CARING FOR THE CAREGIVER IN HIV AND AIDS PROGRAMMES

By

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I declare that **CARING FOR THE CAREGIVER IN HIV AND AIDS PROGRAMMES** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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SIGNATURE
(MW Primo)   **Date: 14 March 2007**

To my parents, pappa and mamma Lemboe with love and gratitude for the unselfish care giving they did without support and recognition.

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Summary

Many of the caring tasks previously done by health care professionals are these days handled by caregivers. Caregivers are selected, trained and to a certain extend supervised. Little attention is however given to the effects that care giving has on their physical and mental health and own needs for caring and support.

This study is an exploratory, qualitative and quantitative investigation into the effects of care giving on the physical and mental health of caregivers in HIV and AIDS programmes to determine their needs for ongoing support.

A literature study was supplemented by an empirical investigation. The literature study and empirical investigation proved that care giving has a tremendous impact on the lives of caregivers.

Recommendations resulting from the study are the need for more education and skills for caregivers, support through counselling, debriefing and support groups, policies and guidelines that makes provision for caregivers to be registered and receive a fixed income.

List of key concepts

- Caring
- Care giving
- Caregiver
- Mental health
- Physical health
- Secondary traumatic stress
- The volunteer
- Volunteerism

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Chapter 1

General orientation

Introduction

Caring for other people is an event that many people will encounter at some point in their lives. The care giving can be related to a terminal illness such as diabetes, cancer, Alzheimer's or Aids. This study explores the effects of care giving on the physical and mental health of the caregiver in HIV and AIDS programmes so that their needs for support can be determined. There is still no cure for Aids, but there is hope and instead of learning how to die from Aids, many people are now struggling to live with it. These distressing circumstances call for caregivers to be available for counselling and remain physically and emotionally healthy.

1.1 Problem statement

According to the Bill of Rights in the Constitution of the Republic of South Africa (1996: 7), everyone has the right to life and the right to have their dignity respected and protected. In terms of this Bill, the South African government makes sure that the rights of the terminally ill, such as the person suffering from Aids, is protected and, by implication, places a big demand on those people who are responsible for caring. Traumatised people feel relieved by a care worker who understands and respects their pain, who engenders hope in their recovering and who performs tasks with confidence. The humane factor therefore plays a very significant role when dealing with people in distress, from the points of view of both the recipient and the provider of counselling.

As much as the work of helping traumatised people is gratifying, exposure to another person's traumatic circumstances has the potential to produce stress in the caregiver and also brings risks. The general public can sometimes see the HIV and AIDS caregivers as people who pose a health risks to others. They are then forced to share the same stigma of rejections,

loss of friends and harassment. The caregivers then also begin to experience feelings of guilt, anger, depression or despair.

This secondary exposure to trauma may cause the caregiver to inflict additional pain on the originally traumatised person. This is called compassion fatigue, compassion stress or secondary traumatic stress. The question is whether the caregiver is helped to cope with this cost of caring. According to Hudnall Stamm (1999: 5), nearly all of the hundreds of reports on traumatised people focus on those who were directly traumatised. Secondary traumatic stress is the least studied and understood aspect of traumatic stress.

The Nigel Caring Community, a community based organisation, was established during October 2001 and is rendering services in the Alra Park, Duduza communities and surrounding farms within the greater Nigel area. The purpose of the organisation is to provide support and care to HIV and Aids infected and affected people. The activities of this organisation are predominantly performed by volunteers. Currently 21 caregivers are responsible for home-based care and 21 are working as social caregivers. The organisation receives funding from the Department of Social Services for its social programmes and the Department of Health is funding the home-based care programmes. The caregivers in these programmes are selected, trained and supervised, but very little attention is given to their own caring and support needs.

According to information received during informal interviews with the program manager, a social worker previously employed by the organisation is responsible for debriefing the caregivers. The caregivers in the Nigel area seem to work under circumstances, which are severely stressful. The average number of terminally ill patients is 2700 over a period of 12 months and they normally die 3 – 6 months after having been identified for home based care. The average number of children in the area who are left orphaned because of Aids is plus/minus 3400 per year. The 42 caregivers, who try to give hope in a hopeless situation, carry the burdens of these traumatised clients.

A thorough research conducted on the caregivers needs has not been done yet and it seems as if the support they receive at present is not sufficient. Due to other commitments, the management members of the Nigel Caring Community do not have the time to attend to the caring of the caregivers.

According to the Human Sciences Research Council, burnout is a major problem faced by the caregivers of people living with HIV and Aids, particularly in home based care. Caring for the caregiver in HIV and Aids programmes therefore ranks very high in terms of priorities for research.

1.2 Aim and objectives

The aim of the research includes its plan and structure. By distinguishing the objectives, the researcher specifies whom he or she wants to draw conclusions from (Terre Blanche and Durheim, 1999: 33 and 37). In this study it is from the caregivers of the Nigel Caring Community Organisation.

1.2.1 Aim

The aim of the study is to do an exploratory investigation into the effects of care giving on the physical and mental health of the caregivers in HIV and AIDS programmes in order to determine their needs for ongoing support.

1.2.2 Objectives

In an effort to achieve the above mentioned aim, the following objectives are distinguished:
Carry out a literature study to:

♦ Acquire useful descriptions on applicable key words such as secondary traumatic stress and caring for the caregiver.

♦ Through the Human Sciences Research Council, National Research Foundation and UNISA library, establish what international and national research has already been done on caring for the caregiver in HIV and Aids programmes.

Carrying out an empirical investigation to determine:

♦ The effects of care giving on the physical and mental health of the caregivers in HIV and AIDS programmes.

♦ What type of caring and support is available for the caregivers in HIV and AIDS programmes.

♦ What the gaps are in existing caring programmes.

♦ What support, caring and empowerment caregivers need to continue with their care giving role in HIV and AIDS programmes.

1.3 Research questions

The research problem that directs this study is the effect that secondary traumatic stress in care giving has on the physical and mental health of the caregivers and the caring needs of caregivers in HIV and AIDS programmes.

Given the research problem, the following questions give direction to the investigation:

1.3.1 What are the physical and mental effects of secondary traumatic stress on the caregivers in HIV and AIDS programmes?

1.3.2 What are the caring needs of the caregivers in HIV and AIDS programmes?

1.3.3 How can the caregivers in HIV and AIDS programmes be empowered to deal with secondary traumatic stress in their care giving role?

1.4 Research design

This is an exploratory qualitative study into the effects of care giving on the physical and mental health of the caregivers in HIV and AIDS programmes, and their needs for support. The research plan consists of a literature study,

supplemented by an empirical investigation.

1.5   Method of data collection.

A literature research is done through the study of existing national and international literature on secondary traumatic stress. The purpose is to determine the effect of care giving on the physical and mental health of caregivers in HIV and AIDS programmes, to identify existing support and to determine their needs for ongoing support. Information from and statistics complied by the Gauteng Department of Health and Department of Social Services and Population Development are also included in the study. An empirical investigation is based on the findings in the literature study. Respondents are interviewed individually by the researcher using a questionnaire, consisting of open-ended questions (Addendum A), which is a qualitative interviewing strategy (Rubin and Babbie, 1993: 374). Themes for the questions are based on the information from the literature study.

1.6   Method of data presentation

A statistical analysis of the data collected through the questionnaire as well as descriptions of categories or themes are presented in the research report. The report thus consists of both quantitative and qualitative data with the purpose of exploring the effects of care giving on the physical and mental health of the caregivers in HIV and AIDS programmes to determine their needs for support.

1.7   Respondents

The population in the study refers to all caregivers in the Nigel Caring Community programme. Criteria of this population determining the selection and size are:
- The type of caregiver.
- Gender.
- Caregivers, both home based and social care, whom are with the organisation for two years and longer.

A total of 22 respondents out of a population of 42 was selected and participated in the study. Determining factor for selection was the respondent's duration of stay in the programme. This probability, quota sampling technique (Rubin and Babbie: 1993: 256), is chosen after the pilot study indicated that it is difficult to obtain information on care giving from caregivers, who are in the programme for less than 2 years.

1.8 Structure of the research report

Chapter 1 is the general orientation towards the research report. It gives the motivation for the study through the problem statement, aim, objectives and research questions. It further explains the research design and research process.

Chapter 2 gives a theoretical perspective of the impact of the HIV and Aids pandemic, the caregiver and the effects of care giving on the caregiver. It further explains the needs of caregivers and provides recommendations for their ongoing support.

Chapter 3 describes the research method used for data collection. It includes details of the characteristics of the respondents and issues considered to protect the ethical rights of the respondents.

Chapter 4 is a summary of the research results. The empirical information is grouped together and discussed according to themes. The chapter concludes with a summary of the results.

In Chapter 5, which is the last chapter, the conclusions, and recommendations of the study are discussed

Chapter 2

The impact of the HIV and AIDS pandemic and effects on the caregiver – a theoretical perspective.

Introduction

As the treatment options for HIV and AIDS has expanded, so have the stresses experienced by caregivers. Many HIV- positive individuals now live longer and enjoy a better quality of life. Marked declines in rates of opportunistic infections and deaths have brought hope that HIV can be managed as a chronic disease. These changes have however created major challenges for the health professions who provide curative and palliative care and for the informal caregivers who provide emotional and practical support to relatives and friends living with the disease. O' Neill and McKinney (2003:1), are of the opinion that the prolongation of the disease causes uncertainty about overall prognosis and a "roller coaster" pattern of repeated exacerbations and remissions in later stages of the disease, intensifying the emotional and physical demands of care giving. The impact of HIV and AIDS, the concepts caring, caregiver and the effects of caring on the caregiver, the effects of care giving on the physical and mental health of caregivers in HIV and AIDS programs and their needs for ongoing support, are discussed in this chapter.

2.1 Impact of the HIV and AIDS Pandemic

According to Nampanya - Serpell (2000:1), AIDS has killed more than 16 million people since the disease was first recognized in 1981. An estimated 5.6 million adults and children became infected with the virus in 1999, bringing the worldwide total during 2000 to an estimated 50 million. The global and ecological catastrophe of this pandemic has given rise to personal tragedies for many individuals, families and communities, facing prolonged illness and premature deaths. Zambia is amongst the countries in sub-Saharan Africa most seriously affected by the HIV and AIDS pandemic. An

estimated 40,000 – 90,000 Aids-related deaths were estimated to have occurred by the end of 2000 (Nampanya – Serpell, 2000:1)**.**

The results of the 1993 HIV Sentinel Surveillance among pregnant women in Botswana, confirmed that the HIV pandemic continued to evolve in that country. The rapid spread was not only in urban, but also rural areas. Statistics have shown that 1 out of 3 pregnant woman was infected in the country's second largest town, 1 out of 5 in the capital city and between 1 out of 10 and 1 out of 5 in the rest of the country (Whiteside, 1993: 5). This placed Botswana among the most infected in the African region. As much as the situation in Botswana is of great concern for the rest of Southern Africa, many of the underlying socio-economic factors aiding to the spread of the pandemic, is also present elsewhere and most of these countries do not even have the wealth of Botswana.

In the United States of America the majority of new AIDS cases are presented by African Americans and Latinos. There is a rapid rate of increase in HIV infection among women and the youth, whilst the incidents of HIV remains high among men who have sex with men and injection drug users. Whereas the incidence of HIV and AIDS has declined in Thailand, the adult prevalence of the disease (approximately 2% of the population) remains a concern. The death of young adults does not only leave their children orphaned behind, but also affects the parents of these adults who experience the death of adult children due to AIDS before their own death. Unlike the case where young adults normally die suddenly because of an accident or violence, persons living with HIV and AIDS require substantial care as well as other resources as they become ill (Kespichayawattana and Van Landingham (2002:3).

HIV and AIDS is one of the challenges facing South Africa which will have an enormous impact on children, youth, families and communities in the coming decade (http://cc.msnscache.com/cache.aspx?2007:1). As in other countries with generalized HIV epidemics, the estimation for HIV prevalence in South Africa are based on blood samples taken from pregnant

women who are attending antenatal clinics. According to
http://www.doh.gov.za/docs/pr/2007:1, Minister Jeff Radebe in an answer to
a parliamentary question indicated that, "To date 3 382 out of 3 663 primary
health care facilities (clinics) are offering Prevention of Mother to Child
Transmission (PMTCT) of HIV. This represents 83% of public health
clinics,"   At least 580 880 pregnant women accessed the PMTCT services
during the calendar year 2006 and of these, 74 052 received Nevirapine
prophylaxis. A total of 19 758 babies born to mothers living with HIV were
tested for HIV infection of which 3 470 babies tested HIV-positive.
According to the findings of an antenatal survey conducted in 2004 (The
National department of Health 2004: 1 - 12), estimated statistics have shown
that there were globally 39, 4 million people worldwide living with HIV.
The estimated total number for positive individuals in South Africa at the
end of 2004 was 6, 2 million, with KwaZulu-Natal province reflecting the
highest prevalence (40.7%) of all HIV and AIDS cases in South Africa.

Some of the major challenges facing South Africa regarding HIV and AIDS
are:

♦   The stigma associated with HIV and AIDS infected and affected
    families and that

♦   Approximately 7 out of 100 South Africans are in receipt of a state
    grant.

Steinberg et al. (2002:7) are of the opinion that HIV and AIDS is the tipping
point for households that are already poor from poverty into destitution.
This impoverishment impact of the disease is even more acute, because it is
the economically active sector of the population who is mostly sick and
dying.

2.1.1 Sub – populations likely to be affected by HIV and AIDS

HIV and AIDS makes no distinctions between age, gender, race, religion, culture and income, but the following groups are more likely to be infected or affected by HIV and AIDS (Ross 2001:22 - 26):

♦ **Persons with transfusion-induced HIV (TI-HIV):**

These people were exposed to HIV through blood transfusion and often experience intense feelings of betrayal and disempowerment, as blood transfusion is normally part of a life-saving medical treatment. In addition of being confronted with a life threatening illness such as cancer or other serious medical condition, which necessitate receiving blood transfusions, these people must also cope with having HIV infection. For those who are already struggling with another serious medical condition, it could be extremely difficult to integrate complex medical information about HIV as well. These people and their families frequently harbour feelings of anger and mistrust towards doctors and the health care system in general.

♦ **Homosexuals:**

Many gay communities are closely knit and the loss of a friend through illness or death tends to reverberate throughout the network and restrict social supports available for those with the illness. The feelings experienced may start with shock on the side of the partner and lead to abandonment of the patient. Both partners may also experience feelings of guilt. Family members, who rejected the person's homosexuality in the past, may continue to reject an ill family member. There may also be conflict about decision making, as the family members may have difficulty in accepting the lover in this role.

♦ **Parents infected and affected by HIV and AIDS:**

For the HIV positive woman the decision to reproduce, which is normally a decision charged with love and hope for the future, is now tainted with the

prospect of infecting one's own child with a painful and lethal disease. In this case the gift of life may be bestowed together with a sentence of death. Many parents of HIV positive children express feelings of powerlessness and anger at not being able to provide for their children, as they become progressively more ill. Parents may keep their child's positive status confidential, or deny it, because of fear that the child may be rejected by other family members and friends, or loss of employment or the child's school placement, or even of the rejection of a sibling or the ostracization of the parents themselves. On the other hand denial of the child's status may prevent the child from getting the services he or she needs for a better quality of life. Parents often also experience forms of guilt.

♦ **Toddlers, children and adolescents infected and affected by HIV and AIDS:**

Children under 2 years do not understand the concept of illness and death and the prospect of separation from their parents are a concern and fear to them. Many children above the age of 3 to 4 years tend to regard death as a process of physical harm. It is therefore not surprising that they develop strong fears of needles, injections and hospitals and may later develop fears of abandonment. Emotional and behavioural problems of school- age children involve disorders of attention, but may also manifest in depression, anxiety and adjustment problems. Adolescents living with HIV and AIDS, not only face a bleak medical future, but must also live with the fear that others, for example teachers, employers and peers might find out about their condition. The fear that peers might find out about deceased parents is often greater than the fear of dying from the decease. Other reactions noted in adolescents include depression, inability to cope, resentment, guilt, concerns about how to convey the diagnosis to their parents, uncertainty on how to confront their families and concerns about having infected other persons. These anxieties often lead to poor school performance, isolation and acting out behaviours. Denial or concealment of the illness often prevents them from seeking sources of support.

2.1.2. Psychosocial issues for HIV and AIDS infected and affected individuals, families and communities

With the HIV and AIDS pandemic in its third decade, it seems appropriate to visit the psychosocial issues likely to impact on the quality of life of individuals, families and communities. On the socio-cultural level, the impact of HIV and AIDS has challenged and broadened traditional notions of what constitutes a family, prompting reconsideration of who is and who functions as a family. According to Ross (2001: 22), family members can be described as individuals who by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive and are obligated to provide support of various kinds to the extent possible, especially in times of need. On an operational level this family includes the spouses, lovers, children, parents, siblings, friends and caregivers of the person with AIDS (Ross 2001:22). The psychosocial impact of HIV and AIDS on families usually begins with the disclosure of HIV infection, which may be how spouses and partners learn for the first time of the affected partner's bisexual, drug-using or commercial sex activities. Besides the fear of being infected themselves as partners or spouses, the previous image of family life is also shattered. Caring for an individual with an HIV and AIDS- related disease is usually time consuming, burdensome and unpredictable and may place an unbearable strain on the family or marital system. Acute or fatal illness may also occur in several members of the same family, which is a factor of major impact on families living with HIV. Reactions to and feelings of the families include:

♦ Social stigma and isolation.
♦ Fear of contagion, which may limit intimacy or involvement of a lover and parent.
♦ Fear of infecting others or straining their lowered immune system.
♦ Fear of abandonment, as caregivers cannot cope with the physical and emotional demands of care giving.
♦ Guilt for having estranged them from the ill individual because of his or her gay or drug-using lifestyle, or

♦ Guilt about having been spared from infection and psychological and physical fatigue.

2.1.3. Social and economic risk factors for HIV and AIDS infected and affected individuals, families and communities

The following information is based on studies on the economic impact of the AIDS pandemic at household level in rural and urban communities of Zambia (Nampanya – Serpell, 2001) and 771 households in South Africa (Steinberg et al 2002: 17). The households in South Africa are situated in rural or urban parts of Gauteng, Mpumalanga, the Free State and KwaZulu-Natal provinces. These studies show that the pandemic has the following impact:

♦ **Change in the socioeconomic status**

When the father as the breadwinner died first, households were more likely to suffer economically than those in which the mother died first. A considerable drop in the income and/ family assets constituted a reduction of monthly disposable income by more than 80% for those families (Nampanya – Serpell 2000: 8). 1n urban areas, the worst affected families were those in which the major breadwinner was the first person to die. These families had experienced a sharp drop in income, and in most cases had been forced to move out of their original home. Steinberg et al (2002: 17), indicated that as households became more desperate, assets were sold to raise funds. One example was a household, which reported selling the shoes of a child to pay the child's school fees. Expenses more likely to be cut down were clothing and food, as households had to cope with a drop in income as well as an increased demand for healthcare spending.

♦ **Family displacement**

Family displacements became a major issue in the urban areas. In Zambia the majority of the HIV and AIDS- affected families (61%) had moved from their original homes, which had been provided by the deceased parents'

employers to cheaper housing on the outskirts of Lusaka (Nampanya – Serpell 2000: 8). Most also moved from relatively wealthy neighbourhoods, with good schools, electricity and piped water supply to poorer sites and service housing and compounds, sometimes without electricity and or piped water. Some families had to rent out some of their rooms for income. This resulted in crowding as many as five children into one room. The worst affected families in the urban areas, were those in which the major breadwinner was the first parent to die. Whilst family displacement was a major issue in the urban areas, labour loss was a critical issue in the rural areas. The majority of the deceased fathers were subsistence farmers. Upon their death the food security of their surviving families became threatened since most of the heads of the households were now maternal grand parents who lacked the energy or resources to grow more food.

Steinberg et al (2002: 22), indicated that HIV and AIDS caused families to split up even before the parents died, because of the strain of coping with the disease. Children were sent to live somewhere else and although some ended up with family members and in institutions, some households ended up not knowing the whereabouts of their children.

♦ **Educational continuity**

According to Nampanya – Serpell (2000: 1), Zambia was one of the countries in Sub Saharan Africa most seriously affected by the HIV and AIDS pandemic. The impact of HIV and AIDS on the educational continuity of children was different for rural and urban orphans. The frequency of dropping out of school following parental death, was much lower for orphans in economically better off families than for orphans in poorer households. There was also a gender difference. Boys were less likely to drop out of school after parental deaths than girls, especially after the 5th grade of schooling. Orphans, who were dispersed within the extended family after parental death, were also less likely to stay in school than those kept together as one family unit. For orphans in the rural areas the educational impact was, affected by age of the orphans and not socio-economic status, or gender. The drop-out rate for older children was much

higher, because caregivers withdrew older orphans from school to help take care of their younger siblings and to work in the fields. According to Nampanya – Serpell (2000: 13), a similar scenario was found in studies in Thailand cited by the 1997 World Bank report. It was found that 13% of older school age children in families where someone was ill and dying of AIDS were withdrawn from school to help support the family (Nampanya – Serpell 2000: 13). In urban areas, proactive intervention by service agencies protected the oldest surviving girl from dropping out of school and eventually being able to perform a more effective role in providing for the care of her younger siblings.

♦ **Health and Nutritional impact**

Age is a significant factor to predict the nutritional status of orphans in both the urban and rural areas. The younger the child, the worse their nutritional status and the poorer the household, the worse the nutritional status of the orphans (Nampanya – Serpell, 2000: 16 – 18).

♦ **Policy implications**

According to Nampanya – Serpell (2000: 16 – 18), the design of policies and services became relevant to mitigate the impact of AIDS on AIDS-affected families and their children. Different approaches were required to help rural and urban-based orphans to remain in school. Selective exemption or subsidy of school fees was considered as an appropriate and effective strategy in urban areas. In rural areas a more effective strategy was to consider assisting affected families to cope with their loss of labour to be able to keep older orphans in school after parental death. An example in Zambia is communal labour sharing, where villagers form teams to help the neediest families plough and harvest fields. The family who is assisted would traditionally provide food and refreshments to the men and women who come to help. This practice could be subsidised by service agencies.

Since age seems to be a critical factor when it comes to health and nutritional issues, "direct targeting" and "characteristic targeting", as policy

options were indicated by the World Health Organisation (WHO), to protect young children. "Direct targeting" involves, for example, exempting low-income populations from paying user charges to ensure that they have access to health care. In the case of "characteristic targeting", exemptions or subsidies are offered to people with certain attributes such as infants, the elderly or people with certain illnesses, such as TB or HIV an AIDS affected families, regardless of income levels. These targeting strategies were to protect the health of vulnerable populations (Nampanya − Serpell, 2000: 16 − 18).

A proactive method to target HIV and AIDS affected families, was to expand the service protocol for patients receiving treatment for AIDS. Patients, who are parents of young children, would for example qualify for a home visit to identify the most vulnerable or "at risk" children. This would be followed by nutritional surveillance and provision of supplemental feeding where necessary and or social and economic support to caregivers to enable them to provide adequately for the children.

2.2   HIV and AIDS care

According to Smart (1999:13), HIV and AIDS care can be defined as "care for those uninfected but at risk; asymptomatic HIV-positive individuals; those with early HIV disease; those with late HIV disease/AIDS; and those who are terminally ill." Care and support needs are however very different at the different stages. The objectives of HIV and AIDS care should therefore be understood as they relate to the patient, his/her family, the community and the caregivers as described in the following package:

♦ **Patient:** To reduce suffering and improve the quality of life; provide adequate treatment of acute inter-current infections.
♦ **Families**: To render practical support; lend bereavement support.
♦ **Care givers**: To improve the quality of care; provide support.
♦ **Communities:** To improve the capacity to cope; reduce stigma.
♦ **Health services**: To reduce pressure on services; safe costs.

The above care package should be judged according to its appropriateness, acceptability, accessibility, effectiveness, efficiency and equity.

2.2.1 Physical and psychosocial aspects of care

To meet the physical needs of people living with AIDS involves a sound understanding of medication, both preventative and palliative and the appropriate nutrition. Preventative medicine consists of anti-retroviral drugs, which may inhibit the spread of the HIV virus for a number of years. Palliative medicine includes control of pain and treatment of AIDS-related opportunistic infections.

Social support is as much a requirement of improving the quality of life of people living with AIDS, as the physical aspects. This may take 3 forms:

♦ **Formal counselling**. Social workers and psychologists who help the person cope with his or her loss of autonomy, privacy and control, provide this type of support. They also support the patient in overcoming grief, facilitate the conquering of guilt, combat denial, allow patients to ventilate anger and to develop coping mechanisms to combat anxiety, depression and suicidal tendencies.

♦ **Informal psychological assistance.** Is provided by caregivers and includes the same aspects of help as provided by counsellors.

♦ **Spiritual support.** According to Cooper (2000:127), spirituality forms an integral part of palliative care, is about anything, which relates to the spirit and is not confined to religious beliefs. It includes issues such as the meaning and purpose in life, search for hope, attitudes to other people and relationships. Spirituality is important for both the carer and the patient.

2.3   The Caregiver or Volunteer

According to Van Delft (2002:15), the history of human existence tells us that there were always people who without compulsion or reward, have cared for those in need. Long before Social Work became an organised profession to render assistance to people experiencing various types of need, many people and organisations, including the church and other religious institutions have already started to give charity and distress relief to individuals, families, groups and communities. This "built in" element in people that moves them to help others is called the "caritas" element, a term derived from the Latin and literally means "love" (Van Delft, 2002:15). Coupled with this element of charity is the issue of social order, which carries the meaning that people should live as effectively as possible. People have an inherent urge for survival. This, together with the inherent characteristic to care about each other, is what enhances the quality of life.

Like many other countries, especially those in Southern Africa, South Africa is currently fighting the HIV and AIDS pandemic. Besides the fact that there are more than 5 500 registered welfare organisations and other non-governmental organisations who share a "fellow-feeling", in the midst of this "terrible" disease," the charity and "caritas" attitude amongst South Africans, is remarkable (Van Delft, 2002:17). It is these charity and "caritas" elements in people that make them become volunteers and eventually take up the role of being caregivers. Caregivers, therefore, need to have the characteristics of volunteerism first, before they can become caregivers.

2.3.1   Description of volunteerism

Whether informal or formal, volunteering can be described as an opportunity to do something positive and rewarding, whereby people invest in each other without seeking financial gain. This generating of giving and sharing makes everybody feel valued and appreciated. It is also a platform for community development and social cohesion and generates networks of friendship and support. It often opens doors to discover untapped energies,

creativity and skills within of which a person is unaware until he or she gets involved (http://www.volcomm.org.uk: 1). Volunteering can further be described as any activity, which involves spending time unpaid, doing something which aims to benefit someone (individuals or groups) other than or in addition to close relatives. It is important to distinguish between formal and informal volunteering. Informal volunteering is volunteering on an individual basis whereby one person is helping another, while formal volunteering takes place on a collective basis. People get together through groups, clubs or organisations to help others, as in case of the Nigel Caring Community Organisation.

2.3.2   Types of volunteers

A volunteer can be defined as "a person who enters or offers to enter into any service of his (or her) own free will with no promise of compensation (http://www.volvomm.org.uk: 2007:01)." The following types of volunteers are discussed in http://www.centerforhospice.org/volunteertypes.htm (2007:1):

♦ **Patient care volunteers**, who provide companionship to patients.
♦ **Extended care facility volunteers**, who provide companionship in extended care facilities, e.g. nursing homes.
♦ **11th hour volunteers,** who provide care and support on an "on call" basis when the patient is near death and resides in an extended care facility.
♦ **Hospice house volunteers,** who provide care and support to patients in facilities and their families.
♦ **Office volunteers,** who provide clerical assistance to organisations.
♦ **Bereavement volunteers,** who provide emotional support to the grieving families.
♦ **Fund raising volunteers,** who provide assistance with fundraising for e.g. hospice homes.
♦ **Board volunteers**, who are those motivated business or professional people and family members who have an interest in the operation of a specific organisation.

♦ **Community volunteers,** who are those people who live in the community and spend time volunteering with the people supported by an organisation. The things they do include shopping, picnicking, dining out or caring for the needs of terminally ill patients and their families. The Nigel Caring Community Caregivers fall within this group of volunteers.

♦ **Student volunteers,** who are those students who spend time volunteering under a service learning program. This gives the students an opportunity to learn more about e.g. people with disabilities or children with difficult behaviour. Students normally volunteer for a specific time.

In http://www.stc-dfw.org/newsletter0510/2501.htm (2007:1), McCleland and Atkinson make the following distinction between volunteers in terms of their motivation:

Achievement - motivated volunteers. The goal of this type of volunteer is to be successful in a situation through excellent or improved performance.

Power - motivated volunteers. This type of volunteer tries to have an impact or influence on others.

Affiliation – motivated volunteers. The goal of this group is to be with others and to enjoy mutual friendship.

According to the above description of volunteerism and types of volunteers the caregiver forms an integral part of volunteerism.

2.3.3 Types of Caregivers

The two types of caregivers providing clinical care and supportive services to people with HIV and AIDS are:

♦ **Formal caregivers**: Include professional, behavioural health specialists and social workers who are trained and compensated for their care giving activities.

This category also includes trained volunteers, spiritual counsellors associated with AIDS service organisations, AIDS care teams and hospice programs.

♦ **Informal caregivers**: Include relatives, spouses or partners and friends who provide in-home care on an unpaid basis.

The focus of the study will be on formal caregivers, but it is important to mention that by adhering to treatment regimes, informal caregivers often prevent unnecessary hospital admissions, reduce the reliance on formal caregivers, keep patients at home longer and maintain their quality of life. Informal caregivers can play an important role in identifying and managing symptoms and side effects and yet are mostly thrust into these roles with little or no training (O'Neill and McKinney 2003:3). Many of the burdens experienced by formal and informal caregivers are the same.

Caregivers involved in the Nigel Caring Community Organisation, are formal caregivers who receive in- service training to operate as community home- based caregivers or social caregivers. Community home- based caregivers are responsible for the physical care of the patient e.g. bathing and dressing of wounds. The social caregivers are responsible for practical tasks such as application for birth certificates. The functions of both groups, however, fall within the framework of palliative care.

2.4   Effects of caring on the caregiver

According to http://www.birf.info/suport/caregivers/for-caregivers.htm1 (2007:1), care giving is a demanding job and the responsibilities cannot be shirked, nor can it always be delegated. It requires physical and emotional reserves that occasionally exceed those of even the healthiest persons. Besides the physical toll, HIV and AIDS survivors and service providers both suffer a form of post-traumatic stress syndrome from the loss, fear, incredible suffering and indignities the disease and associated discrimination call forth (Ross 2001:20). According to De Bruin and Van der Hoeven (1994: 6), the AIDS pandemic does not only affect individuals or families, but threatens entire communities more and more. This makes a

community approach and the need for community home based care programs essential in caring for the HIV and AIDS patient and his/ her family. Miller (1995:17) is of the opinion that being a caregiver can be a deeply meaningful way to spend your days on earth, but it is also not easy to be a caregiver. As the person with AIDS is vulnerable to many physiological, social and emotional affronts, the caregiver may also faces numerous battles in his or her effort to remain effective in the delivery of care. According to O'Neill and Mc Kinney (2003:3), psychologists use the term "caregiver burden", to describe the physical, emotional, financial and social problems associated with care giving. It is therefore important to explore the physical and emotional effects that caring for the HIV and AIDS patient has on caregivers.

Caregiver stress can be divided into primary and secondary stress. Primary stress comes from everyday care giving duties, such as assisting the patient with bathing, toileting and managing the patient's difficult behaviour as well as planning of daily care. Causes of secondary stress include caregiver conflict with other family members (own family or patient's family), economic hardship e.g. loss of work and income, limitations on personal leisure and social activities.

Care giving places limits on the caregivers' social life in the sense that they receive fewer visits from their friends, spend less time with their hobbies and in their house of worship and their vacations often suffer.

2.4.1   Physical effects

According to Leblanc, London and Aneshensel (1997: 915 – 923), informal care has become an increasingly important element in the delivery of health and social services to people living with the HIV virus or AIDS. Yet the provision of such care does not come without cost to the caregiver. Care giving imposes burdens that may compromise caregiver health. Symptoms of poor physical health are markedly present among AIDS caregivers and are significantly associated with care-related demands and stressors. The level of depression for caregivers strongly correlates with physical ailments.

The multiple tasks performed by caregivers often result in them neglecting their own self-care, such as nutrition, exercise, socialisation and sleep. They have the tendency to develop negative health behaviours such as overeating, smoking, not exercising and sleep patterns are disturbed (sleep less than non-caregivers). Some caregivers, especially women, gain weight. The caregivers' immune system weakens and the healing of wounds is often affected.

This caregiver burden often produces high levels of chronic stress resulting from the intensity of the care giving activities, role overload, family frictions or reduction in social contacts. Researchers use the term "caregiver burden" to describe caregiver stress http://www.caregiving-solutions.com/carsters.htm1 2007:1).).

Factors that contribute towards caregiver burden are:

♦ Emotional and physical factors. Caregivers who are angry and resentful reported that they feel more burdened.
♦ The attitude of the caregiver towards the patient. In cases where the caregiver attributes a patient's troubled behaviour to the patient's illness, rather than the patient's wilfulness, the caregiver feels less burdened. If the caregiver sees the patient as less emotionally demanding, but rather disabled, the caregiver burden is less.
♦ Behaviours and attitudes expressed by the patient. Caregivers' burdens tend to increase when patients constantly ask them questions.

2.4.2 Emotional effects

According to Ross (2001:26), the psychosocial issues for professionals, but also for other people working in the field of HIV and AIDS generally include:

♦ **Discriminatory attitudes towards socially stigmatised groups:**

Many family members and patients have reported that they have experienced discrimination and negative attitudes and behaviour from service providers (Ross 2001: 26). Responses documented in the literature include: blaming of the victim for his or her low socio-economic status or drug taking, assigning of negative characteristics to patients belonging to certain racial groups, providing poor quality care and a reluctance or refusal to work with the population sub-groups, most likely to be infected with HIV and AIDS.

♦ **Homophobia:**

Caring for AIDS patients may be a health care provider's first experience in working with overtly gay clients. Some females may have difficulty in working with lesbians, resulting in their non-verbal behaviour revealing unspoken messages of disapproval of for example the client's dress. Other manifestations of homophobia include making comparisons between homosexuals and physically disabled persons, pointing out of lost life opportunities such as marriage and children and implying that the disease is a punishment for variant sexual behaviour. These homophobic attitudes can be a potential source of stress and discomfort for service providers and can interfere with the provision of quality care to the person with HIV and AIDS (Ross 2001: 27).

♦ **Issues of human sexuality:**

There is a discomfort amongst health care workers in dealing with sexuality in general and with a disease such as HIV and AIDS, that is usually sexually transmitted in particular (Ross, 2001:27). This discomfort can lead to inadequate sexual history taking, which is necessary for diagnosis and treatment. If caregivers are unable to accept the patient's sexuality, they might also be unable to respond adequately to the needs of the patient's support system such as parents and homosexual lovers. If the caregivers'

own current or past sexual behaviour put them at risk for HIV exposure, the discussion of AIDS prevention may elicit reactions of guilt and anxiety.

♦ **Fear of contagion:**

The fear of contracting the disease has been noted as a concern among professionals and many regard working in the field of HIV and AIDS as a high risk occupation. This fear is further exacerbated by difficulties experienced in maintaining consistent and appropriate infection control precautions. Despite the well-documented fact that the AIDS virus can only be transmitted through bodily fluids, there are still health care workers who harbour irrational fears of contagion taking place through casual contact, or touching the patient's clothes, bedding, eating utensils or bathing facilities. This fear may result in physical or empathetic withdrawal from persons with HIV and AIDS, resulting in clients being deprived of physical and emotional contact, a most valued intervention, which could make them feel unclean and contaminated. These factors can cause considerable stress, anxiety and discomfort for the client as well as the person working with the AIDS patient.

♦ **Ethical and Legal dilemmas:**

The more pertinent moral and legal challenges raised by the AIDS pandemic include issues such as:
➢ The prolonging of life in treating a technology-dependant condition.
➢ Confidentiality.
➢ Ethical responsibility to patients and profession of the health worker.
➢ Conflict with personal biases.
➢ Duty to warn a spouse or sexual partner.
➢ Dilemmas raised in research with experimental drugs.
➢ Isolation of those thought to be infected.
➢ Unequal access to health care and drugs such as AZT and Nevirapene.
➢ The rights of pregnant women to terminate a pregnancy or of HIV infected women to become pregnant.

➢ Determination of valid consent when competency is declining because of dementia.

➢ Morality of rational suicide.

An additional source of stress is that health workers are often designated as the "keepers of secrets" (Ross 2001:28). Children, adolescents and elderly people are often not informed that they are HIV positive. Family members are not always told about the illness of an adult, child, parent, spouse or sibling and schools, clinics and other organisations are not necessarily given full details about the HIV status of individuals referred to them. The keeping of the secret not only depletes emotional energy and causes inner conflict and isolation, but also affects the ability of the health care provider to establish and maintain a professional relationship. All these ethical dilemmas, together with a lack of appropriate community resources and facilities, can make the caregiver in the field of HIV and AIDS experience a sense of professional inadequacy.

♦ **Issues related to chronic or terminal illness, death and dying:**

Health care workers have been known to express feelings of anger, depression, frustration, despair and powerlessness for not being able to influence the course of the disease. It is also extremely stressful working with people who are often healthy, while facing the possibility of their becoming seriously ill in future. The death of a client can also be extremely traumatic for health care professionals and is likely to elicit existential questioning of their own mortality. This can exacerbate the strain of working in this demanding and challenging field (Ross 2001:28).

♦ **Burnout:**

The above mentioned psychosocial stresses are some of the burdens accompanying the work of health care workers. The worker himself or herself then begins to feel overwhelmed by what the individual and family members have to face emotionally, financially, socially and spiritually. Burnout defined as, "a syndrome of emotional exhaustion, depersonalisation

and reduced personal accomplishment that can occur among individuals who work with people (Ross 2001:29)," is often the result of these stresses.

It is important that health care professionals are aware of the signs and symptoms of occupational stress and burnout, how burnout develops and how it can be prevented. Caregivers, who are experiencing work overload and interpersonal conflict over a period of time, are particularly vulnerable to burnout (O'Neill and Mc Kinney, 2003:6). Supervisors should establish support groups to facilitate the expression and discussion of feelings and provide health care and counseling.

According to Bennett, Ross and Sunderland (1996: 145 – 153), most studies on stress and burnout in AIDS health care, have focussed on the negative and difficult aspects of this work, while few have considered the notion that the rewards of care giving may buffer against stress or counterbalance experiences that may otherwise lead to burnout. AIDS patients require intense physical and emotional care and the terminal nature of the disease adds to the stresses of providing psychosocial as well as physical care. Many carers report the problem of becoming too involved or attached to their patients. Staff can often see similarities between patients and themselves. They often identify with their patient's situations and form close relationships with them. The result is that when the patient's situation deteriorates the sense of loss and the impact on carers is very great. According to Bennett et al (1996:146), there is little information available on the positive psychosocial dimensions of AIDS work. This could be influenced by factors such as the greater prevalence of negative responses and the fact that positive responses are infrequently sought out. Research indicates that higher scores on recognition and reward correspond with lower levels of reported burnout.

According to Bennett et al (1996: 145 – 153), social rewards and recognition items include the following (and may be different to that experienced in other carer's roles):
"My friends recognise that my work in the area of AIDS is a valuable contribution to society."

"I receive status and recognition due to my involvement in the area of AIDS."

Personal effectiveness refers to the volunteers' perception of the effectiveness of his or her work, for example, doing something worthwhile.
Emotional support refers to the volunteer's emotional support from inside and outside the organisation, for example being cared about.
Social support refers to satisfying social activities, for example having autonomy.
Empathy or self-knowing refers to the personal growth of the volunteers and empathy for their clients.

Four primary stress factors identified are emotional overload, client problems lack of support and lack of training.

Results showed that lack of training and absence of personal effectiveness are both independently associated with burnout frequency. A lack of a sense of personal accomplishment is a major contributor to frequency of burnout. As cited in Bennet et al (1996:148), it is useful to see burnout as a function of the balance between stressors and rewards and that rewards may act as a buffer against burnout. Both feelings of lack of adequate training and gaining a sense of personal impact and effectiveness are significant predictors of burnout. It is therefore important to assess whether stressors or rewards are significant by their presence as well as by their absence. Stress and motivation both enhance the degree of reward. Volunteers, who perceive themselves to be effective in their role experience less of a perceived desire to withdraw from the agency. A recommendation could be to assist volunteers with their work rather than with personal needs.

High burnout levels are also seen among volunteers who are supplementing the work of paid staff. Burnout, characterised as a syndrome "that occurs frequently among individuals who work with people (Maslanka 1996:195 – 206)," has long been a phenomenon of interest among the health care professionals. HIV and AIDS- related illnesses place unprecedented demands on volunteers as the breadth and intensity of problems with which

the volunteer deals is unique. Volunteers are encouraged to see the agency as a support but also to rely on the support of a volunteer team for help in the work they do. Elements of social support can be the extent to which volunteers are perceived as being listened to, the extent to which they are helped by others and the extent to which they can rely on others. A reward for volunteer work is an important part of the volunteer experience and includes factors such as new values, efficacy and community appreciation. Other factors to be considered are the length of volunteering, social support, stressful life events, and motivation to volunteer.

2.5 Principles of care giving

According to Miller (1995:17), care giving can be both rewarding and demanding. The caregiver should therefore maintain a balance as he or she cares for others. They give the following guiding principles to help him or her make the most of his or her care giving experience:

2.5.1 The healthiest way to care for another is to care for yourself.

> When caring becomes an essential part of one's life, then caring for the self is just as important as caring for the other person. The caregiver's physical and mental health is vital to the wellbeing of the person who is ill. It is helpful to the patient to know that the caregiver is taking care of him or herself. This can be done through rest and exercises, by sleeping well and eating wisely. Give yourself time off and time away. Be among people who support you, affirm you and uplift you. Open yourself to the healing touch of nature, pamper yourself, love yourself and allow yourself to experience joy. It is important for caregivers to maintain family and friends and to talk problems out in a support group to maintain an optimum immune system functioning (http://www.caregiving-solutions.comcarstress.html 2007:1).

2.5.2 By focusing on your feelings, you can focus beyond your feelings.

Genuine care giving involves the caregivers' emotions. It is therefore important for the caregiver to find someone or even several people with whom he or she can talk and give voice to what he or she feels. He or she may experience feelings of frustrations, fear and sadness. Joy or love might be cried out, laughed out or could be written out, danced, sung or prayed about. By focusing on his or her emotions, and sharing them with others, or releasing them in different ways, the caregiver can ensure that their personal feelings do not get in the way of their care giving.

2.5.3 To be close, you must establish boundaries.

The caregiver might almost merge with the other person, by feeling his or her feelings and pain and fearing his or her fear. A good caregiver must be able to maintain his or her separateness. Setting boundaries is a way of protecting the self.

2.5.4 In accepting the helplessness of your helping, you become a better helper.

The caregivers have the tendency to try to do too much. To understand and accept what you as a caregiver cannot help and should not help with, you create opportunities for genuine care giving to happen.

2.5.5 Care giving is more than giving care. It is also receiving care.

You gain when you give from within yourself and out of the depths of who you are. Through this care sharing, a partnering develops between the caregiver and the patient.

2.5.6   The caregiver's strengths lies in his/her flexibility.

Care giving is not a time to try to be perfect. Strengths should be expressed through gentleness, a tender touch, talk, sensitive interactions and expectations.

2.5.7   Sacredness lies in the everydayness of the caring.

By engaging in the simple acts of care, signs that the divine is in your midst is seen in another's face, is felt in touches and heard in the voice.

2.6   Other recommendations of how caregivers can take care of themselves.

Caregivers should further take care of themselves in the following ways (http://www.plwc.org/portal/site/PLWC/menuitem:2007:1):

2.6.1   Avoiding feelings of being overwhelmed by:

♦ Finding support. Talking to other caregivers can help caregivers cope better with their own feelings of anger, isolation, sadness or grief. Social workers may be able to connect caregivers so that they form support groups.

♦ Doing something they enjoy. Despite the needs of the person who is ill, it is important for caregivers to make time for themselves. This implies doing something regularly that gives them strength, peace and joy. Examples are getting together with friends, painting, drawing or playing music, watching a movie, and attending religious services. Caregivers should not feel guilty for finding their pleasure, because it helps to distract them and to keep them well.

♦ Asking for assistance. Churches or community groups are often willing to assist. Caregivers should accept their help and give them specific tasks to do.

- ♦ Recognising the signs of stress and trying to make changes to help reduce it.

- ♦ Being kind and patient to themselves. Examples of positive ways to cope with feelings of anger and frustration can be exercising or talking to friends. Caregivers sometimes only need somebody to listen to them without giving advice or making comments.

2.6.2 Practical tips to help to relieve anxiety are to:

- ♦ Determine what thoughts are causing the anxiety.
- ♦ Talk to someone.
- ♦ Seek the help of a support group, religious advisor, psychologist or family counsellor.
- ♦ Increase pleasant distracting activities.
- ♦ Increase companionship and spend time with family and friends.
- ♦ Practice relaxation techniques, such as meditation, music therapy, mild exercises and yoga.

2.6.3 Identify personal barriers

To remove personal barriers to self-care is to identify what is in your way for example:

- ♦ Do I feel that I have to prove that I am worthy of the patient's affection?
- ♦ Do I think that I am selfish if I put my needs first?
- ♦ Is it frightening to think of my own needs? What is the fear around this?
- ♦ Do I have trouble in asking for what I need? Do I feel inadequate if I ask for help?

As human beings we base our behaviour on thoughts and beliefs, attitudes and misconceptions and continuously attempt to do what cannot be done and want to control what cannot be controlled. The result is feelings of continuous failure and frustration and often an inclination to ignore our own needs. It is therefore helpful to continuously ask oneself what barriers are in the way and is keeping one from taking care of oneself.

2.6.4   Moving forward

Once we have started to identify our personal barriers to self-care, we can begin to change our behaviour and move forward.

2.6.5   Reduce personal stress

Stress felt by caregivers is not the result of their care-giving situation only, but also the result of the perception of the care giving. The ways in which a person perceives and responds to an event, determines the manner in which he or she adjusts and copes with it. A person can see a glass as half full or half empty. It is, however, important for the caregiver to remember that he or she is not the only one in the care giving situation.

2.6.6   Steps to managing stress

- ♦ Recognise warning signs for example irritability and sleep problems early.
- ♦ Identify sources of stress and the inability to say no.
- ♦ Identify what you can and cannot change. It is important for the caregivers to remember that they can only change themselves and not other people.
- ♦ Take action. Action to reduce stress, which can be in the form of exercise, gardening or having coffee with a friend, can give the caregiver back a sense of control.

2.6.7   Setting goals

Setting goals or deciding what one would like to accomplish in for example the next three months is an important tool for the caregiver to take care of him or herself. Examples of goal setting are:

- ♦ Taking a break from care giving.
- ♦ Getting help with care giving tasks.
- ♦ Feeling healthier.

2.6.8   Decide on action steps

Goals are normally too big for them to be accomplished all at once. A goal is more likely to be reached if it is broken up into smaller action steps. Examples of action steps are to walk three times a week for ten minutes or to take a day off per month.

2.6.9   Seeking solutions

To seek solutions for difficult situations is one of the most important tools in care giving. If a problem is identified, taking action to solve it might not only change the situation, but also changes it to be a more positive one and give the caregiver more confidence in his or her abilities. Steps to seek solutions are to:

♦ Identify the problem. It is important that the caregiver look at his or her situation with an open mind. The caregiver might think that he or she is constantly tired, when the difficulty is that he or she believes he or she is invincible and has to do everything himself or herself.

♦ List possible solutions for example ask for assistance with care giving tasks.

♦ Select one solution from the list.

♦ Evaluate the result for example how well did the choice work.

♦ Try a second solution, but don't give up if the first choice did not work.

♦ Use other resources, such as family and friends, for suggestions.

♦ If nothing helps, it is also helpful to accept that the problem cannot be solved.

2.6.10   Communicate constructively

If a caregiver communicates in ways that are clear, assertive and constructive, he or she might be heard and get the help and support they need.
The following are basic guidelines for good communication:

♦ Use "I" messages instead of "you" messages.

- Respect the rights and feelings of other people. Remember that the other person also has the right to express feelings.

- Be clear and specific. Speak directly to a person and don't hope that the person may be able to guests what it is what you need. When both parties speak directly, the chances of understanding each other are greater.

- Be a good listener, because listening is the most important element of communication.

2.6.11 Ask for help and accept it

Help can come from community resources, the caregiver's own family or professionals. It is better for the caregiver to ask for help, than to wait until he or she is overwhelmed, exhausted or starting to suffer from health problems. Reaching out for help when it is needed is a sign of personal strength rather than a weakness.

2.6.12 Start to exercise

A person can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities such as walking and gardening. Exercise promotes better sleep, reduces tension and depression and increases energy and alertness (http://www.birf.info/support/caregivers/care-effectshtml :2007:11).

2.6.13 Learning from their emotions

It is strength to recognise when emotions are controlling one, instead of being able to control emotions. Emotions carry messages that need to be listened to. Feelings of guilt, anger and resentment can contain important messages. The caregiver should listen to them and take action. If the caregiver is for example unable to enjoy an activity that he or she used to enjoy and emotional pain starts to over-shadow all pleasure, it is time to seek help or treatment. The caregiver might have to make a change in his or

her care giving situation, grief a loss, or need to be assertive and ask for what he or she needs. A summary of self-care practices is:

♦ Learn and use stress-reduction techniques.

♦ Attend to one's own healthcare needs.

♦ Get proper rest and nutrition.

♦ Exercise regularly.

♦ Take time off without feeling guilty.

♦ Participate in pleasant, nurturing activities.

♦ Seek and accept the support of others.

♦ Seek supportive counselling when it is needed, or talk to a trusted friend or counsellor.

♦ Identify and acknowledge feelings.

♦ Change negative ways of viewing situations.

2.7 Summary

These days caregivers are increasingly handling tasks previously done by health care professionals. Caregivers should therefore realise that they cannot stop the impact of a chronic or progressive illness, such as HIV and AIDS, of the person for whom they care. It is, however, important that they take responsibility for their own personal wellbeing and to have their own needs met.

"While care giving is not always easy, it is certainly worth the effort it takes, because someone is helped, loads are lifted, wounds bound, freedom restored and life renewed (Miller 1995:22)." It certainly also teaches the caregiver a great deal about courage, compassion, life, death and the human spirit.

Chapter 3

Research method

Introduction

An exploratory, qualitative and quantitative study was conducted to determine the effects of care giving on the physical and mental health of caregivers in HIV and AIDS programmes and their needs for support.

3.1   Research design

Rubin and Babbie (1993: 332 – 430), discusses three research methods namely, survey research, field research and unobtrusive research. According to Rubin and Babbie (1993: 34), survey research, which was used for this study, is probably the most frequently used and best method available for observation in social sciences. Original data is collected to describe a population too large or complicated to observe directly. Through careful probability sampling the characteristics of a group of respondents are taken to reflect those of a larger population. Survey research is used for descriptive, explanatory and exploratory purposes and individual people are the units of analysis.

3.2   Sampling

The two types of sampling explained by Rubin and Babbie (1993: 220 – 260), are probability and non-probability sampling.

Factors to consider when selecting the sample are the representavity of the population and reliability of caregivers in the Nigel Caring Community programme. A list of all caregivers was obtained from the manager of the programme, which indicated the following characteristics of the population:

Table 1 : Population characteristics

Types of Caregivers		Gender		Duration in Organisation	
Community home based caregiver	Social caregiver	Females	Males	Less than 2 years	Two (2) years and longer
21	21	36	6	19	23

Table 1 indicates that the number of female caregivers and those involved in the organisation for 2 years and longer is in the majority.

The researcher met with the entire population to explain the purpose of the study and the method to be used. All volunteers indicated their willingness to participate in the study. According to literature the effects of care giving on caregivers are related to the length of time care giving has been done. This was proved in a pilot study during which interviews were conducted with 8 caregivers in the programme. Four of the caregivers were in the programme for 7 to 8 years and 4 for less than 2 years. In the case of the latter the volunteers had not even been in the programme for a year. It was therefore difficult to get information from them due to their lack of experience in care giving.

While all the caregivers had an opportunity to be selected in terms of probability sampling, the pilot study indicated that it would be more feasible to concentrate only on caregivers who had been in the programme for 2 or more years.

The determining factor for inclusion in the study was the length of time in the programme, thus probability quota sampling was done (Rubin and Babbie, 1993: 256). Probability and quota sampling were combined but the effectiveness remained to be seen. This study however proved that it could be an effective sampling technique.

3.3   Characteristics of the respondents

Respondents for this study had to be volunteer caregivers in the Nigel Caring Community HIV and AIDS organisation for a period of 2 years or more. Of the 23 selected caregivers 22 were interviewed. One was not available because of absence from work due to death in the family.

The characteristics of the respondents are as follows:

Pie Chart 1: Type of caregiver (n=22)

23%

☐ [Community home based caregiver (n=17)]

■ [Social caregiver (n=5)]

77%
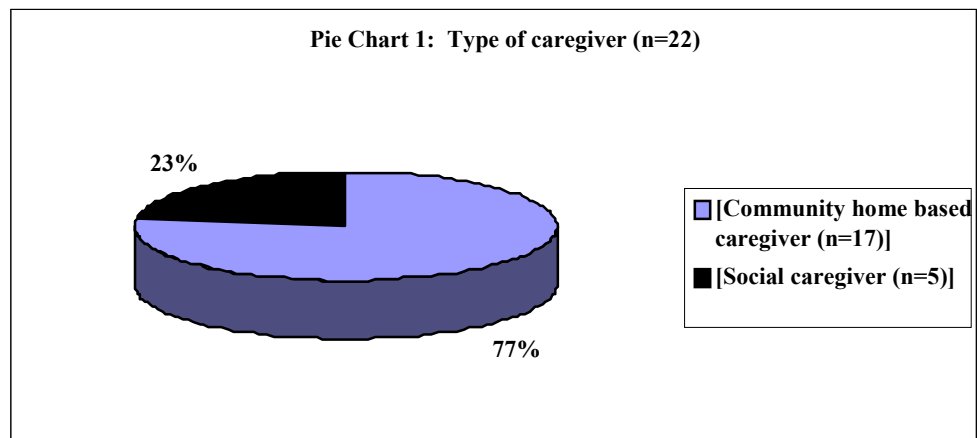
Pie chart 1 indicates that the majority (77%) are community home based caregivers, responsible for physical, emotional, social, economical and spiritual care as well as issues related to death and dying. Social caregivers are not directly responsible for the physical care of the patient, but deal with issues such as applications for birth certificates, social grants, food parcels and funeral arrangements.

Pie Chart 2: Age distribution of the caregiver (n=22)

5%   5%   9%

18%

63%

[20-29(n=2)]
[30-39(n=14)]
[40-49(n=4)]
[50-59(n=1)]
[60-69(n=1)]
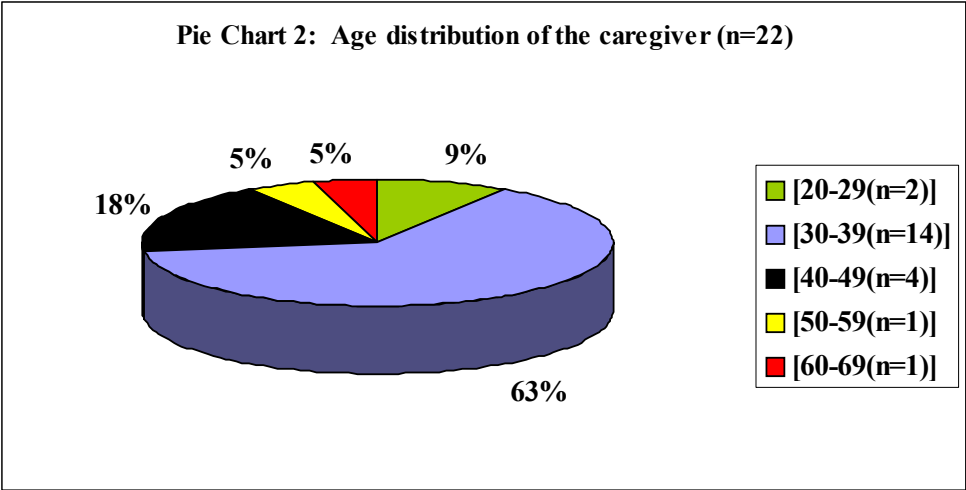
According to Pie chart 2, the majority (63%) of caregivers are between 30 and 39 years old. These are the ages during which most people are economically active, are married or are involved in stable relationships, have children to raise and are expected to be socially and sexually active.

Pie Chart 3: Gender (n=22)

5%

[Female (n=21)]
[Male (n=1)]

95%
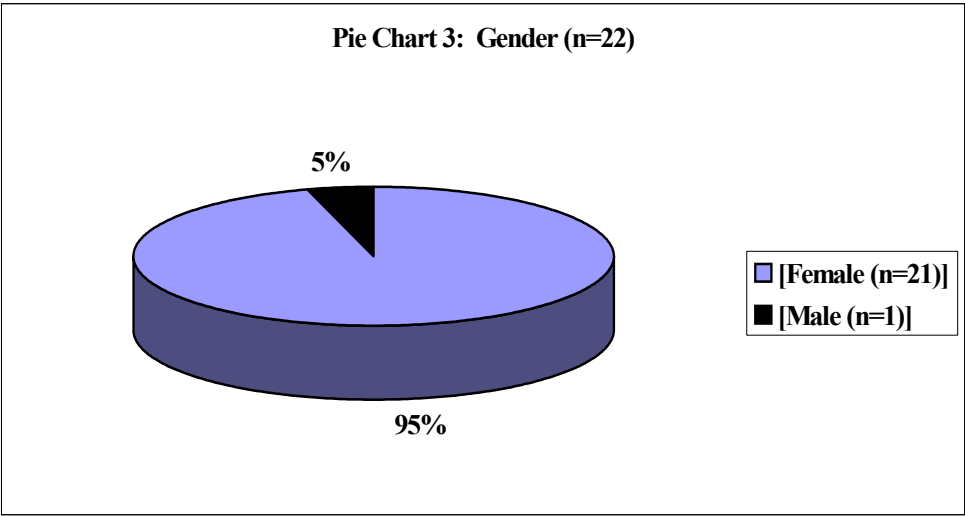
Pie chart 3 indicates that the majority (95%) of caregivers are females.

Pie Chart 4: Marital status of the caregiver (n=22)

5% 5% 5%

14%

5%

44%

27%

[Single (n=10)]
[Married (n=6)]
[Cohabiting (n=3)]
[Divorced (n=1)]
[Widowed (n=1)]
[Separated (n=1)]
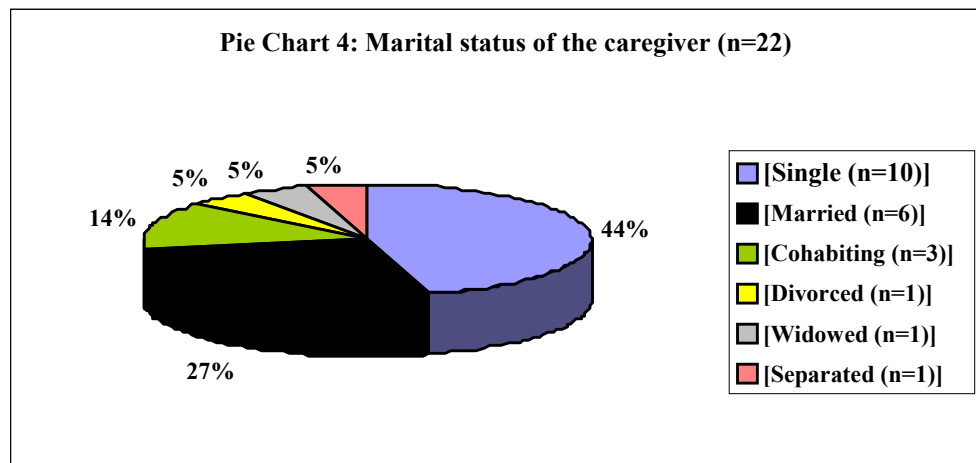
According to Pie chart 4, 59% of the caregivers are not living with a partner through marriage or cohabiting. This can be an indicator that the caregivers struggle to enter into relationships, are not interested in a relationship, or do not succeed in sustaining the relationship whereby they have to stay with a partner.

Pie Chart 5: The caregivers' relationship to the patient (n=22)

0%

100%

[Yes (n=0)]
[No (n=22)]
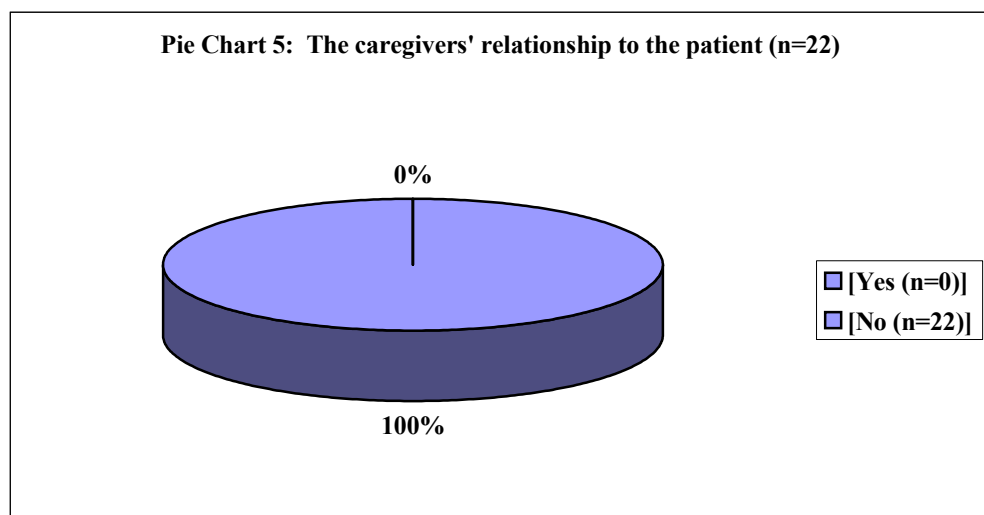
Pie chart 5 indicates that no caregivers are related to the patients whom they care for, which means that they are all voluntary caregivers.

Pie Chart 6: Education of the caregiver (n=22)

5%

23%

36%

36%

[Grade 9(n=1)]
[Grade 10 (n=8)]
[Grade 11 (n=8)]
[Grade 12 (n=5)]
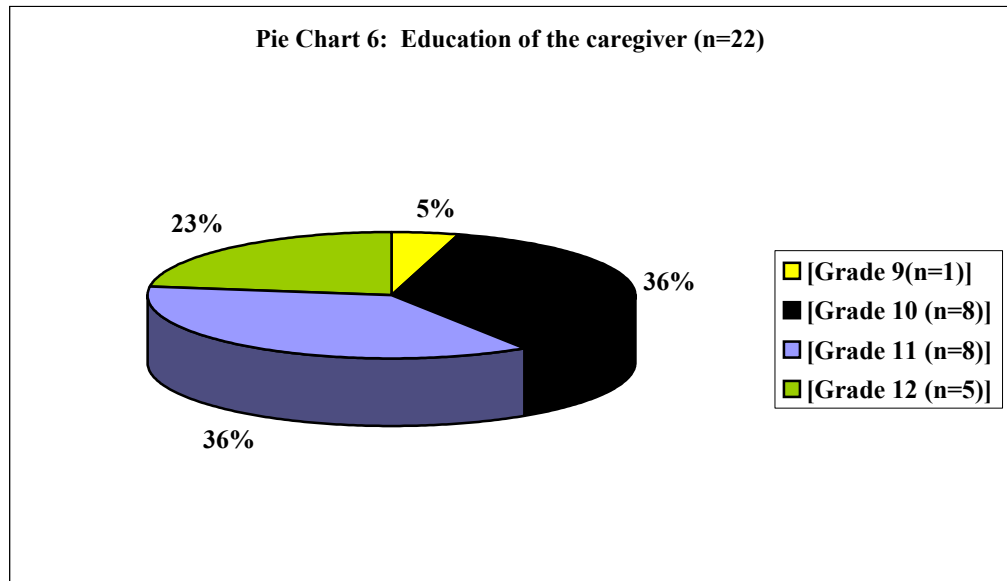
Pie chart 6 indicates that the majority (72%) of caregivers are educated to the level of grade 10 and 11. The lowest level of education is grade 9. Therefore all caregivers qualify for further education and training in order to receive a certificate.

Pie Chart 7: Training of the caregiver in caregiving (n = 22)

23%

77%

[In-service training (n=17)]
[Tertiary & In-service training (n=5)]
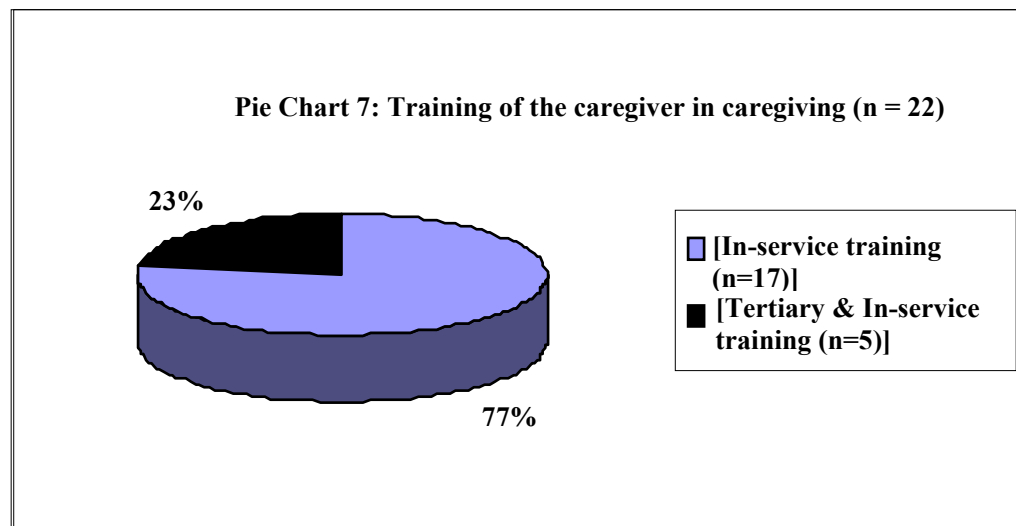
According to pie chart 7, the majority (77%) of caregivers underwent in-service training in care giving related issues in the Nigel Caring Community Organisation. Less than 23% have been educated at tertiary level. A need expressed by some of them was to be more skilled in the care giving services and they therefore wish to pursue further studies in order to obtain a formal qualification.

Pie Chart 8: The caregivers' involvement in support groups (n=22)

0%

[Yes (n=0)]
[No (n=22)]

100%
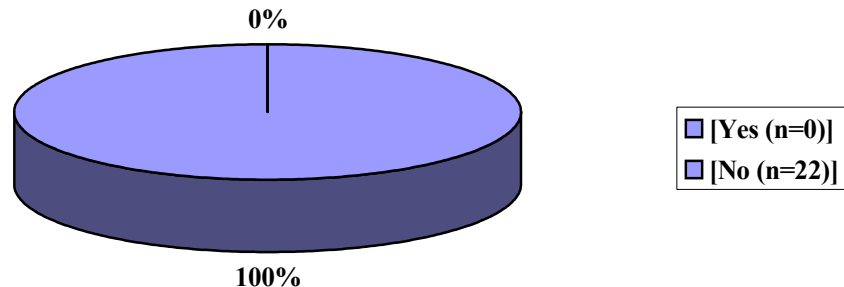
Pie chart 8 indicates that none of the caregivers belong to a support group, although the need for such a support system has emerged from the literature study and was expressed by the caregivers. People in management in charge of the caregivers' programme are not available most of the time to listen to the caregivers' needs. A support system could create opportunities for the caregivers to listen to each other's needs, which in turn would serve as support to each other.

Pie Chart 9: Duration of involvement in the caregiving programme (n = 22)

18%

9%

[3-4 years (n=4)]
[5-6 years (n=2)]
[7-8 years (n=16)]

73%
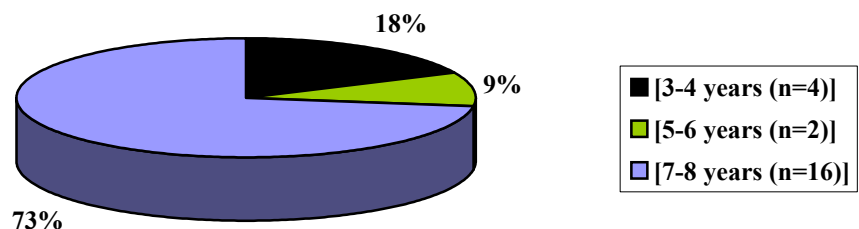
Pie chart 9 indicates that the majority (73%) of caregivers have been in the programme between 7 and 8 years.

3.4   Method of data collection

Data for this study was collected by means of semi-structured interviews. This type of data collection made provision for flexibility and spontaneity.

3.5   Procedure

Individual semi-structured interviews (Addendum A) were conducted at the offices of the Nigel Caring Community programme. The researcher administered the interviews herself. All interviewees were informed of their ethical rights before the interviews commenced (Addendum B) and they gave their consent (Addendum C). The average duration per interview was about an hour. All interviews were audio taped and recorded to ensure that the data was of good quality as well as quantity for the purpose of later reference.

3.6   Research instrument

An interview schedule compiled on the basis of information in the literature study was used to conduct individual semi-structured interviews (Addendum A).

3.7   Summary

Information obtained during the literature study was used to develop an interview schedule for the empirical investigation. The main themes emerging from the empirical investigation are that all the caregivers in the Nigel Caring Community Organisation are volunteers between the ages 30 - 39 years old. Although the need for the caregivers to belong to a support group emerged from the literature study and was expressed by them, none of the caregivers are involved in a support group.

Chapter 4

Research results and discussion

Introduction

The respondents'responses as reflected in the completion of the interview schedule (Addendum A) are to be discussed in terms of the demands made on caregivers by patients and family members living with them; questions or issues discussed by patients with caregivers; the attitude or behaviour of patients and families towards caregivers; the impact of caring on caregivers' lives; caregivers' fear about care giving; and the motivation of caregivers to continue doing care giving.

4.1 The demands made on caregivers by patients and family members living with them

The responses in terms of the demands made on caregivers by patients and family members living with them (Interview schedule issues 2.1 and 2.2-Addendum A), are grouped with reference to physical care; emotional support; material/ economic support; religious support and support regarding death and dying.

4.1.1 Physical care:

- Education of family members on how to take care of the patient;
- Washing or bathing of patient.
- Dressing of patient's bedsores.
- Giving medication to patient.
- Feeding patient.
- Education of patient and family members on healthy eating.
- Doing exercises with patient.
- Taking patient to clinic for assessment by nursing sister.
- Clean patient's room when necessary.
- Taking patient to nearby park for a walk.

4.1.2 Emotional support:

♦ Listening to patient.

♦ Counselling patient and family members.

♦ Supporting family to expect patient's illness.

♦ Taking patient to clinic for pre-test counselling before testing for HIV and AIDS, for which the patient has given his or her permission.

♦ Education of patient and family members on HIV and AIDS for example, that it does not kill.

♦ Hugging patient.

♦ Bringing family members together.

♦ Assisting patient and family members to solve their problems.

♦ Supporting patient when sad or frightened.

4.1.3 Social support:

♦ Supporting patient with application for identity document and birth certificate.

♦ Referring patient to Department of Social Development when alternative placement for children is needed.

♦ Approaching churches to help with clothes for children.

♦ Sleeping at patient's home on request of the family.

♦ Bringing family together.

♦ In the case of child headed households, the care worker acts as guardian for the children at school meetings, applies for excemption from school fees and school uniforms.

♦ Providing opportunities for patient to participate in plays and dramas.

4.1.4 Material/ economic support:

♦ Buying food for patient, using own money.

♦ Giving patient and family members money to buy food when there is no food at home.

- The community home based caregivers refer patient for grant application to social caregivers.

- Referring patients to the Nigel Caring Community Organisation for food parcels and nappies.

- Giving patients money for transport to see a medical doctor or nursing sister at the clinic and to go to the Department of Social Development to apply for a grant.

- Bringing food from own home so that patient can take medication.

4.1.5   Religious support:

- Praying, singing and reading from the Bible during home visits.

- Arranging with pastor to visit the patient.

- If there is no pastor, looking for one to visit patient. Assisting patient to become a member of a church.

4.1.6   Support regarding death and dying:

- Remaining with patient and family when patient is about to die, at the time of death and until the body leaves the home.

- If there is no funeral policy – assisting through Nigel Caring Community Organisation with funeral arrangements, transport and food.

- Asking volunteers to assist with funeral cost if no funeral policy.

- Speaking to patient about drawing up a will before they are too ill.

- Assisting patient to talk to a trusted family member about care for the children.

- Supporting family members through mourning process immediately after death of the patient.

- Helping family members with paper work for funeral arrangements, if needed.

- Sending pastor for family members when patient is dying.

- Preparing family members for death of patient.

♦ Assisting with finding someone to care for children after patient's death so that he or she can die in peace.

4.2 Questions or issues patients discussed with caregivers

According to the responses obtained by the interview schedule (Interview schedule issue 2.3 - Addendum A), the questions or issues that patients frequently discuss with caregivers were family related or related to the patients illness and included the following:

4.2.1 Family related:

♦ Family members want to, or take control of their disability grant and/ or other money.
♦ Family members don't stand together.
♦ Family members don't like them.
♦ Family members ignore them, especially when terminally ill, don't wash them or change their kimbies over weekends when caregiver does not visit them.
♦ Provides address of relative patient feels closest to and trust and should be encouraged to visit the patient.

4.2.2 The patient's illness :

♦ Their HIV status and that of their children.
♦ The dangers of AIDS for example, whether family members can use the same mug as they do without getting infected.
♦ Asks questions about the diet they should follow.
♦ Sometimes requests caregiver not to reveal his or her status to family members.
♦ Discusses the care of their children after their death.
♦ Discusses what should happen to their house after patient's death.
♦ Patient's death and funeral arrangements.

- ♦ Patient's will.

- ♦ Children's education.

- ♦ Shows the caregiver photos of the good old days which patient can use to make a memory box.

- ♦ Discusses previous lifestyle – tells story of how he or she got infected.

- ♦ Talks about feelings around illness and death.

- ♦ Asks questions around medical treatment – "Is it going to help me or not?"

- ♦ Other questions asked are:
  - ➢ "Am I going to die and when will I die?"
  - ➢ "Will you as caregiver bury me?"
  - ➢ "What will happen to my children after my death?"
  - ➢ "Why did illness happen to me?"
  - ➢ "Why is God so unfair to me?"
  - ➢ "Am I bewitched?"
- ♦ States "It will be better to die."

4.3 Attitude or behaviour of patient and family members towards caregiver

According to the responses obtained by the interview schedule (Interview schedule issues 2.4 and 2.5- Addendum A) the patient's attitude or behaviour towards the caregiver is related to acceptance; aggression; rejection; critique and manipulation.

Table 2: Attitude or behaviour of patient and family towards the caregiver (n = 22).

Attitude/Behaviour	Yes	No	Total
Accepting	22	0	22
Aggressive	15	7	22
Rejecting	14	8	22
Critical	11	11	22
Manipulative	13	09	22
Other (Trusting and dependant)	1	21	22

4.3.1 Acceptance by patient and family

Table 2 indicates that all the caregivers interviewed are accepted by the patients and their family members for the care they offered. This helps the patient discuss confidential issues with the caregiver, such as his or her HIV and AIDS status, cause of the illness, status in life and family issues with the caregiver.

4.3.2 Anger by patient towards the caregiver

Anger displayed towards the caregiver is caused by internal factors, such as the patient's illness or feelings of loneliness, because he or she is ignored or neglected by the family. The patient and family also become angry or aggressive towards the caregiver, when he or she does not have medication or equipment such as gloves, antiseptic such as Dettol and soap for the patient's care, or if the patient does not have and has to take medication. The Nigel Caring Community caregivers call this lack of food, equipment and money, the "Dry Season," because during this period they also do not receive stipends and are therefore not in a position to give the patient food or money from their own resources.

Anger is further evoked if the caregiver does not arrive for visits at the usual time, if the patient's wounds or bedsores do not heal or if the patient and family members are referred to someone else for answers he or she cannot answer. Social caregivers often encounter anger from the patient and family members, if they are unable to obtain school uniforms for orphaned children. The anger is displayed by shouting at the caregiver, talking to him or her in a rough manner, banging the table or breaking glasses. Patients also often refuse to take their medication, talk to the caregiver or to be washed by the caregiver.

4.3.3   Rejection by patient and family

The patient and their family members reject the caregiver for having no medication for the patient, if treatment given does not cure the patient or if the caregiver does not have his or her identification card. The rejection is displayed by chasing the caregiver away when he or she visits, or by refusing to talk to the caregiver.

4.3.4   Critique by patient and family

The patient and family members become critical of the caregiver when they are in denial about the patient's HIV and AIDS status, when medical treatment does not cure or bring relief for the patient's illness, when family members realise that not much more can be done for the patient and become scared realising that the patient is going to die. Family members then accuse the caregiver of taking the patient's money or social grant, or revealing the patient's HIV and AIDS status. Family members often refuse to help the caregiver with caring of the patient, for example washing the patient when the caregiver does not visit, or collecting the patient's medication at the clinic. The patients display their displeasure by refusing to talk to the caregiver or turning their backs on him or her.

4.3.5 Manipulation by patient and family

The patients and their family members try to manipulate the caregivers making them cleaning the house or the patient's room, visiting the patient over weekends, sleeping in the house where the patient lives or to being available whenever he or she is called. At times the patient expects the caregiver to pretend that he or she has taken his or her medication when, in fact, he or she has refused to do so. The patients also pity themselves and then demand tasks of the caregiver which will satisfy their own needs.

4.4 The impact of caring on the caregivers' own life

According to the responses obtained by the interview schedule (Interview schedule 2.6- Addendum A), care giving has an impact on the caregiver's eating; sleeping; socialisation; physical appearance; behaviour towards partner and children; sex life and feelings towards death and dying.

Table 3: The impact of caring on the caregivers' own life (n = 22).

Symptom	Yes	No	Duration of symptom	Total
Eating disturbance	16	06	1 Day - 2 Weeks	22
Sleeping disturbance	17	05	1 Week - 2 Years	22
Socialisation	15	07	2 Days	22
Physical Appearance	06	16	3 Days	22
Behaviour towards partner and children	16	06	1 – 3 Days	22
Sex Life	17	05	2 Days and Ongoing	22
Feelings about death	18	04	2 Days and Ongoing	22

Table 3 indicates that care giving has the following impact on the caregivers' own life:

4.4.1 Eating disturbances

The caregiver increases or looses his or her appetite when:
♦ The patient is ill, or has no food to eat.
♦ He or she thinks about the patient's stools, bedsores and vomiting.

4.4.2 Sleeping disturbances

The caregivers' sleeping patterns were influenced (resulting in difficulties in sleeping), when:

♦ The patient's condition deteriorated.
♦ The patient is about to die.
♦ The caregivers' own thoughts how he or she can support the patient.
♦ The caregivers' thoughts about his or her own death and dying.

4.4.3 Socialisation

The caregivers'socialisation decreases when:

♦ The patients become the caregiver's friends. The caregiver then has less time for his or her own friends and family members and eventually looses friendships.
♦ The caregiver prefers to be alone or with his or her patients, resulting in him or her withdrawing from their own family and friends.
♦ The caregiver prefers to have silence around him or her resulting in him or her locking himself or herself in his or her bedroom when sleeping, or switching off the radio.

♦ Community members or friends reject the caregiver due to the fact that they do not understand what care giving is about and therefore do not understand the caregivers' needs and behaviour.

4.4.4 Physical appearance

Care giving can have an impact on the physical appearance of the caregiver, as he or she either gets into the habit of wearing comfortable clothes or does not feel like getting dressed, when his or her patient is severely ill or dying. The caregiver also experiences physical pains and at times does not feel like cleaning his or her home.

On the positive side, the caregiver teaches his or her patients how to care for themselves physically, while they are still able.

4.4.5 Behaviour towards partner and children

This includes caregivers:

♦ Shouting at their partners or children for no specific reasons and being impatient with them.
♦ Getting angry with family members about minor issues or unnecessarily becoming moody.
♦ Preferring not to talk but rather sleep.
♦ Becoming secretive.
♦ Care giving in some instances distanced family members from the caregiver.
♦ Care giving in other instances brought family members closer, as family members became more supportive towards the caregiver. The caregiver adopts a soft approach towards his or her family members, even regarding disciplining his or her children.

4.4.6   Sex Life

♦ The caregiver becomes afraid of sex, as he or she watches how people suffer from HIV and AIDS. Some start to withdraw from sex and to even live a sex free life. As a result, one female caregiver's husband started to abuse alcohol and sleeps away from home.

♦ At times some caregivers prefer not to be touched by their partners, whereas others become more careful and introduce the use of condoms when engaging in sex.

♦ For some caregivers, care giving contributes towards an increase in their sexual activities, whilst others tend to withdraw from sexual activity, because they no longer trust their partners.

4.4.7   Death

The impact of care giving on the caregivers' feelings and behaviour towards death and dying, are displayed in different ways, such as:

♦ The ongoing washing of hands, after having been with a dying patient.

♦ Delayed feelings of sadness after the death of a family member or friend.

♦ Death becoming part of life.

♦ A feeling of pity for the patient who has died.

♦ Ongoing feeling of fear of the person who has died;

♦ Feelings of fear about one's own death and what might happen to own parents and children after one has died being evoked.

♦ Becoming concerned about one's own death and asking questions such as, " How will I look when I die?" " Where and how will I die?"

♦ A concern about whether the patient was saved by God and whether he or she as caregiver did enough to support the patient while he or she was still alive.

♦ Feelings about death being denied and the caregiver starting to dream that he or she is the dying patient.

♦ Thinking that if infected by HIV and AIDS, the duration of life may be very short.

4.5 The caregivers' fear about care giving.

According to the responses obtained by the interview schedule (Interview schedule issue 2.9- Addendum A) the caregivers' fear is related to contagiousness; legal issues; ethical dilemmas; stigmatisation and rejection by family and community members

Table 4: The caregivers' fears about care giving (n = 22).

Type of fear	Yes	No	Total
Contagiousness	12	10	22
Legal issues	04	18	22
Ethical dilemmas	04	18	22
Stigmatisation	09	13	22
Rejection by family and community	04	18	22

4.5.1 The fear of contagiousness is linked to the following:

♦ The caregiver sometimes has small wounds on his or her hands.

♦ The fear that the wearing of gloves may not be sufficient to prevent infection by HIV and AIDS.

♦ Gloves are sometimes torn while working with a patient.

♦ Sometimes gloves are not available and plastic bags have to be used or gloves have to be washed and re- used.

♦ Sometimes the patient does not disclose his or her HIV and AIDS status.

♦ Mistakes, which can cause infection, can be made while caring for an HIV and AIDS patient.

Caregivers, who did not disclose fear of contagion, indicated that they were trained how to protect themselves and also undergo regular testing.

4.5.2   Legal issues:

Fears are that:

◆   The patient and his or her family may take the caregiver to court, if confidentiality was not maintained.

◆   The patient takes the wrong medication in the caregiver's absence;

◆   The caregiver is included in the patient's will and the family members are unaware of it.

4.5.3   Ethical dilemmas:

Caregivers, who indicated fear about ethical dilemmas, did not link it to specific reasons.

4.5.4   Stigmatisation:

People in the community often call caregivers, "HIV and AIDS people who spread the virus," "sisters who are washing the gogos" or "volunteers working for charity and not earning any money."

4.5.5   Rejection by family and community members:

Family and community members, who reject the caregiver, alleged that a caregiver would never be able to live a normal life or to cope as before, because of the traumatic impact of caring for an HIV and AIDS patient. Community members also alleged that caregivers are not properly trained to do the work.

On the other hand, some family members appreciated the work done by caregivers and see them as role models in the home and community.

4.6   The motivation of the caregiver that drives him or her to continue doing care giving.

The caregivers are motivated to continue doing care giving by their love for people, the joy they find in their work and the appreciation they received from the patient.

Table 5: Continuation with care giving (n = 22)

Yes	No	Total	If no, expected duration
22	0	22	N/A

4.6.1   Factors that drive the caregiver to continue care giving includes:

♦   The need to see people living and feeling healthy.

♦   The caregiver's feeling of being invincible. "The patient only has me to care for him or her. What will happen to the patient if I leave him or her?"

♦   Enjoying helping communities.

♦   Enjoying it to work with terminally ill patients.

♦   Caregiver's own family members also died of AIDS. "This motivated me to get information regarding HIV and AIDS in order to help other people."

♦   Helping patients to recover and live a normal life seeing patients survive.

♦   "People are suffering and health sisters cannot reach the rural areas."

♦   "Me and my family may also need help from the community at some stage."

♦   "My love for people."

♦   "My ability to use the strengths God has given me."

♦   "The fact that I know my caring is appreciated, because I am always thanked for the work I am doing."

♦   "I am caring for the sick people since my youth years."

♦ "I believe that I must help other people, I am also involved in church and community activities."

♦ "I fulfill my goals through caring."

♦ "I wanted to become a nurse.

♦ "God created me to help other people."

♦ "I made an agreement with God to help other people."

♦ "Don't want to see people suffering."

♦ "I wanted communities to have information on illnesses such as Tuberculoses and HIV and AIDS and that these illnesses can be controlled."

♦ "I do care about others."

4.6.2   Reasons to continue care giving

Caregivers indicated that they would continue care giving, as long as they live, until death calls, indefinitely, as long as possible, because:

♦ They have decided to help other people in the community.

♦ They have skills and knowledge.

♦ They fulfill their dreams through care giving.

4.7   Support or resources needed to continue care giving

Respondents indicated that they would require the following support or resources to enable them to continue their care giving:

♦ More training for example auxiliary nursing, computer skills and role of volunteer.

♦ Sufficient equipment for example masks, aprons, commodes and first aid kit.

♦ Increase in stipend.

♦ Fixed income.

♦ Registration as caregiver

♦ More training and skills for example in advanced counselling.

- ◆ Debriefing.
- ◆ Support group.
- ◆ Counselling sessions.
- ◆ Stress relief sessions.
- ◆ Transport for patients.
- ◆ Clinic services on farms.
- ◆ Financial Support, for example from the government and private sector.
- ◆ Ability to help orphaned children to receive school uniforms.

4.8   Summary

According to the above information, the caregivers' role and responsibilities towards the patient and their family members include, physical care, emotional, social, material/ economic, religious support and support regarding death and dying. Issues the patient discusses with the caregiver are mainly around the patient's illness, attitude and behaviour of family members, the patient's care of children after he or she has died. Although all the caregivers interviewed, indicated that the patient and family members accepted them, caregivers also have to deal with the anger, rejection, critique, and manipulation from the patient and family members.

The impact of care giving on the caregivers' own life can be negative and positive. They experience eating and sleeping disturbances, difficulty to socialise with family and friends, difficulty how to behave towards partner and children, difficulty with their sex life and fears around own death. The caregivers are further confronted with fears of contagiousness, ethical dilemmas, stigmatisation and rejection by family and community members for the work they are doing. As much as the impact of care giving on the caregivers' own life is negative, it is also rewarding. They find joy in their work and to see people living and feeling healthy and receive appreciation from the patient for the work they do.

The resources and support caregivers need to continue doing care giving, are internal and external, such as self-empowerment, training, sufficient equipment and a fixed income. The motivation that drives the caregiver to continue doing care giving, is the need to care for those in need, which according to van Delft (2002:15), is called the "caritas" element.

Chapter 5

Conclusions and recommendations

Introduction

The purpose of this chapter is to present the conclusions and recommendations of both the literature and empirical investigations.

5.1. Conclusions

The following conclusions were drawn from the literature study and the empirical investigation:

5.1.1. Research problem, aim and objectives of the study

Concerns which motivated for this study were the effect of caring on the physical and mental health of caregivers in HIV and AIDS programmes and their needs for ongoing support. There is an increase in the number of people infected and affected by HIV and AIDS. As there is still no cure for AIDS, more and more people are struggling to live with it. This places an enormous burden, resulting in secondary traumatic stress, on the caregiver in HIV and AIDS programmes, as many of the caring tasks previously done by health care professionals are these days handled by caregivers. Caregivers are selected, trained and to a certain extent supervised, but very little attention is given to their own needs for caring and support. Based on these concerns, the aim of the study was to do an exploratory investigation into the effects of care giving on the physical and mental health of caregivers in HIV and AIDS programmes in order to determine their needs for ongoing support.

The researcher is of the opinion that the aim of the study has been achieved based on the following:

Concepts in the literature study such as HIV and AIDS care, the caregiver, the effects of caring on the caregiver and caring for the caregiver were

described. HIV and AIDS care relates to the patient, the patient's family, the community and the caregivers. To meet the physical demands or needs of people infected and affected by HIV and AIDS requires a sound understanding of preventative and palliative medication, appropriate nutrition and palliative care. Social support is as important as physical care to improve the quality of life of people living with AIDS. Social support refers to formal or informal counselling provided by social workers, psychologists and caregivers. The aim is to support the patient to cope with issues such as the loss of his or privacy, feelings of guilt and denial. Spiritual support is an integral part of palliative care including issues such as the meaning of life, search for hope and relationships. Spiritual care is important for the patient, his or her family and the caregiver. According to van Delft, (2002: 17), people naturally have a charity and "caritas" element in them. This motivates them to become volunteers and eventually take on roles of caregivers. An understanding of the meaning of care giver therefore needs an understanding of the meaning of volunteerism. Whether volunteering is formal or informal, it involves spending time unpaid, while doing something to benefit someone other than close relatives. Volunteers involved in the Nigel Caring Community Organisation, who operate as formal caregivers, have received in-service-training to do community home-based care or social care giving.

Being a caregiver can be a deeply meaningful way for a person to spend his or her days on earth. This "caritas" deed however not only poses physical demands on the caregiver, but also is a form of traumatic stress. The post traumatic stress syndrome derives from the loss, fear, suffering, indignity and discrimination with which the HIV and AIDS survivor and caregiver are confronted on a daily basis. According to the literature, care giving is a demanding but also a rewarding task. The caregiver is therefore tasked with keeping a balance in his or her life, as he or she cares for others. This includes caring for the self, physically and emotionally, avoiding feelings of being overwhelmed, identifying personal barriers, reducing personal stress, setting goals for the self, seeking solutions for problems, using constructive ways of communicating, asking for help and accepting it, exercising and to being in touch with and learning from his or her own emotions.

Through the empirical study, the researcher now has an understanding of the effects of care giving on the physical and mental health of caregivers, type of care or support available for caregivers in HIV and AIDS programmes and the type of support, caring or empowerment caregivers need to continue with care giving in HIV and AIDS programmes. According to the empirical investigation, the majority of caregivers in the Nigel Caring Community Organisation are females. The majority of these females (58%) are single, divorced, separated or widowed. Only 4% of them are widowed and of the rest the conclusion can be drawn that the demands posed by care giving may have an impact on the female caregivers' ability to enter into or sustain a marriage or cohabiting relationship.

5.1.2 The themes derived from the literature study in order to answer the research questions

The following themes were identified from the comprehensive literature review:

- Demands made on caregivers by the patients and their family members living with them in terms of physical care, emotional, social, economic, religious support and support re death and dying.
- The questions or issues the patient discusses with the caregiver.
- The attitude of the patient and family members toward the caregiver.
- The impact of care giving on the caregivers' own life in terms of eating and sleeping disturbances, socialisation, physical appearance, behaviour toward his or her partner and children, sex life and death.
- The caregivers' fears about care giving with regards to contagiousness, legal accountability, ethical concerns, stigmatisation and rejection by family and community members.
- The motivation of the caregiver to continue with care giving.
- Reasons why caregivers wish to continue with care giving.
- Support and resources needed by caregivers to continue with care giving.

5.1.3 Issues that stood out in the caregivers' responses during the interviews.

The following issues were identified:

♦ All caregivers indicated that the patient and family members with whom he or she lives accept them. From this it can be concluded that the patient and family members trust the caregiver, resulting in them to discussing confidential issues with the caregiver.

♦ Anger towards the caregiver is normally evoked by outside factors such as the lack of medication, money or food.

♦ The impact that caring has on caregivers' own lives is tremendous and a real cause of concern. Between 68%-82% of the caregivers indicated that they have experienced disturbance with regard to their eating, sleeping, socialisation, behaviour towards partner and children, sex life, feelings and behaviour regarding death. For some caregivers these disturbances lasted for one day, for others up to two years and are in some instances ongoing.

♦ The caregivers' motivation to continue with care giving is embedded in their love for other people, the need to see other people living as effectively as possible and their belief that it is a demand from God.

♦ Considering the need for support expressed by the caregivers to help them continue care giving, it is clear that they currently receive very little, if any support from the Government and the management of the organisation. A strong need to be equipped with more education and skills and to be supported through counselling, debriefing and support groups, were expressed. The need for registration as a caregiver and to receive a fixed income poses a challenge for the people who are responsible for policy-making in South Africa, in particular the Departments of Health and Social Development.

5.2 Recommendations

In terms of the South African Constitution (as indicated in 1.1) the caregiver has as much a right to life and to have his or her dignity respected and

protected as the person and his or her family living with HIV and AIDS. Based on the concerns which constituted the aim of the study and the above mentioned conclusions that derived from the empirical investigation, it is clear that the responsibility for caring for the caregivers in HIV and AIDS programmes rest with three parties. These responsible parties are the caregivers themselves, the organisations rendering HIV and AIDS programmes and the Government. The following recommendations to the respective parties are therefore made to ensure and safeguard the position of caregivers serving in HIV and AIDS programmes, as well as to ensure that they are adequately cared for to continue rendering their essential service to HIV and AIDS sufferers, their families and the community as a whole:

5.2.1 Caregivers

To care for oneself, is as important as to care for another person. According to 1 Corinthians 3: 17 the human body is God's temple and because of its sacredness should be cared for (Bible Society of South Africa: The New Testament, 1978: 209). It is beneficial to both caregiver and patient if the caregiver is physically and mentally well. This can be achieved by the caregiver through sufficient rest and exercise, sleeping well and eating wisely.

5.2.2 Organisations rendering HIV and AIDS programmes

The organisation which, in most cases is a non-governmental organisation, should provide opportunities for:

- Timeous supervision by a professional social worker or psychologist.
- Regular debriefing sessions under the leadership of a professional social worker or psychologist.
- A social worker, psychologist or religious minister to be available should care givers have the need for counselling.
- On-going training in appropriate palliative care skills.
- On-going evaluation of caregivers' interest and ability to undergo formal training in health care.

- Opportunities for the caregiver to be part of a support group under the leadership of a mentor.

- Community involvement for a better understanding of the roles and responsibilities of a caregiver and to assist the caregiver in his or her tasks when and where applicable.

5.2.3 Government

During the last decade the British Government has realised the critical contribution volunteering makes towards building a strong and cohesive society (http: www.volcomm.org.uk 2007: 1)**.** As many elderly people are now living longer and more people struggle to live with AIDS instead of dying of it (as discussed in Chapter 1), the elderly and chronically ill persons have no choice but to move prematurely to a care facility, without the availability and support of caregivers. This will add to the financial burden of any Government, as it has a responsibility towards its elderly and terminally ill citizens. The South African Government, through the Departments of Health and Social Development, should therefore recognise the valuable role that caregivers play through the following:

- Sufficient financial budgets for voluntary organisations to provide caregivers with sufficient ongoing resources and equipment such as gloves transport for home visitations and nutritional food parcels for the patients.

- Policies and guidelines that provide for the care givers' further education and accredited training.

- Registration as health caregivers, employment contracts and minimum wages.

- Guidelines for Health and Wellness Programmes within organisations and

- Research on issues such as the impact of care giving on the sex life of caregivers, the role the church can play in the lives of caregivers, determining whether care giving can still be treated as part of volunteerism, considering the demands and responsibilities of the job and discourses around care giving for example, that the care givers are

"HIV and AIDS people" or are "spreading the virus."

5.3   Concluding remarks

The physical and mental effects of care giving on the caregiver call for the caregiver him or herself, the community, voluntary organisations and the Government to seriously consider the manner in which caregivers are cared for. Techniques, programmes, guidelines, policies and structures should be developed as part of the care and support for caregivers to enable them to continue with care giving. If these are developed, the aim of the research study will have been met.

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Addendum A.

Interview schedule – Caring for the Caregiver in HIV and AIDS Programmes

1. Details of caregiver:

1.1. Surname::………………………………….

1.2. Name::………………………………………

1.3. Age::…………………………………………

1.4. Gender: Male/ Female

1.5. Marital Status: Single/ Married/ Widow/ Divorced/ Cohabiting

1.6. Family relationship to patient: Yes/ No

1.7. Highest Educational Level::………………………

1.8. Training in care giving:

1.9. Member of Support Group: Yes/ No

2. The following issues will be discussed:

2.1. What demands are made upon you by the patient in terms of:
♦ Physical care?
♦ Emotional care?
♦ Social support?
♦ Economic support?

- ♦ Religious support?
- ♦ Support re death and dying?
- ♦ Other?

2.2. What demands are made upon you by the family of the patient in terms of:
- ♦ Emotional support?
- ♦ Social support?
- ♦ Economic support?
- ♦ Religious support?
- ♦ Support re death and dying patient?
- ♦ Other?

2.3. What type of questions/ issues does the patient discuss with you as caregiver regarding him/ her and his/ her family?

2.4. How do you experience the attitude/ behaviour of the patient regarding the caring you offer?
- ♦ Accepting?
- ♦ Aggressive?
- ♦ Rejecting?
- ♦ Critical?
- ♦ Manipulating?
- ♦ Other?

2.5. How do you experience the attitude/ behaviour of the family regarding the caring you offer to the patient?
- ♦ Accepting?
- ♦ Aggressive?
- ♦ Rejecting?
- ♦ Critical?
- ♦ Manipulating?
- ♦ Other?

2.6. Does caring have an impact on your own life in terms of:

♦ Eating habits?

♦ Sleeping patterns?

♦ Socialisation?

♦ Physical appearance?

♦ Behaviour towards partner?

♦ Behaviour towards children?

♦ Sex life?

♦ Feelings about death?

♦ Other?

2.7. Do you regard the impact as temporary?

2.8. If not, what is the duration of the symptoms mentioned under 2.6?

2.9. What are your fears around doing care giving re:

♦ Contagiousness?

♦ Legal issues?

♦ Ethical dilemmas?

♦ Stigmatisation?

♦ Rejections by own family and community?

2.10. What motivates/ drives you to do caring?

2.11. Will you continue with caring for the foreseeable future?

2.12. If no explain and give an indication of expected duration of caring

2.13. If yes explain and indicate the expected duration.

2.14. What do you need to continue doing care giving?

Addendum B

Subject information sheet: Caring for the Caregiver
in HIV and AIDS Programmes

Dear Participant:

My name is Marlene Primo and I am a Masters Degree Mental Health (Social Work) student at the University of South Africa. I am required to do a research as part of my degree. The topic for my research is: **Caring for the Caregiver in HIV and AIDS Programmes**. As someone who works as a caregiver, I would like to invite you to participate in my study.

The purpose of my research is to do an investigation into the effects of care giving on the physical and mental health of caregivers in the HIV and AIDS programs to determine their needs for ongoing support.

As an informant to the study you have the right to request that your personal details remain confidential. You further have the right to refuse participation and agreement to participate may be withdrawn at any time. If you should choose not to participate, negative consequences will not result due to such a decision.

Data will be collected by means of semi-structured interviews and you will be able to interact spontaneously in relation to questions asked. I will administer the interview myself. The interview consists of 23 questions, therefore the interview will be plus minus one hour in duration. The researcher will have to audio tape record the interview in order to ensure that the data recorded during the interview is of good quality as well as quantity for the purpose of later reference.

You are free to make any inquiries regarding the study at any point during or after the interview.

Should you be interested in seeing the results of the study, a summary of the results will be made available after completion of the study.

Thank you for taking the time to consider participating in my study.

Yours sincerely.

Addendum C

Consent form

I understand the purpose and procedure of the study, also that information will be confidential and that I have the right to withdraw at anytime, before and during the study.

I …………………………………… do wish to participate in this study.

……………………………………
Participant's signature
Date:

……………………………………
Researcher's signature
Date: