; for instance, a chronically ill person may be unable to perform well at work.
- The economic dimension: A disabled person will have a greater need for economic resources because earning capacity may be reduced.

Social workers working with people living with HIV/AIDS attempt to maintain congruence between the individual and the environment.

### 3.6 ECO-STRUCTURAL SOLUTION

According to Lewis (1991), one of the efforts of an ecological solution to an ecological problem such as HIV/AIDS is the eco-structural approach. This approach attempts to bring together families and the community with therapists and their agencies. The ecological network or the therapeutic system includes the therapist (social worker). Therapists working with the chronically ill must deal with the following:

- The immediacy and concreteness of their problems.
- The structural organisation of the family.
- The values of the family and its community.
- The community resources of the family.
- The links between family and community.

The eco-structural model attempts to work with all family members and community institutions that are part of the problem and potentially part of the solution. Therapists according to this approach view their clients as part of their community. For instance, a social worker dealing with people living with HIV/AIDS focuses not only on the client but on the family and the community as well (Lewis, 1991).

According to the eco-structural model, the therapist addresses the issue with all that are involved by viewing how they relate to the problem. This gives the therapist an opportunity to study how they relate to the problem. The therapist intervenes actively in the interactions between the family members and the community. Intervention takes place when a social worker or therapist tries to link the client with available resources in the community such as support groups or organisations that work specifically with people living with HIV/AIDS. The therapist intervenes with an aim of achieving change, hoping that the right results will be achieved.

When a family is experiencing a crisis such as HIV/AIDS, it may also need to start therapy with an extraordinarily intensive effort. According to the eco-structural perspective, there is an intensive effort with a complex and under-organised ecosystem of family and community, which demands a team of at least two therapies (Lewis, 1991).

A therapeutic team requires active institutional backing from an agency or clinic. Institutions such as clinics are vital to people infected with HIV as they are of great assistance in providing information. Firstly, the agency will integrate organically with the structure of the community. Secondly, it will find ways of operating from within the community that will mobilise resources for therapists' work with families. Thirdly, it may seek out an already existing agency or help to organise a forum where community and local government representatives can meet to plan and talk (Lewis, 1991).

A community resource such as an agency can also organise multifamily groups receiving service from the agency. These groups can be sources of daily support for the member families. They also become part of the network through which therapists do their work.

### **3.7 CONCLUSION**

This chapter has covered a description of the ecological perspective. The chapter started by giving an overview of GST as one form of ecology. The term ecology and its background were discussed. The chapter gave an overview of how an individual operates when she or he comes across life transitions. This chapter also covered other systems in the life of an individual such as the family and the community because they are part of a person's support system.

The ecological perspective is very useful for social workers or therapists who work with people living with HIV/AIDS. The perspective fits well into social workers' mission (Germain & Gitterman, 1990). The approach contains three core concepts pertinent to social work practice: adaptedness, stress and coping. These concepts help the social worker to focus on how a person fits into the environment. The eco-structural approach is viewed as a solution to ecological problems such as HIV/AIDS because it attempts to bring together the family, therapists, the community and organisations. This is important because an epidemic such as HIV needs teamwork; the battle cannot be fought by an individual or family alone.

The following chapter will present the psychosocial stressors experienced by people living with HIV/AIDS.

## **CHAPTER 4**

### **CONSEQUENCES OF LIVING WITH HIV/AIDS: STRESSORS EXPERIENCED BY INFECTED AND AFFECTED PEOPLE**

#### **4.1 INTRODUCTION**

HIV/AIDS is a chronic illness that causes stress for infected and affected people. Infected people are those who are living with HIV/AIDS, and affected people may be family members and friends. Infected and affected people experience different stressors. HIV has an impact on the infected person's choice of partners, availability of support and relationships with family and friends (Bor & Elford, 1998).

HIV/AIDS is a chronic illness that is viewed as stressful, and this stress starts with infected people. The previous chapter showed different reactions of people when they learn that they are infected with HIV. Certain factors have been identified as stressors for people living with HIV/AIDS and those who are affected by HIV/AIDS, meaning family members and friends. The purpose of this chapter is to discuss the stressors experienced by persons infected with HIV and affected by HIV/AIDS. The chapter seeks to cover the impact that HIV/AIDS has on both infected and affected persons. Different types of stressor will be discussed.

The following section will define and discuss the stress concept in social and psychological perspectives.

#### **4.2 PSYCHOSOCIAL STRESS: ORIGIN OF THE CONCEPT**

The concept is familiar nowadays, but the literature shows that researchers and theorists are still struggling for a clear definition of stress (Hobfoll, 1988). The reason is that stress is a complicated phenomenon that involves all the systems of the psyche – cognitive, emotional and unconscious – and it occurs in all social systems – interpersonal, intrapersonal, small group, large group and societal. It involves people's loves, hates, closest attachments, competition, achievement, indeed every matter that humans are involved in.

Hobfoll (1988) explains that the concept “stress” is derived from the natural sciences, physics and materials science. It is argued that human beings, like metals, may be subjected to stressors because a stressor is an outside force that is exerted on the metal. The metal will return to its original shape only if the stressors are low in magnitude. Sometimes when the stressors are too great, the metal becomes overburdened, resulting in a change in the molecular structure. Although metal does not break, stressors may take the form of a briefly exerted extreme force and the damage may occur very slowly. This is obviously the same for human beings.

Schafer (1992) accepts that definitions of stress are neither right nor wrong. He defines stress as an arousal of mind and body in response to demands made upon them, and defines a stressor as any demand on mind or body. The fact that there are definitions shows that stress is ever present and is a universal feature of life.

The following section will look at stressors experienced by people living with HIV/AIDS, meaning infected people.

### **4.3 PSYCHOSOCIAL STRESSORS EXPERIENCED BY PEOPLE LIVING WITH HIV/AIDS**

When one is diagnosed with HIV infection, one is always profoundly shocked, and this may be followed by feelings of anger, fear and despair as well as thoughts of suicide (UNAIDS, 2000). These feelings will always be there, even if a person had some suspicion that he or she might test positive due to the symptoms of the virus that he or she had experienced.

Van Dyk (cited in Uys & Cameron, 2003) adds to these psychosocial stressors loss, grief, guilt, denial, anxiety, depression, socio-economic issues and AIDS dementia. Each of these psychosocial stressors will be discussed below.

### **4.3.1 Fear**

Infected people may have many fears. They may fear being stigmatised, isolated and rejected. They are uncertain of the future, meaning there is uncertainty about who will look after them should they become disabled.

Van Dyk (2005) states that HIV-infected people are afraid of dying alone in pain. Many of them have experienced the pain of death of loved ones and friends who have already died due to AIDS, so they know and fear what awaits them. Lack of knowledge regarding HIV and how its problems can be handled may be the cause of fear.

#### ***4.3.1.1 Fear of stigma***

“The stigma of HIV/AIDS is especially pronounced because many of the sufferers, at least in the early stages of the epidemic, were homosexuals, injecting drug users, or the poor. Stigma is prejudice and discrimination against people who are regarded and treated in a negative way” (Singhal & Rogers, 2003).

The above statement defines stigma and discrimination together with its background. According to Singhal and Rogers (2003), the AIDS stigma is a barrier to humane treatment of infected individuals throughout the world. In many countries, for instance India, HIV-positive people are stereotyped as having behaved immorally and are punished accordingly. South Africa is not an exception to this, as highlighted by Singhal and Rogers (2003). South Africa is one of the countries where HIV-positive people have been fired by their employers, evicted by their landlords and assassinated. The civil rights of HIV-positive people are routinely violated in every nation. People living with HIV/AIDS have become empowered to fight stigma, to lobby for making antiretrovirals more widely available and to seek policies that benefit them (Singhal & Rogers, 2003).

Singhal and Rogers (2003) refer to an international conference on HIV/AIDS and African children held at Ohio University in April 2002. One of the participants in the conference shared the plight of a Grade 4 student in Soweto School, Johannesburg. An orphan who lived with her

grandmother, she asked the teacher tearfully why her friends laughed at her, and she was wondering whether it was because her parents had died due to HIV/AIDS. It is distressing that society stigmatises AIDS victims and those affected by it, including orphaned children.

The problem of stigma occurs in every nation and among the members of every culture, and the stigmatisation of people living with HIV/AIDS is a severe problem, according to Singhal and Rogers (2003). There is no illness in the history of humankind that has generated such a strong stigma, except leprosy in biblical times. The problem of stigma has interfered with the gathering of accurate information about the extent of infection. It is a barrier to prevention programmes, it inhibits effective testing and counselling, and in many cases it interferes with effective treatment and care.

The reason for the stigma is that in most countries, HIV infection spreads through networks of gay men, commercial sex workers and/or injecting drug users. These groups have already been heavily stigmatised by society. This prejudice is carried over and strengthened when such individuals become identified as carriers of HIV.

Herek and Glunt (cited in Singhal & Rogers, 2003) state that this “double stigma” of AIDS stems from the identification of AIDS with already stigmatised groups. The following are the reasons for the stigma:

- The gay community in the United States of America was blamed for starting the epidemic. Those who contract AIDS through behaviour that is controllable, such as commercial sex workers or drug addicts sharing needles, are perceived as “guilty” and assigned more blame, receive less sympathy and face more anger than those who are perceived as victims, such as individuals who were infected through blood transfusions. People living with HIV/AIDS also tend to be of lower socio-economic status. The epidemic thus came to be associated with people who were already perceived negatively, creating and strengthening the stigma of HIV/AIDS. The AIDS-related stigma would have been far less severe if the epidemic had been identified with upper-class, heterosexual individuals, haemophiliacs or children.

- In many nations homophobia is an important reason for the stigma. In many countries, for instance India, intercourse between men is illegal.
- Another important reason for the stigma is ignorance of the means of transmission. There is a common fear that by associating with people living with HIV/AIDS, individuals might put themselves at risk. Such fear of infection may be based on an irrational reaction even among people who know and understand the actual means of transmission. The dangerous nature of HIV/AIDS undoubtedly raises the level of fear.

The abovementioned state clearly that HIV/AIDS is associated with people who are gay, sex workers, drug addicts and people with lower socio-economic status and that there is still much ignorance of how the virus is transmitted. People may fear being infected because they do not have information on how a person becomes infected.

According to Parker & Aggleton, cited in Kalichman, 2009, women who reported suicidal thoughts reported more HIV-related symptoms, more perceived stigma, greater depressive mood, more emotional distress and less family cohesion than did women who reported no suicidal thoughts. It is proposed that family life has a moderating effect on suicide, presumably because of the greater social integration that occurs within a family context. In view of the aforementioned, social integration, including integration into the family, is a protective factor with respect to suicide.

In addition, people living with HIV/AIDS are stigmatised in the community. In a study by Feldman (2008) that was conducted amongst Zambian students in 1992-1994, respondents expressed themselves about how they felt about persons with AIDS. In their responses, some suggested that people living with HIV/AIDS should be detained in hospitals because if they were out of hospital, they would misbehave. Some students stated that people with AIDS should not be allowed to marry. One student went further by saying that since there was not yet a cure for AIDS, people with AIDS should be killed to stop or reduce the spread of AIDS. People with HIV are mistrusted by others because they are scared of being infected with the virus. According to Feldman (2008), one student stated that there were some unscrupulous people with HIV who would do anything to infect others. The student stated that people with HIV would go to the

extent of putting the virus in ice blocks. Some people think that those who are living with HIV/AIDS are punished by God. The youth in this study believed that AIDS was a punishment from God.

AIDS stigmas create significant barriers to HIV prevention, testing and care and become internalised by people living with HIV/AIDS. This has been discovered by Kalichman (2009). This may be one of the reasons why people living with HIV/AIDS may not go to places that offer help. Some are afraid even to attend the support groups for people living with HIV/AIDS, and they can even be afraid to go to the clinics.

“AIDS stigmas are pervasive and can interfere with HIV/AIDS prevention, testing and treatment” (Parker & Aggleton, cited in Kalichman, 2009). Kalichman states that there is evidence that AIDS stigmas can become internalised among individuals living with HIV/AIDS and that internalised AIDS stigmas adversely affect physical and mental health.

People living with HIV/AIDS are ashamed of their HIV status. Kalichman (2009) reported that this was found among South African HIV-positive men and women. The findings suggest that internalised AIDS stigmas may play a crucial role in the emotional well-being or distress experienced by many people with HIV/AIDS across cultures.

Goffman's model (cited in Kalichman, 2009) identifies three dimensions of stigma, all of which are characteristic of HIV/AIDS: blemished personal character, stained social identity and physical deformity or defects. HIV-related stigma is closely associated with a number of negative consequences, including being labelled and stereotyped, experiencing separation from others, experiencing loss of social status and being the recipient of actual discrimination and prejudice. Those who live with this virus can be the target of such experiences from loved ones such as family members and friends, as well as from co-workers, health care providers, employers and others. Government public policies can also contribute to the stigmatisation of HIV/AIDS.

HIV stigma can be harmful to those who live with the HIV virus in many ways. The harm can include a loss of self-esteem as well as deteriorated social interactions with others. Additional negative correlates of stigmatisation for HIV-positive people are depression, anxiety, loneliness, suicidal ideation and poor treatment adherence. There are a number of negative consequences associated with stigma, and stigma itself is usually composed of factors such as social rejection, financial insecurity, internalised shame and social isolation. Other potential negative correlates of HIV-related stigma are maladaptive forms of alcohol consumption. When alcohol screeners were used, it was found that people experiencing HIV-related stigma reported more alcohol use.

HIV-positive African-American women reported a fear of societal stigma related to HIV from a variety of sources, including family members, fellow church congregants, health care professionals and the broader community. What is needed by this group of people is both social and psychological support, as Simoni and Cooperman (2000) put it.

“Social support correlated with better psychological and physical functioning among HIV positive women, suggesting this low-cost and highly beneficial resource should be tapped for this group. Women with HIV might benefit from the support of other women if informal peer support groups were offered” (Simoni & Cooperman, 2000).

Stigma is viewed as an obstacle to achieving healthy sexual relationships. The study conducted by Bor and Elford (1998) shows different reactions when people receive the news that they are infected. Some felt that they did not want to have anything to do with sex, they blamed themselves, for the first to three weeks after the notification they were totally revolted by sex and they felt unattractive after the notification, which was worse if they showed signs of illness.

Partners' fear of being infected, their desire to protect each other and uncertainty about the future are other factors that are obstacles to achieving a healthy sexual relationship. The infected partner fears infecting the other and vice versa. The infected partner feels guilty and does not want to forgive him- or herself. Although couples have such fears, research has discovered that they do not express these fears to each other (Bor & Elford, 1998).

#### ***4.3.1.2 Fear of isolation***

When the disease progresses, it may eventually necessitate some form of physical isolation and this is made worse by the accompanying social isolation (Webb & Tossel, 1991). This is caused by ignorance and widespread media-based scaremongering and the fact that society has shown little tolerance of people who are seen in some way to have contributed to their condition through their own lifestyles. Instead of society showing empathy, blame is all too easily apportioned to people living with HIV/AIDS. As a result, people with HIV infection are reluctant to seek help and they attempt to keep their condition secret for fear of rejection and further damage to their self-image.

According to Henshel (1990), people living with HIV/AIDS are subjected to ostracism, meaning that they are isolated and come across vile abuse and a paranoid level of fear and loathing. Ostracism may be caused by the crisis that a person experiences when he or she is diagnosed with HIV; as Bezuidenhout (1998) states, being diagnosed with HIV or becoming sick from the condition often causes a crisis for the person and his or her immediate family or partner. It is during this time when family and partner relationships may break down that people may think of committing suicide, and many hurtful things may be said or done in this time of crisis (Bezuidenhout, 2004).

Fanning (1997) highlights women living with HIV as the group most likely not to have a natural support group and state that they often feel isolated in their disease. As a result, some women who have tested HIV positive are at risk of physical or verbal violence from their partners after diagnosis.

#### ***4.3.1.3 Fear of uncertain future (sexual relationships)***

Couples could view life as foreshortened, have different perceptions of the future and experience difficulties in expressing their own thoughts and understanding the perspective on their partners (Bartlett & Finkbeiner, 2006).

People's feelings about sex are different. Some people regard sex as joy, comfort, distraction, release, intimacy, reassurance or bonding. For some, positive feelings about sex depend on feeling healthy, enjoying life, liking themselves, trusting others, feeling relaxed and having the freedom to be spontaneous. HIV infection changes much of this. Everyone knows that the virus occurs in great numbers in blood and semen and in smaller numbers in vaginal fluid. While making love, people infected with HIV can unthinkingly transmit the virus. They link making love with becoming infected. They feel guilty about having sex. They mourn the loss of the sexual freedom that they once enjoyed. They feel violated by the virus because the virus invaded their bodies when they were doing something enjoyable and natural. These feelings come when people intensely need the closeness that sexual intimacy brings (Bartlett & Finkbeiner, 2006).

Safer sex, which means the use of condoms, is encouraged, but the problem is that this is no fun. It seems to detract from spontaneity and the feeling of relaxation and sometimes seems to add a barrier of constraint or artificiality between partners (Bartlett & Finkbeiner, 2006).

People living with HIV/AIDS may start to reengage in romantic relationships and sexual activities when their physical condition becomes stable. Bartlett and Finkbeiner (2006) are of the opinion, however, that some people not in long-term sexual relationships fear that if they meet someone they like, they will have to begin the relationship by telling that person something unpleasant to hear. Perhaps they will be rejected, or the prospective partner may spread information about the diagnosis.

#### **4.3.2 Loss**

HIV-infected people often feel that they have lost everything that is important to them. They experience loss of control, loss of autonomy, loss of their ambitions and their physical attractiveness, loss of sexual relationships, loss of status and respect in the community, loss of financial stability and loss of independence. They fear the loss of their jobs, their friends and their family. They mourn the loss of life itself. They feel that they have lost their privacy and their control over their lives once they begin to need constant care. They lose confidence in

themselves and suffer a loss of self-esteem and self-worth, occasioned by the rejection of people who are important to them (Van Dyk, 2005).

### **4.3.3 Grief**

People living with HIV grieve all the above losses and also experience anticipatory grief in respect of their own death. They grieve for friends and loved ones who have died due to AIDS and also for those who must stay behind and try to cope with life without them (Van Dyk, 2005).

### **4.3.4 Guilt**

Infected people express guilt and self-reproach for having contracted HIV and also for having possibly infected others. The feeling of guilt may be associated with being homosexual or with sexuality in general. Disclosing their HIV-positive status to family and friends may mean that they have to tell them for the first time about their sexual preferences or sexual behaviour. Infected people also experience guilt about the sadness that their illness will inflict on their loved ones and families, especially children (Van Dyk, 2005).

### **4.3.5 Denial**

Denial is an important defence mechanism that can temporarily reduce stress, and most infected people go through it. Denial can be viewed as being destructive, however, if it causes destructive behaviour such as refusing appropriate medical care or continued indulgence in unrestrained high-risk behaviour (Van Dyk, 2005).

### **4.3.6 Anger**

The following was said by a person living with HIV in Mthatha, in a study conducted by the Human Sciences Research Council in 2007: “The anger of being HIV positive doesn’t end.” HIV-infected people are often angry at themselves and angry at the world in general and the fact that there is no cure for AIDS and that the future is so uncertain (Uys & Cameron, 2003).

### **4.3.7 Anxiety**

Chronic uncertainty associated with the progress of HIV infection often worsens feelings of anxiety, and the risk of infecting others can also change lifestyles radically. People infected with HIV often experience anxiety because of the prognosis of the illness, the risk of infection with other diseases and the risk of infecting loved ones (Van Dyk, 2005).

### **4.3.8 Low self-esteem**

The self-esteem of HIV-infected people is often severely threatened. Being rejected by friends, colleagues and loved ones can cause loss of confidence and loss of a person's sense of social identity, leading to feelings of reduced self-worth. The inability to continue in a career or to participate in social, sexual and loving relationships also diminishes the infected person's self-esteem. Loss of strength and body control contributes even more to a lowering of self-esteem (Van Dyk, 2005).

### **4.3.9 Depression**

HIV-infected people often suffer from depression due to multiple losses that they experience in their lives. They have lost many things in life and blame themselves for that. Sue (cited in Van Dyk, 2005) categorises the symptoms of depression as follows:

- **Affective symptoms:** Depressed mood that is characterised by feelings of sadness, unhappiness, worthlessness, anxiety and apathy is the most striking symptom of depression.
- **Cognitive symptoms:** In this category patients report feelings of futility, emptiness and hopelessness. They have pessimistic beliefs about the future. They find it difficult to cope with daily life because of a loss of motivation, interest and energy. Other common problems among depressed people are suicidal thoughts, guilt, negative thinking and concentration problems.
- **Behavioural symptoms:** Lack of energy is the most common behavioural symptom of depression, together with other symptoms such as neglect of personal appearance, crying, agitation, social withdrawal, slow or reduced speech and passivity. Depressed people are

often dull, have mask-like facial expressions, move slowly and do not initiate new activities.

- Physiological symptoms: Loss of appetite and weight, although some experience an increased appetite and gain weight, sleep disturbance, insomnia, nightmares, aversion to or dislike of sexual activities, disrupted menstrual cycle in women and constipation are common symptoms.

In order for the condition to be diagnosed as major depressive disorder, symptoms of depression should be present for at least two weeks.

#### **4.3.10 Suicidal thinking**

Anger that is directed inwards manifests itself as self-blame, self-destructive behaviour or suicidal impulses or intention. The suicide rate among HIV-positive people is higher than in the general population. One may opt for suicide because one wants to avoid pain and discomfort, lessen the shame and grief of loved ones and try to obtain a measure of control over one's illness. Suicide may be either active or passive. Active suicide occurs when a person deliberately injures him- or herself, resulting in death, and passive suicide is committed when a person disregards the onset of possibly fatal complications of HIV infection or disease (Van Dyk, 2005).

#### **4.3.11 Socio-economic losses**

HIV-infected individuals face the loss of their job and income, discrimination, social stigma, relationship changes and changing requirements for sexual expression, financial problems and inability to afford expensive drugs or lifesaving treatment (Van Dyk, 2005).

#### **4.3.12 AIDS dementia**

AIDS dementia complex is an important symptom experienced by the AIDS patient. Family and friends may describe a sense that the patient has "changed" in ways that are subtle but important. Family and friends may feel that the patient is less interested in things that he or she used to have a great interest in and is maybe less talkative and less "sharp", meaning less intelligent. Some patients complain about slow thinking and difficulty in completing and carrying out tasks. They

may report balance and coordination problems. Behavioural changes such as social withdrawal and slowness of speech and movement may also be observed (Van Dyk, 2005).

#### **4.3.13 Loss of support of each other**

It is reported that couples in which one of the partners is infected with HIV do not communicate with each other to address their fears. Bor and Elford (1998) view this avoidance as a barrier to maintaining a safe sex life. HIV-seronegative partners often feel that their emotional needs are less valid as they do not want to express their sadness and fears because they do not want to burden seropositive partners.

It is clear that when a person is diagnosed with being infected with HIV, he or she becomes stressed. People living with HIV/AIDS become stressed in different ways. They are shocked when they receive the news. The shock is followed by many feelings. They feel angry with themselves or others, they fear death, they fear the uncertainty of the future and they fear being stigmatised by their families, loved ones, friends and community. Other stressors such as depression, anxiety, denial and suicidal thinking also come into play because these people live in fear most of the time. Their anger is always there. People living with HIV/AIDS seem to live with these stressors for the rest of their lives.

### **4.4 PSYCHOSOCIAL STRESSORS EXPERIENCED BY PEOPLE AFFECTED BY HIV/AIDS**

HIV causes stress not only for a person who is infected with it but also for those who are close to the infected person, namely family and friends (affected people). The problems of coping with the illness are compounded by the stigma of AIDS. People living with HIV/AIDS and their families may experience rejection by friends, loss of jobs and harassment. Disclosure may be a concern for families affected by HIV/AIDS as they may face difficulty in seeking support (Hays et al., cited in Pequegnat & Szapocznik, 2000). It may not be easy for the family to obtain help from others because they may have to disclose the status of significant others if they want relevant help.

#### **4.4.1 Family affected by HIV/AIDS**

Each individual receives an identity from his or her family. The family is the social network from which one derives an identity and with whom one has strong psychological bonds. Family has different meanings for different people because its members are not always related by blood or through law. It is in the family where one receives protection, socialisation, physical care, support and love. Each family member plays some role that is incorporated into everyday family function (Falvo, 1999).

Chronic illness such as HIV/AIDS has an emotional and economic impact on the family as well as on the individual. Family reactions to chronic illness may be similar to the reaction experienced by the individual, such as shock, denial, anger, guilt, anxiety and depression (Falvo, 1999). Minkoff, DeHovitz & Duerr (1994) are also of the opinion that the demands of chronic illness extend well beyond the infected individual. Familial bonds are tested during all the stages of illness of a family member.

Kennedy et al. (cited in Bor & Elford, 1998) are also of the opinion that caring for a chronically ill person is generally viewed as a stressful task. Chronic distress is associated with caregiving and has been linked to negative psychological and immunological changes in carers.

According to Falvo (1999), the family of the HIV-infected person must make adaptations, adjustments and role changes, both as a unit and as individual family members. The way in which the family reacts or adapts to the situation can have a major impact on the infected individual's subsequent adjustment. There are specific issues that affect a family when a member becomes disabled (HIV/AIDS may lead to disability). The family may grieve and lose related or normal family functioning or the functioning of the individual, the family may have a strong desire to function as normal family again, the members of the family may increasingly need to become more involved with health professionals and service agencies, and they may need to be assertive in order to obtain the necessary services.

Moos and Tsu (cited in Minkoff et al., 1994) identify seven major adaptive tasks for individuals and families adjusting to critical illness:

- Adjusting to pain and incapacitation.
- Dealing with hospital environments and special treatment procedures.
- Developing adequate relationships with professional staff.
- Preserving a reasonable emotional balance.
- Maintaining a satisfactory self-image.
- Preserving relationships with family and friends.
- Preparing for an uncertain future.

As the family grows, there are some adaptations that the members need to make, such as have been mentioned above. Family members need to adjust to the pain of their loved ones, establish new relationships with professional staff and deal with new environments, such as a hospital. It is also the family's responsibility to preserve family and friendly relationships as well as preparing each other for the future that they are uncertain of.

Wortman and Dunkel-Schetter (cited in Minkoff et al., 1994) provide a theoretical analysis and review of interpersonal relationships for victims of life-threatening disease. Family responses to a patient can be demonstrated in two ways:

- By their feelings about the patient and the specific illness.
- By their beliefs about appropriate behaviours to display when in the presence of the ill person.

When feelings about the illness are extremely negative yet beliefs that a cheerful countenance is required are held, inconsistencies in behaviours are inevitable, which means that they have to be expected.

The tendencies of HIV/AIDS-affected families are as follows:

- To physically avoid patient.
- To conduct shallow communication with the patient.
- To give ambiguous feedback to the patient.

These responses leave patients feeling neglected, confused and alone within their own family (Minkoff et al., 1994).

Like individuals, families have differing resources, depending on life circumstances, previous experiences and personalities involved. Individual family members may be asked for assistance such as providing not only emotional support but also physical care, supervision, transportation or a variety of other services necessitated by the individual's condition. Family members' goals and plans may be altered by the changes in roles or financial circumstances caused by chronic illness or disability. These changes may put emotional strain on the family, discussed in the following section.

#### ***4.4.1.1 Emotional strain***

Family members may experience emotional strain due to the amount of care and attention required by the individual with an illness or disability. That strain may result in feelings of resentment, antagonism and frustration. Role change and ambiguity with regard to new roles may make it necessary to redefine family relationships as new and unaccustomed duties and responsibilities come to the fore (Falvo, 1999). It has been mentioned above that infected and affected people suffer from almost the same stressors.

The AIDS stigma will be discussed in the following section as one of the stressors that the family undergoes when a member is infected with HIV.

#### ***4.4.1.2 Stigma***

The situation is further complicated in the case of HIV/AIDS because of stigmatisation associated with the disease and the fact that family members may be forced to cope with issues of infidelity or drug use previously unbeknown to them. The most severe social impact of HIV/AIDS is on family life. The stigma that is associated with the disease often makes disclosure of a family member's positive HIV status traumatic for both the individual concerned and the other members of the family. The infected person always needs a great deal of care,

which can place an intolerable burden on the family, particularly since caring for a person living with HIV/AIDS may put the caregiver at risk of becoming infected (Bezuidenhout, 2004).

#### ***4.4.1.3 Multiple health care and psychological problems***

Families affected by HIV/AIDS face multiple health care and psychosocial problems. Problems that they talk about include complex medical management and caregiving issues, disruption of family roles and routines, and concerns about the family's future as the illness progresses. The illness trajectory or route and treatment efficacy are unpredictable, making it impossible to anticipate what problems families will confront and when (Pequegnat & Szapocznik, 2000).

Bezuidenhout (2004) states that the most severe social impact of HIV/AIDS is on family life. The stigma that is associated with the disease often causes disclosure of a family member's HIV-positive status to be traumatic for both the infected individual and the other members of the family. The infected person always needs a great deal of care, which can place an intolerable burden on the family, particularly since caring for a person living with HIV/AIDS may put the caregiver at risk of becoming infected.

Families of people living with HIV/AIDS, including their spouses or partners, often experience great concerns, worries and a sense of being burdened after learning of the HIV-positive diagnosis of their loved ones. It can be difficult for them to solicit or request social support and seek empathy from their social network or other family members. Caregivers most of the time are spouses or partners, and they may experience burnout in the course of taking care of their loved ones.

The following discussion will look at specific family members such as children affected by HIV.

#### **4.4.2 Children affected by HIV/AIDS**

HIV/AIDS, just like any other chronic illness, challenges dominant conceptualisations of childhood, specifically the notion of children as dependent, passive and non-productive

(Aggleton et al., 1999). There is a need to understand children's experiences in families living with HIV/AIDS. In many families affected by HIV/AIDS, children end up being caretakers.

Aggleton et al. (1999) state that in African countries, the role of caring is different from that in other countries because of a family structure of extended families. AIDS orphans within the extended family receive care and support from family members. In countries like the United Kingdom it is different. There is a complicated and varied response due to the diversity and differences among various African communities and their reactions to the AIDS epidemic. In African refugee families, children affected by HIV/AIDS are often unaware of the cause of illness in the family. This happens because HIV-positive parents are in a dilemma about disclosing their status in the family.

Newton and Becker (cited in Aggleton et al., 1999) noted that children caring for families affected by HIV/AIDS suffer from "courtesy stigma". The caring also poses a threat to children to lose their childhood because it affects their psychosocial development as a result of exclusion, isolation and interference with education. In African children, it has been discovered that loss of childhood is compounded by language barriers, which can lead to a "problem in a vacuum". This results in difficulty for children to express the stress that they are going through as a result of their caregiving roles and HIV/AIDS in the family.

Affected children often miss school, and doing homework and participating in after-school activities are affected as a result of their caregiving. Caregiving can lead to lateness at school, poor attendance and poor performance (Newton & Becker, cited in Aggleton et al., 1999). Children face future disruptions through death of siblings, parents or other family members and sometimes orphanhood.

Children affected by HIV/AIDS are vulnerable due to a lack of a loving family environment. It is in the family that they should receive the support, nurturing and guidance that would help them to cope with life's challenges and fulfil their needs (Van Dyk, 2005).

Kluckow (cited in Van Dyk, 2005) identified the following challenges that children affected by HIV/AIDS face due to parents' illness and death:

- **Role changes:** The role of being a child changes into that of caregiver as children have to care for their parents, and older siblings become parents to younger siblings. The result of this change, which is the loss of childhood, has serious implications for normal childhood development.
- **Isolation from family and peer group:** Most children affected by HIV/AIDS drop out of school due to financial problems or the new responsibility of caregiving. They are robbed of an influence that is crucial to their ongoing identity development. Loss of learning has grave implications for their development. These children have no time to play or spend leisure time with their friends of the same age because of the responsibility they have for their parents. They are often further traumatised by stigmatisation and rejection, which leaves them more vulnerable and isolated.
- **Traumatic exposure to suffering, sickness and death:** The trauma of nursing and watching parents die is facing these children as they are not emotionally equipped to deal with the roles that they have to take on.
- **Physical poverty and deprivation:** The epidemic affects the economy of the family. Illness of the parents leads to loss of income and changes in the family economy. Relatives may grab the deceased parents' property and leave children without shelter.
- **Multiple losses, emotional trauma and complicated grief:** Children start to grieve before the death of a parent. After death they may experience multiple losses as they are caught up in inheritance squabbles and experience sibling separation and relocation, which might result in separation anxiety. This may cause a child to have little time to grieve for the parent, and that may result in complicated grief.

With regard to the above, Van Dyk (2005) explains Max-Neef's theory that if the needs of a child are not fulfilled, the child lives in poverty, which has the terrible consequence of generating pathologies. If children affected by HIV/AIDS do not receive psychosocial support to fulfil their basic needs, they may suffer long-term social and emotional impairment and may be at risk for developing depression, anxiety, suicidal thinking, behavioural disorders (which may result in

school dropout, delinquency, substance abuse, promiscuity, prostitution, criminal behaviour and violence), learning disorders, developmental delay and psychosomatic illness.

## **4.5 CONCLUSION**

The chapter has covered the psychosocial stressors experienced by people infected with HIV and affected by HIV/AIDS. People living with HIV/AIDS experience stress as they see their loved ones die and know that they will undergo the same process. They also experience stress because of the fear of stigma, isolation and uncertainty of the future. They grieve for their loved ones and friends who have died due to AIDS and have to learn to cope without those who have passed away. They feel guilty because of being infected and possibly infecting others. Denial is an important defence mechanism that most people infected with HIV experience because it is viewed as lowering stress. Anger is not uncommon in infected people as they are angry with themselves for being infected and angry almost with the whole world. Depression is also one of the common stressors, and isolation and rejection by friends cause low self-esteem. Socio-economic stressors arise as an infected person may lose his or her job due to illness and there may be no source of income in the family. Some may lose their memory due to the illness, called "AIDS dementia".

A family has strong psychological bonds and gives one an identity. Chronic illness such as HIV/AIDS has an economic and emotional impact on the individual as well as the family. Family members' reaction to the diagnosis of HIV infection may be the same as that of the infected person, namely anger, shock, and so forth. Family members may find themselves having to adapt to as well as having to be capacitated for the situation, having to adapt to a new environment, such as professional staff and a hospital environment, having to balance their emotions, having to preserve family relations as well as having to prepare for an uncertain future.

A chronic illness such as HIV/AIDS is challenging to children because it affects their childhood heavily. Children become the caregivers of their parents when the parents become sick; the terrible part is that they may not even be aware of the sickness as parents may fear to disclose to the children.

It has been noted that children who care for affected families suffer from “courtesy stigma”. Their psychosocial development is affected due to isolation from other children as they nurse sick family members. They also often miss school, which leads to poor attendance and performance and affects them in doing their homework.

These children face many disruptions in their lives, such as losing parents, siblings, family members or friends. They face many challenges such as isolation from peers and family, the trauma of the sickness and death of a family member, poverty because the parent was the source of income, role changes from child to caregiver and grieving over their multiple losses.

The following chapter will present the data gathered during the empirical investigation in order to explore the social support networks of people living with HIV/AIDS. Social workers working with people living with HIV/AIDS were interviewed to explore whether people living with HIV/AIDS received enough support.

## **CHAPTER 5**

### **EXPLORATION OF THE SUPPORT NEEDED BY PEOPLE LIVING WITH HIV/AIDS**

#### **5.1 INTRODUCTION**

The previous chapters explored HIV/AIDS as terminal illness within the context of the ecological perspective together with the stressors experienced by infected and affected people. These chapters established an understanding of the stressors that people living with HIV/AIDS experience and the nature of the support that they need.

As has been discussed in the previous chapters, HIV is the cause of terminal illness and HIV/AIDS is different from other chronic illnesses because it is experienced as a psychological burden. The disease affects a person's life both physically and emotionally and also affects a person's relations with others (Hobfoll, 1996).

The ecological perspective provides a framework for the assessment of the needs of people living with HIV/AIDS. This perspective stresses that assessment is about the person-environment context as a whole (Germain, 1979). The assessment shows how stress experienced at each level of the ecological perspective has an impact on the lives of people living with HIV/AIDS, and it also shows the support that is provided at each of these levels.

This chapter will present and discuss the results of the empirical study. The findings of the empirical study will be verified with literature and will be explored in terms of the support needed by people living with HIV/AIDS. The results will be presented in tabular or narrative form. The aim of the chapter is to verify the findings of the literature review and to explore the support needed when a person is living with a disease such as HIV/AIDS.

## **5.2 DELIMITATION OF THE INVESTIGATION**

The participants in the study were social workers working in child and family welfare organisations and a hospice in Stellenbosch, Somerset West and Helderberg in the Western Cape Province. The sample for the study consisted of 20 participants who were selected by means of a purposive sampling method. As has been already mentioned, this method is based on the judgment of the researcher and is composed of elements that contain the most characteristic, representative or typical attributes of the population (Bless & Higson-Smith, 2005; Singleton et al., cited in De Vos et al., 2005). According to De Vos et al. (2005), this method ensures that participants who are selected meet the criteria for inclusion and hence can fulfil the purpose of the study.

## **5.3 EMPIRICAL STUDY**

This study is classified as an exploratory and descriptive study (Babbie & Mouton, 2001). The aim of the study was to explore the views of social workers on the support needed by people living with HIV/AIDS, to describe whether the support that they received was enough, and if this support was not enough, to explain what other kind of support they needed.

Data were collected by means of a semistructured questionnaire, which consisted of both open- and closed-ended questions. This method of data collection is helpful in exploratory research as it allows a list of possible answers and solutions (Bless & Higson-Smith, 2005). The researcher administered the questionnaire to each participant who completed the questionnaire on his or her own in the presence of the researcher. This was helpful as participants could ask questions that they did not understand or needed clarity on.

The researcher conducted a pilot study with the aim to check whether the questionnaire was suitable for use during the main study. During the pilot study, some questions were raised by participants. These queries were taken into consideration, and the questions were adjusted.

## 5.4 RESULTS OF THE EMPIRICAL INVESTIGATION

The following are the findings of the empirical study. The findings will be discussed in the same sequence as the questions in the questionnaire.

### 5.4.1 Profile of respondents

Participants were asked to indicate the number of years that they had been practising as social workers, the size of their case load, the number of cases of people living with HIV/AIDS and the number of years that they had been working with people living with HIV/AIDS. These details allowed the profile of the participants to be created. Table 5.1 summarises the profile of the participants, and each aspect will be discussed separately.

**Table 5.1: Identifying details of participants**

	<b>No of years in social work practice</b>	<b>Size of case load</b>	<b>No of cases of people living with HIV/AIDS</b>	<b>No of years working with people living with HIV/AIDS</b>
1	2 yrs, 4 months	51–100	2	0
2	21 yrs	51–100	± 10	± 15 yrs
3	4 yrs	51–100	20	4 yrs
4	2 yrs, 2 months	51–100	2	2 yrs, 2 months
5	1 yr, 10 months	51–100	3	1 yr, 2 months
6	13 yrs	51–100	20	7 months
7	24 yrs	21–50	9	1 yr
8	10 yrs	51–100	28	3 yrs
9	25 yrs	101–150	2	20
10	16 yrs	21–50	Don't know	8 yrs
11	4 yrs	51–100	10	4 yrs
12	10 yrs	200+	± 10	± 7 yrs
13	3 yrs	151–199	3	3 yrs

	No of years in social work practice	Size of case load	No of cases of people living with HIV/AIDS	No of years working with people living with HIV/AIDS
14.	8 months	51–100	2	0
15	1 yr, 6 months	151–199	10	1 yr, 6 months
16	11 yrs	101–150	8	11 yrs
17	4 yrs	51–100	0	3 yrs
18	4 yrs	1–20	0	2 yrs
19	3 yrs	151–199	70	3 yrs
20	5 yrs	151–199	0	4 yrs

**N=20**

Table 5.1 shows that two participants indicated that they did not work with people living with HIV/AIDS; they however do. They do come across cases where HIV/AIDS is diagnosed, but that is not the problem that is dealt with for the purpose of intervention.

#### ***5.4.1.1 Number of years in social work practice***

The participants were asked to indicate the number of their years in social work practice. This was to measure the experience they had in the field. The number of years in social work practice of participants was less than two to four years; five to 10 years and ranged from two to 25 years.

#### ***5.4.1.2 Size of case load***

The participants were asked to indicate the size of their case loads and to state the number of their cases of people living with HIV/AIDS. Participants were also asked to indicate the number of years that they had been working with people living with HIV/AIDS. This was to determine whether the participants would be able to give a perspective on the needs of people living with HIV/AIDS.

Ten (50%) of the participants indicated that their case load ranged from 51 to 100, four (20%) indicated that their case load ranged from 151 to 199, two (10%) indicated that their case load

ranged from 101 to 150, two (10%) indicated that their case load ranged from 21 to 50, one (5%) had a case load of 200+ and one (5%) indicated that the case load ranged from 21 to 50.

The findings show that the participants were in a position to discuss the needs of people living with HIV/AIDS as the participants did work with infected people for the purpose of intervention.

## 5.5 STRESS AND STRESSORS EXPERIENCED BY PEOPLE LIVING WITH HIV/AIDS

Participants were asked to choose from a list which stressors they thought were experienced by people living with HIV/AIDS and to motivate their choices.

**Table 5.2: Stressors experienced by people living with HIV/AIDS**

Stressor	Frequency	Percentage
Fear	18	90%
Loss	5	25%
Guilt	9	45%
Denial	11	55%
Anxiety	7	35%
Low self-esteem	5	25%
Depression	11	55%
Suicidal thinking	6	30%
Socio-economic issues	11	55%
AIDS dementia	1	5%

**N=20\***

\*Participants gave more than one response, and the responses will be discussed in the sections below.

### 5.5.1 Fear

Table 5.2 shows that 18 (90%) of the participants indicated that fear was a stressor that most people living with HIV/AIDS experienced. The findings of this study stated that these fears were related to death: “*Fear of their future, fear of death.*”

The above findings are supported by Van Dyk (2005) who states that people living with HIV/AIDS fear dying in pain and alone. The reason is that some have experienced the death of their loved ones and friends and think that death is waiting for them also. One of the reasons for this fear is that they are uncertain of the future. In addition, lack of knowledge about the disease may be one of the causes of fear as infected people are uncertain how to handle the problems of the sickness. Stigma and discrimination that are attached to the disease often lead to ill-treatment by others as people who live with the disease are treated in a negative way and may even lose their jobs (Singhal & Rogers, 2003).

### **5.5.2 Denial**

Eleven (55%) of the participants indicated that denial was a stressor experienced by most people living with HIV/AIDS. The motivation of participants that this stressor was experienced most was expressed by one participant: *“Clients often do not believe they have the illness, and will thus not continue treatment, or even start treatment once diagnosis has been made.”* According to the participants, people living with HIV/AIDS feel that they are judged if others know their status and therefore they go through denial. Denial may be destructive if one refuses to take treatment due to denial of the disease (Van Dyk, 2005).

### **5.5.3 Depression**

Eleven (55%) of the participants indicated that depression was a stressor experienced by people living with HIV/AIDS. *“The depression that people living with HIV/AIDS have is cognitive depression.”* According to Van Dyk (2005), in this category of depression, people report hopelessness, pessimistic beliefs about the future and lack of motivation, interest and energy.

### **5.5.4 Socio-economic issues**

Eleven (55%) of the participants indicated that most people infected with HIV experienced stress because of socio-economic issues. It is because of the stigma that is attached to the disease that HIV-positive people lose their jobs or are discriminated against in their workplace. This will lead

to financial problems, and people may not be able to afford treatment. The family also experiences loss of income because some members are sick and cannot work anymore. Most HIV-positive people become sick, and as a result they cannot work anymore. They would then need assistance such as social grants.

### **5.5.5 Guilt**

Nine (45%) of the participants indicated that most people infected with HIV experienced guilt caused by careless sexual behaviour and multiple sexual partners: *“Guilt is more if the person is in a relationship and had an extramarital affair, sickness and knowing that they are dying leads to guilt feelings for people living with HIV/AIDS.”*

Results have shown that guilt is caused by carelessness and multiple sexual partners. The guilt is more if the person is in a relationship and has had an affair. Sickness and knowing that they are dying lead to guilt feelings for people living with HIV/AIDS.

The findings correspond with the view of Van Dyk (2005) who states that the feeling of guilt of HIV-positive people is generally associated with sexuality. Disclosing their HIV-positive status to the family will mean telling them about their sexual behaviour. Infected people feel guilty because they contracted HIV or even because they infected others.

### **5.5.6 Anxiety**

Seven (35%) of the participants indicated anxiety as one of the stressors most experienced by people living with HIV/AIDS. Participants did not motivate their answers with regard to this stressor although they indicated that people infected with HIV did suffer from anxiety.

### **5.5.7 Loss**

Five (25%) of the participants indicated that people living with HIV/AIDS experienced loss. One participant stated, *“Loss of life that they could have had is something that really depresses the clients I work with.”*

This statement corresponds with the view of Van Dyk (2005) who states that HIV-infected people often feel that they have lost everything that is important to them, such as control, anatomy, ambitions, physical attractiveness and status and respect from their communities.

### **5.5.8 Suicidal thinking**

Six (30%) of the participants indicated that most people living with HIV/AIDS experienced suicidal thinking, but they did not motivate their answers. These findings correspond with the opinion of Van Dyk (2005) who states that the suicide rate is higher among people living with HIV/AIDS than in the general population. This is because one may opt for suicide because one wants to avoid pain and discomfort.

### **5.5.9 Low self-esteem**

Van Dyk (2005) states that the self-esteem of people living with HIV/AIDS is severely threatened and that rejection by friends and loved ones can cause loss of confidence. Five (25%) of the participants indicated that most people living with HIV/AIDS experienced low self-esteem.

### **5.5.10 AIDS dementia**

One (5%) of the participants indicated that most infected people experienced AIDS dementia, but the participant did not motivate her answer. Van Dyk (2005) states that AIDS dementia is an important challenge that is experienced by AIDS patients.

## **5.6 SUPPORT THAT PEOPLE LIVING WITH HIV/AIDS NEED**

When one is diagnosed with HIV infection, one is always profoundly shocked. The shock will likely be followed by feelings of anger, fear and despair and by suicidal thoughts (UNAIDS, 2000). This statement shows that an infected person needs support.

### 5.6.1 Provision of support

Participants were asked whether people living with the disease received the support that they needed, and participants were asked to motivate their answers.

**Table 5.3: Support provided to people living with HIV/AIDS**

	YES		NO		YES and NO	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
<b>Support that people living with HIV/AIDS receive</b>						
<b>Receiving support</b>	12	60	7	35	1	5

**N=20**

Table 5.3 shows that 12 (60%) of the participants agreed that people living with HIV/AIDS received the support that they needed, seven (35%) stated that people living with HIV/AIDS did not receive the necessary support and one (5%) said that people living with HIV/AIDS did receive the support that they needed whereas at the same time they did not.

#### 5.6.1.1 Positive responses

Twelve (60%) of the participants indicated that people living with HIV/AIDS did receive the support that they needed from friends, family, support groups, health care systems and churches. One participant said, “*Some disclose to family and they get support from family. Support from the clinic to get their ARVS. Support in community – support groups in some areas where they share their loss, fears and situations.*”

This response is supported by Miley et al. (2004) who state that people living with HIV/AIDS receive support offered by organisations such as clinics and churches in addition to support from their family.

### 5.6.1.2 *Negative responses*

Seven (35%) of the participants stated that people living with HIV/AIDS did not receive the support that they needed and motivated their responses in the following way:

- Gap in the counselling process

*“There appears to be a gap in the counselling process, when results are received individuals are very often unaware of the support services available to them.”*

- No support from the family and community

*“People living with HIV/AIDS are always not supported by the family and the community.”*

*“They need support from their families but support is not there.”*

*“They do not get the support from their family members whereas they need support from their family members, however there are people in the community who make it their mission to reach out and support HIV positive people.”*

*“People living with HIV/AIDS are judged by their communities for getting the virus, they do not get support from their families because sometimes families are not educated with proper information to deal with this virus.”*

- Financial constraints

*“People are faced with financial constraints when they get sick while they are waiting for the grant.”*

The above comments from the participants show that infected people do not receive the necessary support from their families. This view is supported by Falvo (1999) who states that the family also experiences an emotional strain when a family member is diagnosed with HIV. This strain may result in resentment, antagonism and frustration.

### 5.6.1.3 *Conflicting responses*

One (5%) of the participants stated that people living with HIV/AIDS did get the support that they needed, but at the same time she stated that they did not receive support. The participant ticked both “yes” and “no” to this question. The following is the comment of the participant:

*“Most supportive services are easily accessible, but due to the occurrence of fear, guilt and embarrassment, the sufferers stigmatise themselves. Stigmatisation is also projected onto sufferers by their inherent communities.”*

The above narrative shows that supportive services are accessible easily but that feelings of fear, guilt and embarrassment cause HIV-positive people to stigmatise themselves. The findings correspond with those of Kalichman (2009) who is of the opinion that people living with HIV/AIDS may not go to places that offer help; some are afraid even to attend support groups and go to clinics.

## 5.7 LEVELS OF SUPPORT

It was investigated whether people living with HIV/AIDS did receive support at the micro-, mid- and macro-level. The support provided at the different levels will be discussed below.

### 5.7.1 Support at micro-level

The findings with regard to support provided at the micro-level are presented in the table below.

**Table 5.4: People from whom people living with HIV/AIDS receive support**

<b>People that give the most support</b>	<b>Frequency</b>	<b>%</b>
Family	12	60
Friends	5	25
Partner/spouse	5	25
Support group	14	70

**N=20\***

\*Participants gave more than one response.

From the above it is evident that 12 (60%) of the participants indicated that people living with HIV/AIDS received support from the family, five (25%) indicated that infected people received support from friends, five (25%) indicated that infected people received support from their partners or spouses and 14 (70%) indicated that infected people received support from a support groups.

These findings correspond with the literature in which it is stated that people living with HIV/AIDS receive support at the micro-level from family, friends and support groups because when a person is infected with HIV, the family and friends are expected to give the person the necessary support (Bor & Elford, 1998).

#### ***5.7.1.1 Type of support provided at micro-level, mid-level and macro-level***

According to the ecological approach, there are three levels of intervention: micro-, mid- and macro-level. The micro-level system refers to families, individuals or small groups. Mid-level support intervenes by creating changes in task groups, teams, organisations and the network of service delivery. At the macro-level, activities go beyond individual interventions but are often based on needs, issues, problems and concerns.

Participants were asked about the type of support that people living with HIV/AIDS received from people at the micro-, mid- and macro-level.

**Table 5.5: Type of support at micro-level**

	<b>Frequency</b>	<b>Percentage</b>
<b>Physical</b>	12	60%
<b>Emotional</b>	16	80%
<b>Financial</b>	6	30%

**N=20\***

\*Participants gave more than one answer

The findings in the above table show that according to 16 or 80% of the participants, people living with HIV/AIDS receive emotional support more than any other type of support. Physical support is the second most common type of support that they receive, as indicated by 12 (60%) of the participants, and financial support is the least common type of support received, as reported by six (30%) of the participants.

### **(a) Physical support**

The kind of physical support that was mentioned by the participants will be discussed below.

#### **(i) Family support**

Participants stated different views regarding who provided physical support. Some participants experienced that family members took care of their members when they became sick:

*“Families take care of them when they are ill.”*

*“Most of the clients do not take care of themselves but if they are really weak the families step in.”*

It was also mentioned that family did supply basic needs such as food and transport:

*“They get transport and food.”*

*“They need to get the treatment and support from the family and to be taken to hospital or clinic.”*

Two (10%) of the participants indicated that people living with HIV/AIDS needed to receive support from the family in order to be adherent in their treatment.

One participant said, *“If a family member is very sick and cannot go to hospital, the other members will find a way to take him or her there.”*

#### **(ii) Medical support**

One participant claimed that treatment for HIV-positive people was available but that support was insufficient.

*“The ARV’s and medications are available.”*

*“Medication such as antiretroviral treatment is available but medical facilities are insufficient.”*

Some participants believed that although medical facilities were available, they overburdened the public health system.

*“They are depending on public health system which is often over burdened.”*

*“They get transport and food.”*

However, some participants were of the opinion that people living with HIV/AIDS were still in need of medical support and that those who cared for them needed to be educated.

*“Home based carers, clinic and other people take physical care of HIV positive people. The support is not enough because people are not well educated to help these people.”*

The above responses with regard to medical facilities show that ART is available but that medical facilities are insufficient. This may overburden the public health system. Support for HIV-infected people is not enough as people are not educated sufficiently.

No literature corresponds with the above findings.

## **(b) Emotional support**

Participants indicated that people living with HIV/AIDS received emotional support in a support group and from other sources.

### **(i) Support groups**

The findings of this study show that support groups play a role in supporting people living with HIV/AIDS. According to the participants, a support group provides a platform for its members to express their feelings.

*“Some patients feel they can’t share a lot with family members and prefer a support group.”*

*“People in the support group share mostly the same emotion.”*

*“Debriefing emotional feelings with individuals enable them to disembark from clouding negative and selfless thoughts.”*

The above findings of this study correspond with the view of Uys and Cameron (2003) that small groups, such as support groups, are important for HIV-infected people to share their experiences with other infected people. A support group provides a safe environment and is non-discriminatory, blame free and informative and fulfils a vital function as the infected person might lose the support of family members, friends and the community.

#### **(ii) Other sources**

A source of emotional support other than support groups is the counselling service that is available to people living with HIV/AIDS. The following comments were made by the participants:

*“Counselling is available.”*

The support provided by the counselling service is the following:

*“Empowerment to overcome fear.”*

*“Comfort and motivation.”*

*“Through hugs.”*

The above findings do not correspond with the literature review.

#### **(c) Financial support**

According to Table 5.5, six (30%) of the participants indicated that HIV-infected people received financial support at the micro-level. Participants indicated that financial support was not really available but that sometimes social workers assisted infected people to apply for a disability grant.

**(i) Need for financial support**

It is indicated in the findings of this study that infected people need ongoing financial support as they need medical attention but that financial support is not really available.

*“It is not really available in the community.”*

*“They are normally in financial distress because of lost income.”*

*“Most people come from poor background, so family can’t really support them financially.”*

*“People living with HIV/AIDS have a special diet, need regular medical attention etc, sometimes they don’t have the finances for above mentioned things.”*

These findings correspond with literature (Van Dyk, 2005) that indicates that people living with HIV/AIDS suffer socio-economic losses because they are stigmatised, leading to loss of jobs. They have financial problems and may be unable to pay for expensive drugs for life-saving treatment.

**(ii) Social grants and food parcels**

The findings of this study show that people living with HIV/AIDS are assisted by support groups and by social workers to apply for social grants and to receive food parcels. Participants explained as follows:

*“Depending on their CD4 count they can’t receive a grant.”*

*“It is a problem when they don’t qualify for social assistance.”*

*“The support group does not provide financially, but they do support in grant application.”*

*“Giving them a grant to support their needs.”*

*“Grants and food parcels.”*

The above findings correlate with the views of Miley et al. (2004) who state that social workers work directly with clients and available resources and intervene with organisations to enhance the responsiveness of resource systems. They work as advocates for just social policies to ensure the equitable distribution of resources, in all aspects of social work practice.

**(d) Other kinds of support needed**

Participants were asked whether there were other kinds of support at the micro-, mid- and macro-level that were needed by people living with HIV/AIDS.

**(i) No other kind of support needed**

Seven (35%) of the participants indicated that no other kind of support was needed by people living with HIV/AIDS. One participant stated that people living with HIV/AIDS did receive the support that they needed:

*“In my opinion the clients do get support, but in some cases the clients don’t take the support of the family.”*

Two of the participants indicated this type of support as not applicable to people living with HIV/AIDS: “N/A.”

Four of the participants did not respond to this question. The answer to the question was left blank.

**(ii) Care for children**

One of the participants indicated that people living with HIV/AIDS wanted to see that their children were well cared for:

*“To see that their children are well cared for before they die, if somehow a trust can be started, I don’t know just an idea.”*

**(iii) Support from family**

Four (20%) of the participants indicated that people living with HIV/AIDS needed more support from family members:

*“They receive support from the group, but they need more support from close family members and community members.”*

Two (10%) of the participants indicated that people living with HIV/AIDS needed support from the family in order to be adherent in their treatment:

*“Family support is vital.”*

#### **(iv) Spiritual support**

According to the findings of this study, people living with HIV/AIDS are comfortable with their religious leaders and in church.

*“They find more comfort in church with religious leaders.”*

#### **(v) Education of community members**

According to the findings of this study, people living with HIV/AIDS receive support but need more support from family and community members through educating them about the virus because lack of education leads to stigmatisation of people living with HIV/AIDS. One participant said,

*“Community members are ignorant about HIV/AIDS and stigmatise people infected with the virus. Educating the community about ‘life’/living with the virus will help that already infected.”*

The stigmatisation of those living with HIV/AIDS that is mentioned in this study corresponds with that described in the existing literature. Singhal and Rogers (2003) state that people living with HIV/AIDS, including their families and children, are stigmatised in society.

### **5.7.2 Support at mid-level**

At the mid-level of the human ecosystem, people living with HIV/AIDS receive support from treatment groups. Kirst-Ashman and Hull (1993) list the types of treatment group that are relevant to people living with HIV/AIDS, namely growth, remedial, education and mutual-aid groups. These groups are designed for people living with HIV/AIDS to support and encourage one another. The findings of this study show that 14 (70%) of the participants stated that infected people did receive support from a treatment group.

### 5.7.2.1 *Support treatment groups*

Participants were asked to indicate whether they agreed, disagreed or strongly agreed with the statement, “People living with HIV/AIDS fit well into treatment groups.”

**Table 5.6: Treatment groups**

<b>People living with HIV/AIDS and treatment groups</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>No response</b>
People living with HIV/AIDS fit into treatment groups	1 (5%)	17 (85%)	1 (5%)	1 (5%)

**N=20**

Table 5.6 shows that 17 (85%) of the respondents agreed that people living with HIV/AIDS fitted well into treatment groups, one (5%) strongly agreed, one (5%) disagreed and one (5%) did not respond to the question.

The findings of this study correspond with the view of Kirst-Ashman and Hull (1993) that people living with HIV/AIDS fit well into treatment groups. These groups may be helpful as people with a common sickness meet to give support and advice to one another.

### 5.7.2.2 *Type of group that people living with HIV/AIDS need most*

Participants were asked to indicate the type of group that people living with HIV/AIDS needed most and were asked to motivate their answers.

**Table 5.7: Groups that people living with HIV/AIDS need most**

<b>Group</b>	<b>Frequency</b>	<b>Percentage</b>
Growth	0	0%
Remedial	0	0%
Educational	5	25%
Mutual aid	9	45%

**N=20**

Table 5.6 shows that five (25%) of the participants said that an educational group was the group that people living with HIV/AIDS fitted into best and that nine (45%) participants were of the opinion that mutual-aid groups were the groups most needed by people living with HIV/AIDS. No responses were made with regard to growth and remedial groups.

**(a) Educational groups**

Five (25%) of the respondents indicated that people living with HIV/AIDS needed educational groups most. They were asked to motivate their answers. The following were their motivations:

**(i) Lack of knowledge**

Participants made comments such as the following:

*“An educational group will stimulate people infected to take action in their own communities to stop the spread of the virus and they can also live their own lives to demonstrate healthy living with the virus.”*

**(ii) Need for education**

Participants made comments such as the following:

*“We still have people living with HIV/AIDS who refuse to take their treatment. Some of them don't really know the long term effects of doing so.”*

*“Some people are not aware of the impact that the illness may have on their lifestyle.”*

*“Our people need to be educated correctly to understand HIV.”*

*“People need to be educated first to be able to understand and supported by what the outcome of their status might be.”*

*“People need to be educated how to deal with HIV/AIDS and people should be taught how to give support to such a person living with this disease.”*

*“People hear about HIV/AIDS daily, but don't know the real effect and treatment about it and sometimes don't know what or how to deal with it.”*

The above responses indicate that people living with HIV/AIDS still need information about the disease, and the findings correspond with the views of Kirst-Ashman and Hull (1993) who state that educational groups are designed specifically to provide members with information.

Some participants indicated that infected people needed to be educated about their sickness as some refused to take their treatment and did not know the long-term effects of that. As the name of these groups indicate, they are helpful as they are designed to provide group members with information (Kirst-Ashman & Hull, 1993).

### **(b) Mutual-aid groups**

Nine (45%) of the participants indicated that people living with HIV/AIDS needed mutual-aid groups. To motivate their answers, participants stated the following aspects:

#### **(i) Sharing similar needs**

Participants made comments such as the following:

*“I would think a support group, but I am not sure, I only have experience of support groups, and in my experience it does incorporate elements of the other types of groups.”*

*“There is very often more than enough education and information provided on diagnosis, however the support thereafter dwindles and this is where support and mutual aid groups would be important, as they have individuals in similar situations as themselves as support, and possibly, motivation for treatment and a future.”*

*“When diagnosed, they are afraid of the unknown and mostly need to know that they are not alone.”*

*“They need to know other people also suffer from AIDS so they can support each other emotionally.”*

*“You need all the support (mutual) from friends, family and spouses.”*

Kirst-Ashman and Hull (1993) are of the opinion that in mutual-aid and support groups people share certain experiences. The aim of these groups is for the members to provide one another with advice, emotional support and information. When motivating their responses about this type

of group for people living with HIV/AIDS, participants stated the importance of support. According to the participants, people living with HIV/IDS need all the mutual support they can get from friends, family and spouses. If people living with HIV/AIDS know each other, it gives them the chance to know that there are others who live with the disease and they can support one another emotionally.

### 5.7.3 Support at macro-level

At the macro-level, people living with HIV/AIDS receive support through the programmes offered by the clinic, such as basic health care, counselling and ART. They receive assistance from social workers at nongovernmental organisations, and churches also offer support to people living with HIV/AIDS. Assistance by social workers is described by Miley et al. (2004) as a social worker being an advocate for the client and a facilitator of social change.

Participants were asked whether they disagreed, agreed or strongly agreed with the following statement: “Practitioners such as social workers are engaged in organisational, community and policy arenas through macro-level activities.”

**Table 5.8: Engagement of social workers in organisational, community and policy arenas through macro-level activities**

Engagement of social workers	Disagree		Agree		No response			
	F	%	F	%	F	%		
	1	5	17	85	0	0	2	10

**N=20**

One (5%) of the participants disagreed that social workers were engaged in organisational, community and policy arenas through macro-level activities. Seventeen (85%) of the participants agreed that social workers were engaged in organisational, community and policy arenas through macro-level activities. Two (10%) of the participants did not indicate whether they disagreed, agreed or strongly agreed. The results of most (17 or 85%) of the participants correspond with

the view of Netting and Burnett (2004) who state that social workers address the issues through services within the system of the social work profession.

### ***5.7.3.1 Social workers' experience in being confronted by major issues and policies with regard to HIV/AIDS***

Participants were asked to indicate whether in their experience as social workers they had ever been confronted by major issues and policies with regard to HIV/AIDS on behalf of their clients. Their responses are shown in Table 5.7 below.

**Table 5.9: Confrontation with regard to HIV/AIDS**

<b>Social workers' experience</b>	<b>Yes</b>		<b>No</b>	
	<b>Frequency</b>	<b>%</b>	<b>Frequency</b>	<b>%</b>
Confronting major social issues with regard to HIV/AIDS	0	0	20	100%

**N=20**

All (100%) of the participants, as shown in Table 5.7, indicated that they had never been confronted by major issues and policies with regard to HIV/AIDS in their experience as social workers. As a result, they could not motivate their answers.

## **5.8 CHALLENGES**

HIV is a chronic illness that is viewed as stressful. The stress starts with infected people, and infected and affected people experience different stressors (Bor & Elford, 1998).

### **5.8.1 Main challenges experienced in working with people living with HIV/AIDS**

The participants were asked to name the main challenges that they experienced in working with people living with HIV/AIDS. They stated the following as the main challenges:

### **5.8.1.1 Telling the children**

Two (20%) of the participants indicated that their main challenge was having to tell children that one or both parents were infected with HIV. Another challenge was that when the parents died, the children were orphans.

*“When the person has children and you have to tell the children that his mother/father is not going to live forever.”*

*“They have young children and die at a young age, so the children are orphans.”*

The above findings do not correspond exactly with the literature, but if the parents die, as indicated in the findings, the children will depend on other people. Aggleton et al. (1999) state that a chronic illness such as HIV/AIDS is a challenging dominant conceptualisation of childhood; this is specifically a notion of children as dependents, passive and not productive.

### **5.8.1.2 Stigmatisation**

Three (15%) of the participants indicated that persistent ignorance and fear of rejection were due to stigmatisation:

*“Stigmatisation of persistent ignorance.”*

*“The feeling of exclusion of your client from society. The fear of the future.”*

The literature corresponds with the findings of this study. According to Van Dyk (2005), people living with HIV/AIDS have many fears, such as a fear of being stigmatised, isolated and rejected. They are uncertain of their future.

### **5.8.1.3 The denial of a diagnosis of HIV**

Three (15%) of the participants mentioned denial of the diagnosis of HIV as one of the main challenges that they were experiencing in working with people living with HIV/AIDS. It is difficult for social workers to help a person to reach the acceptance stage. Denial of illness delays the therapeutic process. People either believe that it is better not to know their status or choose not to believe the outcome of the test when tested positive.

Participants made the following comments:

*“It is difficult to help the person to reach the acceptance stage. Once this stage is reached, the future planning can begin.”*

*“There is naivety about knowing one’s status, people either believe it’s better not to know their status, or choose to not to believe of the test when positive.”*

*“The denial delays the therapeutic process.”*

The findings of this study correspond with the views of Van Dyk (2005 who states that denial is an important defence mechanism that can temporarily reduce the stress that most HIV-infected people go through. Denial can be viewed as destructive, however, if it causes destructive behaviour such as refusing appropriate medical care or indulging in continued unrestrained high-risk behaviour.

#### **5.8.1.4 Poverty**

Two (10%) of the participants mentioned poverty as one of the main challenges that they experienced because in their organisations, people came to enquire about the availability of food parcels.

Respondents made comments such as the following:

*“Poverty is very challenging especially to those who are willing to take treatment.”*

*“Our organisation used to receive funding for the period before a grant is paid out to give nutritional support to our clients but it was stopped. The people still enquire about food parcels but you have to say you can’t help them.”*

This challenge is supported by Herek and Hunt (cited in Singhal & Rogers, 2003) who state that people living with HIV/AIDS tend to be of low socio-economic status.

#### **5.8.1.5 People are not upfront in disclosing their status**

Two (10%) of the participants highlighted that people living with HIV/AIDS are not upfront in disclosing their status and experience difficulty in disclosing their status. It is difficult for service providers to access the necessary resources when clients do not reveal their HIV status.

*“People are not upfront in disclosing their status.”*

*“It is difficult to access the necessary resources not revealing their status.”*

Kalichman (2009) state that HIV-infected people are ashamed and embarrassed by their status and that it is difficult for them to tell others their status.

#### **5.8.1.6 Other challenges**

Four (20%) of the participants indicated other challenges that they experienced in working with people living with HIV/AIDS. Responses were the following:

*“People are not well educated and it makes it difficult to explain, e.g. boyfriend and girlfriend.”*

*“They still don’t use the condoms when having sex; difficult for infected people to be responsible further on and to make use of available services.”*

*“Infected people live with this disease without any support.”*

*“They die without having experienced any kind of support from their families and friends; the clients don’t take care of themselves like don’t take medicine.”*

The above findings show that HIV-infected people live with this disease without any support. This may be caused by the fact that the family grieves and loses the normal functioning of the individual (Falvo, 1999).

### **5.8.2 Main challenges experienced by people living with HIV/AIDS**

People living with HIV/AIDS experience challenges such as profound shock when diagnosed with the virus, and this shock may be followed by anger, fear, despair as well as thoughts of committing suicide (UNAIDS, 2000).

Participants were asked to identify the challenges that people living with HIV/AIDS are experiencing.

### **5.8.2.1 Weakness in their bodies**

Participants indicated different challenges that people living with HIV/AIDS are experiencing.

“They cannot work due to weakness in their bodies although the CD4 is not low enough for the grant and sickness leads to job loss sickness, although there is financial aid due to CD4”.

This finding corresponds with the view of Van Dyk (2005) who states that people living with HIV/AIDS face loss of their job and income, discrimination, social stigma and financial problems. As a result they are unable to afford expensive drugs or life-saving treatment. To add to what Van Dyk says, Singhal and Rogers (2003) state that people living with HIV/AIDS tend to be of lower socio-economic status.

### **5.8.2.2 Rejection from family and community**

Participants indicated the following:

*“Suffer from rejection from family, friends, and community members.”*

*“No support from their families; support from the community.”*

*“Families don’t want to have anything with them; rejection by family; alienation & rejection.”*

The above findings show that people living with HIV/AIDS suffer rejection from their families and communities as well as lack of support. The findings correspond with the view of Uys and Cameron (2003) who state that people living with HIV/AIDS might lose the support of family and friends due to stigma and discrimination.

### **5.8.2.3 Stigmatisation**

Participants indicated that infected people experience the following:

*“Stigma and discrimination is a challenge, infected people live with stigma from community members.”*

*“People are judged by other people for having this sickness.”*

The above findings of the study correspond with the literature in which Uys and Cameron (2003) state that people living with HIV/AIDS might lose the support of family, friends and community members due stigma and discrimination.

#### **5.8.2.4 Taking antiretroviral drugs**

Taking medication regularly is also a challenge for people living with HIV/AIDS. Participants commented as follows:

*“Taking ARVs for the rest of their lives or using medication regularly is seen as a challenge by the infected people.”*

*“Availability of medication or inadequate counselling is another challenge.”*

Van Dyk (2005) associates this factor with socio-economic losses whereby HIV-infected individuals face the loss of their job, discrimination, social stigma, relationship changes and changing requirements for sexual expression and financial problems, which can lead to an inability to afford expensive drugs or life-saving treatment.

### **5.8.3 Main challenges experienced by people affected by HIV/AIDS**

Families, for instance, may face the challenge of having to disclose the status of their infected member if they want to obtain the relevant help. They may suffer rejection and loss, as often happens to people living with HIV/AIDS (Hays et al., cited in Pequegnat & Szapocznik, 2000).

The following are the main challenges experienced by people affected by HIV/AIDS:

#### **5.8.3.1 Family and friends are not educated to deal with the disease**

Two (10%) of the participants indicated that family and friends were not educated to deal with this disease and that there was no proper education.

*“They often do not know how to assist and provide support to this individual.”*

*“Family and friends are not well educated to deal with this disease. They sometimes feel guilty like it’s their fault. They don’t know always how to give their support.”*

*“In some cases the family is afraid to live with them because they think that they will also be infected.”*

Van Dyk (2005) states that lack of knowledge regarding HIV and not knowing how to handle its problems may be the cause of the fear of the family to deal with this.

### **3.8.3.2 Family members deny the status of the relative**

#### **(i) Stigma and judgment**

Participants indicated that family members felt judged. Family members denied the status of their HIV-infected member.

*“Family members also feel stigmatised and judged. They will deny the status of their family member and find it hard to accept the truth.”*

*“Family members deal with stigma and loss.”*

These findings correspond with the view of Bezuidenhout (2004) who states that in cases of HIV infection, the situation is further complicated because of the stigmatisation associated with the disease and the fact that the family members may be forced to cope with the issues of infidelity or drug use previously unbeknownst to them. The most severe social impact of the disease is on family life.

#### **(ii) Support**

Participants indicated that the family had the challenge of looking after the children of the deceased members.

*“The family must look after the children when the person dies.”*

The above findings do not correspond with the literature review.

## **5.9 SOUTH AFRICAN GOVERNMENT SUPPORT TO PEOPLE LIVING WITH HIV/AIDS**

Participants were asked whether the South African government did enough to support people living with HIV/AIDS and to motivate their answers.

**Table 5.10: Support by the South African government to people living with HIV/AIDS**

South African government support to people living with HIV/AIDS	Yes		No		Yes/No	
	Frequency	%	Frequency	%	Frequency	%
	12	60%	6	30%	2	10%

**N=20**

Table 5.8 shows that 12 (60%) of the participants indicated that the South African government did enough to support people living with HIV/AIDS because all sorts of services were available to clients, but these should, however, be more visible.

### 5.9.1 Positive responses

Participants offered the following motivation for the positive responses:

Twelve (60%) of the participants stated that government services were available to their clients who could not afford these services. They commented as follows:

#### 5.9.1.1 Information/education

Participants indicated that concerning education, the government had done enough to educate and inform people about the HIV/AIDS epidemic.

*“There is a lot of information available as people are informed over the radio, TV, at clinics, schools and many other places.”*

*“The government has done enough education about ways of protecting and dealing with challenges if already affected or infected people. State grants are also available.”*

*“Government has held many HIV/AIDS awareness campaigns and supports severely ill people with the disability grant. I believe their focus can shift to living with the disease and educating communities about stigmatisation and the damage it causes.”*

*“All over you hear about workshops about HIV/AIDS, whether schools, clinics etc. People are aware but still they do their own thing. People must take responsibilities for their actions instead of blaming others.”*

According to the above responses, the government has done enough to inform the public about the HIV/AIDS pandemic. There is a great deal of information available; the government has held many HIV/AIDS awareness campaigns, and workshops concerning HIV/AIDS are held at schools, clinics, and so forth.

### **5.9.1.2 Medication**

Participants mentioned that the government gives support through medication that is provided by government institutions such as clinics. The government also sponsors the nongovernmental organisations that work specifically with people living with HIV/AIDS. Participants made the following comments:

*“The government gives enough support because the patient can go to any clinic whether mobile or not and there are support groups to get help.”*

*“Advocacy in South Africa is ongoing and continuously tries to create awareness in terms of prevention as well as treatment drugs.”*

*“The government sponsors NGOs that work with HIV infected and affected people and there is an access to clinics and treatment.”*

*“The government provides medication. It is not government’s job to support people with HIV/AIDS.”*

*“I think yes because the government provides the medicine to clients that cannot afford it and counselling.”*

*“I think they give enough support, because the patient can go to any clinic or mobile, support groups to get help”.*

*“The antiretrovirals are available at some clinics. Feel they can roll-out at more sites.”*

According to the above findings, the government is doing well and enough by giving support to the clinics. One participant felt that there could be more sites to roll out the medication. Patients receive support from clinics and support groups.

### 5.9.2 Negative responses

Seven (35%) of the respondents indicated that the South African government was not doing enough to support people living with HIV/AIDS. Their responses are mentioned below:

*“The government doesn’t have money to give all the support needed by infected people such as housing.”*

*“The government does make the treatment available but there is a gap in the training of individual to provide the correct counselling of infected people.”*

*“The period before grant is paid out the government must support the people as they cannot take medication on an empty stomach.”*

*“Public health system needs to improve. More support for OVC’s (orphan vulnerable children).”*

*“People can start earlier on ARV treatment.”*

*“Even though there are awareness campaigns they are not effective. People still don’t know about AIDS and how to prevent it. They don’t understand it.”*

*“I don’t think the government has enough money to give all the support such as housing etc.”*

According to the above findings, the government does not provide the support that is needed by people living with HIV/AIDS. There is not enough money to support these people. Support such as housing and the social grant (because patients cannot take treatment on an empty stomach) is needed. Awareness campaigns appear to be effective as people still do not know enough about HIV/AIDS. There is still a need to improve the public health system.

### 5.9.3 Conflicting responses

Two (10%) of the participants indicated that the government gave support but at the same time did not. They commented as follows:

*“My response is yes and no because in the rural communities it is sometimes difficult to get the proper treatment for HIV people. Yes the government is trying to monitor the process.”*

*“There are enough programmes to inform people about HIV/AIDS but we need to look at how much support is given to these people in our poor communities due to lack of resources.”*

According to the above responses, although the government is trying to monitor the treatment process, rural communities are struggling to obtain the proper treatment for HIV. Programmes to inform people about HIV/AIDS are adequate, but there is a need to focus on poor communities due to a lack of resources.

## 5.10 CONCLUSION

The aim of this study was to explore the support needed by people living with HIV/AIDS. This chapter presented the findings of the empirical study.

It started by presenting the profile of the participants: number of years in social work practice, size of case load, number of cases of people living with HIV/AIDS and number of years working with people living with HIV/AIDS. The stress and stressors experienced by people living with HIV/AIDS were identified. The support that people living with HIV/AIDS receive was explored.

At the micro-level, different types of support as well as the source of support available to people living with HIV/AIDS were explored. At the mid-level, different types of treatment group were explored. These are the groups that people living with HIV/AIDS need. At the macro-level, the author sought to determine how practitioners such as social workers were engaged in organisational and policy arenas through macro-level activities.

The challenges that are experienced by those who are working with people living with HIV/AIDS, the challenges that people living with HIV/AIDS come across and the challenges experienced by affected people such as family and friends were then explored. Finally, the support that the South African government gives to people living with HIV/AIDS was explored.

The chapter has successfully explored the support needs of people living with HIV/AIDS. The empirical study has verified the data found in the literature and highlighted the areas in which people living with HIV/AIDS need increased support. This information will be useful to guide social workers to gain an ecological understanding of how to improve support for people living with HIV/AIDS.

The findings of this study show that many people living with HIV/AIDS are living in denial of their condition, which is shown by discontinuation of treatment. Some suffer from cognitive depression. Some feel guilty about having affairs. Socio-economic factors are one of the stressors that infected people experience because some lose their jobs when they are diagnosed with HIV/AIDS due to the stigma that is associated with the virus.

The findings indicate that people living with HIV/AIDS receive the support that they need; some participants, however, believe that these people do not receive the necessary support due to the gap in the counselling process. At the micro-level, the people who give support to people living with HIV/AIDS are family and friends, and at the mid-level. Groups that people living with HIV/AIDS fit into best are educational and mutual-aid groups. At the macro-level, people living with the virus receive support from the programmes offered by clinics such as basic health care, counselling and ART. They receive social assistance from social workers at nongovernmental organisations.

The findings show that telling children about parents' HIV status, stigmatisation, denial of the diagnosis, poverty and unwillingness of people to disclose their status are the main challenges experienced by social workers in working with people living with HIV/AIDS.

The main challenges experienced by people living with HIV/AIDS are the following: weakness in their bodies, rejection by family and community, stigmatisation and taking antiretroviral drugs. The main challenges of affected people with HIV/AIDS are the following: family and friends are not educated to deal with the disease, family members deny the status of their relative and the family has to look after the children of the deceased member.

Most participants indicated that the South African government did enough to support people living with HIV/AIDS. People living with HIV/AIDS receive information, education and medication from the government. Seven (35%) of the participants indicated that the South African government was not doing enough to support people living with HIV/AIDS. The findings show that the government does not give money to infected people so that they can have houses; there is a gap in the training of an individual. Some of the findings show that the government is trying to monitor the process, yet there is still much to be done in the rural areas where people are still struggling to obtain the necessary resources.

The following chapter will present the conclusions and recommendations for support for people living with HIV/AIDS.

## **CHAPTER 6**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **6.1 INTRODUCTION**

The exploration of social workers' perspective on the support needed by people living with HIV/AIDS originated from an identified gap in the literature and an apparent lack of support available to people living with HIV/AIDS. The exploration was achieved by first acquiring an overview of HIV/AIDS as terminal illness, as presented in Chapter 2. The second objective of the study was to establish the psychosocial stressors experienced by people infected with HIV and affected by HIV/AIDS, as described in Chapter 3. The third objective was to establish an ecological perspective on people living with HIV/AIDS, as discussed in Chapter 4. The fourth objective was to explore the support needs of people living with HIV/AIDS by means of an interview; the findings of the empirical study are presented in Chapter 5.

The aim of this chapter is to present the conclusions drawn from the study and to make appropriate recommendations. The recommendations will serve as a guideline for social work interventions to improve the support available to people living with HIV/AIDS at different ecological levels.

Through conducting a literature review and an empirical study, conclusions can be drawn and recommendations can be made. The conclusions and recommendations are related to the aim and objectives of the study.

**Table 6.1: Conclusions and recommendations as evidence of meeting the objectives of the study**

<b>OBJECTIVE</b>	<b>CONCLUSIONS AND RECOMMENDATIONS</b>
<b>Objective 1:</b> To explain HIV/AIDS as terminal illness.	Awareness campaigns Educating communities about HIV/AIDS
<b>Objective 2:</b> To describe the psychosocial stressors experienced by people infected with HIV and affected by HIV/AIDS.	Fear Denial Depression Socio-economic issues Guilt Anxiety Loss Suicidal thinking Low self-esteem AIDS dementia
<b>Objective 3:</b> To discuss the relevance of the ecological perspective to people living with HIV/AIDS.	- Support at micro-level Physical support Family Medical support Emotional support Support groups Other sources Financial support Need for financial support Social grants and food parcels - Support at mid-level Treatment groups Educational groups Mutual-aid groups

OBJECTIVE	CONCLUSIONS AND RECOMMENDATIONS
	- Support at macro-level Social workers' perspective on being confronted by major issues and policies regarding HIV/AIDS
<b>Objective 4</b> To investigate the perspectives of social workers on the nature of the support needed by HIV-positive people.	Social workers' perspective on being confronted by major issues and policies with regard to HIV/AIDS

## 6.2 CONCLUSIONS

### 6.2.1 Identifying details

The number of years in social work service of the participants ranges from one year to 20 years. This indicates that some participants have long service in the social work profession and have much experience regarding their work.

The size of the case load of most participants ranges from one to 50. One (5%) of the participant has a case load of 200. It can be concluded that the participants are rendering services to large numbers of cases.

### 6.2.2 Stress and stressors experienced by people living with HIV/AIDS

The majority of participants indicated that fear was the stressor that most people living with HIV/AIDS were faced with. Socio-economic issues, depression and denial follow after fear,. This is followed by guilt, anxiety, suicidal thinking, low self-esteem and loss and AIDS dementia. These findings indicate that fear is the stressor that most people living with HIV/AIDS are experiencing. Socio-economic issues, depression and denial follow, and AIDS dementia is the stressor least experienced by people living with HIV/AIDS.

### **6.2.3 Support that people living with HIV/AIDS receive**

The majority of participants indicated that people living with HIV/AIDS received the necessary support, some indicated that people living with HIV/AIDS did not receive the necessary support and a few were uncertain whether people living with HIV/AIDS received the necessary support or not.

Based on the above findings, it can be concluded that people living with HIV/AIDS do not receive the support that they need.

#### **6.2.3.1 Support at the micro-level of the ecosystem**

Just more than half of the participants indicated that people living with HIV/AIDS received support from the micro-level of the ecosystem. This support comes from their family and friends. Family and friends offer physical support, with families taking care of their loved ones when they are sick. Some participants believed that adequate medical facilities were available, while one participant claimed that medical support was available but insufficient.

Emotional support is another kind of support that people living with HIV/AIDS receive at the micro-level of the ecosystem, as participants indicated.

Participants indicated that infected people received financial support through assistance by social workers in applying for support grants and food parcels. Some participants stated that financial support was not really available in the community. People living with HIV/AIDS are normally in financial distress due to low income, and some come from poor backgrounds and their families consequently cannot support them financially.

It can be concluded that people living with HIV/AIDS receive support from their family members and friends. Emotional support is received from the support groups where they have a platform to express their feelings. Although financial support is available to people living with HIV/AIDS, it is not enough as some of these people are from a poor background.

### ***6.2.3.2 Support at the mid-level of the ecosystem***

The majority of the participants indicated that people living with HIV/AIDS received support from the support groups that they were involved in. The type of group that people living with HIV/AIDS fit into best, according to the participants, is treatment groups. There are different types of treatment groups, such as growth, remedial, educational and mutual-aid groups. Educational and mutual-aid groups were the groups that were stated by participants as needed most by people living with HIV/AIDS.

The reason why educational groups are needed is that people living with HIV/AIDS need education and that they lack knowledge on how to deal with HIV/AIDS. According to the participants, people living with HIV/AIDS need mutual-aid groups because they share similar needs. People living with HIV/AIDS get the chance to meet others who live with the virus, and they can support one another emotionally. The findings of the study show that support groups play a supporting role in the lives of people living with HIV/AIDS. According to participants, a support group is a platform that provides its members with a place where they can express their feelings.

It can be concluded that support groups, especially educational and mutual-aid groups, are vital to people living with HIV/AIDS.

### ***6.2.3.3 Support at the macro-level of the ecosystem***

The majority of the participants indicated that practitioners such as social workers were engaged in organisational, community and policy arenas through macro-level activities. People living with HIV/AIDS receive the assistance that they need from social workers at nongovernmental level. Organisations such as churches also offer support to people living with HIV/AIDS.

According to the above findings, it can be concluded that at the macro-level, practitioners such as social workers are engaged in organisational, community and policy arenas through macro-level activities.

## **6.2.4 Challenges**

The sickness is viewed as stressful by participants, and they indicated some challenges that they experienced in working with people infected with and affected by the virus.

### ***6.2.4.1 Challenges in working with people living with HIV/AIDS***

Telling children that their parents were infected with the virus was indicated as a challenge by the participants. It is also a challenge when the parents die and leave children as orphans. Participants indicated that stigmatisation was a challenge because infected people are excluded from society.

Denial of illness by those living with HIV/AIDS was identified as a major challenge as it is difficult for social workers to help the person to reach the stage of acceptance of the diagnosis. According to participants, denial delays the therapeutic process.

Participants highlighted poverty as another major challenge, especially for those who are receiving treatment. It is difficult when infected people come to nongovernmental organisations to enquire about food parcels that are not always available.

Participants indicated that people were not upfront in disclosing their status due to fear of being rejected. When people do not reveal their status, it makes it difficult for service providers to access resources that are needed by these people.

Another challenge is that people living with HIV/AIDS still do not use condoms when having sex.

It can be concluded that the major challenges experienced by service providers are related to the feelings of people living with HIV/AIDS, denial of their diagnosis, stigmatisation, fear of rejection and poverty.

#### ***6.2.4.2 Challenges experienced by people living with HIV/AIDS***

One of the challenges experienced by people living with HIV/AIDS indicated by participants was physical weakness. These people often cannot work due to the weakness of their bodies.

Rejection by family and community, stigmatisation, judgment by others and discrimination were found to be experienced by some infected people, while others did not receive the needed support from family, friends and community.

Taking medication regularly for the rest of their lives is also a challenge for people living with HIV/AIDS. Sometimes there is inadequate counselling concerning the medication.

It can be concluded that the major challenges experienced by people living with HIV/AIDS are related to their physical and emotional conditions.

#### ***6.2.4.3 Challenges experienced by people affected by HIV/AIDS***

Challenges experienced by people affected by HIV/AIDS are lack of education regarding the disease, fear of living with an infected person, stigmatisation of the family by others, denial of the status of the infected family member and lack of support.

It can be concluded that the stigma of HIV/AIDS is a challenge to those who live with the disease and also to those who are affected by the disease, such as family members and friends. In addition, a lack of education for both infected and affected people concerning the disease is a challenge.

#### **6.2.5 South African government support to people living with HIV/AIDS**

The majority of the participants indicated that the government of South Africa gave enough support to people living with HIV/AIDS. Some of the participants indicated that the government did not give enough support to people living with HIV/AIDS. A few of the participants indicated conflicting responses on whether the government gave support to those who live with HIV/AIDS.

### **6.2.5.1 Positive responses**

Most of the participants stated that there was a great deal of information available in the media and that governmental institutions such as clinics and schools offered education about protection and awareness by means of campaigns and workshops about HIV/AIDS.

The provision of health care services is another kind of support that the government offers to people living with HIV/AIDS. According to the participants, the government gives enough support as the patients can go to any medical clinic that they can reach. In addition, medication and counselling are offered free of charge to patients who cannot afford it.

It can be concluded that educational and medical services are available to people living with HIV/AIDS.

### **6.2.5.2 Negative responses**

According to some of the participants, the government is not doing enough to support people living with HIV/AIDS. These people need support from the government with regard to suitable accommodation and financial assistance. Some participants thought that awareness campaigns were not effective as people still did not know enough about HIV and how to prevent it. Patients are also struggling to survive financially while they are waiting for disability grants. For instance, they cannot take medication without eating.

It can be concluded that some of the basic needs of people living with HIV/AIDS are not being met due to a lack of financial support.

### **6.2.5.3 Conflicting responses**

Ten per cent of the participants stated that although the government supported people living with HIV/AIDS in a number of ways, people living in the rural areas did not have access to these support services.

Participants held the view that there were enough programmes to inform people about HIV/AIDS but that service providers needed to inform people about HIV/AIDS.

On the one hand, it can be concluded that the government is doing well concerning the support that is given to people living with HIV/AIDS. On the other hand, it can be concluded that the government needs to do more to provide people with housing and to help those infected to start the medication early.

## **6.3 RECOMMENDATIONS**

The following recommendations have been formulated:

### **6.3.1 Stress and stressors experienced by people living with HIV/AIDS**

- It is recommended that people living with HIV/AIDS receive thorough counselling, pretesting and post-testing. Stressors such as fear, depression, low self-esteem and suicidal thinking need to be addressed during counselling sessions by service providers.

### **6.3.2 Support needed at the levels of the ecosystem**

- It is recommended that people infected with HIV and affected by HIV/AIDS receive counselling at micro-level from service providers in addition to support from support groups at the mid-level of practice.
- It is recommended that the government improve the health care system, establish more health centres and employ more staff in the health care system to provide services to people living with HIV/AIDS.
- It is recommended that the government make funding available to nongovernmental organisations to establish and run support groups for people infected with HIV and affected by HIV/AIDS.
- It is recommended that the government make funding and training on how to utilise these funds available to people, which may assist those who live with the virus to live better lives. For instance, if the government establishes community gardens, people can plant

their own vegetables and will not need to wait for the government to give them food parcels and disability grants.

- It is recommended that religious institutions such as churches be equipped by the government and nongovernmental organisations to handle people who live with the virus as the findings show that people living with HIV/AIDS are comfortable with their religious leaders.
- It is recommended that practitioners such as social workers in nongovernmental organisations be trained to render effective and efficient social welfare services to people living with and affected by HIV/AIDS as these people are part of their daily practice.
- It is recommended that the government offer more awareness and education campaigns on HIV/AIDS to avoid stigmatisation of and lack of support to those who live with the virus together with their families. The media could be involved in these campaigns.
- It is recommended that the government try by all means to eradicate poverty as the findings have shown that poverty is one of the challenges that people living with HIV/AIDS come across. This can be achieved by the creation of jobs and training of people to become self-sufficient.

## **6.4 FUTURE RESEARCH**

It is recommended that future research be undertaken on the following:

- The views of people living with HIV/AIDS on the stressors that they come across and how these can be dealt with by service providers.
- What kind of support people living with HIV/AIDS and their families need.
- How citizens can be educated about and made aware of the impact of HIV/AIDS on the quality of life of people infected with HIV and affected by HIV/AIDS.

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## **LETTER OF CONSENT**

**Department of Social work  
University of Stellenbosch  
October 07, 2011**

**The Regional Director  
Child Welfare South Africa  
Bellville  
7530**

Dear Mrs Marais

### **RE: PERMISSION TO DO RESEARCH IN YOUR AGENCY**

I'm hereby requesting you to please grant me permission to do research at Child Welfare South Africa Agencies in Stellenbosch, Somerset West and Wellington. This will be done by interviewing social workers who are working with people living with HIV/AIDS. I am sending a copy of the questionnaire.

I hope that my request will receive your favourable attention.

Thank you

Yours faithfully

Joyce Kulu  
MSW student  
University of Stellenbosch  
0833114101

## **QUESTIONNAIRE**

**UNIVERSITY OF STELLENBOSCH  
DEPARTMENT OF SOCIAL WORK  
SEMI-STRUCTURED QUESTIONNAIRE**

### **Social workers' perspectives on social support needed by people living with HIV/AIDS**

Please Note:

- Respondents' names will not be made known.
  - All the information recorded in this questionnaire is confidential.
- 

#### **Instructions**

There are four types of questions in this questionnaire:

1. Closed ended questions – yes/no questions. The respondent chooses between yes and no, but in some cases will be requested to explain his/her answer.
2. Scaling questions – the respondent indicates the level of his/her agreement with a particular statement.
3. Lists – the respondent is given a number of possible answers to a question and is requested to choose the answers that are applicable to the respondent's situation.
4. Open-ended questions – the respondent is asked to answer a question in his/her own words. Answers will vary from one word to a paragraph.

**1. Profile of respondent**

1.1. How long have you been a social worker?

-----

**2. Background**

2.1. How big is your caseload?

Mark with "X"	Size of caseload
	1 - 20
	21 - 50
	51 - 100
	101 - 150
	151 - 199
	200 +

2.2. How many of these cases are people living with HIV/AIDS cases?.....  
(write the number)

2.3. How long have been working with people with HIV/AIDS? ..... (No of years)

**3. Stress and stressors experienced by people infected by HIV/AIDS**

3.1. The following list contains the stressors that are experienced by people infected with HIV/AIDS.

a) Choose the stressor from the list that you usually come across when you deal with people infected, by marking it with "X".

Mark with "X"	Stressors
	Fear
	Loss
	Guilt
	Denial
	Anxiety
	Low self-esteem
	Depression
	Suicidal thinking
	Socio-economic issues
	AIDS Dementia

3.2. Which one of the stressors above do you think they experience most? Motivate your answer.

.....

.....

.....

**4. Support people living with HIV/AIDS get**

4.1. Do people living with HIV/AIDS get the support they need?

Yes	No
-----	----

4.2. If the answer is “No” please motivate your answer.

.....

.....

.....

.....

4.3. If your answer is “Yes” where do they get the support from according to the levels (micro; meso; macro) of the ecological perspective?

.....

.....

.....

**4.3.1. Micro level system**

a) From which of the following people do people with HIV/AIDS get the support most?

Mark with “X”	People
	Family
	Friends
	Partner / spouse
	Support group

b) What kind of support do they get from the people identified above?

Mark with "X"	Type of support
	Physical
	Emotional
	Financial support

c) To what extent do you think the support they get is enough to meet their needs? Explain.

Physical.....  
 .....  
 Emotional.....  
 .....  
 Financial.....  
 .....

d) If the support they get is not enough, what other kinds of support do they need? Explain.

.....  
 .....  
 .....  
 .....

**4.3.2. Mid (Messo) level system.**

a) Consider the following statement.  
 "People living with HIV/AIDS fit well in treatment groups".

Please indicate your level of agreement with "X".

<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
-----------------	--------------	-----------------------

- b) Which one of the following group according to your experience do you think people living with HIV/AIDS need most?

Mark with "X"	Group
	Growth
	Remedial
	Educational
	Mutual aid / support

- c) Please explain and motivate your answer.

.....

.....

.....

.....

**4.3.3. Macro level system**

“Practitioners such as social workers are engaged in organizational, community and policy arenas by macro level activities”.

- a) Please indicate your level of agreement with “X”.

<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
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- b) In your experience have you ever found yourself in a situation where you find yourself were confronting major social issues and policies with regard to HIV/AIDS on behalf of your clients?

<b>Yes</b>	<b>No</b>
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- c) If your answer yes please explain.

.....

.....

.....

.....

**5. CHALLENGES**

5.1. What are the main challenges that you experience in working with people living with HIV/AIDS?

.....  
.....  
.....

5.2. What are the main challenges that people living with HIV/AIDS come across?

.....  
.....  
.....

5.3. What are challenges that affected people such as family and friends of people with HIV/AIDS come across?

.....  
.....  
.....  
.....

5.4. Do you think the government of South Africa does enough to support people living with HIV/AIDS?

Yes	No
-----	----

5.5. Motivate your answer.

.....  
.....  
.....  
.....

**THANK YOU VERY MUCH FOR YOUR TIME!**