THE EXPERIENCES OF CAREGIVERS IN FORMAL INSTITUTIONS CARING FOR TERMINAL AIDS PATIENTS

by

MARGARET WILLIAMS

Submitted in partial fulfilment of the requirement for the degree

MAGISTER CURATIONIS

in the

Faculty of Health Sciences

at the

NELSON MANDELA METROPOLITAN UNIVERSITY

Supervisor: Prof R.M. van Rooyen

Co-Supervisor: Mrs. E Ricks

January 2007
“What can we know of death, we who cannot understand life? We study the seed and the cell, but the power deep within them will always elude us. Though we cannot understand, we accept life as the gift of God. Yet death, life’s twin, we face with fear. But why be afraid? Death is a haven to the weary, a relief for the sorely afflicted. We are safe in death as in life. There is no pain in death. There is only the pain of the living as they recall shared loves, and as they themselves fear to die. Calm us, O Lord, when we cry out in our fear and grief. Turn us anew toward life and the world. Awaken us to the warmth of human love that speaks to us of You. We shall fear no evil as we affirm your kingdom of life”.

From Gates of Prayer: The New Union Prayer Book.
To Craig,

MY HUSBAND AND FRIEND.

WITHOUT YOUR UNFAILING BELIEF IN ME,
THIS STUDY NEVER WOULD HAVE BEEN COMPLETED.
ACKNOWLEDGEMENTS

“Therefore we do not lose heart” 2 Corinthians 4:16

I need to express my sincere gratitude to the following people:

- **Prof. RM van Rooyen** - for your inspiring guidance, encouragement, enthusiasm, wonderful ability to identify the essence, for being so much more than a mentor, something that makes you so special, and most of all, your unfailing belief in the fact that I could do this, thank you.

- **Mrs. E Ricks** - for your calm, methodical approach and encouragement, for your talent of finding just the right terminology and most of all, for keeping me on track when nothing seemed to make sense.

- **Dr S Carlson** - for doing the independent coding.

- **Rosemary Batchelor** – For editing this document and for your kindness, understanding and concern when I really needed it, thank you.

- **My children** - Matthew and Rebecca, for coping so well with having a ‘treatise mum’ (as Rebecca calls me) and for being so well behaved when dad was in charge, which happened often for many months.

- **The caregivers** – thank you all for sharing so honestly and for trying so hard to open up, when memories were painful. You all have my respect and admiration for who you are, and how hard you try, under difficult circumstances.

- **Steven Lancaster** – my fieldworker, for conducting interviews, in your own time, and best of all, transcribing them, and for continuing to believe that one day, this study would be completed.

- **My mum and dad, Ian and Hannelore Logie** - for their love and prayers over the years, that has helped to make me who I am today.

- **Richard T Logie** – Your untimely, tragic death, ironically gave me even more insight into the tragedy of young people dying, for the first time in my life, so close to home. Rest in peace, angel.

- **My friends** – Dorita, Gianni and Valentino Tistelli, thank you for understanding why ‘get –togethers’ were constantly cancelled due to the ‘treatise stuff’, for all the times you took Matthew to ‘Kids Galore’ so that I could study, and for being so incredibly supportive, I am forever grateful.

- **Sharron Frood** – for your help, comfort in times of need, love and support, prayers and incredible friendship, thank you.

- **Anne-Marie Gerretsen** – Esteemed colleague and friend, thank you for believing in me and sharing in the trials and frustrations of completing this study, and for the constant encouragement, prayers and support.
Craig – I have already dedicated this study to you. I thank God for your incredible patience with me, for putting up with the moods, the despondency when nothing fitted or moved into place, and for coping so well with the children while I was stuck in the study. I would not have completed this without your help, support, unselfishness, and love; I am eternally grateful.
ABSTRACT

One of the greatest challenges facing sub-Saharan Africa, which incorporates South Africa, is the AIDS pandemic. The devastation wrought by this disease is unsurpassed in recent times. The health and social development structures, already overburdened, are totally overwhelmed by the needs of poverty-stricken households and communities affected by AIDS. Caregivers attempting to support those affected and infected are also facing unique challenges and demands, particularly relating to dealing with the large numbers of deaths due to this disease. Experiences for these caregivers are likely to be varied, ranging on a continuum from positive to negative, for instance, the recovery of patients versus the death of patients. The objectives of this study are to explore and describe the lived experiences of caregivers working with AIDS patients, particularly patients who die from this disease whilst resident in a formal institution.

The research is based on a qualitative, explorative, descriptive and contextual research design. The study is grounded in a phenomenological approach to inquiry. Caregivers working fulltime in a formal institution caring for patients who are dying from AIDS were interviewed in an in-depth, unstructured manner in order to gather spontaneous, rich descriptions of their experiences. Through this study the researcher wants their voices to be heard, the potential richness of their reflections acknowledged and the generated data to be applied to the benefit of the field of HIV/AIDS – both for staff and patients.

Thirteen in-depth, unstructured interviews provided saturated data, which was then transcribed and coded to yield the central and sub-themes that were identified in this study. One central theme identified the fact that in their daily duties (at their place of work), caregivers experience various challenges as a result of having to deal with the death and dying of their patients suffering from AIDS. These caregivers face the death of their patients daily, from a disease that causes untold suffering to the patient, family members and to the caregivers themselves, who wish they could prevent the anguish, the pain and the inability of the medical profession to do more than they are at present towards curing this disease.
By describing the lived experiences of these caregivers by means of the research interviews, the researcher gained a clear picture of the AIDS environment. The information shared by the participants formed the foundation of the broad guidelines that were formulated. These are intended to provide support for the caregivers centering around the equipping of mentors of the caregivers, to enable them to support the caregivers in their daily task of caring for patients dying from AIDS. These caregivers, thus supported, will then be in a position to provide optimal care for these dying patients. These broad guidelines are intended to provide support by focusing firstly on the physical environment in which these caregivers work; secondly in providing education for the caregivers to enable them to fulfill their duties, and thirdly to provide adequate counselling to ensure that they do not succumb to caregiver fatigue/burnout, a constant threat in this type of environment.

The study concludes with recommendations regarding the areas of nursing practice, education and research.
KEYWORDS

HUMAN IMMUNODEFICIENCY VIRUS (HIV)
ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)
DEATH
THE DYING PATIENT
PALLIATIVE CARE
CAREGIVERS
EXPERIENCE
HOSPICE
SUPPORT
LIST OF CONTENTS

ACKNOWLEDGEMENTS  i
ABSTRACT  ii
KEYWORDS  iii

CHAPTER 1 OVERVIEW OF STUDY  1

1.1 INTRODUCTION AND PROBLEM STATEMENT  1
1.2 PROBLEM STATEMENT  8
1.3 RESEARCH OBJECTIVES  12
1.4 CONCEPT CLARIFICATION  12
1.5 RESEARCH DESIGN AND METHOD  16
  1.5.1 RESEARCH DESIGN  16
  1.5.2 RESEARCH METHOD  18
    1.5.2.1 Phase One  18
    1.5.2.2 Phase Two  19
1.6 PILOT STUDY  19
1.7 TRUSTWORTHINESS  20
1.8 ETHICAL CONSIDERATIONS  20
1.9 CHAPTER DIVISION  21
1.10 CONCLUSION  21

CHAPTER 2 RESEARCH DESIGN AND METHOD  22

2.1 INTRODUCTION  22
2.2 RESEARCH DESIGN  22
2.3 RESEARCH METHOD 26

2.3.1 PHASE 1: Exploration and description of the lived experiences of the caregivers while nursing patients dying of AIDS. 26

2.3.1.1 Sampling Strategy 26
2.3.1.2 Data Collection 28
2.3.1.3 Role of the Researcher 29
2.3.1.4 Communication Skills 30
2.3.1.5 The Interviews 32
2.3.1.6 Field Notes 36
2.3.1.7 Analysis of Data 37
2.3.1.8 Literature Control 39
2.3.1.9 PHASE 2 39

2.4 MEASURES TO ENSURE TRUSTWORTHINESS 39

2.5 ETHICAL CONSIDERATIONS 43

2.5.1 Freedom from Harm 44
2.5.2 Informed Consent 44
2.5.3 Principle of Justice 45

2.6 CONCLUSION 47

CHAPTER 3 DISCUSSION OF DATA ANALYSIS AND LITERATURE CONTROL 48

3.1 INTRODUCTION 48

3.2 OPERATIONALISING OF DATA ANALYSIS AND LITERATURE CONTROL 48

3.3 IDENTIFIED THEMES 51
3.4 DISCUSSION OF THEMES AND LITERATURE CONTROL

3.4.1 Central Theme: In their daily duties (at their place of work), caregivers experience various challenges as a result of having to deal with the death of their patients suffering from AIDS:

Sub-theme one: Caregivers initially experienced emotional challenges in caring for patients dying of AIDS

1.1 Difficulty, and fear, in accepting death
1.2 Sadness, and pity, when a patient dies
1.3 Anger at relatives not visiting patients
1.4 Helplessness, and distress, at not being able to alleviate the suffering when patients are dying

Sub-theme two: Caregivers experience a difference in death and dying for adults as opposed to children

2.1 Caregivers appear to avoid bonding with those that are destined to die
2.2 Caregivers experience adults as having a role in acquiring this disease
2.3 Caregivers are more comfortable with adults dying than with the death of children and babies

Sub-theme three: Caregivers experience the rationalisation of death and dying differently

3.1 Caregivers describe death as God’s will
3.2 Caregivers experience the process linked to death as fascinating / intriguing
3.3 Caregivers experience that working with PWA’s has enabled them to grow mentally and spiritually

Sub-theme four: Caregivers experience that faith in God gives them strength to cope with death and dying

4.1 Caregivers experience that God provides hope and faith
4.2 Caregivers experience death as a reality of life
4.3 Caregivers experience prayer as an integral measure of strength
Sub-theme five: Caregivers experience caring for patients as fulfilling and meaningful despite the sadness of death and dying

5.1 Caring so much for patients emotionally and physically that there are no regrets when the patient dies

5.2 Working with terminal PWA’s provided a positive contribution towards the patient’s last days

5.3 Being in constant contact with death and dying reaffirms an appreciation for being alive

3.5 CONCLUSION

CHAPTER 4 GUIDELINES, RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS

4.1 INTRODUCTION

4.2 SUMMARY OF FINDINGS

4.3 BROAD GUIDELINES THAT WOULD ENABLE MENTORS OF THE CAREGIVERS TO PROVIDE SUPPORT TO THE CAREGIVERS, SO THAT THEY CAN OPTIMISE NURSING CARE OF PATIENTS DYING OF AIDS

4.3.1. Principal guideline 1: Create a work environment conducive to being supportive to the caregivers

4.3.1.1. Create a physical environment conducive to optimal palliative care.

i. Provide an exclusive restroom as a place of safety and silence for use by the caregivers
4.3.1.2. Create a supportive occupational environment conducive to enabling the caregivers to provide optimal palliative care for their patients

i. Enhance and facilitate understanding, insight and empathic support from management

ii. Institute 3-monthly counselling/debriefing sessions

iii. Ensure that caregivers are kept updated regarding patient treatment and prognosis

4.3.1.3. Create an educational environment to enable the caregivers to provide optimal care for their patients who are dying of AIDS

i. Provide in-service education for the caregivers

ii. Develop a library in the ward

4.3.2 Principal guideline 2: Identify and enhance areas where support for caregivers can be instituted which could help to prevent caregiver fatigue/burnout

4.3.2.1. Description of caregiver fatigue/burnout

4.3.2.2. Strategies for preventing burnout and promoting self-care

4.4 LIMITATIONS OF THE STUDY

4.5 RECOMMENDATIONS

4.5.1. Recommendations for Nursing Practice

4.5.2. Recommendations for Nursing Education

4.5.3. Recommendations for Nursing Research

4.6 CONCLUSION

BIBLIOGRAPHY
ANNEXURES

ANNEXURE A: LETTER REQUESTING CONSENT FROM THE MANAGEMENT OF INSTITUTION 162
ANNEXURE B: CONSENT FORM FOR PARTICIPANTS 164
ANNEXURE C: CONSENT FROM FACULTY OF HEALTH SCIENCES 167
ANNEXURE D: TRANSCRIPTION OF INTERVIEW 169
ANNEXURE E: LETTER OF PERMISSION FROM MANAGEMENT OF INSTITUTION 176

TABLES

TABLE 2.1 Criteria to ensure trustworthiness 41
TABLE 3.1 Identified themes related to the views of caregivers regarding caring for patients with AIDS 52
TABLE 4.1 Broad guidelines that will enable mentors of the caregivers to provide support to the caregivers, to enable them to optimise nursing care for their patients dying of AIDS. 135

FIGURES

FIGURE 3.1 Diagrammatic representation of the central and sub-themes 54
FIGURE 3.2 Diagrammatic representation of sub-theme 1 62
FIGURE 3.3 Diagrammatic representation of sub-theme 2 76
FIGURE 3.4 Diagrammatic representation of sub-theme 3 89
FIGURE 3.5 Diagrammatic representation of sub-theme 4 104
FIGURE 3.6 Diagrammatic representation of sub-theme 5 114
CHAPTER ONE

OVERVIEW OF STUDY

1.1 INTRODUCTION AND PROBLEM STATEMENT

“We are all human, and the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic affects us all in the end. If we discard the people who are dying of AIDS, then we can no longer call ourselves people. The time to act is now. We can make a difference” (Eaton & Etue, 2002:27).

An estimated 38.6 million people worldwide were living with HIV at the end of 2005. An estimated 4.1 million became newly infected with HIV and an estimated 2.8 million lost their lives to AIDS (UNAIDS, 2006:6). Whereas in most countries the overall HIV incidence rate (the proportion of people who have become infected with HIV) is believed to have peaked in the 1990’s, and to have stabilised subsequently, South Africa’s AIDS epidemic – one of the worst in the world - shows no evidence of a decline (UNAIDS, 2006:6). Based on its extensive antenatal clinic surveillance system, as well as national surveys with HIV testing and mortality data from its civil registration system, an estimated 5.5 million people were living with HIV in 2005. An estimated 18.8% of adults (15-49 years) were living with HIV in 2005 and one in three pregnant women attending public antenatal clinics were living with HIV in 2004 (UNAIDS, 2006:7). Of concern is the fact that trends over time show a gradual increase in HIV prevalence, rather than the declines noted in the rest of the world’s statistics (UNAIDS, 2006).

HIV is caused by a retrovirus that attacks the immune system, compromising it progressively. A person is described as having AIDS when the HIV-related deficiency is so severe that various life-threatening, opportunistic infections and/or cancers occur because the immune system is weakened. These infections and cancers are called ‘opportunistic diseases’ because they take the opportunity provided by the lowered immune state in the body. If the
immune state were adequate or functioning normally, these infections would not usually occur (Evian, 2000: 8).

“In 2005, there were close to five million new HIV infections worldwide, three million, two hundred thousand (3 200 000) of these in sub-Saharan Africa alone. In the same year, three million people died of AIDS-related diseases; more than half a million (570 000) were children. Today the number of people with HIV stands at 40.3 million, double the number (19.9 million) in 1995. Despite progress made in a small but growing number of countries, the AIDS epidemic continues to outstrip global efforts made to contain it” (UNAIDS, 2005:6). One of the reasons for lack of accuracy of statistics is related to the stigma of being HIV positive, which is exacerbated because the disease is incurable, which is inclined to make people fearful. The stigmatisation of this disease is one of the reasons given why the government in South Africa reversed its decision of making the disease notifiable (Whiteside & Sunter, 2000: 90).

Data from South Africa has shown that the HIV prevalence among pregnant women has reached its highest levels to date: 29.5% of women attending antenatal clinics were HIV-positive in 2004, according to the Department of Health, quoted in UNAIDS (2005:21). Prevalence was highest among women aged 25-34 years, in which age group more than one in three women were estimated to be living with HIV. Among women in the 20-24 year age group, almost one in three was infected. In the country’s worst affected province, KwaZulu-Natal, prevalence has reached 40%, while it has remained exceptionally high at between 27% and 31% in the Eastern Cape, Free State, Gauteng, Mpumalanga and North West Provinces (UNAIDS, 2005:21).

These latest data underline an outstanding feature of South Africa’s epidemic: the astonishing speed at which it has evolved. National adult HIV prevalence of less than 1% in 1990 rocketed to almost 25% within ten years. Among pregnant women in their late teens (15-19 years), HIV infection levels have remained at 15-16% since 2000, while among their 20-24 year old counterparts those levels have stayed between 28% and 31% in 2000-2004 according to the Department of Health, (quoted in UNAIDS, 2005:22).
Having lagged behind most other epidemics in the sub region, AIDS in South Africa is now taking a devastating toll in human lives. A recent study of death registration data has shown that deaths among people of 15 years of age and older increased by 62% in 1997-2002, with deaths among people aged from 25-44 years more than doubling. Based on information from nearly 2.9 million death certificates, the study showed that more than one third of all deaths were among people in that age group, according to Statistics SA, 2005, quoted in UNAIDS (2005:22). AIDS is believed to be responsible for a large proportion of these deaths, with South Africans dying in patterns that closely match those predicted by AIDS models (UNAIDS, 2005:22).

Of further significance is the fact that an increasing number of women are being infected with HIV. It is often women with little or no income who are most at risk. Widespread inequalities including political, social, cultural and human security factors also exacerbate the situation for women and girls. In sub-Saharan Africa young women between 15 and 24 years of age are at least three times more likely to be HIV-positive than young men (UNAIDS, 2005:9). In many countries marriage and the women’s own fidelity are not enough to protect them against HIV infection. Among women surveyed in Harare (Zimbabwe), Durban and Soweto (South Africa), 66% reported having one lifetime partner, 79% had abstained from sex at least until the age of 17 (roughly the average age of first sexual encounter in most countries in the world). Yet 40% of the young women were HIV-positive, many of whom had been infected despite staying faithful to one partner (UNAIDS, 2005:9).

Most AIDS care occurs within households and surrounding communities, with women providing care for those infected and affected, plus providing financial resources for the survival of the family. It must also be taken into consideration that most of these women, who are caring for others, are frequently battling AIDS-related illnesses themselves (UNAIDS, 2004:5). “Poverty and faltering public services in many areas are combining with AIDS to turn the care burden for women into a crisis that will have far-reaching social, health and economic consequences (UNAIDS, 2004:15). In South Africa more than 40% of affected households reported that the main caretaker had taken time off work or school to care for an AIDS patient (UNAIDS,
effectively preventing these households from relieving their poverty status, or increasing their living standards in any way.

What tends to happen is that families, communities and governments tend to rely on the resilience of volunteers, mostly women, who are tending the sick, trying to earn an income, looking after children or all three at the same time; but fail to provide any means of support for these caregivers. The government in particular needs to acknowledge the fact that women’s work is an essential part of household and national economies, and needs to acknowledge further the burdens added by AIDS to not only the women and their households, but also to the economy at large; and that these burdens have to be relieved (UNAIDS, 2004:16). AIDS care programmes need to be extended beyond medical and nursing care to include counselling, food assistance and welfare support in order to help these women with their burden of caring for those sick and dying of AIDS (UNAIDS, 2004:17). Caregivers are also attempting to assist the child-centred households who have no parental support and no government support, financially or institutionally. What needs to happen is that older children in a household should be freed to attend school instead of having to care for younger siblings, which does not happen.

The addition of hospice-type facilities to care for those dying of AIDS would be an added benefit, to reduce the stresses experienced in child-centred and over-crowded households, particularly when a loved one is dying in the same room as 3 – 5 family members. Palliative care (Hospice Care) is considered to be comprehensive care of people who have any active, progressive and far advanced disease, for whom the prognosis is limited, and where the focus of care is centred on quality of life (Uys & Cameron, 2003:8). The objectives of palliative care are to make patients comfortable and try to improve their health. Of importance in palliative care is to relieve the burden or care load of the family or friends, which is clearly not occurring in South Africa (Uys & Cameron, 2003:8). Help is also needed for babies and young children who have AIDS, but such care facilities are too few for the current rising needs of little ones. There is a definite lack of residential care facilities in general for those with AIDS, mostly because they are too expensive to maintain, which is why the Governments in most sub-Saharan countries prefer to leave the burden of care of those affected and infected with HIV to their families, friends
and communities. What is becoming rapidly clear is that many households simply cannot cope with the stresses of caring for critically ill and/or dying patients, and frequently those patients, adults, children and babies, are admitted to the institution where the researcher works. So, despite the insistence of Government on patients being cared for in their own communities, there is a definite need for care in institutions; and the few institutions available are currently overburdened with those in need of care, especially hospice care.

The decision to centre care for AIDS patients in their own communities is most likely based on studies and subsequent decisions taken by the Committee on National Strategy for AIDS (CNSA) in the USA, which divided the care of AIDS patients into a system comprising three components, viz., hospital care, out-patient care and community-based care. In an adequately functioning health care system, this model has a good chance of working effectively and is clearly potentially more cost-effective than care rendered in institutions (Uys & Cameron, 2003:1). However, in a poorly-developed, under-resourced health care system patients are unlikely to receive the care and support they require using this approach. Even in the USA those with AIDS are often unable to access the care they require (despite the positive-sounding policies), and this when AIDS cases are in the minority compared to the staggering statistics of African countries. It stands to reason, therefore, that those in countries with inadequate resources for health-based needs would receive minimal care, and if it were not for the efforts of families and surrounding communities, little would be done to relieve the suffering of these patients. Regrettably the communities also have to suffer. The following story highlights the effects of this pandemic on those infected, even as long as 20 years ago:

“At the emergency room of St. Vincent’s Hospital in Greenwich Village, the patient lay on a gurney, wheezing from *Pneumocystis*. He had lain there for twenty-four hours, waiting for a room. Under normal circumstances, his doctor would have called the hospital and had the man admitted. But hospital administrators preferred not to take any more AIDS patients; they already had so many. Throughout the city, AIDS clinicians could not imagine what they would do in coming months when burgeoning numbers of patients
overwhelmed the hospital’s finite resources. ‘We’re not talking about a nightmare that is going to happen’, said St. Luke’s-Roosevelt AIDS expert, Dr Michael Lange, ‘It is already a nightmare’ (Shilts, 1988:507). This scenario occurred in New York in January 1985. Twenty years later in Port Elizabeth, South Africa, the same scenario plays out daily in the metropole’s hospital complex, comprising Livingstone, Provincial and Dora Nginza Hospitals. “The three cash-strapped government hospitals in the Port Elizabeth area are most often forced to turn adults, children and even babies with AIDS away to make space and resources available to those with curable ailments” (Eaton & Etue, 2002:162). Owing to these circumstances the burden of care on poverty-stricken households is rendered even more strenuous, causing severe strain on caregivers, who simply cannot access adequate care for their desperately ill patients.

On 30 May 2005, there was a story reported in The Herald about a young child admitted to one of the local government hospitals. This child, transferred from an AIDS Care institution, had been inadequately cared for by staff at this hospital. In further commentary in the media it was stated that there were occasionally patient ratios averaging around 47 patients per nurse/caregiver (1:47) at the government facilities! (Theodosiou, 2005:1). According to the California Department of Health Services (Zondach, 2004: 38-42) the correct nurse-patient ratios per unit are one nurse to four children in paediatrics (1:4) and one nurse to five patients in a step-down facility and/or medical unit (1:5). It is clear from these suggested ratios that optimal nursing care would be impossible and adequate care is even unlikely, in the above mentioned Eastern Cape Hospital. It is therefore not just local households and communities that are suffering the indignity of poverty, but also the overburdened health and social systems in South Africa and the Eastern Cape in particular. So caregivers at these institutions are under pressure from their employers, the community, and media to perform to Developed World standards.

As stated previously, there is a disproportion between men and women affected by HIV. Most papers presented at the 2005 South African AIDS conference attest to the fact that HIV appears to be a highly discriminating virus because it does not infect people equally. Prevalence is higher in
females, particularly in the age group 20-35 years, with an estimated three times as many young females dying in the last two years than previously recorded (UNAIDS, 2004:10-24). HIV prevalence in the age group 20–24 year olds is the highest of all age groups in South Africa, at a figure of 50.8% in rural areas, and 24.5% in urban areas. It is only once the age group 30-35 years is reached that the statistics start to even out regarding male and female infection rates (UNAIDS, 2004:23). This to exacerbates the problems linked to HIV care, because there are insufficient caregivers to provide care for all these young people who are dying in their families and communities. Many caregivers in institutions are also caring for relatives at home who are HIV positive (UNAIDS, 2004:23-24). To summarise, the macro-impact of AIDS on households is essentially the lowering of income/earning capacity, which leads to increases in poverty. The money needing to be spent on health care by these households reduces the money available for other essentials such as education, which will have far reaching consequences not only on the individual households, as youngsters stay out of school to work, or care for siblings and sick relatives, but also on the economy as a whole (South African AIDS conference 2005). Households are clearly becoming increasingly unable to cope with the enormity of this pandemic and are equally unable to care adequately for those infected. Women are unable to continue working since the burden of caring for the sick often falls onto their shoulders; but care with no financial resources is an impossibility, creating further dilemmas for these affected households (UNAIDS, 2005:9).

The increase in numbers of those in the AIDS stage of HIV means that affected individuals, the families and communities, are expected to care for an increasing number of terminally ill people, a task for which they are often ill-equipped, physically, emotionally and financially. They desperately require adequate support, which needs to come from the health care services, both hospitals and palliative care institutions. What is clear is that due to lack of finances, in the country as a whole, this is simply not a current possibility. There are very few facilities for AIDS patients in Port Elizabeth, which is stressful for the staff working at the institution where the researcher works, because of the high incidence of death, consistent with the terminality of the disease. It has to be overwhelming for these caregivers that as soon as beds
are vacated following the death of one patient, the next patient is waiting to be admitted, due to the lack of facilities available for those dying of AIDS.

To combat this negative effect, caregivers need to be supported. This needs to be hands-on and related to dealing with both the spectrum of needs required by the patient(s) and their families and the emotional, physical, spiritual and educational needs of the caregiver(s). An enhanced level of understanding of the situation in which the caregivers are working, by the management team, which constitutes people who are not actually working in this institution but are responsible for the management thereof, would assist the caregivers in planning their work and personal lives – hopefully creating a win-win situation.

AIDS has created unique social and psychological conditions, in which death and dying are immediate, day-to-day concerns for increasing numbers of people. The caregivers nursing patients with AIDS in palliative care institutions are of particular concern in this study, since they are continually surrounded by death and dying and they experience daily the nursing of an incurable disease. This has to have a huge impact on these caregivers, emotionally as well as physically, as they attempt to support their patients and the families, as well as supporting themselves and their own families.

1.2 Problem Statement

“The problems experienced by caregivers in AIDS institutions in having to mourn multiple losses are unique. A direct relationship between the number of bereavement episodes suffered by one person and the development of ‘stress response’ symptoms or ‘psychic numbing’ has been found” (Alexander, 2005:20). Although the phenomenon of ‘multiple losses’ has been acknowledged in association with natural disasters and concentration camp survivors, there has been little published about how to cope with, and resolve, issues raised by multiple loss” (Alexander, 2005:20).

Studies have shown that survivors of multiple loss are afraid, or even unable, to grieve openly, since they fear losing control of their emotions. It is considered best to hold onto the feelings and cover them with an outward display of coping, doing fine, expressing no need for help and carrying on as
usual. When discussing feelings the focus tends to be on day-to-day issues and an academic type of discussion on how the person should be feeling, rather than a heartfelt ‘I can’t do this anymore’. The results of this stoicism would be symptoms similar to those seen with the syndrome of ‘burn out’, such as emotional numbing, withdrawal from others, misdirected anger and resorting to the use of drugs and/or alcohol (Alexander, 2005:20). The experience of multiple losses due to AIDS could therefore be considered a unique one, often further complicated by the fact that the caregiver may herself be infected and facing death (Alexander, 2005:20).

The researcher works in an institution where care is given to patients who are in the terminal stages of AIDS, and death is the norm. There are also babies and toddlers there, and during the last three years approximately 35 babies and children have died. It is extremely difficult for staff to cope with young adults dying (age 20-35 years); but it is even harder to watch children and babies suffering from this disease. The reason for this is that AIDS leads to a protracted death in all patients, irrespective of age, in the experience of the researcher; and this is supported by the fact that palliative care becomes essential for these patients (Evian, 2000:178).

AIDS patients usually suffer from more than one opportunistic infection in the final stages of the disease, and therefore need 24-hour care, often for weeks or months before they die. Incontinence of urine and faeces, breathlessness from chest complaints and skin diseases that cover 90% of the body, are some of the problems facing the patients and health caregivers (Evian, 2000:97-120). The caregivers, even in the formal situations, rarely have more education than a Matriculation certificate, and perhaps a 3-month theoretical and practical course at an accredited academy for training of caregivers. This is inadequate education to enable these caregivers to cope with the type of work currently being required in a hospice situation dedicated to caring for AIDS patients. It takes considerable expertise to deal with patients and their relatives, all of whom are seeking answers, or seeking a cure. The families of these patients are usually unwilling to accept that a young person is about to die, giving rise to anger, which can be daunting foe the caregiver who is lacking in the skills needed to deal with such situations.
Even the professional nurses working with AIDS patients are struggling to deal with the myriad of emotions they experience as they are surrounded by staggering numbers of patients that are dying, and they have at least had the benefit of a basic training in Psychology. Thus for the caregivers with limited training, who mostly come from disadvantaged backgrounds, and are lacking in even the most basic of life skills, it must be challenging to cope with all the emotion and hardship surrounding them.

It is hardly surprising then that with the constant death that occurs at this health care facility, the caregivers, particularly those that have worked there for more than five years, will be struggling emotionally. Talking about death is difficult for all concerned: family, friends, the patient and the caregivers. Most people try to control themselves around those that are dying, but maintaining such composure is sometimes perceived as a display of indifference or of not caring (Callanan & Kelley, 1992: 60-62). This could explain the distance that many caregivers develop towards their patients and, in the experience of the researcher, it often manifests as a lack of care.

Patients often do not receive the kind of care they require when dying, often because the staff might not fully understand the magnitude of terminal illness, of the dying experience as it affects the patients and their families (Callanan & Kelley, 1992: 32-33). Any illness causes physical discomfort, such as pain and nausea, while emotional discomfort includes depression, anger, anxiety, fear, or any one of the spectrum of feelings caused by death’s approach (Callanan & Kelley, 1992: 34). Caregivers need to analyse the kind of assistance the patient will need, to be able to deliver on the patient’s needs, and support the family at the same time. This is obviously difficult and sometimes impossible for the caregivers to do, given the fact that palliative care is difficult work because it requires that team members suspend personal needs or beliefs in deference to the desires of the patient and family. This requires a significant degree of emotional maturity and insight, which the caregiver has to develop in order to learn to cope with both external and internal stressors (Alexander, 2005:21).

Terminal illness also causes social discomfort that can upset the patient’s relationships with others. The patient may feel rejected by family or friends (Callanan & Kelley, 1992: 34). Spiritual discomfort can result from the impact
of mortality on the patient and family. Caregivers can also feel uncomfortable if they are not able to cope with the concept of death, theirs or other’s (Callanan & Kelley, 1992: 34). Often dying patients communicate in strange or obtuse ways, which can make it difficult for the staff to understand them and often caregivers become upset with the patients and take things said or done as personal, when in fact the patient’s words or actions often have nothing to do with the caregiver. (Callanan & Kelley, 1992: 35).

It is so important to ensure that caregivers, who are working in a facility rendering palliative care, are supported to the extent that they can offer their patients the kind of specialised care that they require at this time in their lives. The researcher has observed that the caregivers in the institution where she works appear to be distant from their patients, which does manifest as an uncaring, or switched off, attitude. “When patients become increasingly sick and death becomes such a frequent occurrence, that it is nearly banal, there is increased anxiety on the part of the caregiver, which is sometimes transmitted into an unconscious tendency to ‘abandon’ the patient emotionally” (Goodson-Dunlap, 2004: 43). This description often shows in unwillingness to become attached to any more patients or an inability to relate correctly or appropriately towards dying patients.

Facing constant death causes caregivers to seek to avoid internalising deaths of patients to avoid grief overcoming them cutting off emotion or using denial as a defence mechanism. In such cases there is the danger that by forcing down natural sadness and grief reactions caregivers (and others) may manifest transferred reactions, such as cruelty towards patients, lack of caring for others and lack of self-respect (Freeman, 2004:153). Dealing constantly with patients suffering from pain and fear of impending death, has a profound impact on caregivers, as shown above, which must lead to some sort of emotional response, or more disturbingly, a lack thereof.

It is evident from the above discussion that the experience of multiple losses to AIDS is a unique one. Care of persons with AIDS is often complicated by the fact that caregivers may themselves be infected and facing death (Alexander, 2005: 20). This phenomenon has been noted in the institution where the researcher works, plus the fact that many caregivers are nursing
relatives at home who have AIDS. Several of the caregivers working in this institution have buried family members who have succumbed to AIDS.

In the one case, which was particularly poignant, the caregiver only notified management on the morning of her only son’s death that he had died suddenly. During a counselling session, following her return from the funeral, she shared the fact that her son had died of AIDS. Asked why she did not share this sooner in order to receive appropriate support, she indicated that she was struggling with the stigma of the disease. The researcher was quite surprised at this statement, having thought that caregivers in this facility were more comfortable with the concept of AIDS as a disease than those in their communities.

The following research questions have been formulated from the above problem statement:

- How do caregivers experience caring for patients dying of AIDS?
- How can the caregivers be given adequate support in order to ensure optimum care to AIDS patients and their families?

### 1.3 Research Objectives

The objectives of this study are:

- to explore and describe how caregivers in formal settings (an institution) experience caring for their patients dying from AIDS, and
- to develop broad guidelines that would enable mentors of the caregivers to be able to provide support to the caregivers, to enable them to optimise nursing care of patients dying from AIDS.

### 1.4 Concept Clarification

For the purposes of this study the key concepts of the study will be defined as follows:
Auto Immune Deficiency Syndrome (AIDS)

AIDS, which follows on from infection with the Human Immunodeficiency Virus (HIV) is considered the final phase of HIV, progressing from the symptomatic phase of HIV. AIDS is almost always associated with severe immune deficiency, usually corresponding to CD4 counts below 200cell/mm3 and to a low lymphocyte count. This tends to allow the development of severe opportunistic infections, some cancers and HIV-related organ damage. These conditions are then referred to as ‘AIDS-defining” illnesses, for example, pneumocystic carnii pneumonia, toxoplasmosis of the brain, cryptosporidiosis with diarrhoea, cytomegalovirus, herpes simplex infection, lymphoma and kaposi’s sarcoma (Evian, 2000: 28 & 92).

Death

According to the Concise Oxford Dictionary (1990:297) death means “the final cessation of vital functions in an organism; the ending of life”. From a spiritual perspective, a person’s death could be considered to be the single most important experience in the person’s life, especially considering that it is something that the individual must do alone. Accordingly, everyone is aware of the fact that death is something that will occur to each individual; and therefore all people have needs and concerns about death and dying that need to be addressed. Death remains an important phenomenon in all cultures and with all people, religious or not, and frequently remains a concept to be feared, something ‘we don’t talk about.’ For the purposes of this study death, or people’s views about death and their mortality, is defined. How they cope with death and dying needs to be addressed, to enable the caregivers in this specific area of nursing to receive the help and support that they require.

The Dying Patient

For the purposes of this research, the dying patients are considered to be those patients with end-stage AIDS, who have succumbed to one or more opportunistic diseases. In patients with AIDS, death may take up to seven days, during which time the patient’s body appears to shut down slowly. Nurses working with AIDS patients know the signs of this stage, and are often able to predict an approximate time of death. During this period, the patient
alternates between consciousness and unconsciousness, slowly moving towards longer periods of unconsciousness.

This period, then, is the time that the nurse “cares “ for the patient, up until the patient dies, and also includes the period after death until the deceased patient has been removed from the premises.

**Palliative Care**

According to Chamber’s Dictionary (1983:12), palliative means “serving to extenuate: mitigating: alleviating, that which lessens pain or gives temporary relief.” Palliative care is also termed comfort care and is primarily directed at providing relief to a terminally ill person through symptom and pain management. The goal of palliative care is to provide comfort and maintain quality of life for as long as life remains (Alexander, 2005: 20).

**Caregivers**


“Who are the caregivers? Africa has so many AIDS patients that hospitalisation is not always an option. The enormous need for care leaves the community with no other choice but to care for their own sick.” (Van Dyk, 2001: 282). In South Africa the caregivers comprise family members, particularly women, volunteers working for AIDS care programmes, namely “formal” volunteers trained by the organisations for whom they work, Health Care Professionals, and Traditional Healers (Van Dyk, 2001:283).

**Experience**

“Experience refers to the sum total of an individual's thoughts and feelings and the things that have happened to an individual. It includes the internal environment (body, mind and spirit) as well as the external environment (physical, social and spiritual dimensions)” (Maritz, 2003:11).

**Hospice**
Considered to be a home-like alternative care setting, a hospice is designed specifically for the terminally ill to create a home-like atmosphere wherein death with dignity may be achieved. Palliative care is rendered with pain control optimalised to ensure the highest possible quality of life for a long as life remains (Alexander, 2005: 20).

**Guidelines**

According to the Concise Oxford Dictionary (Allen, 1990:525) “guide” means “a directing principle or standard” and “guidelines” refer to “a principle or criterion guiding or directing action”. In other words, guidelines will enable caregivers to follow certain directions formulated to optimise patient care in the AIDS field. Guidelines are there to standardise care and to lead the caregivers in the right direction.

**Support**

The word “support” has many meanings; in this context support for the caregivers would mean that they would receive moral and psychological support from mentors who would assume responsibility for, or leadership of, the sponsorship or support of these caregivers (Free dictionary, 2000:4). Support also means that management undertakes to support staff and their activities, implying that appropriate management systems must be in place, to facilitate team co-operation and education of staff, which would include an orientation programme and in-service education, to ensure that staff are equipped with sufficient information to be able to carry out their duties (Free Dictionary, 2000:8). Social support is also imperative to enhance the working conditions of any employee and includes both support from management and co-operation amongst co-workers. Failure to ensure social support amongst workers often leads to conflict in the workplace, which exacerbates staff stress levels (Mikkelsen, Saksvik & Ursin, 2004:197-209). Adequate situational support can promote autonomy, provide control over practice, ensure group cohesion, promote manager consideration and thus reinforce caregivers’ coping mechanisms. This would provide the benefit of preserving the integrity of the caregivers and management with the added benefit of promoting quality patient care (Brooks, Wilkinson & Popkess-Vawter, 1994: 305-307). All caregivers require adequate resources to enable them to develop into
competent practitioners, and the important areas for this support are practice, education and research. The more the caregivers are taught, the better they will be able to function, which would increase their confidence levels and reduce their stress (Scarborough Hospital, 2005:1).

1.5 RESEARCH DESIGN AND METHOD

In the next section a brief overview of the Research Design and Method will be presented, as it will be discussed comprehensively in Chapter Two.

1.5.1 RESEARCH DESIGN

Qualitative research

Qualitative research is a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live (Holloway and Wheeler 2002:3). Qualitative research takes place in the natural setting of the participants to involve their actual experiences, which makes it humanistic in nature (Creswell 2003:182). A qualitative design will enable the research to reveal, through stories and reflections, the experiences of caregivers in an environment where patients with AIDS are being cared for.

Explorative research

According to Mouton and Marais (in de Vos, 2002:124) the goal in exploratory studies is the exploration of a relatively unknown research area. In this study the researcher would like to gain insight into and understanding of the experiential world of caregivers in an AIDS care setting, where the death of young adults from AIDS is constant and becoming the norm. Exploration is needed in this field, specifically the effects, emotionally, physically and spiritually, on caregivers participating in this kind of work. The experiences described by the caregivers will generate new knowledge that should lead to improved understanding of these experiences.
Descriptive research

Descriptive research presents a picture of the specific details of a situation, social setting or relationship. It focuses on “how” and “why” questions. (Fouche, 2002:109). “Descriptive” refers to the accurate portrayal of particular individuals or real-life situation (in words), for the purpose of discovering new meaning by describing what exists and categorising information (Burns & Grove 1997:29). In the proposed study the caregivers’ experiences of working with death and dying in caring for patients with AIDS will be described so that complete and accurate information can be obtained.

Contextual

The context involves situating the object of the study or phenomenon of study within its immediate setting (Creswell 1998:62), avoiding the separation of components from the larger context. Context also implies the conditions and situations of an event (Strydom, 2002:281). An aspect of context is the immediate environment and physical locations of the patients being studied, in this case a palliative care institution (Holloway & Wheeler, 1996:192). The context of this research will be described in detail in chapter two.

Phenomenological approach

Phenomenology is primarily concerned with the nature and meaning of human experience, its aim being the insightful understanding and description of the phenomena of human experience (Madjar & Walton, 1999:3). Phenomenological studies, then, examine human experience through the description provided by the people involved. “What phenomenology offers is the possibility of studying human experience in the context of the life-world. This context includes not only the physical and social environment but also one’s history, concerns and aspirations” (Madjar and Walton 1999: 4).

Phenomenology holds appeal for nurses because it conceptualises ‘bodily consciousness’ or the ‘lived body’. The phenomenal body is more than a physical entity; it remembers past hurts, falls ill, hurts, it is aware of itself and it is our only means of being in the world (Madjar & Walton, 1999: 4). Because of the person-centred, contextual approach accepted in nursing, the phenomenological approach is popular in nursing research. In this study the
caregivers will tell their stories in their own words of how working with patients who are dying of an incurable disease (AIDS) affects each of them.

1.5.2 Research Method

The research method involves data collection and data analysis and can be divided into two phases:

1.5.2.1 Phase One

This phase, which consists of data collection and data analysis, involves the exploration and description of caregivers’ experiences of nursing dying AIDS patients. The following sections comprise Phase One:

Population and Sampling Strategy

The target population is identified as caregivers working in a 24-hour care centre specialising in hospice care for people dying of AIDS. They experience a form of bereavement weekly when their patients die. The caregivers chosen for the study will be those who have worked in the facility for a year or more.

In this study a criterion-based, purposive sampling strategy will be used to select participants for the study. The idea behind qualitative research is to select purposefully participants or sites that will best help the researcher to understand the problem and the research question (Creswell 2003:185). It is assumed that the researcher’s knowledge about the population will be used to select the participants. Criterion-based sampling indicates that the individuals being studied will represent people who have experienced this particular phenomenon which, as explained above, is the case in this study.

Data-collection Method

The researcher will make use of in-depth interviews based upon a phenomenological approach, field notes and observation notes as a means of data collection. According to Strydom (2002:278) qualitative studies usually employ unstructured or semi-structured interviews, also known as in-depth interviews. As the interview progresses a story line emerges (the narrative) that focuses on specific research questions. The in-depth interview is used to determine individuals’ perceptions, opinions, facts and reactions (Strydom,
The in-depth interviews are personal and intimate, with emphasis on depth, detail, vividness (intensity) and nuance (subtle difference in meaning) (Strydom, 2002:298-299). The researcher aims to conduct such interviews with the caregivers in their place of work, to enable them to share their lived experiences, which will then be used to formulate broad guidelines to enable the caregivers to function optimally in their situation.

**Analysis of data**

Data will be analysed using Tesch’s method, as described in Creswell (1994:153). Tesch proposes 8 steps to consider in data analysis. Identified themes will then be formulated. This will be discussed in more detail in Chapter Two of this study.

**Literature Control**

The literature control will provide a framework as well as the benchmark for comparing the findings of the study and contrasting the results, themes or categories of this research with other findings (Creswell, 1994:23). In this study literature pertaining to death and dying will be analysed as well as articles relating to the effects of death on caregivers, which will be applied to the results of the interviews.

**1.5.2.2 Phase Two**

The information obtained from the data analysis and literature control will be used as a basis for describing broad guidelines in phase two, enabling mentors of the caregivers to be able to provide support to the caregivers, so that they can provide optimal nursing care for the patients dying from AIDS.

**1.6 PILOT STUDY**

In qualitative research the pilot study is usually informal and consists of the researcher determining whether the relevant data can be obtained from the participants. By testing the nature of the questions in a pilot interview the researcher is able to make modifications with a view to quality interviewing during the main study (Strydom & Delport, 2002:337). The pilot study will
consist of a pilot/trial interview with one of the caregivers working in the 24-hour care centre, from which the interview technique and questions can be assessed.

1.7 TRUSTWORTHINESS

In qualitative designs validity and reliability are described through strategies for trustworthiness (Strydom & Delport, 2002:351). In this study, the shared experiences of caregivers in a palliative care environment will be brought in relation to the effectiveness of strategies to support them in their daily tasks. Guba’s description (in Kretting, 1991:217) of the trustworthiness of any qualitative research study provides four criteria. These are:

- truth value;
- applicability
- consistency and
- neutrality

Chapter two of this study elaborates further on these criteria.

1.8 ETHICAL CONSIDERATIONS

Conducting research is an ethical enterprise, ethics being considered to be ‘a system of morals, rules of behaviour’ (Struwig & Stead, 2001:66). Therefore, throughout the research, the rights of the individual to not be harmed, to give informed consent, voluntary participation, confidentiality, anonymity and justice are paramount; and must be considered throughout the research (Holloway & Wheeler, 1996:39). As a nurse involved in a research study the researcher is responsible for assuring all participants of their above-mentioned rights by explaining the purpose of the study; and to ensure that none of the participants is deceived about the nature of the study (Creswell, 1998:132). Ethical considerations will be discussed comprehensively in chapter two.
1.9 CHAPTER DIVISION

Chapter 1: Overview of the study.

Chapter 2: Research design and method.

Chapter 3: Discussion of data analysis and literature control.

Chapter 4: Guidelines, recommendations, limitations and conclusion.

1.10 CONCLUSION

In this chapter the researcher identifies:

- problems arising from having to deal with constant death and dying related to AIDS patients in a palliative care institution;

- the research design of this study;

- the analysis of data and

- the manner in which research findings and recommendations are communicated and reported.

This study aims to describe the experiences of caregivers in an institution caring for AIDS patients, which will hopefully lead to the development of broad guidelines, which would enable mentors of the caregivers to provide support to the caregivers, so that they can optimise nursing care of patients dying from AIDS.
Chapter Two

Research Design and Method

2.1 Introduction

In the first chapter a brief introduction to the study was given, the research problem was identified and the objectives were introduced. In this chapter, a detailed description of the research design and method will be given. The researcher wished to ascertain the lived experiences of caregivers working with patients dying of AIDS in an institution. Data was collected by means of semi-structured interviews. Data analysis enabled themes to be identified and coded. Broad guidelines will then be constructed that will enable the mentors of the caregivers to provide support to the caregivers, so that they can optimise nursing care of patients dying from AIDS.

2.2 Research Design

The research design is a qualitative, explorative, descriptive, contextual study based on the phenomenological approach of enquiry. The research design will now be discussed.

Qualitative research

Qualitative research is a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live (Holloway & Wheeler, 2002:182). Qualitative research takes place in the natural setting of the participants to involve their actual experiences, which makes it humanistic in nature (Creswell, 2003:182). Research is interpretive and views social phenomena holistically (Creswell, 2003:182), which helps people interpret and make sense of their experiences and the world in which they live (Holloway & Wheeler, 2002:3). A qualitative design will enable the researcher to reveal through stories and reflections the experiences of the
Caregivers in an environment where patients dying from AIDS are being cared for. These lived experiences of the participants will provide a wealth of information, which will assist the researcher in constructing broad guidelines to provide support for the caregivers who are working with patients dying of AIDS.

Qualitative research is also useful in understanding human experiences of pain and hurt (Burns & Grove, 1997:338). Since qualitative research is a more effective method of investigating emotional responses, it will be useful in exploring and describing the participants’ lived experiences of caring for AIDS patients through death and dying.

Creswell (1994:154) states that qualitative research has the following characteristics:

° Qualitative research is concerned with processes rather than outcomes of products. The focus of this study is to explore and describe participants’ lived experiences of caring for patients dying of AIDS. The researcher is, therefore, interested in participants telling their story; and in this process a non-judgemental attitude is required for the researcher to become party to the true thoughts and feelings of the participants;

° Qualitative research is interested in meaning (that is, how people make sense of their lives, experiences and structures of the world). For the purpose of this study, the researcher is interested in the participants’ experiences of working with patients who are dying of AIDS and on developing broad guidelines to ensure support for these workers. The meaning that the participants assign to their experiences is the focal point of this study.

° Qualitative research is the primary instrument for data collection and analysis. The aforementioned characteristics have consistently been applied to this study.

The researcher used a fieldworker in this study to conduct the required in-depth interviews. This was because the researcher was part of the nursing
staff at the institution where the caregivers were working, and it was felt that this could prevent the accumulation of accurate data. The fieldworker chosen for this task has a Diploma in Theology, and was comfortable with the concept of research. He was fully informed about the purposes of the research and the main question. Possible follow-on questions were discussed before the interviews, to ensure the accuracy and relevance of the data collected (Strydom, 2002:218-219). The interviews were conducted in a private area, the counselling room, with a ‘Please do not disturb’ sign on the door during the interviews.

**Explorative research**

Exploratory research which is aimed at assessing the full nature of a phenomenon, implies that the researcher will investigate a problem about which little is known (Struwig & Stead, 2001:7). The main purpose of this design is to develop and clarify ideas in order to obtain a rich familiarity with a phenomenon, and the formulation of questions and hypotheses which could be used for a more precise investigation later (Struwig & Stead, 2001:7). This type of research is useful when a new area or topic is investigated and thus little information is known about it, which applies to this research study (Struwig & Stead, 2001:7).

Exploratory studies may be used to gain insight into an area for which there is little available information. In South Africa in general, and the Eastern Cape in particular, there is very little information available on the impact of HIV/AIDS on caregivers, particularly with reference to those working in formal institutions with patients dying of AIDS. An exploratory study such as this allows the views and lived experiences of the caregivers working in this particular institution to be explored, which will generate new knowledge and provide insight into and understanding of their experiences. This in turn will assist the researcher in constructing broad guidelines which would enable mentors of the caregivers to be able to provide support to the caregivers, to help them to optimise nursing care of patients dying of AIDS.
Descriptive research

Descriptive research, which is the description of phenomena in real-life situations, provides an accurate account of characteristics of particular situations, individuals or groups. Through descriptive studies researchers discover new meaning, determine what exists, determine the frequency with which something occurs and categorise information (Burns & Grove, 1997:24). Accordingly, the researcher utilised this approach to describe the experiences of caregivers working with patients who were dying of AIDS. The data gathered from the participants will assist the researcher to obtain complete and accurate information for the research study. The interview method, usually used in descriptive research, was the method of choice for this research study.

Contextual

Contextual research involves the immediate environment and physical location of the people being studied (Holloway & Wheeler, 1996:192). Context also refers to the cultural and historical situation which is important for an understanding of the phenomenon and the meaning that the participants give to it (Madjar & Walton, 1999:4). The researcher should understand the context in which participants act and must also take into account their own location in time, space and culture. The awareness of this as a basis for their own assumption can help in understanding the meaning of the context of participants (Holloway & Wheeler, 1996:192).

This research study was contextual in nature as the participants were interviewed within the physical environment and cultural context in which they were currently working.

Phenomenological Approach

The purpose of this approach is to describe what people experience in regard to some phenomena; how they interpret it and the meaning these lived
experiences hold for them (Brink, 1996:119). This approach examines the human experiences through the description provided by the people involved and these experiences are referred to as *lived experiences*. In this research the focus was on the lived experiences of the participants as they nurse patients dying from AIDS, how they interpret it or what meaning the experiences hold for them. In attempting to describe these lived experiences the researcher will focus on what is happening in the lives of these caregivers, what is important about their experiences and what alterations can be made. This approach will lead to the development of concepts and themes that can be applied to developing broad guidelines that will enable mentors of the caregivers to provide support to the caregivers, to enable them to optimise nursing care of patients dying from AIDS.

The success of this research is thus dependent on having a phenomenological approach throughout the study through which the researcher aims to bring the ‘human side’ of the participants to the fore. The research method will now be discussed.

### 2.3 RESEARCH METHOD

The research method which involves data collection and data analysis can be divided into two phases.

#### 2.3.1 PHASE 1: Exploration and description of the lived experiences of the caregivers while nursing patients dying of AIDS

This phase comprises sampling strategy, data-collection activities, data-collection method, data analysis and literature control. Each of these processes will now be discussed.

#### 2.3.1.1 Sampling Strategy

Criterion-based, purposive sampling was used in the recruitment and preparation of research participants. For the in-depth interviews, participants
were selected so as to maximise the richness of information obtained pertinent to the research question.

Brink (1996:141) and Polit & Hungler (1993:237) describe purposeful sampling as a sampling method based on the researcher’s judgement about subjects that are typical or representative of the phenomenon being studied in cases where the researcher is particularly knowledgeable about the problem. The researcher, in such cases, intentionally selects the participants she feels are suitable and requests them to participate. The advantage of purposeful sampling is that it allows researchers to select the sample on the basis of their knowledge of the phenomenon being studied.

The researcher drew a purposive sample from the available caregivers that met the research population criteria. Criterion-based sampling was successful, as all the individuals studied were people who had experienced the phenomenon being studied. This is an element critical to phenomenological studies (Creswell, 1998:119). In order to participate in this study participants had to meet specific criteria, which were that they:

- had all worked at their place of work for more than a year
- had all worked with patients dying of AIDS
- had agreed to have a translator present, if required, to facilitate the translation of data into English
- were representative of different gender groups (one was male and the remaining twelve were females)
- had all worked with both adults and children dying from AIDS.
- were representative of different cultural groups according to the South African demographics (five were Coloured, one was Indian, and seven were Xhosa) and that
- saturation of data was accepted when themes and categories in the data become repetitive and redundant to the extent that no new information emerged from further data collection (Polit & Hungler, 1993:48). The fieldworker did, however, continue with individual interviews until the participants presented the same storyline repeatedly.
2.3.1.2 Data Collection

The researcher made use of unstructured, phenomenological, in-depth individual interviews as a means of data collection. Holloway & Wheeler (2002:79) state “interviews have become the most common form of data collection in qualitative research”. Interviews are personal and intimate, with an emphasis on depth, detail, vividness (intensity) and nuance (subtle difference in meaning) (Crabtree & Miller, 1999:93).

An in-depth interview can be defined as one or more face-to-face interactions between an interviewer and interviewee, the purpose being to understand interviewees’ life experiences or situations, as expressed in their own words (Greeff, 2002:298). The researcher utilised such interviews to gain insight into the experiential worlds of the caregivers who met the criteria stipulated for the research population. The unstructured interview does not use an interview schedule that contains a common set of standardised questions. The questions emerge from the interactive process between the interviewer and interviewee (Greeff, 2002:298).

The researcher used open, direct and verbal questions to elicit the experiences and gain information from the selected research participants. The goal in this study is to describe the caregivers’ experiences, as well as to explore the meaning of their experiences related to caring for patients dying of AIDS. In-depth interviews were recorded on audiotape. The interviews were transcribed the data was analysed, and themes were formulated, that were then recontextualised within the framework of existing literature. For the purpose of this study, unstructured phenomenological interviews were conducted, beginning with the following one central question:

• “Can you tell me about your experiences of working with patients with AIDS?”
As mentioned previously, data was collected by means of phenomenological in-depth interviews. The fieldworker took cognisance of his defined role in order to ensure that high-quality interviews were conducted. The role of the researcher, and in this study, fieldworker, will now be discussed.

2.3.1.3 Role of the researcher

A qualitative researcher is the primary instrument of data collection and analysis, rather than through inventories, questionnaires or machines; and implies an openness on the part of the researcher with regard to examining new ideas (Creswell, 1994:145). A qualitative researcher functions in the capacity of a human instrument in an effort to explore how caregivers experience nursing patients who are dying of AIDS. The research interview is an interpersonal situation, a conversation between two partners about a theme of mutual interest, a specific form of human interaction in which knowledge evolves through a dialogue. The interaction is neither as anonymous and neutral as when a subject responds to a survey questionnaire, nor as personal and emotional as a therapeutic interview (Burns & Grove, 1997:80).

This means that the researcher, with the aid of the fieldworker, utilised bracketing (Burns & Grove cited in de Vos, 2002:337) by placing their knowledge and preconceived ideas about the phenomenon between brackets, and focusing their awareness and energy on the experiences of participants, and the research process (intuiting). Bracketing implies that the researcher willingly laid aside what was known about the experience being studied to achieve an open context, and to facilitate “seeing” all facets of the phenomenon. The researcher and the fieldworker explored their concepts in detail. Intuiting, which is the process of actually “looking at” the phenomenon and developing insight into it, requires concentration and complete absorption of the experience being studied (Strydom & Delport, 2002:337). In order to achieve meaningful bracketing and intuiting, continual self-evaluation was a prerequisite for the fieldworker in order to avoid bias related to preconceived ideas and notions.
The way in which the participants viewed the researcher was of cardinal importance, hence the decision to use a fieldworker for the interviews. The researcher was a Registered Nurse in charge of the care side of this facility, and as such she formed part of the management team, in which position she attended meetings with the management structure. The researcher did not wish to make the caregivers feel uncomfortable during the interviews, hence the decision to use the fieldworker to interview the participants. The fieldworker was encouraged to be sensitive with regard to the physical setting, the participants, their behaviour and conversation, as well as to the information being gathered. This implies the creation of an atmosphere that encouraged freedom of expression, by portraying a non-judgemental and respectful attitude based on the notion that all participants had dignity and equal worth (Burns & Grove, 1997:428). The quality of the data collected depends on the quality of the interviews and observation; so establishing rapport, of which empathy and trust were the foundation, was essential in collecting quality data. The interviewer needed sound communication skills to ensure high-quality interviews. The person chosen to be the fieldworker fitted this profile perfectly, since, having a Diploma in Theology, he was able to communicate well with the caregivers. He had also worked at this institution as the fundraiser from 1999-2000; so he was aware of the difficulties of working there, which helped tremendously with the interviews.

### Communication Skills

To encourage the caregivers to articulate their experiences freely, non-directive communication techniques, which included probing, paraphrasing, summarising, silence, clarifying, reflecting of content and minimal verbal responses, were used.

#### Probing:

This technique refers to the interviewer’s ability to help the participant to identify and explore experiences, behaviours and feelings that will help him engage constructively in any of the steps of communication (Kvale, 1996:133). Accordingly, the fieldworker, (as the interviewer) pursued the given answers
and probed in a non-threatening and reassuring way to obtain added information. Examples of questions and/or statements that were used include: *Would you elaborate on that*” or “*Tell me more*”.

♦ **Paraphrasing**

Paraphrasing involves listening to the participant’s basic message and then repeating or restating these thoughts or feelings in similar words. The degree of interpretation may involve merely rephrasing an answer. For example, a caregiver could be asked, “*You mean that…*” or “*So what you are saying is..*” (compare Kvale, 1996:133).

♦ **Summarising**

In summarising at the end of an interview, the fieldworker synthesised what had been communicated, which means that he tied together the different views and feelings into one single statement by focusing on essential cognitive and affective themes that had emerged. This both enhanced the feeling of progress in communication and created a sense of movement in exploring ideas and findings (compare Greeff, 2002:295).

♦ **Silence**

Silence can extend an interview. The fieldworker used silences and pauses during the conversation, which allowed the participants time to express emotions, to reflect on issues and then to break the silence themselves with significant information (compare Kvale, 1996:134).

♦ **Clarifying**

Clarifying is an attempt to focus on or understand the basic nature of the participant’s statement if the response is unclear, vague or confusing. The fieldworker asked for clarification when both he and the participant could not make sense of a communicated message and, by so doing, prompted mutual understanding (Greeff, 2002: 295).
♦ Reflecting

The fieldworker used reflecting by repeating what the participant had said in order to clarify the latter’s ideas and validate that the understanding of the fieldworker corresponded with that of the participant (Delport, 2002:195).

♦ Responsive listening

The fieldworker used responsive listening to attend to verbal and non-verbal messages of the participants (for example, eye contact, body language, gestures and posture) and the apparent and underlying thoughts and feelings of the participants. This implied genuine understanding (empathy) and the acceptance and concern that was essential in establishing rapport (Greeff, 2002: 293).

♦ Minimal Verbal Response

The fieldworker adopted a passive role, allowing added time for the participant to talk. Minimal verbal response indicated that the fieldworker was listening to the participant, and following what was being said. The interviewer made use of gestures like head nodding and/or verbal cues such as “mm”, “uh”, and “I see” (Greeff, 2002: 294).

2.3.1.5 The Interviews

The pre-interview (planning), the actual interview (implementation) and post-interview (evaluation) as part of data collection will be discussed.

A pre-interview (Planning)

Planning was a vital part of the interviewing process. Crabtree and Miller (1999:99) call it *staging the scene*. Staging the scene included setting the
scene, learning the part, equipment checking and the pilot interview. Each of these sections will be discussed.

• Setting the scene

According to Crabtree & Miller (1999:100), setting the scene includes the initial pre-interview contact to set up the interview. The ensuing steps were followed:

- The fieldworker made contact with each potential participant individually.
- The fieldworker explained the objectives of the research and invited the participant to participate.
- The fieldworker obtained consent from the participants before any interviews were conducted to ensure protection from any harm (Annexure B).
- The fieldworker interviewed the participants in their on-duty time at an agreed date, time and venue (the counselling room was utilised).
- Disturbances were kept to a minimum by placing a ‘Do not disturb’ sign on the door and there was no telephone in this room.
- The fieldworker informed the participants about the use of an audio-tape recorder and note-taking, and explained the rationale for their utilisation.
- The fieldworker notified all the participants of the length of the interview and reassured them that confidentiality and anonymity would be maintained.

• Learning the part

This refers to knowing as much as possible about the local setting and the participants themselves.
- The researcher, who had worked in the same setting as the participants for five years, and the fieldworker, who had worked in this setting for two years, were familiar with the context.
- The researcher and fieldworker were both familiar with the different cultures of the participants, namely Xhosa, Coloured and Indian.

• Equipment checking
Prior to the interview the fieldworker ensured that:
- the environment was conducive to conducting the interview, namely clean, quiet, private, at a comfortable temperature and non-threatening; and that
- the tape recorder was in working order and extra batteries, blank tapes and a back-up tape recorder were available. According to Greeff (2002:304), it is important when using an audio-tape to test the equipment to make certain that it will record both the interviewer’s and the participant’s voices adequately.

**Pilot Interview**

The fieldworker conducted a pilot interview in order to assess whether the sequence and wording of the questions posed were understandable to the interviewees and within the framework of a phenomenological approach to the enquiry. Conducting a pilot interview enabled the fieldworker to assess whether the research questions generated the desired effect. It also served as an assessment tool for the fieldworker with regard to the technique of interviewing. Furthermore, Crabtree & Miller (1999:98) state that once the main question is asked, the interviewer must be prepared to keep the story flowing and maintain narrative competence.

**The Interview**

The interview was conducted after staging the scene. As discussed in 2.3.2.6, the interview process required that cognisance be taken of the interviewer’s role and attitude. Throughout the interview the fieldworker incorporated the following aspects:
- The fieldworker put the interviewees at ease by merely chatting generally to “break the ice” and reinforcing the ethical considerations, namely the right to confidentiality and anonymity.
- The fieldworker did his best to display these communication skills and attitudes so as to ensure that the participants shared information freely and openly.
The fieldworker was sensitive to any changes in the type of communication, especially during the deep stages when the participants tended to reveal information that evoked emotion, for example, if the participant started to cry the fieldworker allowed the time needed for him/her to regain composure (called toning down).

- The fieldworker remained alert and evaluated the content of the ongoing conversation and used bracketing to avoid any misinterpretation.

- In the closing stage of the interview, the fieldworker summarised the areas covered in the interview and clarified any misunderstandings or questions that the interviewee might have had (Crabtree & Miller, 1999:101-106).

- **Post-Interview (evaluation)**

Once the official interview had ended, the fieldworker turned the tape recorder off and engaged in “small talk” for 5-15 minutes. This time served to:

- assess how the interviewee felt about the interview;
- assess whether the interviewee needed referral for a debriefing or counselling session, as this was possibly the first time that he/she had conceptualised his/her experiences; and verbalising their experiences could have been traumatic; and
- give the fieldworker a chance to thank the interviewees for their participation and valuable contribution to this study (Crabtree & Miller, 1999:105).

In this research study, the fieldworker kept field notes. The types of notes and rationale for their use will now be discussed.

### 2.3.1.6 Field Notes

Field notes were made after each interview (in this study) while the events were still clear in the mind of the fieldworker. The recording of field notes creates a detailed record of all occurrences during the interviews, enhancing the richness of the data gathered. Notes taken during the interviews may disturb the participants, hence the rationale of documenting briefly, straight
after the interview, details that may not be clear on the tape (Holloway & Wheeler, 2002:86). Field notes deepen the insight of the fieldworker into the life-world of a participant in a research study by creating thick data with the richness to give a precise portrayal of the phenomenon being studied. Several types of field notes may be used in qualitative research, some examples of which include:

- **Observational notes**: Observation and interviews go hand in hand allowing for a more complete understanding of what is being studied, such as a description of the “setting, people and location” (Holloway & Wheeler, 2002:262). During the interviews the fieldworker may gain useful insight into the phenomenon being studied by observing the body language and attitude of the participants (Holloway & Wheeler, 2002:104). Some of the participants in this study appeared uncomfortable at first at the thought of being tape-recorded. However, when the interviews commenced, they appeared to relax and they displayed an interest in the study, and in their patients and their welfare. Thus observational notes presented an account of what happened had during the contact sessions with little or no interpretation (Greeff, 2002:292).

- **Theoretical notes**: Theoretical notes are described in de Vos (2002:259) as *self-conscious, systematic attempts by the researcher to derive meaning from some or all observational notes*. The researcher attempted to identify patterns or themes found repeatedly in the course of the research by interpreting, inferring and hypothesising, as well as through developing new concepts and linking these to older ones or relating to any other observations (Strydom, 2002:259).

- **Methodological notes**: The researcher kept these as instructions to herself, for critique of her own tactics and reminders about methodological approaches that might improve the interview situation in terms of proposed research design and method (Creswell, 1994:152). Feasibility of a particular research design may be a problem in the clinical setting so a continuous assessment of the methodology used is required to maintain relevance of the data gathered (Creswell, 1994:152).
- Personal notes: Creswell (1994:152) describes personal/reflective notes as the researcher’s own reactions, reflections, and experiences. The fieldworker displayed openness to self-evaluation by displaying a reflexive stance. Being reflexive implied that the fieldworker acknowledged his own inner dialogue and attempted to focus on his own judgements and feelings regarding the research phenomenon and process (Wilson, 1998:434). These notes were used to provide added insight into the working experiences of caregivers nursing patients dying of AIDS.

2.3.1.7 Analysis of Data

The recorded interviews were transcribed and then analysed together with the field notes. The researcher attempted to capture the essence of the recorded accounts of the participants during the data analysis which was done according to Tesch (cited in Creswell, 1994:155) to reduce the data to themes or categories. Tesch’s approach proposes eight steps to engage a researcher in a systematic process of analysing all qualitative data that is generated:

i) To get a sense of the storyline the researcher read through all the transcriptions carefully, jotting down ideas that came to mind.

ii) The researcher selected one interview – the most interesting and shortest, and asked herself, “What is this about?” Focusing on the underlying meaning of the text, she jotted down thoughts in the margin. This process was followed with all data generated.

iii) The researcher then formulated a list of all themes, clustering similar topics together. These themes were formed into columns, namely central themes, unique themes and leftover themes; and implied making comparisons and contrasts.

iv) The researcher took this list and revisited all the data that had been collected, in order to reduce the total list of themes by grouping inter-related themes together, following a process of comparison and contrasting themes. with one another and the whole.

v) The researcher found the most descriptive words for each topic and turned them into categories and sub-categories. Coding refers to the process whereby data is divided into smaller parts, conceptualising field notes. Preconceived ideas or pre-coded
protocols were not be used. Instead, codes were developed to be part of ‘making sense’ of the caregiver’s world, as described in each interview.

vi) A final decision was then made about the abbreviation for each category; and then the codes were alphabetised.

vii) A preliminary analysis was performed after assembling the data that belonged to each category.

viii) Existing data was recorded where necessary.

Once the researcher had coded the data and developed themes, a clean set of the transcribed interviews was given to an independent coder, experienced in the field of qualitative research. The independent coder was asked to assist with the identification of themes. On completion, the researcher and independent coder communicated to discuss themes and categories on order for consensus to be reached. Both the researcher and the independent coder agreed that data saturation had been achieved and that there was no need for further interviews to be conducted.

These categories, themes and sub-categories portrayed the storyline in a meaningful, descriptive way.

2.3.1.8 Literature Control

The literature control was conducted after the themes had been developed through data analysis. The findings of this study were combined with existing literature to determine current knowledge of the phenomenon (Burns & Grove, 1997:706). The literature control provided a framework as well as a benchmark for comparing and contrasting results (or themes or categories) of this research with other findings (Creswell, 1994:23). If no specific literature was found to support or contradict statements, the researcher highlighted this during the discussion of results in Chapter Three of this study.

2.3.1.9 Phase 2
Phase 2 entailed developing broad guidelines, which would enable mentors of the caregivers to provide support to the caregivers, in order for them to optimise nursing care of patients dying of AIDS.

2.4 MEASURES TO ENSURE TRUSTWORTHINESS

An inquiry is trustworthy if the researcher can convince the reader that the results are worthy of attention and worth taking account of. Guba’s model (in Krefting, 1991:214) was employed to assess the trustworthiness of the qualitative data. Guba identified four criteria of trustworthiness, namely truth value, applicability, consistency and neutrality. Each of these criteria has its specific strategies (Krefting, 1991:215). All these aspects will be discussed and a tabular presentation will follow to indicate the application of this model to the research study. The criteria are as follows:

- Truth value

Truth value is based on the criterion of credibility which refers to the findings of the research study being based on the discovery of human experience as it was experienced and observed by the informants (participants). Strategies to ensure credibility included authority of researcher, field experiences, interviewing technique, member checking, peer examination, reflexivity and structural coherence (Krefting, 1991:215). The researcher’s attempt to establish the credibility of this research by applying these strategies is set out in Table 2.1.

- Consistency

Consistency refers to whether the findings would be consistent if the enquiry were replicated with the same participants or in a similar context. In qualitative research it is acknowledged that it is difficult to expect consistent results if a study is replicated even if the same participants or similar contexts are used because the participants, the researcher and the specific circumstances of the study can vary greatly within the research (Krefting, 1991:216). Guba 1985 (in de Vos, 2002:351) states that the criterion for consistency is thus
dependability, which refers to the researcher’s attempting to account for these changing conditions of the phenomenon chosen for the research and the changes in the design. The measures used to ensure dependability include procedure, dense description of research methods, triangulation and peer examination. The application of these strategies will be discussed in table 2.1.

Applicability

Applicability refers to the degree to which the findings can be applied (fitted) to other contexts and settings or with other groups. Transferability, which is the criterion against which applicability is assessed (Krefting, 1991:216) refers to how similar the findings of the research study would be in contexts outside that of the original study. The purpose of this research study, as with other qualitative studies, was not to generalise findings, but rather to gain in-depth understanding of the research phenomenon. The researcher thus attempted to enhance the possibility of transferability by providing a comprehensive description that served as a base of knowledge. Nominated sample and dense description were strategies used to ensure applicability in this study, as set out in table 2.1 (Krefting, 1991:216).

Neutrality

Neutrality means that there is no prejudice evident in the research procedure and research results. Confirmability, which is the criterion against which neutrality is measured, refers to whether the results attained from the research can be confirmed by another. It places the evaluation on the data. Strategies used by the researcher in this study to ensure neutrality were triangulation and reflexivity (Krefting, 1991:217). The application of these strategies is set out in table 2.1.

Table 2.1 Criteria to ensure trustworthiness

<table>
<thead>
<tr>
<th>Criteria to ensure trustworthiness</th>
<th>Strategy</th>
<th>Criteria</th>
<th>Application</th>
</tr>
</thead>
</table>
| 1. Truth value                    | Credibility | Prolonged and varied field experience | • Contact was made with the participants prior to the interview to build rapport with them.  
• The researcher has twenty-eight years of |
nursing experience and five years specialising in AIDS care and palliative care.
- The researcher has gained insight into the context in which participants experience nursing patients who have AIDS and are dying of AIDS.

| Reflexivity         | • The fieldworker will make use of a journal and diary in which he will reflect on his thoughts, own ideas and feelings from exposure to participants while conducting the research.
• The researcher may become aware of biases while writing these notes.
• Objectivity will be maintained throughout the research study as far as possible. |

| Triangulation       | • Data will be collected from participants and field notes.
• Data will be verified by literature control.
• The researcher and independent coder experienced in qualitative research will analyse data.
• Participants from various cultures, ages and gender will be interviewed.
• Participants will be interviewed at different times in various wards to avoid limiting the experiences of participants to one ward only.
• Examples of sources that will be used by the researcher are as follows: literature control will be done through the use of books, journals, newspaper articles, internet searches, etc. |

| Peer Examination    | • Discussions will be held with nursing colleagues who have experience in palliative care nursing and HIV/AIDS nursing care.
• Independent checking of data will be done by experts in qualitative methodology |

| Interviewing technique | • All the participants will be asked the same research question to determine if a logical rationale is present.
• In-depth interviews with a phenomenological approach will be conducted.
• Open-ended questions will be asked.
• The researcher will follow all the steps in conducting in-depth interviews to the best of her |
ability.
- Verbal and non-verbal skills be used to encourage participants to talk freely.
- The researcher will enhance her interviewing skills through conducting pilot interviews.

| Structural coherence | • The researcher, supervisor and co-supervisor will ensure that there are no inconsistencies between the data and its interpretation.
  | • The participants’ experiences of nursing patients who have AIDS, and who are dying from AIDS, will be the main focus of the study. |

| Authority of the researcher | • The researcher, having had five years of experience in the field, is familiar with the phenomenon being studied.
  | • The researcher received post-graduate training in research methodology and is familiar with qualitative studies.
  | • The supervisors have extensive experience in conducting qualitative research that will guide the researcher.
  | • A pilot study that will increase the researcher’s confidence in research methodology will be conducted. |

2. Applicability | Transferability | Nominated sample | • A purposive, criterion-based sample will be drawn from the available participants who were working with patients dying of AIDS.
  | • The researcher set sample criteria. |

| Dense description | • A detailed description of the research methodology, including literature control, was provided to maintain clarity.
  | • This data would provide information on the repeatability of the study.
  | • This dense description was written in such a manner that another researcher would be able to follow the proceedings of the study.
  | • Guidelines were also be discussed |

3. Consistency | Dependability | Dense description Triangulation Peer Examination | • As discussed above
  | • As discussed above
  | • As discussed above |

4. Neutrality | Confirmability | Triangulation Reflexivity | • As discussed above
  | • As discussed above. |
As adapted from Krefting (1991:214).

2.5 ETHICAL CONSIDERATIONS

Ethical issues are always an important consideration in any type of research as they are intended to prevent any emotional or physical harm knowingly befalling any participants in a research study. The concept of ethics has several meanings, examples of which, relevant to this study, are the practices or beliefs as well as standards and codes of behaviour of a particular group of individuals such as nurses or doctors (Pera and Van Tonder, 1996:4). These standards and codes are widely accepted as providing a basis for practice in that group and guide their actions in everyday practice. Another meaning relevant to this study is a “philosophical method of enquiry which enables us to understand the moral dimensions of human conduct” (Pera & Van Tonder, 1996:4). Ethics, therefore, is also an activity investigating particular aspects of human welfare (Pera & Van Tonder, 1996:4). Ethical codes for professions set the parameters of the responsibilities the nurse owes to her patients. Standards provided by ethical guidelines should, therefore, form a basis for judging the conduct of the researcher and assessing the extent to which ethical principles are adhered to (Strydom, 2002:74). The following standards were utilised as a guide throughout the research study.

2.5.1 Freedom from harm

All participants in a research study must be protected from any physical or emotional harm, and be informed about the possible impact of the study. An ethical researcher must also be prepared, at any time during the research, to terminate the research if there is reason to suspect that continuation would result in undue stress to participants. The participants were given the choice of withdrawing from the study, if they so wished. (Polit & Hungler, 1993:130). If the researcher becomes aware of any prospect of physical or emotional harm, there is equally an ethical duty to change the focus of the study to prevent this from befalling the participants (Strydom, 2002:64). The fieldworker was aware of this and applied these principles to all interviews conducted.
2.5.2 Informed Consent

The concept of informed consent is a necessity in research so that all participants may take a reasoned decision on their participation or on withdrawal from the study at any stage. Participants must also be legally and psychologically able to make a decision regarding informed consent (Strydom, 2002:74). Researchers document the informed consent process by having participants sign a consent form which includes information about the study purpose, specific expectations regarding participation and voluntary nature of participation (Polit & Hungler, 1993:134) (refer to Annexure B). The following information was conveyed to each participant:

- The title of the research
- The objectives of the research
- Research methods, including all the procedures that would be followed.
- The type of participation that would be required of the participants.
- How the results would be utilised and published.
- How any of the participants could contact the researcher if they had any further questions or personal inquiries (Burns & Grove, 1993:105-106).
- The researcher informed each participant that a professional counsellor’s name and contact details would be provided if any participant felt the need for emotional support after the research interview.

2.5.3 Principle of Justice

This includes the following:

- **Right to fair treatment**

Participants have the right to fair and equitable treatment before, during and after their participation in the study. Fair treatment includes the following aspects:

- The fair and non-discriminatory selection of participants. In this research study participants will be selected by purposive, criterion-based sampling strategy. Participants will not be selected because they are vulnerable or could be manipulated easily.
- Those participants who decline to participate or who withdraw from the study after agreeing to participate, will not be compromised or made to feel guilty in any way.

- Sensitivity and respect for the beliefs, habits and lifestyle of people from different cultures. This is especially relevant in South Africa with its ‘rainbow’ nation that comprises many cultural groups (Polit & Hungler, 1993:137).

• **Right to privacy**

According to Strydom (in de Vos, 2002:65) privacy means, “that which normally is not intended for others to observe or analyse”. Individuals who agree to participate in research have a right to expect that the information collected from them will remain private. This can occur through:

- **Anonymity**

Anonymity refers to the act of keeping individuals nameless in relation to their participation in the research. No-one, including the researcher, should be able to link specific data to a specific person or institution (Brink, 1996:41). In order to ensure anonymity for these participants, the researcher will utilise the following mechanisms as outlined by Brink (1996:45) i.e. provide each participant with a number or code name, keep the master list of participants and matching code numbers in separate locations, destroy the list of actual names and use code names when discussing data. Audio-tapes will be kept in a safe place and destroyed after the research. Privacy can also be ensured through confidentiality.

- **Confidentiality**

All information was handled in a confidential manner by the researcher, which means that the research data should never be shared with outsiders, colleagues or other professionals. Research data should be closed and only persons involved in the research should have access to it, unless the participant has given the researcher explicit permission to make the data known. The participants were told before they consented to participate that the researcher would do her best to ensure that personal characteristics would not be made known (Brink, 1996:40). Anonymity and confidentiality is
very important, and particularly in the case of this study, since the identity of
the subjects were well known to the researcher, the researcher promised that
their identity would be kept anonymous from others (Burns & Grove, 1997:99).
2.6 CONCLUSION

Chapter Two described the research design, research method, trustworthiness and ethical considerations comprehensively. The research method consists of two phases. During phase one individual depth interviews within a phenomenological approach were described as well as the data-collecting method. Data analysis followed, whereby the recordings made during the data collection were transcribed verbatim and then analysed for the occurrence of themes and categories. An independent coder assisted in this process. After data analysis, a literature control was undertaken to compare findings with other studies and literature. The first objective of this study is to explore and describe the participants' lived experiences of nursing patients with AIDS, and who are dying of AIDS. This objective will be reached through the completion of phase one.

Phase two consisted of developing broad guidelines which would enable mentors of the caregivers to provide support to the caregivers, for them to optimize nursing care of patients dying of AIDS. The identified themes and literature control will be discussed in Chapter Three.
“The tragedy of life is not in the fact of death. The tragedy of life is what dies inside a man while he still lives – the death of inspired response; the death of awareness that makes it possible to feel the pain or the glory of other men in oneself…No man need fear death: he need fear only that he may die without having known his greatest power – the power of his free will to give his life for others.”
(Albert Schweitzer).

3.1 INTRODUCTION

In Chapter Two, a full description of the research design and method was given. In this chapter, the identified themes derived from the data collection will be discussed in a narrative manner with relevant quotations from the caregivers. All the interviews were audio-taped and transcribed verbatim and a literature control is also included. The aim of the literature control is to re-contextualise the themes identified during data analysis, as well as indicate, within existing literature, the extent to which these themes have been documented.

3.2 OPERATIONALISING OF DATA ANALYSIS AND LITERATURE CONTROL

The operationalising of data analysis and the implementation of the literature control will now be discussed.

Interviews

Thirteen in-depth interviews, each lasting 30-45 minutes, were conducted. Data saturation was reached when no further new themes emerged.
The thirteen participants interviewed all met the inclusion criteria which meant that they:

- had all worked at their place of work for more than a year;
- all had experience working with AIDS patients who were dying;
- had agreed to have a translator present, if required, to facilitate the translation of data into English;
- were representative of different gender groups (one was male and the remaining twelve were females);
- had all worked with both adults and children suffering from AIDS; and
- were representative of different cultural groups according to a South African cultural profile (five were Coloured, one was Indian and seven were Xhosa).

A pilot interview was undertaken and included for data analysis. Participants said to the researcher that it was good to have the opportunity to share their experiences.

**Independent coder**

An independent coder was appointed to assist with identifying and ensuring trustworthiness of the themes relating to the experiences of the caregivers working constantly with death and dying, linked to AIDS, at their place of work. The independent coder had completed a Doctorate Degree and, accordingly, had an understanding of the qualitative research process. After discussions with the coder, supervisor and co-supervisor it was confirmed that data saturation had been reached. Consensus on themes was reached, and interviews with the supervisor and co-supervisor followed this initial analysis, the formal discussions highlighting the fact that the emergent themes did indeed express the storyline as told by the caregivers.
Literature Control

The broad aim of any literature control is to synthesise the critical evaluation of existing work on a topic (Fouche & Delport, 2002:265). The researcher conducted a literature review in order to:

- outline what was known about the topic;
- verify if identified themes had been previously documented; and
- identify the context in which the topic was being explored;

Literature pertaining to death and dying was plentiful, but to find information related specifically to caregivers of people living with AIDS in institutions, and particularly to how they cope with multiple deaths from AIDS, has not been widely documented. Literature pertaining to caregivers, generated by first-world countries, and some African countries such as Kenya, used the term “caregiver” to denote family members or friends/partners who were caring for the AIDS patient. Therefore the researcher had to search for pertinent data by using the word ‘nurse’, to ensure that a more objective caregiver, similar to those in this study, could be found. In this way the family link was avoided, since such data was not conducive to this study. What is certain from the data that was collected, is that there are going to be mental health implications because of the effects of HIV and AIDS, that will be felt by individuals, families, communities and society; and this equally includes caregivers working with AIDS patients (Freeman, 2004:139).

The impact of HIV/AIDS on the lives of women is one of the most critical reproductive health concerns of our times. In sub-Saharan Africa, where the epidemic has spread to the general population, mainly through sexual contact, women make up 59 percent of people living with AIDS (PWA’s) (Ashford, 2006:3). Young women between the ages of 15 and 24 are between two and six times as likely to be infected as young men their age, particularly owing to the interplay of biological, economic and cultural factors. In addition, as caregivers in their immediate and extended families, women usually care for dying family members and for children orphaned by the disease (Ashford, 2006:3). These are the facts that make the work of the caregivers interviewed for this study so much harder, in that the average age of death in the
institution where they work is 24 years; and comprises mostly young women who are leaving young children behind.

Accordingly, the researcher found it difficult to limit information to the caregivers’ feelings and emotions pertaining to death from AIDS, since there are so many other variables pertaining to this disease, for instance, the ugliness of the disease related to suffering and disfigurement, of the patient. There is also the lack of support for these caregivers both in formal and informal settings, and a slow response in general to this disease from government, churches and the private sector. All of these variables have played a role in determining how caregivers cope with the enormity of this pandemic, and have been included in this study to ensure that their story is told as succinctly as possible.

3.3 IDENTIFIED THEMES

According to Chamber’s Dictionary (Kirkpatrick, 1983:1340) ‘theme’ refers to a subject set or proposed for discussion or spoken about and associated with a certain character, idea and/or emotion. The one central theme that emerged was that in their daily duties (at their place of work), caregivers experience various challenges, as a result of having to deal with the death and dying of their patients suffering from AIDS. This theme emerged as a major finding in the qualitative study. The central theme and sub-themes were identified from the interviews and field notes taken by the interviewer. These themes will be elaborated upon in the rest of the chapter and supported by diverse quotations from participants and literature (Holloway & Wheeler, 1996:178). When working with dying patients, the staff also suffer from grief, since by definition the rewards for curing people, normally present in most branches of medicine, are not present in this situation, where terminal care is being offered (Hector & Whitfield, 1982:27). This often leaves those nursing patients distressed at being unable to help the patient, since help, by definition in a medical context, usually means to cure (Hector & Whitfield, 1982:28).

The researcher discovered in this study that grief, a recurring concept throughout, has many facets, which are discussed throughout the sub-
themes, with various nuances. It was difficult to separate the focus due to the related attributes of the themes; therefore grief, in its many forms and descriptions, is mentioned in more than one theme.

Table 3.1 provides a tabular presentation of the central theme and sub-themes. Subsequently each theme will be explained and discussed. These discussions will be illuminated and substantiated by verbatim quotations from the interviews as well as references to relevant literature.

<table>
<thead>
<tr>
<th><strong>Central Theme</strong></th>
<th><strong>Sub-Themes</strong></th>
</tr>
</thead>
</table>
| In their daily duties (at their place of work), caregivers experience various challenges as a result of having to deal with the death of their patients suffering from AIDS. | **Sub-theme 1:**
Caregivers experienced emotional challenges in caring for patients dying of AIDS, which included:
1.1. Difficulty, and fear, in accepting death.
1.2. Sadness, and pity, when a patient dies.
1.3. Anger at relatives not visiting patients.
1.4. Helplessness, and distress, at not being able to alleviate the suffering when patients are dying.

**Sub-theme 2:**
Caregivers experience a difference in death and dying of adults as opposed to children:
2.1. Caregivers appear to avoid bonding with those that are destined to die.
2.2. Caregivers experience adults as having a role in acquiring this disease.
2.3. Caregivers appear to be more comfortable with adults dying than with the death of children and babies.
3.4. DISCUSSION OF THEMES AND LITERATURE CONTROL

The participants in this research study have described their feelings and experiences related to working with patients in a palliative/hospice care setting which specialises in care for those with AIDS. The participants’ experiences have been reflected in one central theme: that of experiencing various

Sub-theme 3:
Caregivers experience the rationalisation of death and dying differently:
3.1. Caregivers describe death as God’s Will.
3.2. Caregivers experience the process linked to death as fascinating or intriguing.
3.3. Caregivers experience that working with PWA’s has enabled them to grow mentally and spiritually.

Sub-theme 4:
Caregivers experience that faith in God gives them strength to cope with death and dying:
4.1. Caregivers experience that God provides hope and faith.
4.2. Caregivers experience death as a reality of life.
4.3. Caregivers experience prayer as an integral measure of strength.

Sub-theme 5:
Caregivers experience caring for patients as fulfilling and meaningful to them despite the sadness of death and dying, which includes the fact that:
5.1. caring so much for the patients emotionally, and physically, that there are no regrets when the patient dies;
5.2. working with terminal PWA’s provides a positive contribution towards the patient’s last days; and
5.3. being in constant contact with death and dying reaffirms an appreciation for being alive.
challenges as a result of having to deal with the death and dying of their patients. Additionally, having to deal with the death and dying of their patients was found to be the common thread that permeated through each of the subsequent sub-themes. The researcher found that the data analysis revealed an interrelatedness of concepts amongst the various themes, which made it difficult to isolate the information gathered, and confine it to individual themes. Accordingly, there is an occasional overlap of information within the sub-themes, which the researcher was unable to avoid, in order to explain the concepts highlighted in this study.

Figure 3.1: Diagrammatic Representation of the Central and Sub-themes

3.4.1 Central Theme: In their daily duties (at their place of work), caregivers experience various challenges as a result of having to deal with the death of their patients suffering from AIDS:
During discussions between the examiners of this study, the co-examiner, independent coder and the researcher, the many different experiences that were shared by the participants, were summarised as set out in the aforementioned theme. These experiences are as varied as the nature of the work that these caregivers are called to do; and are related in the course of this chapter.

What is death? Is there a definition that covers this word? When reading about death it is rare indeed to find a physiologically, scientifically clear definition. Mostly the literature covers fear, anxiety, ambivalence towards, feelings about, emotions pertaining to, death, one’s own as well as those close to us, rather than a clear cut definition of death. Whilst contemplating why this is, one is left with the thought of one’s own death, or the death of those close to us; and then it becomes obvious why death is not easily explained in the form of a definition.

For the purposes of this research study, however, one could consider death to be “a complete change in the status of a living entity characterised by the irreversible loss of those characteristics that are essentially significant to it” (Backer, Hanna & Russell, 1982:176). In other words clinical death occurs when spontaneous respiration and heartbeat cease irreversibly (Backer et al, 1982:172), which would be tested by visual observation of respiration, feeling the pulse, and checking if the patient is still responsive or still has any reflex actions. In the place where the caregivers in this study work, the patients enter a process of death, rather than a sudden death, because the patient’s body ‘shuts down’ slowly over a period of days, sometimes weeks.

Patients dying of AIDS suffer from a high prevalence of pain, as well as other symptoms such as dyspnoea, fever, night sweats, neurological disease (peripheral neuropathy), loss of mental functioning, weakness, cough, vomiting and diarrhoea (Evian, 2000:120-124). In other words, AIDS has most of the elements that make for a thoroughly catastrophic vision of death. The death-in-life appearance of the body that marks advanced tuberculosis is present also in AIDS, leaving patients unlovely to look at, unable to care for themselves, in the end stages of a distinctly ‘unsafe’ disease which can be
passed on by body fluids, which thus conjures up the death toward which our unconscious fantasies surge, so fearful can the patients appear (Gilmore & Gilmore, 1988:12). Healthcare workers, including the caregivers in this study, are often fearful of contracting this disease, however small the risk may be, according to research and statistics (Evian, 2000:125). Add to this the prospects of an undignified death, as explained above, and it becomes clear that there are serious difficulties encountered related to care of dying AIDS patients not found in other disciplines. Death is the antithesis of life, and is often seen negatively, viewed with fear, denial, rage and sadness. These emotions are often very pronounced in the dying AIDS patient who has already been ostracised by friends, family and society in general, due to the stigmatisation of this disease and the resultant discrimination (Jayasree, 2002:1-2).

There is little doubt, from various studies, that caregivers experience difficulties in caring for patients dying of AIDS, which includes fear of contagion, reactions to repeated exposure to death and dying, plus feelings of helplessness, grief and loss (Hertz, 1994:1). The problem with dying patients is that they no longer fit into the total societal system, in that they cannot be healed, which is usually the whole point of the health-care system. This leaves the caregivers, and other medical personnel who may deal with them, with a dilemma, in that the patient with an incurable disease is perceived to be a failure to the health professionals. Regardless of how far we have evolved in health care, the disease process and the diseased organ remains the emphasis, which is counterproductive to the needs of the dying patient. Added to this, most health-care facilities, including the one where this research study was conducted, are vague about death, regardless of how much death occurs, which indicates that denial is frequently used by personnel to protect themselves from having to communicate with one another, with the patient or the patient’s family. It also protects the staff from becoming involved with the patient and having to face their own feelings about death and dying. Denial is emphasised by the language used by medical personnel, including the caregivers in this study, who refer to the patient as not having died, but expired, passed away, being lost on the table and so on (Kubler-Ross, 1975:10).
“And then I knew that she was going and that evening she passed away. You know, it’s like that. I immediately distance myself from it, you know, because I know that the person is busy going, and that's how I try to handle it, but it’s not easy”

“No we don’t say died, it’s so…dead, it’s so, disrespectful I shall say, passed away would be a more appropriate word. Death (pauses) - it sounds so, so harsh. So, he's dead. Ja, like, Oh...he’s dead. Passed away sounds more respectful”.

These caregivers have multiple challenges that they must face whilst working with those dying of AIDS. In a hospice type of situation the death rate is high, especially since most of the patients are admitted in the terminal stage of AIDS. Many die within the first few days of admission, and in extreme cases, patients have died within hours of admission. With up to three deaths a week not an unusual occurrence, these caregivers have an unprecedented, largely undocumented, type of working existence, with death having become so commonplace and so frequent that it is difficult to describe the effects on the person of this type of work. Indeed, the caregivers themselves are not sure how to define their feelings, and describe a day at work; yet they try to explain:

“You know what, we used to have three in one day, three corpses in a one day sometimes, you know. If the whole week ends up in there’s nothing then we say: ‘Thank you Lord’.”

“Oh, it's stressful, it's a stress. You know, this is not a thing you can say you get used to, you know you can't, it's a stress to see people going, you know, one after another…one after another”

There is no ‘best way’ to cope with death: this comes through clearly in the interviews with these caregivers. There is only the way that all people develop, as a manner of ‘coming to terms' within their capacity, at any given moment (Ahmed, 1992:168). “Nancy Phelps, a Registered Nurse on a dedicated AIDS unit...has already encountered 50 deaths from AIDS in this last year alone. She describes her AIDS nursing as the most intense in her entire nursing career, except for her experience of triage in Vietnam 22 years ago” (Ahmed, 1992:154). This excerpt highlights the enormity of what
caregivers nursing those in the terminal stages of AIDS must be going through emotionally, spiritually and, consequently, physically. Caregivers often represent the extended, reconstituted, or even substitute family for the PWA, and this is highlighted in several of the interviews in which the caregivers expressed their relationship with their patients as being like family (Ahmed, 1992:169).

“And you must talk the patients and you must make a friends the patients because you take like a brother or sister, you know, that’s why I say the patients like a brother, yes, yes”

“I’ve got friends in this place...when I work night duty I like to talk to the patients, about their problems, my problems, the patient, mos, you took a friend, I say ‘betho’ to my patients, it’s a friends”

The caregivers who were interviewed commented that while it was hard to care for those dying of AIDS, and frustrating, yet there is also a sense of fulfilment, of a job well done. Most of the caregivers are married with children and extended families to care for. Following counselling sessions with many of the workers, the researcher is aware that at least 75% of the caregivers have family members, close friends, or both, living with HIV or AIDS. During the last year, 6 caregivers lost a family member each to AIDS, whilst 2 others are caring for their family members at home. Therefore, these caregivers are caring for a patient at home with AIDS while at the same time nursing AIDS patients at work.

“I don’t like to see a person lying dead or dying slowly, you see, it is the pain because I lost my members of family through HIV and AIDS”

“I have lost...seven of my family members, my brothers, my sister, then my other sister of...died from it”

There is insufficient documentation about the effects of caring for those dying, especially on the unprecedented scale that we are currently witnessing. The burden of care falls onto women, especially in countries such as South Africa,
where there is an inability on the part of the health services to care for all those living with AIDS. This leaves the care in the hands of informal caregivers, comprising family members and neighbours, and is a form of home-based care (Unaid, 2004:36).

“I was the only person they used to visit, they used to come to my house, to my shack, because I am staying in a shack; there are two of the sick ones that used to sleep at my place because they felt that I am a sister”.

“In the township when they know that you are working with PWA’s, when you have been called in a certain home that got somebody who’s sick they will conclude that the person has got HIV”.

These caregivers, then, not only have to deal with caring for those that are dying, but also with the stigma that accompanies this disease. Many people are afraid of AIDS, because there is no cure for it, hence the stigmatisation of those with the disease and those working with AIDS patients. “Stigma is defined as something that detracts from the character or reputation of a person – a mark of disgrace or reproach. AIDS appears to be equated with sin, requiring retribution and punishment” (Ahmed, 1992: 99).

“Some, I would say 20%, say I’m mad, um, the others say that it takes a lot of guts to work at a place like this”

“Really, people need to be educate, there are people who are not yet (sighs), they like to be down about this disease”.

A further challenge for the caregivers is anticipatory grief, also known as ongoing sadness, and its effects on these workers. The diagnosis of HIV/AIDS is seen as a death sentence in most areas. Certainly, in the hospice setting where these workers are employed, 95% of the adult patients admitted will die, so it is only the time frame of this fact that varies from patient to patient. Taking this into account, these caregivers, whether aware of this or not, are experiencing anticipatory grief, where anticipation, in this context, refers to the anticipation of an event in the future, in this situation the inevitable death of
their patients (Abbey Hospice, 20061). Unconsciously the caregivers will change their focus (outlook) from the hopes of a miracle cure for patients, to quality of care at life’s end; or they should. What has to be remembered is that caregivers and the patients have to work through the grief cycle, which, according to Dr Kubler-Ross comprises five stages, namely denial, anger, bargaining, depression and, eventually, acceptance (Kubler-Ross, 1975:10). Anticipatory grief is a grief response that begins, not at the death of the patient, but as soon as symptoms indicate that the condition has become life threatening. Both patients, and persons caring for them, will experience anticipatory grief. It includes changing assumptions (from assuming that the patient will recover, to accepting death as inevitable), finding a balance for staying separate from, yet involved with, the patient, and experiencing feelings of sadness, depression, denial and anxiety, whilst accepting that an opportunity has been given to absorb the impending loss gradually (Keene Reder, 2003:2).

Caregiver grief is a relentless and ongoing process, brought about by constantly having to deal with death. Considering the amount of death that these caregivers have to deal with it would, by definition, be impossible to work through each death before the next death, which would lead to a perpetual type of grief, into which the caregiver is inevitably thrown back each time there is another death. “The neat bow we tied around our pain begins to unravel and we grieve again, but not in quite the same way we did the first time or the second or the third; but in a way that reflects who we are now, at this time of our lives and in our current circumstances” (Healthology, 2005:1-3).

“When a patient passes away, I like, finish the patient until the undertakers fetches this body and then I, it’s another patient that’s coming in and I must prepare myself for a new patient that’s coming in. So I must stop thinking about the patient that has passed away and start thinking on the patient that’s still coming, that I must nurse, so my mind can’t continuously stop at death, it must go for this still live patient that is coming for treatment”.

There are numerous studies related to caregiver burden, depression, stress, and coping, which emphasises coping with stress; but what needs to be considered, currently, especially with the AIDS pandemic, is how personal suffering may influence caregivers’ emotional health (Marwit & Meuser, 2002:1). In the study highlighted in this quoted article, 94 caregivers were interviewed about their losses, regrets and attitudes. The results of these interviews were that grief reactions were as common as examples of personal growth. “In a later study, difficulty dealing with grief was ranked as 10th on a list of 30 caregiving challenges, which suggests that grief reactions play a tangible, yet often overlooked, role in caregiver stress” (Marwit & Meuser, 2002:1).

The challenges for these caregivers continue when one considers the many disorders with which AIDS patients are admitted. Persons with AIDS can have, at any given time, dementia, plus severe and multiple illnesses such as diarrhea, anorexia, protein-energy undernutrition, electrolyte imbalance, anaemia, bone marrow depression, seizures, diabetes mellitus, renal disease and gastro intestinal infections. Added to this heartbreaking list would be the multiplicity of medicines for both treatment and prophylaxis of opportunistic infections, and, in some cases, antiretroviral combination therapy and management of psychiatric disorders, plus pain medication (Cohen, 1998: 154-157).

The mortality rate for AIDS remains extremely high in sub-Saharan Africa, with South Africa continuing to have the highest number of people living with HIV in the world. An estimated 5.3 million people were living with HIV at the end of 2003, 2.9 million of whom were women. South Africa’s death registration has shown a rise in the total number of adult deaths in the last six years, with a rise of more than 40% and, in the case of women aged 20-49 years, an increase of more than 150% (unaids, 2004:25). The increase in death rates certainly warrants an exploration of attitudes about death and certainly anticipatory grief, in order to facilitate coping with loss and the grief that has to follow. This is highlighted by comments from the caregivers:
“Some of the things that makes me sad… to see someone really ill, and there’s actually nothing you can do… just make the last few months or days as comfortable as possible you can make for them. That’s all. It really touching... it’s really sad”.

“I really feel sad for them, to see someone dying and you can only do your 20% or 50%. That’s all. You feel... can’t I do more, or... that’s to feel totally helpless”.

“On the long run, you really think that sometimes you wish you can change the clock, why did HIV start? Why can’t it stop? But you can’t ask those questions, it’s all in the Lord’s hands”.

There is no amount of knowledge that can prepare us for bereavement of any kind; therefore it would be expected that the continual death and dying that the caregivers in this study are experiencing would be more intense than that experienced generally. Grief is the most enduring emotion we can experience; there are no ‘quick fixes’. The only way out of it is through it; and all people have to find their own way at their own pace. It is clear that each caregiver in this study is going through the grief pathway, which could be more difficult for them because of the extremes of their work life, followed by having to deal with more AIDS patients and death when at home.

The central theme has highlighted certain aspects of the challenges that these caregivers are facing whilst dealing constantly with patients dying, and the fact that there are many emotions that they have to deal with. These challenges will be discussed in detail under the following sub-themes, namely, the emotional challenges in caring for patients; the differences experienced in caring for adults as opposed to children, that caregivers experience the rationalisation of death differently, with their faith in God which gives them the strength to cope with death and dying and that caregivers experience caring for patients as fulfilling and meaningful, despite the sadness of death and dying.
Sub-theme One: Caregivers initially experienced emotional challenges in caring for patients dying of AIDS:

The caregivers in this study, although skilled in the tasks that they are required to perform, which encompasses basic nursing functions, with added short courses in HIV/AIDS and basic listening skills, are expected to handle patients in the last two stages of AIDS (stages 3 & 4). This means that they have to deal with extreme behavioural problems, with patients who become violent, scream incessantly, refuse medication and some who simply walk out of the facility refusing treatment or help. These problems must be overwhelming to caregiving staff, since professional nurses who were interviewed regarding working with AIDS patients have indicated that they experience a lack of specific training regarding HIV/AIDS, leading to insufficient and inadequate knowledge regarding treatment of these patients (Smit, 2003:3). These professional nurses also indicated that they felt a sense of futility in nursing patients who were destined to die, in fact the comment “sometimes I think that nurses these days are nursing only for the mortuary” sums up the emotional challenges faced by those caring for AIDS patients (Smit, 2003:3). These caregivers also have to deal with aggressive behaviour which can be frightening and dangerous. The researcher was once called in over a weekend to help control a psychotic, aggressive patient, who would not remove himself from the duty room, which highlights how difficult this type of

Figure 3.2: Diagrammatic Representation of Sub-theme One
situation is for caregivers to deal with. Caregivers also have to cope with patients regressing to the point of being unable to bathe alone, refusing to attend to personal hygiene and to take medication. The researcher has frequently helped the caregivers to encourage a recalcitrant patient into a bath following a few days of refusal to wash.

“Working here is difficult at times, not always. Sometimes you feel sad, hopeless and angry emotionally. These things can be caused by the stress that you come across, the stress of not coping to help your patients and generally everybody that you can't get help to; and sometimes you feel bad now that it’s caused by the stress that you have got, from working here”.

Other emotional challenges experienced by the caregivers interviewed for this research revolve around dealing with death and dying, which includes: difficulty, linked to fear, in accepting death; sadness, and pity, when a patient dies; anger at relatives not visiting; and helplessness at not being able to alleviate suffering in dying patients. These emotions were noted as being the most prevalent, as expressed by the caregivers during the interviews; and they appear to constitute a challenge to the workers as they perform their daily duties.

1.1 Difficulty, and fear, in accepting death:

Death and dying are often surrounded by a conspiracy of silence, usually it is an unconsciously organised silence, leaving those whose lives are threatened by terminal illness or accelerated death with a physiological insult and without much-needed communication. This silence seems self-protecting for relatives, medical and nursing staff along the lines of the denial phase discussed previously. This silence, part of the denial, is a false reassurance and offers no emotional growth or understanding of the events which surround death in its finality for the patient, family members or the caregivers (Youll, 1989:88-94). “Death frightens, fascinates, humbles and remains an outstanding
enigma. How can we articulate the spiritual character of dying and death when the brutal facts of mortality cause such pain and anguish? “(Cobb, 2001:12).

“Death is terrible, because you don't know what happens after death, so you can never be sure you do really what happening death, that why you are scared because you don't know happening during death.”

“First you know, in all my previous years, when there is a death, I used to cry, you know, a lot, and I feel that pain and I used not to take it, but as the years go by, I always know when I see a person is going to die and I pray for strength for that person”.

The challenge to all of caregivers when dealing with patients dying, is to accept that facing dying patients daily is hard and to live life accordingly. In other words, be reminded not to leave until tomorrow what you could do today and learn to live life fully rather than simply passing through it, thereby avoiding the regrets. It is important to realise that death is an integral part of life, not an enemy to be conquered (Kubler-Ross, 1975:5). For most of the caregivers interviewed, the concept of death was difficult to discuss, even acknowledge, with some indicating how hard it was to accept the deaths of their own family members, let alone the multiple deaths that they faced at the place where they were working:

“And all the time they are talking about the AIDS with them, Oh, sis, I going to die one day because this disease has no cure, and I say to them No! you must pray, you are not going to die, everything is coming from God, He knows you will not die, you must pray”

“My mother died 2000, but to me it’s as if she is in Jo’burg. One day she is coming back, I don’t know, I’ve always had this thing, you know, it’s as if to me she is still coming back”.

So why is it so hard to die, or to accept someone else’s death? Each time that a caregiver works with a dying patient, she has to face her own fear of death, otherwise it is not possible to help the patient work through the death
process (Hurtig & Stewin, 1990:29). Working with people who are seriously ill or dying involves supporting them to live their lives fully and with quality. To do this we have to learn to face pain, anger and fear in the grieving process so that we are free to experience love, hope and inner peace (Ahmed, 1992:179). One of the greatest needs of people facing a catastrophic disease is to be listened to and to be heard. To be able to hear at all of these levels we must regularly cleanse ourselves of our own fears to be fully present for another person; we need to cleanse our heart with our own tears, by allowing it to break from sadness from time to time. We need to learn to discharge anger in a safe manner, rather as positive energy which could bring about change than negative (Ahmed, 1992:179-180).

“I don’t want to die suffering, not like these patients, no, I don’t want to suffer, then rather I’ll say cut it short, I know it’s the easier way out, but I don’t want to suffer...to see someone else suffer, it’s... it’s not right”.

Fear is defined in Chamber’s Dictionary (Kirkpatrick, 1983:460), as “a painful emotion excited by danger; apprehension of danger or pain; anxiety or to be in doubt”. Fear is a normal reaction and can make people feel angry, depressed or aggressive, which is something that caregivers need to be aware of so that they will be able to monitor their own reactions. The primary fear of death is linked to not knowing where we will be or where we will go in the afterlife; so fear of the unknown is a natural concern, as one of the caregivers stated:

“It was, like, the way I thinking of death it was like, what happens after that? Why are they dying? Its like, can it happen to me? Will there be pain? How will I die? How will it be? How will I feel it? You know, that’s only what scares a person, how will it feel?”

Few of us are ready to face our own death, despite the fact that we know we will die one day: that is an intellectual realization; but the emotional impact of this fact is usually avoided. Caregivers, together with other medical personnel, are also inclined to question the death of a patient, wondering if there is more that could have been done? “Is there someone, somewhere, who has new knowledge that could have made the difference?” (Kubler-Ross, 1975:9).
“But you think that when that person was becoming all right, all of a sudden that person goes, then I felt like, what was it? Did we make, did we do enough? Is there anything we didn’t do for this person, you know, that he all of a sudden die? Then I feel bad and have that guiltiness that maybe there is something that I didn’t do”.

It appears as though those who exhibit great anxiety around death have difficulty relating to and communicating with the dying (Kubler-Ross, 1975:11-12). Despite this, fear of death is not considered as undesirable as it seems in those who are involved in caring for the dying, since fear of death may well by psychologically unavoidable, and in fact it may be considered impossible to render care to the dying without the caregivers candidly and honestly acknowledging their fear of death (Nokes, 2000:3). No one can learn to accept death by avoiding and denying it; death has to be faced squarely if it is to be dealt with constructively (Kubler-Ross, 1975:74).

The grief process is present in both the patients and the caregivers to enable them to work through death and dying; therefore it needs to be acknowledged and understood. In many cultures crying is thought to be a sign of weakness or breakdown and anger is also an emotion that people avoid or fear; yet AIDS often causes patients and caregivers alike to feel fearful and uncertain as pointed out above. Often this anger is projected onto others, fellow workers, family and friends (Ahmed, 1992:158).

“You know you done wrong and yet you want to rectify yourself and the person around you will always put a negative thought or point at you, or ask you ‘why didn’t you do this?’ This is the hardest part for me because you are trying so hard to help people”

“The impression I get is that the caregivers treat the patients as if they are a burden to them; and then I have many words with some of them, I ask them if they are just coming off the street or so, as if they don’t care”

AIDS confronts us with a complicated conjecture of physical, psychological and social factors. Most of us are raised with two big social taboos, sex and death, and since AIDS is connected to both, the fear is increased (Ahmed, 1992:182). With no cure in sight and the majority of patients comprising young people in the prime of life, there is a great feeling of guilt and shame (the
disease is sexually transmitted), rejection and fear. Often patients are estranged from their families and therefore require long-term intensive care from others, or institutions. AIDS is not a disease from which people die suddenly or swiftly, but a long, slow process, which engenders a wide range of emotions, the most “infectious” of which could well be fear (Ahmed, 1992: 182). Caregivers working with those dying of AIDS are aware of the fatal outcome, but are powerless to change it, which could equally lead to feelings of pity and fear (Ahmed, 1992:99). Death is a part of the life cycle, an inevitable outcome of life that brings closure to a life story, but when it occurs in so many young people, it is natural to wonder who is to blame? (Ahmed, 1992:99-100). These are some of the difficulties that the caregivers who were interviewed are facing; and there are clearly no easy solutions to be found to deal with this myriad of challenges which confront them daily.

Whilst these aspects are being analysed and blame is apportioned, the denial phase is firmly in place as the person(s) view this pandemic as an interesting phenomenon, rather than confronting their thoughts and feelings in the wake of the consequences of this disease, which is the death of their patients. This denial prevents each individual from being overwhelmed and saddened (Ahmed, 1992: 170).

“To be honest with you, death is a scary thing, you know, but because I read a lot about death and things like that, you know, and that gives me reassurance that there’s life after death”

“Sometimes I am scared but in my heart I, oh, God, what must I do? Because I can’t do otherwise, I must go to them and help them when they are dying”.

A study performed in Australia found that caregivers who had suffered many bereavements experienced greater anxiety and fears of death than the less bereaved and that they began to accept the inevitability of death. Caregivers, who were termed paraprofessionals, were said to have a great deal more contact with AIDS patients than professional nurses, but owing to a lack of adequate training in bereavement, they had a very negative attitude about
people with AIDS, and felt little comfort in caring for dying AIDS patients (Demmer, 2001:38). This scenario is a close description of the caregivers interviewed in this study, and the concept of paraprofessionals would accurately describe the educational background and work expectations of these women. This study reveals an interesting phenomenon, one which could, in fact, increase the potential for caregiver burnout, particularly in those workers who lack the educational background to assess their situation and the effects thereof on themselves.

There can be no doubt that caring for persons suffering the ravages of a highly stigmatised disease, with little hope for the future, has created particular difficulties or stresses for the health care providers; yet it is also said that nursing practitioners and caregivers get used to death, and that each experience hardens practitioners making them better able to deal with the next (Dickenson & Johnson, 1993:268) than before. What is certain is that the fear of death is related not only to what the end signifies but also to the tangible prospect of what happens to the body, which does not become anything, but is the subject of decay, disposal and ritual. In this context the corpse, which is the most immediate consequence of death, is a significant body demanding attention, emotions, care and ritual. It is the living that have to deal with death, in this case the caregivers; therefore for the living death is always something to fear (Dickenson & Johnson, 1993: 52).

1.2 Sadness, and pity, when a patient dies:

"Working here it's very difficult at times, not always. Sometimes you feel sad, helpless and angry emotionally"

"Actually for me, sometimes it's a little bit sad. But I would say 40% sad and the other 60% I would say, I'm actually happy, because not a lot of people would choose this career to help the adults, and I've learnt a lot".

To be sad, according to The Oxford Thesaurus, (Urdang: 1991:413), means to be “unhappy, melancholy, dejected, depressed, heartsick and
downhearted”. Sadness is part of the grief cycle that was mentioned previously. Grief is a normal reaction to loss, whether that is the loss of a loved one, patient, job, in fact anything that can cause pain, self-doubt and emotional upheaval (Zastrow, 2004:1). Grief has been defined simply as intense emotional suffering related to misfortune or injury; it has also been described as conflicting feelings that are experienced following any major change to a familiar state of affairs (Taylor, 2004: 1). From the effects of grief and the grief cycle, stems the possibility of burnout for the caregivers, especially in situations of accumulated grief due to multiple deaths, such as the caregivers in this study are experiencing. Palliative care is, by definition, terminal care for patients with AIDS, which is defined as a chronic disease that is progressive despite efforts to prolong life, the progress of which, if unchecked, will kill the patient (Buchholz, 1993:203-9). Palliative care has equally been cited as a major cause of burnout in nurses, and more recently, studies are identifying the prevalence of staff stress in HIV related- palliative care (Prabha, Jairsm & Anila, 2004:48). This study found that as the epidemic continues to spread, the number of patients that will seek palliative care will equally continue to rise, thus continuing to draw on health-care resources, which inevitably means health-care personnel. These personnel will require support to ensure their psychological well-being since ‘exhaustion syndrome’ is a potential risk for palliative care workers. Burnout, which leads on from exhaustion syndrome, has been associated with sub-optimal patient care practices; and it is therefore important to identify the prevalence of stress and burnout among caregivers and identify factors contributing to this stress in the palliative care settings (Prabha et al, 2004:49).

In a study by Smit (2004:9), many nurses stated that they felt extremely emotionally drained by having to help their patients, who were dying of AIDS, actually deal with the suffering imposed by the disease, and the process of dying resulting from AIDS. It has been suggested, in this study by Smit (2004:19) that this experience of emotional stress and physical fatigue expressed by nurses could be linked to the symptoms of occupational burnout, which can be exacerbated by the age group of those dying, most terminally ill AIDS patients are young adults; and the numbers of patients being admitted and dying of AIDS. Some of the caregivers interviewed for this
study attested to how difficult it was to nurse patients dying of AIDS, especially owing to the way that these patients had to suffer.

“The patients, it affects me because when I I look there I saw them through pains so I, I, I feel very very bad, when I saw them in pains, I help them very much because I feel very very pity of them”

“Death and dying, I think, I’ve been thinking say one day a cure for HIV can come, then it could help a lot of people, really, and then you wouldn’t see people in so much pain, because I mean, it’s an ugly disease”

*It is a fact that a particularly upsetting death or a run of deaths, which these caregivers often experience, can lead to physical reactions such as tiredness, irritability, false cheerfulness or depression. The manager of the facility or professional nurse in charge of the care unit should be aware of this and be alert to the needs of the staff (Hector & Whitfield, 1982:103-105). The researcher experienced this phenomenon with many of the caregivers during the last year; and referred five workers to a doctor for anti-depressant therapy in order to prevent an exacerbation of symptoms that could lead to burnout, due to the continual emotional sadness and physical exhaustion that often occurs with continual caregiving duties. In the words of Hector & Whitfield (1982:105) “later on a different kind of unhappiness may arise. Nurses may feel drained, depressed, indifferent and unable to give the kind of service that once was possible”. This quote has relevance when linked to a comment by one of the caregivers:*

“Ja, like for instance, when you know, to me, to work here it's a caring business, nothing else. And I, I sense, I pick up a sense of people not really, you know, having that caring within them.. they are doing this for themselves actually, it’s not an emotional thing, that’s one of the things that I pick up ever since I’ve worked here”. 
The problem with the above-mentioned symptomology is that there is an implication that perhaps these caregivers will not be able to give the kind of care dying people need, not through any fault of their own. Our work with the dying should stem from respect for them and that we pay very close attention to their distress because what the dying person needs is both skill and compassion (Fox & Wood, 2005:133).

With the sadness and pity that the caregivers have expressed, it is clear that the grief process is firmly in place for most of them, and the message to these workers needs to be that they must not deny their grief; for that would deny their humanity: it is because they care that they feel so bad about their patient’s suffering; and it is important to deal with the grief and accept it as a normal part of their working life. The more they bond with their patients, the more pity, sadness, and, therefore, grief, they will feel; and the longer someone works with a patient, the more the sadness at the time of death. This is always going to be a potential cause of burnout and needs constant monitoring (Dana-Farber Cancer Institute, 2003:1)

1.3 Anger at relatives not visiting patients:

It has been said that social support enables patients to cope with their illness; and clearly such support would be considered essential in the case of a dying patient, especially a young one. AIDS patients are required to deal with many losses at the same time: loss of health, appearance, self-esteem - due to their appearance, and frequently their families as a support system. Social support is essential to the well-being of all people, and in the case of the AIDS patients it is imperative that their family and friends support them to enable them to cope with the progress of the disease and the inevitability of death (Poor & Porrier, 2006:283). In far too many cases the family abandons
the patients, especially when they are admitted to the place where this study was conducted, and the patient rarely, if ever, sees the family again.

This is a tragic occurrence that has serious effects on the patients, and staff members, who observe the patients hopefully waiting for a visit, which would prove that they have worth and are still loved and cherished despite the unlovely disease. Many die without this affirmation, for whatever reasons the family might have to avoid their family members. It could be that the well-documented stigma of the disease means that families are not able to cope with their loved one being HIV positive; and it is certainly true that in other countries there was a term known as ‘hidden grievers’ who were grieving a loss due to AIDS but they were unable, owing to the stigma and discrimination, to divulge this fact (Demmer, 2001: 37).

“You know people outside will say ja you’re just working with those AIDS patients, to them AIDS is so ugh! It can’t happen to me”

Stigma related to AIDS has been well documented in the workplace, in the community and among family members (Hayter, 1999:984-993). Since it has been documented that nurses are afraid of contracting AIDS whilst working with their patients, (Demmer, 2001:38), one would have to presuppose that the family members are equally afraid of contracting this disease, which is clear from the way that some AIDS patients have been treated by their families prior to admission. This could well be one of the main reasons why families do not visit those admitted to the place where these caregivers work. Patients often fear that their families will become aware of the reason for their illness, because they rarely tell them the diagnosis, again due to the stigma and fear of discrimination; therefore disclosure is difficult for most patients. “A very complex relationship of ‘fear’ and ‘attitude’ between the clients and staff was noticed, the fear of the patient that his HIV sero-positive status would become known to his immediate relatives, colleagues and community”(Soyinka, 1996:783-790). This still leaves the dilemma for the caregivers, who are not only caring for these patients but becoming a
substitute family as well, which means increased emotional output, bonding and, accordingly, more grief to work through than they should have to endure.

“You know another thing, that one day if more patients will come, the only thing that I would like to see is the family’s response and the family support to give to these patients”

“I’ve experienced that you sometimes have to phone them to remind them, ‘Hullo’! One of your relatives is here, can you please come in and visit?’”

“Mostly they need love because most of them don’t get love from their families and some are neglected by their families”

Many of the caregivers have realised what many books and articles have pointed out: that all people with a terminal illness really need in order to cope at all, is love and acceptance. With love the terminal phase of any illness is made that much easier, for it is obviously better to die with one’s family around one than alone and isolated.

“The only thing that they need for them to get well is the love for themselves, and to have the love of their family and the caregivers, they can then go a long way”

1.4 Helplessness, and distress, at not being able to alleviate the suffering when patients are dying:

The impact of AIDS on most people has been said to be overwhelming. There is much sadness in watching vital, energetic young adults begin to wither
away physically and mentally. Many caregivers feel rage at the total ignorance and bigotry of those who do not acknowledge the disease or its severity on those on whom it impacts the most: those with the disease and their loved ones (Kain, 1989:276). Many caregivers have developed accumulated or complicated grief as a result of having to deal with multiple deaths and not being able to grieve properly prior to the next death. This causes them often to feel overwhelmed and unable to cope with even their daily tasks, which leads to feelings of despair, distress and, frequently, anger (Kain, 1989:277).

“I talk to God, I ask Him to save these people, I know if He like to He can save them; I just wish He can save all of them so they can’t die”

“It would be very foolish to be angry with God, because whatever He does, He does. There is a purpose to all that He does, I take it that way, maybe He wants to show me something through all of this, so I am not cross with Him, even if I cry I am not cross with Him, but I cry just to say ‘maybe I was supposed to do this, then I fail. Please, God, show me’.”

It can happen that the above-mentioned overwhelming feelings can be counterproductive, in that these very feelings can prevent the caregivers from showing the compassion they experience (Kain, 1989:277). The caregivers could get to the stage of not being able to deal with one more death, which being a form of accumulated grief would cause them to feel intolerant to suffering and numb to their own emotions, in other words, leading to occupational burnout (Kain, 1989:278).

“Really, the deaths that I went through, like it hardened me. I had to stand in front of the patient, the patient passed away and you have to prepare it for the undertakers and you just, ag, you just do this; slap your mind out of it, ag, and imagine yourself that it’s not a dead person”

Helplessness and despair will certainly be present when the average age of patients being admitted is 28 years, and all with a high level of medical acuity, with frequent onset of new infections, metabolic derangements, seizures, diabetic ketoacidosis, as well as chronic medical problems such as
toxoplasmosis, progressive multifocal leukoencephalopathy, protein energy undernutrition, HIV neuropathy and nephropathy and diarrhea (Cohen, 1998:150). These acutely ill patients require total care, which can be exhausting for caregivers and completely overwhelming.

“You know the hardest part of working here is coping with the workload that is being set out for you. Sometimes, you know, your own system is off, like you don’t feel well and then you have to pull through it”.

Added to the above, and what compounds the feelings of helplessness, is a lack of understanding of exactly what is wrong with the patients. All the terminology and medical conditions mentioned above are unknown to the caregivers working in this place. They are responding to the fact that these patients are all dying; but usually do not know why.

“Because AIDS don’t say you want get it. You must know that you can get one day, because it is a disease you don’t know, one day…”

“To work with deteriorating patients who do not benefit from recent treatment advances can result in feelings of helplessness, anger, frustration and depression” (Demmer, 2001:40). The way that most people who have lived through multiple deaths respond to this traumatic experience is by numbing their emotions and denying their grief (Demmer, 2001:40).

“I am able to switch off (from death) by thinking about other things, the people who’s around me still, thankful for them and the others, ja, I can say that, today I cry for you but tomorrow I will be fine, I can say that because it shows me that life goes on, it doesn’t stop, it goes on”

This caregiver repeated the above type of statement many times during the interview: that death did not affect her at all, that she recovered immediately, with no problem whatsoever in dealing with the next death. Then she would contradict herself to say that she had actively to keep her mind off death by listening to music, watching television, or some such activity to avoid thinking about death; that she discussed her work with her mother, family and
colleagues in an attempt to cope with the death she witnessed, and that if she ‘bottles it up she will go mad’. This is in line with the literature that speaks, as above, about the grief overload, or accumulated grief, an experience of so much death that the workers do not have a chance to recover from one death before the next one occurs.

**Sub-theme Two: Caregivers experience a difference in death and dying for adults as opposed to children**

![Diagram illustrating Sub-theme Two](image)

**Figure 3.3. Diagrammatic Representation of Sub-theme Two**

The death of children appears to be difficult for adults to cope with and accept, which is ironic since children themselves frequently end their lives with a sense of fulfilment and meaning not often present in adult deaths (Kubler-Ross, 1975:65). Adults do have the challenge, however, to enable children to reach this stage, to provide the psychological support required to lessen any fear or confusion that they feel (Kubler-Ross, 1975:67). “A child’s terminal illness and/or death is an almost unspeakable, and a rare, tragedy; in the developed world the death of a child is considered an affront to the natural order because parents are not supposed to outlive their children” (Levetown, 2006:1).

Patterns of childhood death vary substantially among nations, related primarily to level of education, availability of resources and other public health issues.
In developing countries children often die in the first five years of life from diarrhea related illnesses and pneumonia (approximately 3 million deaths worldwide per year). AIDS is changing these statistics, however, by becoming epidemic in many countries, particularly sub-Saharan Africa. Every day 6000 young people under the age of 24 are infected with HIV and 2000 infants contract HIV through mother-to-child transmission. Every day more than 6000 children under the age of five are orphaned due to AIDS; and every day 1600 children die of AIDS. According to the World Health Organisation, during 2001, 2.7 million children under the age of fifteen were living with AIDS, 800 000 children were newly infected with HIV and 580 000 children died of the disease. Of these the vast majority are in sub-Saharan Africa (Levetown, 2006:1). Whether or not caregivers perceive this, children differ from adults with regard to the process of death and dying. Even infants and younger children differ physiologically from older children in many ways, such as with regard to enzyme maturity, organ function, percentage of bodily water and neural processing. In addition infants and children differ dramatically according to age and maturity in their perceptions of their situations, the ability to employ self-calming techniques: the success of external sources of comfort; the degree of the spiritual impact of illness and other psychosocial ramifications of their conditions. It appears as though the caregivers interviewed are unaware of how children perceive their death and the deaths of other children:

“I feel very bad, sometimes I cry when a baby dies, because this little child, he don’t know nothing, he don’t know nothing about life”

“I feel sorry about all the death, especially the children, because they don’t know what is happening to them”

There is also a possibility that the caregivers interviewed, while perceiving a difference between adult and child deaths, are inclined to consider this subjectively, from their personal feelings: that it is more natural and better for adults to die than children:

“I feel very, very painful when a child dies, it’s better the adults”
“If a child dies or suffers, it’s like, why? Why him? Why not the parents? Why not someone else? Why was it this child?”

How caregivers will cope with death will depend on many factors, mostly related to their own perceptions of death, fears, and coming to terms with their own death, as mentioned previously. At the place where these caregivers work, the children who are admitted are orphans (in 95% of the cases) with little, or no extended family support; therefore for various reasons the caregivers will bond with these little people, often to the extent of becoming mother substitutes especially in the cases of the younger caregivers who do not yet have children of their own:

“Working with babies and toddlers, I’m a mother to them, which is a big experience for me, to be a mother, so that I know, one day, if I have my own children then I know what to do”

“God has given me my strengths. I don’t even have a baby, but I’ve got 10 babies here, and my strength comes from God to help me care for them”

When caregivers identify to such an extent with their patients, especially in the field of paediatric palliative care, there is a danger that when the child dies, the caregiver will grieve as if she has lost her own child, which could explain the numerous references in the interviews to a difference in feelings related to adult and child deaths.

“Ah with the children dying, it’s quite traumatic for us because most of the children that come here are orphans and some of them don’t have anybody else around them when they die, except for us, the staff”

There is no doubt that a primary stressor for AIDS healthcare workers is dealing with dying patients (Levetown, 2006:4). Caregivers are generally deeply caring people who commit themselves to their patients; therefore they tend to become extremely drained following every death (King, 2002:1). It has been noted that this type of draining can lead to burnout caused by
“compassion fatigue”. Previously this was noticed after nurses had worked 35-40 years in their profession; but since the advent of the AIDS epidemic, those only 2-3 years in the service are experiencing ‘fall out’ (King, 2002:2). This burnout, or compassion fatigue, is a possibility for all caregivers working with AIDS patients. It includes formal caregivers (those working in institutions) and informal caregivers (which encompasses women caring for relatives, friends and neighbours, in their communities). It bears repeating that many of the women interviewed in this institution are both formal and informal caregivers, thus the enormity of their burden, which includes their stresses, would be hard to describe.

Having to cope with the death of babies and children clearly compounds their stresses, as it does in any other institution where children die: “we had a 4 year old girl here die of AIDS. Her attending nurse was really hurt by the death. These children we care for, you can wonder: Why were they born? We don’t know” (Alaniz, 2001:1-2). This is a quote from a palliative care institution in America, which resembles one of the quotes used above, and the following quote from one of the caregivers interviewed by the researcher.

“I’m a married woman, I have children who have youngsters; so I always think, what if it was my child? You know? I always relate to that child as if it was my child that’s lying there, that’s dying at such a young age, never had any life, and that is quite traumatic”.

This is a poignant reminder of how a child’s death affects caregivers. Perhaps it could help to explain why caregivers experience a difference in the death of adults as opposed to children.

2.1 Caregivers appear to avoid bonding with those that are destined to die:

In order to care for people one has to experience loss oneself and then create and maintain one’s own balance. The challenge here is to find meaning and purpose in all experiences, even death (Alaniz, 2001:2). How does a caregiver maintain enough distance and still provide a caring environment for the patient
and family. Becoming too attached or too involved increases stress for the caregiver; and yet it could also be rewarding in that the patient, and family could be helped to make the transition from life to death that much more peacefully (Alaniz, 2001:2).

Caregivers in South Africa are potentially more at risk than other areas because the epidemic is so widespread and there are so few structures in place to adequately provide care for those in need. Added to this is that the levels of discrimination are still high, therefore HIV positive people and AIDS patients are nursed by volunteers or family members largely in secret (King, 2002:1).

“For instance there was my neighbour, she was sick and they says she got AIDS. I told her about this place here, but the people in the location are scared to come here to be admitted”.

Many caregivers become physically and emotionally drained from their experiences and the hard work that resulted from nursing those with AIDS. Should they choose to remain in their jobs these caregivers are at risk of the burnout syndrome mentioned previously, the results of which could be to become toughened and emotionally cold, which is a means to survive psychologically as well as materially (King, 2002:2).

“No favourites (babies). I had, I had. And the baby passed away. But now for me, everyone is my favourite. I can’t have one, all of them is my favourite, I see to that”.

When asked if she avoids bonding with the babies to protect herself from further hurt, she answered:

“I think so, ja, because I do get very attached to people, very, and babies very easily. Don’t want to sit with that broken heart again. It’s so sad, and it’s too painful. And it’s too sad. Ah, they’re all so sweet!”.
When asked how she felt when she was informed that the baby, discussed above, had died, she answered:

“I was, I was angry. I was heartbroken, and stressed out. I thought if I’d got the night shift maybe things would have been so, maybe if they’d checked, it would have been so, or, stuff like that; it made me very angry”

This caregiver was going through the grief process, and three stages are clearly identifiable from the above short quote: anger, bargaining and depression. This process was the result of this one death, which occurred approximately 9 months into her working life at this place. She was interviewed eighteen months later, when she had, at such a young age, expressed the need to prevent herself from experiencing more pain by avoiding bonding with her patients as far as possible. This interview brings up some of the psychological and emotional concerns common to HIV/AIDS caregivers, such as a sense of futility in caring for patients who are going to die anyway. This creates a tendency for the caregivers to distance themselves from the patients in order to prepare themselves for the inevitable loss (Curtis, 2003:5-7).

Another caregiver describes avoidance of bonding with children, in relation to death and dying in the belief that she is not bonding with them and that she is not affected by the death of a child. She cares for them whilst at work and is then able to switch off. The quote was repeated many times over in slightly different ways as if the caregiver needed to believe, and have the interviewer believe, that all was well with her emotionally:

“There are sometimes, then I overcome it as quickly with a child as with an adult (death), because then I know a newborn will be born again, and life goes on”.

The last caregiver quote also indicates an avoidance of emotional bonding

“But you must just keep your heart cool. There is nothing, you know, because even with the children, the children don’t know that they are sick…but it
depends on your heart because you must not always think about these children, that these children are going to die”.

When patients become increasingly sick and death becomes a frequent occurrence, there is often increased anxiety (stress) on the part of the caregiver, which can transmute into a tendency to ‘abandon’ the patient emotionally (Alaniz, 2001:3-5). This seems to be occurring with many of the caregivers interviewed. Subconsciously there appears to be an unwillingness to become attached to any more children, even the ones they might naturally bond with.

2.2 Caregivers experience adults as having a role in acquiring this disease:

As the HIV/AIDS pandemic continues to intensify, much has been documented of the social, as well as the bio-medical impact that it has on individuals, their families, and their communities. HIV/AIDS-related stigma and its associated discrimination are known to affect negatively all aspects of HIV prevention, diagnosis, treatment and care (Bond, Chase & Aggleton, 2002:1). Stigma was defined previously; but in this section the researcher wishes to draw attention to the fact that caregivers working with dying AIDS patients are not immune to discriminating against their patients, in other words believing that the patients acquired the disease through their own actions. The stigma in HIV/AIDS appears to be linked to the actual infection itself (that there is no cure for what is a painful disease process leading to an unpleasant death), and to behaviours believed to lead to infection, in other words pre-existing stigmas related mostly to sexual conduct. AIDS patients themselves also play a role in this stigma by blaming themselves for contracting the disease which leads to self-deprecation on the part of the person (Bond et al, 2002:2).

Stigma manifests most commonly as gossip, verbal abuse and name-calling, with blame being assigned to people with AIDS, and assumptions being made as to their past history,
“Like even Marilyn, she was now in Die Son (The Sun), what they wrote there, she had a beautiful life, famous, but yet she was admitted here, her life ended with HIV/AIDS, you know? She knew she had AIDS but what did she do? No positive life she lived, she still continued with her negativity, until she died”

Another common form of stigma in most settings is people putting physical distance between oneself and the person suspected of having HIV/AIDS. Even contact with items (utensils, cups, clothing) is avoided (Bond et al, 2002:3).

“With other people they don’t know that you can’t get HIV from working here, even educated people who visit here, they ask me questions like, you are working here? Are you careful? They say so to me, and they’re educated, they should know about that”.

It appears, then, as though the disease itself is not the only problem these patients with AIDS face. They face being ostracised, discarded, avoided and feared. In reply to the question “Why don’t people in various communities tell those around them that they have HIV?” one caregiver said:

“Because they know that people are to neglect them; that others do not know that you can’t get HIV from being near the person”.

Many of the patients admitted to this institution are unable to admit to having AIDS; they remain in denial of having such a disease:

“And some of them talk about AIDS and how they got AIDS, the others, they keep quiet, say, ‘no I don’t have nothing. I don’t know how I am here; I’m sick with stomach or I got a leg or I have…you know’."

The presence of stigma and discrimination indicates clearly that most societies hold adults responsible for having this disease. Education is essential to attempt to change this mindset; yet even with education people remain afraid of the disease and of those with it. There are, therefore, reasons why those with AIDS are discriminated against; but that hardly makes it easier for them, to live with. When patients have a terminal illness, and is suffering
physically and psychologically (described previously), they seek care, kindness, compassion and understanding. Most of the caregivers interviewed verbalised this kind of support, and yet in the course of the interviews it became clear that assumptions about adult patients were made, which contradicted many of the statements. In literature one reads that young people are blamed for being ‘foolish’ and ‘careless’ and bringing HIV/AIDS upon themselves (Bond et al, 2002:4).

“If I must go into that, then you have to face the consequences of what ever the way you live, and I tell my children to avoid things like that, because if something happen, in the sense that it’s an accident, then its natural, and fits in with what I’ve told them; but if something happens to them that I have told them and warn them about, then I feel it is supposed to be like that and they must face the consequences, because that’s what they chose. I say whatever you sow, you will reap”.

Despite all the veiled references to promiscuous behaviour, the message is clear that this caregiver is of the opinion that AIDS is self-inflicted. Another form of stigma is built upon pre-existing prejudices. For instance, women who frequent clubs and bars are considered to be spreading HIV/AIDS (Bond, 2002:4).

“Sometimes on a Saturday I look at the nightclubs, how they are, the lifestyle. It’s like they don’t care what they are doing, they don’t realise that actually, we need to be cautious about this, you know?”

Women in general are discriminated against in this disease, especially young married women. Little sympathy is given to them and they are open to blame, ridicule and rejection, even more so if they are pregnant (Bond, 2002:5).

“Now, like this year, I buried two of my sisters-in-law. They passed away with AIDS, and they were scared to tell me. They were young, young, young, without children. They know that they were guilty because it was not a long time they, when they, after marriage, so we don’t know who brought it to each other. Maybe they didn’t tell me because they thought that I’d blame them”.

For those that know they are HIV-positive, the impact of stigma is psychosocial pain. People are worried about being condemned, about illness and about death (Bond et al, 2002:6).

“So nobody is making that sickness on purpose, just like playing, you know? Nobody is seeing that this one is sick so I must go to that one. Everybody would run away if they discover that this person is sick, that is my problem, because when I see the adult patients, then I think they were just playing, and maybe they didn’t know that the end would be like this”.

“The impact of stigma is devastating; we need to get rid of it. People living with AIDS die because of stigma. They get depressed because they are looked down upon and pushed around. They need love and care but they get stigma. Their immune system dwindles and they are affected” (Bond, 2002:6). There is hope that attitudes are changing, that a gradual shift in the attitudes of health workers has been noted. While clearly more needs to be done, there is increasing recognition that with so many people close to you dying, you cannot always run away, you have to offer care and support (Bond, 2002:7).

2.3 Caregivers are more comfortable with adults dying than with the death of children and babies:

With the emotional stress that caregivers nursing AIDS patients endure, it is hardly surprising that they themselves describe their work as “overwhelming, ongoing, never-ending” (Stajduhar, 1998:15). With caring for dying children, this is even more so, since caregivers struggle in general with the concept of dying children. There is a feeling that they should not be dying, they should be alive and playing with sandcastles or blocks; the children should not be orphaned and living with AIDS, they do not need to suffer, do not need to die; more needs to be done for children, especially regarding prevention of HIV infection. What happened to prevention of mother to child transmission? Why is more not being done to prevent children from contracting HIV and dying of AIDS? (Bilheimer, 2006:2).
“I’ve got hope with the kids, maybe one day the cure will come and then we can have a child (from here) that we say that one is working now and then that one is living, we can say was living with HIV and we can say now he’s a man who is working”.

There is evidence that children, even young ones, are usually aware that they are dying, from cues that they pick up from other children, parents, caregivers and other staff. It has also been noted that caregivers spend significantly less time with children who are terminally ill than with others, which means that whilst the child is very likely aware of the impending death, there is no opportunity given to the child to discuss the approaching event (Black 1998:1376). This appears to indicate that adults are uncomfortable talking about death with children, especially the parents of the child, who have to come to terms with the death of the child, which would be based on their own feelings at the time, how they would approach the grief cycle and the effects of bereavement. As has been mentioned previously, the caregivers in this situation have boundary issues, because they are treating these babies and children as their own (they are often asked by a dying parent to do so, which makes the responsibility that much harder for them). Therefore as mentioned previously, the normal type of caregiver grief is going to intensify, to mimic that of a parent losing a child. When a person has to deal with so many children dying, and more in line for the same fate, bereavement counselling and help with the grief cycle is essential.

“She said, please man, I’m very sick, could you look after my baby, and I saw him growing you know, to 4 years old, but then he’s passed away, early last year, and I’m crying to him, really, he passed away, Oh, shame, he was so sick, I’m so worried and I’m crying”.

Children are remarkably resistant, which makes it more painful to watch them die, because one minute they can appear critical, the next they rally and want to play or draw or watch a video. This could cause the caregivers to feel really bad when the children die since they might have thought that the child was recovering, which made them happy, and then suddenly the child died.
“What worried me the most is that even though he was sick, but he was so alive, but, so I didn’t realise that he was very sick, that he can pass away by that time. He was sick, but you don’t give yourself that the child is going to die. You think that he’s going to be all right, and now that child pass away. Its sad, because you don’t give yourself to that, I don’t give myself to that, because I thought that the child will be all right. I wish he can be all right”.

“When they told me that he’d died (a five-year-old child), I went from shock to disbelief. In my head I was saying’ but you don’t understand, he wasn’t supposed to die, and not now, this morning he was sitting up in a wheelchair eating porridge, he smiled at me, he smiled at me, it was a recovery look, that was not the look of someone who is going to die today, how can you tell me he’s dead?’”.

Caregivers are clearly extremely uncomfortable about a child dying, which causes more problems for the child who has the right to air his feelings, fears, and questions about what is happening. Children who are dying also share the same fear of pain as adults with terminal illness. Even infants feel pain, especially those dying of AIDS; and the caregivers need to ensure that the child is kept as comfortable as possible. To do this the caregivers would have to encourage their patients to describe how they are feeling and what their needs are especially in the absence of a parental figure. Discomfort in discussing death is universal and not a problem unique to health care workers, but has its roots are in our society’s denial of dying and death. It is important, therefore, for caregivers to recognise that it is natural to find it difficult to discuss death and dying; but that they can work at minimising some of the common effects of such discomfort. For instance, discomfort in discussing death may cause the caregivers to give mixed messages about the patient’s prognosis to themselves and others, to use euphemisms for death and dying or even to avoid speaking to the patients, which means that an extremely important part of providing good quality care for patients dying of AIDS could be missing (Evans, 2005:10).

“Ja, Soso the little one because it was my first and I was working with him, so my Soso was my first baby here, so I am thinking about him all the time, all
sorts of things about him, like maybe he could be a doctor, maybe he was not affected with HIV or AIDS, maybe he could be a doctor, whatever, you know, nice things about Soso, and he was such a handsome boy”.

There is also a possibility that the caregivers are unhappy about the death of children because it is not their fault that they are ill. It could be considered to be the fault of the parents, as stated previously when stigma and discrimination were introduced. If it is the parent’s fault that their behaviour caused them to be infected with HIV, then it would follow that the children have been infected unnecessarily as a result of the parent’s actions which are now considered to be irresponsible, self-inflicted even:

“Because these children are here; they don’t even know why. They don’t know that they are sick and that worries me, and I get worried just because these children are dying just because of the parents. It’s not them, it makes me angry, you must condomise but it makes me angry, because these children, it’s not them; it’s the parents”.

“The people in my area are getting high every day, they neglect themselves. They just don’t care, then they get HIV. I don’t know what can be done about this HIV/AIDS so that it can be known. People just do as they want; it depends on each person”

“For instance, the children, you know it hurts very much, children, because I feel that they are not, you know, they carry the burden; but then again the Bible states to us that the children will, you know, they will carry what the parent does, it says in the Bible it goes from generation to generation”.

It appears as though caregivers do find it more comfortable to deal with adults dying than with children, from the simple fact that they are older. Therefore the implication is that adults should know how to cope with death. There is a poignancy in watching a small child struggle with a painful death that caregivers clearly feel could have been avoided if people learnt how to behave correctly and not take risks. The fact that the adults die the same way is not discussed with such emotion by the caregivers although it has been
stated previously that they suffer. One caregiver did comment that she would
not wish to suffer in such a way; but the sadness and pity expressed at the
death of all these children is not as evident when the talk turns to the adult
patients and their deaths.

Sub-theme 3: Caregivers experience the rationalisation of death and
dying differently:

The caregivers who were interviewed for this study all appeared to use a form
of rationalisation as a form of coping with death and dying. When the definition
of rationalisation is taken into consideration, it is obvious that this would
indeed be an ideal way of coping with trauma, and is one that most people
use, whether to make the situation appear bearable, to find acceptance by
pretending that the incident is not as bad as it seems or to convince oneself
that things are as they should be since a higher being has ordained it so. All of
these are forms of rationalisation that are evident in the next section as
caregivers attempt to rationalise the enormity of the constant deaths that they
face daily in their workplace.

To rationalise, according to The Oxford Thesaurus (Urdang, 1991:378)
means: to make believable, understandable, acceptable, reasonable, to
explain away. In psychological terms, rationalisation is a mechanism by which
one unconsciously justifies (or makes excuses for) ideas and behaviour about which one feels guilty, inferior, or anxious. Rationalisation is a defence mechanism used subconsciously to soothe and comfort the person, usually by providing reasons for words or actions which sound rational but are not, in fact, the real reasons for the behaviour (Fisher, 1987:108). It seems strange, though, with the current ‘commercialisation of death’ that anyone would feel the need to rationalise death at all, since it is such a well-talked-about subject; with courses being run from school level to university and books and articles, all to teach us how to die with dignity, how to ensure a ‘good death’ and how to be a good death counsellor/practitioner (Backer, Hannon & Russel, 1982:299-300). The present preoccupation with death flows from a variety of societal forces such as nuclear war, the effects of mass death caused by such events as the holocaust, Hiroshima, and, more recently, the twin towers in New York, which force society to develop new ideas and hypotheses. Add to that the virtual disintegration of the extended family, which means that death rarely takes place at home anymore, which removes the exposure to a ‘personal death’; but does not remove the constant barrage of mega-deaths, fictional deaths, and violent deaths in the media, which leaves many people unsure as to how they should handle death at all. Despite this the death and dying movement has been a major force in helping to humanise medical care, one branch of which is the hospice movement, which has promoted personal care versus technological care and family inclusion versus exclusion. But it can still leave caregivers and other members of the health care team unsure as to how they should be handling their patients and their own feelings about death, especially when the deaths are frequent and traumatic (Backer et al, 1982:300).

Caregivers might use rationalisation, then, to enable themselves to cope with so many of their patients dying. They might declare themselves fully in control of the situation and insist that they are coping perfectly well with death whereas it could be equally obvious to the interviewer and others that certain comments are rationalisation rather than their true feelings. Asked to describe death, one caregiver who was interviewed said:
“At this (place), because of death here, I see death as a coffin... or what. It is like a goat, the shape of a goat”

When prompted by the interviewer to elaborate on the goat and whether it was a good or a bad thing, she said:

“When I think of a goat? I think of a …at least that. I see that, and it’s a good thing”

It is important to remember that, unlike a lie, or an excuse which has been purposefully thought up, rationalisation is an unconscious mechanism which can help caregivers to overcome anxiety which would help to preserve their mental health (Fisher, 1987:108) Most caregivers interviewed for this research indicated a reasonably positive outlook about death and dying, which seemed at odds with the view the researcher had of their coping with the constant death and dying; and it does appear as though, in order to deal with this constant death, the caregivers do use rationalisation as a form of survival in an otherwise too-difficult-to-contemplate situation.

When constantly dealing with dying and mournful people, most caregivers will experience an expansion in their empathic horizons; but they must also guard against a hardening and coldness of attitude, which has been mentioned previously, It is an important issue since it prevents their being effective as caregivers and reaching out to the bereaved. If the caregivers are in the position of being the only presence at the dying person’s bedside, whenever they give nursing care, then also, as stated previously, they will end up doubling up as both caregivers and the bereaved, which is extremely difficult, especially when family members then arrive to claim the body or to make funeral arrangements; but did not take the time to visit whilst the person was dying. The caregivers may then rationalise that they are the only ones who care about the patient who died and they may respond accordingly:

“So, ehh, at that moment, I was shocked, but because I used to see the adults dying, I was shocked. The day that I was crying more than Rochie’s mother
was the day of the funeral. I was really crying then, for that child that I loved and she loved me”.

In the above quote it is clear that the nature and quality of the attachment determines the intensity of the grief that follows death (Dickenson & Johnson, 1993:241). “Dying is a complex occurrence, a mystery of which one cannot rightly fathom the depth” (De Villiers, 1988:112). In the care setting described in this research, there is a need for trained palliative care nurses, who would be of assistance to the caregivers in dealing with the multiple deaths of adults and children that occur. Nurses are expected, by society, to have a moral, intellectual and practical approach to patient care, balanced by moral integrity, spiritual awareness and intellectual acuity (Dickenson & Johnson, 1993:26). Henry Dom, in Dickenson & Johnson, (1993:27) observes that “spirituality is concerned with a transcendent, inspirational and existential way of living, as well as fundamentally and profoundly with the person as a human being, in relation to God and creation. Spirituality is normally heightened as the individual confronts spiritual pain and the ultimate death of the human body”. Therefore the caregivers are not only required to care for the human body and its death but also for those individuals who may be in emotional pain, which makes their work both spiritual and existential in nature, since they are caring for individuals who are confronting their own humanness, existence and future non-being, which, being an essentially ontological and spiritual pursuit needs to be facilitated by an expert in ‘being human’ (Clarke, Flanagan & Kendrick, 2002:26-28). Of course one is trying to be human whilst patients are being equally human, which means they can be difficult, and try the caregiver’s patience. Therefore, although nurses and caregivers are perceived by society as demonstrating an ethical approach to their work, they do not always respond accordingly. Nurses and caregivers have abused patients, failed to maintain confidentiality and even harmed children (Clarke et al, 2002:28).

Whilst considering how the caregivers in this workplace rationalise death, and their experiences thereof, the researcher has considered the above comments and wonders if the general demeanour of the caregivers, when discussing death, was not in itself a rationalisation, not only of death but also of the care
actually offered and given. One of the caregivers, when asked about the care of those dying, spoke of the other caregivers thus:

“To me, I think they show a kind of rebellion attitude, I pick that up, you know. It’s as if they are just here, just doing a job, nothing more, that type of thing, I can’t explain properly, but to me, they don’t really care”.

Caregivers also explained how good the care was that was offered to dying patients. For instance, many of the caregivers indicated that the patient was not left alone prior to dying; yet in the researcher’s experience, this is not an exact reflection of the care offered, simply from a staffing point of view, and this is therefore not intended as criticism of the nursing care offered:

“It is important that people should have somebody there until the last minute when they die, and it’s also stated in the bill of rights, that the patient has the right to have somebody there when they die, when he or she dies, and, um, they may or may not die alone if they don’t want to”.

All of the above could also be an indication of burnout on the part of the caregivers concerned, since all such rationalisation and distancing oneself from dying patients are indications of ‘compassion fatigue’, or to put this more basically, caregivers become saturated with death and dying and can no longer feel the way they should about each person’s death due to being overwhelmed.

The last example of rationalisation found at this place of work and mentioned briefly, previously, is to avoid the use of the word ‘death’ and to use pseudonyms instead:

“I was helping with the communion and the bread would not go down, I had to give her some water; and then I knew that she was going, and that evening she passed away. I immediately distance me, you know, because the person is busy going”.
“Like over here, mos, we are one family, so if somebody, the thing is happening here, they will take that thing home to your heart, because they are family”. (This caregiver is actually describing the death of a patient, and is one of the caregivers who stated that she was totally “okay” with death).

All of the caregivers interviewed have rationalised death, some by avoiding it, some by using phraseology to make it all sound better and some by deciding it is all God’s will, as will be discussed in the next section.

### 3.1 Caregivers describe death as God’s Will:

Rationalisation has been described in the last section, with a definition provided, describing it as a defence mechanism which enables people to cope with difficult situations, in this instance the constant death and dying of the patients in the place where these caregivers work. God’s will is often referred to in cases of personal tragedies and disasters, for instance, “Saudi’s blame God’s will as 300 pilgrims are crushed to death at Haj” (Fisk, 2004:1), where the severity of the event was rationalised by saying that there is nothing that could have been done to prevent this occurrence; it was God’s Will. The caregivers at their place of work use the same approach:

“Okay, it is sad if I see a patient dying, or a child, but for me, it’s like God’s decision. If He feels like you must go now, then it’s your time to go”.

The question has been raised, related to God’s will, of whether or not AIDS is a manifestation of divine judgment, with God showing humanity that moral as well as natural laws order the universe. It is considered that God’s judgment will be corrective, and that many will choose to repent, return to God, and through faith experience God’s mercy all because they contracted HIV/AIDS (White, 1987: 18):

“Because these people are suffering, it’s a death bed disease, this AIDS, sometimes the adults, they say, ‘Oh! If I listened to my parents’, they said this, ne, last year, two girls who past away, I talk with them, and they say so to
me, they say, ‘Sis, sis, I was very naughty, if I listen to my parents I, l, get this AIDS, because I was very naughty.’"

In the above article, the comment is also made about the suffering of the ‘innocent’ as one of the most troubling aspects of the AIDS judgment, and here we are cautioned to avoid judging anyone with AIDS, and rather to consider that some people may have contracted the disease through practices not in keeping with society, whilst others, like babies, children and faithful partners, have been given the disease by those who strayed. The article exhorts all who read it to help anyone who has the disease, regardless of how they contracted it, and to continue, as the Bible tells us to, to feed the hungry and care for the sick (White, 1987:18).

“And what most people say is that if we break God’s laws, there are consequences, and one of those consequences is HIV, but there are times when things do happen innocently, for instance, the children”.

“I speak to my patients a lot about God, and if I see that they are suffering or in pain, then I tell them to start now to pray to God and ask Him to forgive whatever sins they have and to bring them through this illness, and I tell them to read the Bible”.

The rationalisation of death being God’s will could be a means to hide personal anxiety about death, since anxiety was found to be higher in caregivers than in professional nurses, which, as stated previously, also tends to lead to suboptimal caregiving practices and an attitude of ‘they are going to die anyway’ (Neimeyer, 2004:11). This could be linked to the ideology that it is God’s will that the patients die. Perhaps, owing to the supposed self-inflicted nature of this disease the caregivers can cope with all the deaths, of the adults at least, if they can rationalise death in this way.

‘And we are nursing the patients and seeing that there is no way that we can, you know, help them to live longer, then we see that the patient has reached the end and that it would be, be best for that person to go rather’
One of the caregivers had this to say, regarding the alluded references to the self-inflicted nature of AIDS:

“I personally think that, you know, we’ve got to go out into the world and talk to, you know, more people, especially when you see teenagers; have more talks about HIV and how people are dying of this”

Perhaps viewing death as God’s will, whilst being a rationalisation, a means of coping, could also be a way of locating death into a larger cycle of life or nature. The interpretation of death as part of a cycle is important because it draws attention away from questions to do with how people die; and suggests, instead, an answer to the question of why they die. From this perspective people die because it is through the ongoing cycle of birth and death that the human species reproduces itself. Locating death within a cycle of life provides a rationale, a justification, for dying. As part of a cycle mortality becomes meaningful and death purposeful (Banerjee, 2005:16).

“From nursing and loving the child it was just something that you just need to tell yourself, that the child has passed away, there’s nothing that you can do, you can’t take the Lord’s work out of His hands. You have to go on with life, because life goes on”

“If I see a patient passed away, or if I go to a funeral, it’s like, it needs to happen, you need to pass away. It’s just how’s life, the circle of life is”.

This caregiver describes life as a cycle that goes on, which helps her to cope with death. “Of course, is God’s will that the child dies”. Another caregiver describes the way she views death as God’s will:

“I can say it’s very...um, death, it make you strong, when you tell yourself, this is not in your hands, so it must happen. You can’t blame yourself when you are not, when it’s not in your hands”
Another caregiver expresses death in terms of finding answers in the Bible; and, by believing that death is God's will, finds herself able to cope with all the death witnessed at this place of work:

“Because in the Bible it says rejoice for those that go and mourn for those that are coming, you know, and the Lord is actually telling you, although you can’t see”

Again, the concept of the cycle of life is raised, indicating to themselves that death and dying, like birth, are all part of God's plan: and by accepting this, one can find peace in much of the devastation wrought by AIDS in this workplace:

“The Bible says that before you were born, while you were still in your mother’s womb, then your life span is planned, and no matter how, you can’t run away from it”

The feeling here appears to be that one’s life is planned, and no matter what you do, you will die when God decrees that this should occur. If this were to be linked to the concept of death as a cycle, it encouraged thoughts of transcendence of self, the perception that one’s death is part of something greater than the end of individual life. “The importance of transcendence has been observed to be fundamentally important in coping with existential suffering, thus the representation of death as part of a cycle may serve as a source of healing in itself” (Banerjee, 2005:15-16).

As the Chinese poet, Li Po writes, in (Fox & Woods, 2005:80):

“If you were to ask me why I dwell among green mountains
I should laugh silently, my soul serene,
The peach blossom follows the moving water,
There is another heaven and earth beyond the world of men”.
3.2 Caregivers experience death as fascinating/intriguing:

It has been said that the public are fascinated by death; but, according to Levy (2001:2037), there is a thin line between being fascinated by death and being frightened. Not everyone with AIDS faces imminent death; yet most will say the prospect of death is never far away, hovering in the background. Patients have stated that they themselves are frightened but also fascinated by the thought of death. The person facing death is often made aware, through dreams, or inner thoughts of some kind that time is of the essence (Levy, 2001:2038). Each person has to attend to his own personal sources of guidance, whether these are religious convictions or philosophical beliefs in order to find a way of meeting death (Levy, 2001:2037).

A discussion which followed ‘The Performance of Dying’, a piece of theatre used by The Royal Academy of Dramatic Arts as part of their ‘Art of Dying’ series, showed that people were both fascinated and scared by death. As Peter Pan said, ‘To die will be an awfully big adventure’ (Desai, 2003:3). People facing death themselves or faced with the death of others undergo a variety of emotions as each person explores the correct approach coping with the inevitable death, and how to find the ingredients for a ‘good death’ (Desai, 2003:3). The fascination with death extends far back into human history. Throughout time people have been obsessed with death and dying and all things related to death. People observing death often report feelings of initial fright, but this is frequently followed by awe. Even in the media the most popular material is based on death both in the news and the movies (Wikipedia, 2006:1-2).

One of the caregivers who was interviewed appeared to use fascination with death as a coping mechanism”

“No, like this morning I have experience, Wow! It’s amazing, amazing how quick can a person be swept away from here, and you still communicated with that patient in the morning, understand? You know, like this morning when you came on duty you started to greet them and he was smiling and I ask how you, okay? He says ja; then ten minutes to nine I went to give him his tablets,
I thought he was sleeping and I just shook at him, and thought, okay, something not right here, that’s when I realised he’s actually gone. He has left this, the earth, to start uh, a new, uh…”

“With the children, starting with Somi, his death was quite amazing. He was giving high five’s the whole day, then he suddenly passed away, he was sitting up and he (pauses) passed away”.

This could be interpreted as the caregiver’s way of coping with the trauma of death or it could indicate that there is a little fascination about death, which might help this person and others who use this mechanism to intellectualise in an attempt to avoid the emotional side. Another caregiver explains it thus:

“The thing about the children here, was, when nursing them and you know this child is going to pass away, you actually see death in their eyes, you know, and they seem frightened, and then the child passes away. It’s like, the child stares in your eyes and you look at him and it (death) staring back in your eyes; and you know you can’t do anything because this child needs to go”.

In the above quote, the caregiver appears to personalise death which is not an unusual occurrence and has been done many times in literature, art and films. In these cases death is depicted as having some sort of presence and personality even; and is frequently seen as evil, good, fair in judgment, mild -mannered or any other ramification decided on by the person depicting death in an art form (Wikipedia, 2006:2). To be fascinated by death could be yet another form of rationalisation which was described previously. Since rationalisation is an unconscious response to anxiety, which accompanies fear, both of which are a natural response to death, then it could be that one uses fascination with death to cover fear and enable the person to cope with death:

“Standing next to the adult’s beds, nursing them for the last time, you know, the adults, it really other way of death. When they die it’s like gasping, and their breaths, you know. You just sit next to them, and they know that they really are going now, and they are frighten to go, they sometimes scream, cry,
and then moaning sounds and then they gasp off. It’s like, something amazing to see it. How the patient actually pass away. Then you know, okay, the patient has gone”.

In this quote the caregiver sounds in control of the situation, in fact it sounds quite callous. In the following quote the caregiver adds to this:

“For real, the deaths I went through, like it hardened me; I had to stand in front of a patient, the patient passed away and you have to prepare it for the undertakers and you just, ag, like to do this. So you slap your mind out of it and imagine yourself that it’s not a death person, you just working like you do, or something, and you just get over it”.

This shows how traumatic dealing with death can be and also how the caregivers actively have to switch off to cope at all. What is interesting in the above quote is the use of the word ‘it’ instead of the pronoun he or she to depict if the patient was male or female, or the use of a name or anything to personalise the patient at all. This patient, in order for this caregiver to cope with the preparation of the body, was dehumanised, and whilst this does not equate to fascination the previous two quotes are from the same interview, which means that this caregiver has vacillated between fascination with death and what appears to be a totally uncaring attitude, initially; but which develops into a contradiction as the caregiver explains the need to pretend to be somewhere else in order to get this ‘work’ done. This could be someone who is not coping with death and dying at all, which would certainly raise the possibility that he could be inefficient regarding nursing the patients, although she is fascinated with the dynamics of dying.

3.3 Caregivers experience that working with PWA’s has enabled them to grow mentally and spiritually:

Providing a nurturing and caring environment for the dying is even more important for the living than it is for those who are dying. It is important that pain and suffering in others should evoke in us a compassion and desire to meet the physical, emotional and spiritual needs of the dying and of their
grieving families. In order to be able to deliver such a service, health-care providers also have needs which must be addressed so that they can help those who are dying to complete that task and achieve “healing” during those final days (Koenig, 2002:5). Caregivers who spend their working life fighting disease and death may have a difficult time accepting when death is the necessary and preferred outcome; for instead they may see death as a reminder of their failure and inability to help the patient (Koenig, 2002:5). Some caregivers may then feel guilty:

“When the day ends I debrief myself:, Where did I went wrong? Is there something that I could have done better? Did I go that extra mile?”

This kind of introspection can be positive and/or negative, the caregiver could start to feel demoralised. Caregivers could have had negative experiences of death within their own families, which might influence their responses to patients. There may also be, as mentioned previously, a reluctance to become attached to dying patients, thereby avoiding exposure to the emotional pain of separation when death occurs (Koenig 2002:5).

“You can’t get used to death, like me when my son died. I knew that he was hit in the, in the head. But I said I wonder if He would, if God can make a miracle and he would just wake up. You know I had that feeling, maybe he’s just sleeping there, and dreaming, and any minute now, he’ll wake up”.

Unmet emotional or spiritual needs of caregivers can serve as barriers that prevent them from being fully present with the dying person and family. Such unmet needs may cause the caregivers to abandon patients and families or reduce their willingness to interact with them and form the bonds that are necessary for compassionate and meaningful care (Koenig, 2002:5-6). Psychological and spiritual conflicts will certainly prevent caregivers from allowing dying patients to define their own dying experience (Koenig, 2002:6). One caregiver explained how she felt about children dying which is exacerbated by the fact that her own child had died:
“I prayed, I said, please God, I don’t want to see another child dying. I am telling you, this year, since this year started, the child, every children are dying when I am not here”.

On the other hand many of the caregivers in this study have stated that they experience growth in the mental and spiritual areas of their lives. Spirituality defies a simple definition, since it is not restricted to those who belong to a religious denomination. Spirituality is innately part of all living entities; and is open more so than religion to continual growth and change. Spirituality can be expressed in a loving way as having purpose and meaning in one’s life, feeling connected or belonging and in being authentically oneself (Dom, 2000:1). There is a great lack of understanding between spiritual and religious (or pastoral) care. Spiritual care comes from the heart and is at the core of palliative care. To be able to provide effective spiritual care, the practitioner first needs to look inward to examine his or her own spirituality, which can be painful for many caregivers (Dom, 2000:2). In order to help their patients with their spiritual needs, the caregiver, then, must be in touch with and at peace with their own spirituality especially as related to death and dying:

“I can’t breathe death and dying, I don’t like to see a person lying dead or dying slowly, you see, it the pain because I lost my family members through…”.

This caregiver feels that she copes well with death and dying, since in other parts of the interview she talks of counselling patients and describes the stages of the grieving process. She is cognitively well in tune with the process of death; so mentally she has grown, but spiritually she appears more in line for burnout, or caregiver fatigue, than she admits, or realises.

What does happen with many caregivers is that, if they are forced into contact with dying persons, they put up emotional barriers to protect themselves and avoid becoming too attached to the patients (Koening, 2002:6). This is not necessarily a sign of failure to grow mentally, and spiritually, for in many cases this could be part of the growth process. Such barriers may be necessary to allow them to function, otherwise they would become
emotionally overwhelmed from the pain that repeated contact with dying patients would evoke (Koenig, 2002:7). When asked if she was afraid of dying, one caregiver answered:

“You know at first, yes, but as life goes on, I told myself that if I have to die, I have to die. So being scared of dying, really, you need to search yourself deeply and ask why you are actually scared of dying. How was your life on earth? Did you actually do what the Lord wanted you to do? That a person is scared of dying, I think that person is walking with negative thoughts”.

This same caregiver is sure that she has grown mentally and spiritually and says so in the interview:

“Something told me I’m in a place where my mindset will change dramatically, my maturity is going to change drastically, I’m going to see things in reality”

This same caregiver continues to talk about death and dying as reality; and when counselling patients, she relates:

“When the patient is admitted here, you need to sit with that person and tell him that you are in reality now...that person must also realize, sorry but I’ve stepped into reality now. We need to strictly counsel that person, you know, and tell him sorry, this is reality, and one day is the longest that you can depend on”.

This all sounds a little harsh for the patients to have to deal with and does not really show that caregivers are truly growing mentally and spiritually. Such statements, stating that growth is taking place, could still be a form of rationalisation, due to the undisputed daily dealings with death and dying in young patients. It would be natural for the caregivers to want to feel that they have grown, rather than heading for burnout syndrome, but the researcher, although noting this, has not found evidence of real mental and spiritual growth, just the words uttered during certain interviews.
“I have grown up mentally, physically and it’s really strengthened me, inside of me, really”.

This person, however, states further on in the interview:

“My spiritual need is now lying on the rock, like, I’m not discouraged but, when I go to church, it’s like, why am I sitting here? You know, it’s those type of things, and then I think why doesn’t the Lord take me, quickly? Why do I still need to face these people, and stuff like that, you know? You just ask the Lord: Why, why, why?”

This caregiver clearly does not feel as comfortable with death as she would like to, and yet, perhaps the previous statement about maturity and growth, spiritually, was not too far from the truth, in that there is awareness that all is not well. Perhaps not the growth the person is attempting to signify, but there is a form of growth in acknowledging spiritual discomfort. Spirituality definitely plays a role in helping caregivers to meet the needs of their patients physically, emotionally and spiritually. Whether or not it enables them to be more ‘present’ with patients by making death less threatening is debatable. Certainly not many of the caregivers interviewed expressed the view that they had grown mentally and spiritually; and of the few who did so, there were the contradictions, noted above, leaving one to wonder how much growth had been achieved, and how much more could be attained with the right support and help to enable them to learn to cope adequately in this situation. There is very little research available pertaining to educational or training interventions that could help caregivers enhance their spirituality in a way that would enable them to meet the needs of dying patients adequately (Koenig, 2002:6), particularly in a field of work where there are so many deaths of young adults, children and babies.
Sub-theme 4: Caregivers experience that faith in God gives them strength to cope with death and dying:

CENTRAL THEME
In their daily duties (at their place of work), caregivers experience various challenges as a result of having to deal with the death and dying of their patients suffering from AIDS

Caregivers experience that God provides hope and faith
Caregivers experience death as a reality of life
Caregivers experience prayer as an integral measure of strength

Diagram 3.5 Diagrammatic Representation of Sub-Theme 4

All the caregivers interviewed for this study indicated that the only way that they could get through their working day, and indeed work in this environment at all, was due to faith in God, and the belief that He was with them and their patients at all times. Most of the caregivers mentioned how powerful prayer was in their lives, again as a means of coping with their task of dealing with patients who were dying of AIDS.

Palliative care, as a requirement for all patients facing death, has expanded in recent years to incorporate a family-centred approach to care, which needs to address the patient’s physical, intellectual, emotional, social and spiritual needs in a way that is appropriate to each person’s culture and economic situation. At least this occurs in developed countries, whereas in developing countries palliative care remains a neglected area, with most personnel not knowing what to do. In order to support personnel a multi-disciplinary team approach needs to be implemented to ensure that people with HIV disease and those dying of AIDS receive care despite the current limited resources (Aidsmap, 2003:2-3). It is important to emphasise the need for palliative care work for although it is not essentially curative, it still provides hope since it offers relief from physical suffering and emotional distress. In order for
palliative care to be effective, caregivers have to be supported to prevent burnout, and should be adequately remunerated (Aidsmap, 2003:3).

Spiritual beliefs were said to heighten job satisfaction and mitigate stress, especially when working with AIDS patients, according to a study done amongst hospice staff in Washington D.C. (Hoare & Nashman, 1994:185). Spiritual well-being was further found to be a significant factor related to both sleep quality and mental and physical health status of caregivers, which in turn enhanced their ability to nurse AIDS patients effectively in a holistic manner as detailed in the previous paragraph (Hoare & Nashman, 1994: 185).

“Now Faith is being sure of what we hope for and certain of what we do not see” (Hebrews 11:1).

Spirituality, a form of faith, has been described as the depth of human life, with individuals seeking significance in their experiences and in the relationships they share with family, friends, colleagues and, in the case of the caregivers, their patients. Spirituality is viewed as a construct that involves concepts of faith and meaning, with the faith component being most often associated with religion, whereas the meaning component appears to be a universal concept that can exist in religious or non-religious individuals (Chochinov & Cann, 2005:S106-S107). Spirituality does appear to be a new ‘catch phrase’, occupying a niche once occupied by the term faith, or what sociologists once called personal or invisible religion. In fact spirituality appears to be used as a vague synonym for religion, focusing on the personal side of religion, as opposed to organised religion (Chochinov & Cann, 2005: S107). If faith in God is cited by caregivers as enabling them to cope with the difficulties of dealing with death and dying, this would indeed be in keeping with literature, which does point out that a healthy spirituality has been identified as being associated with a long, healthy life, while the opposite is equally true, that spiritual pain would manifest itself in the form of symptoms such as: physical (intractable pain), psychological (anxiety, depression and hopelessness), religious (crisis of faith) or social (disintegration of relationships). (Chochinov & Cann, 2005:S108). However, it is not always possible to recognise spiritual pain on the basis of symptoms alone but the
combination of the symptoms with characteristic descriptions and behaviours that help identify this form of suffering (Cochinov & Cann, 2005: S108). Many of the caregivers interviewed, whilst saying that faith in God enables them to continue with their work, did tend to contradict many such statements (of faith) with statements depicting hopelessness and helplessness (discussed in a previous theme), which are symptoms of demoralisation (Cochinov & Cann, 2005: S110). One caregiver described a feeling of hopelessness with the situation where they worked:

“Death became all encompassing, everything in my mind was about death, there was so much death it’s all I could think about”, which describes the above mentioned spiritual pain. However, as the interview progressed, the caregiver was asked how she managed to continue with her work with such feelings:

“Spiritually I had to ask the Lord really to strengthen me inside, because it will kill me afterwards, and continually I will think of it (death);” and the caregiver added to this by speaking of the Faith for daily Living booklet, which helped her to cope:

“Matron is giving this little Daily Faith Bible, I would just open it and that little verse would say a lot to what is going on in my life and I would feel much better. That books help also a lot if you are feeling down and depressed and miserable”.

So while there are many comments from all the caregivers interviewed about faith in God, which helps them to cope, it appears that the many contradictions also speak volumes as to their inner conflict, turmoil and spiritual pain, which can only escalate if not treated adequately. In the next section the discussion continues with caregivers experiencing that God provides hope and faith.
4.1 Caregivers experience that God provides hope and faith:

One of the particular challenges for caregivers of those who are dying is the very universal nature of the experiences. Everyone dies eventually; and over time everyone experiences the loss of significant others. In some ways that makes each person an expert on these experiences. It reminds us too of our own mortality, the mortality of everyone we love, and makes us aware that we are all powerless in the face of death. It is equally clear that faith does not ultimately prevent the inevitability of death or the pain of grief. How then can persons of faith be helpful to us? Is there a body of knowledge or an array of skills that can be of assistance in the face of death, dying and grief? (Harris, 2006:2-3).

“Some of the people, when they are dying, put out their hand at the last minute, or they will look at you although they haven’t looked at you for some time, but they will turn their eyes to you, some of them do that, and if you touch them you can see that they are responding to it even though they are closed”.

Although death, dying and grief are universal experiences, every person’s life and relationship with another is unique. Therefore no one can experience death, dying and grief in the same way. What is clear, however, is that all people experience grief albeit in their own way. There has been a perception, and still is, that persons of faith who trust in God will not experience doubt, fear, pain or even grief. To express fear of dying and doubt about healing, is perceived by some to be a lack of faith. Christians are supposed to welcome death, in the belief that death is far better than life (Harris, 2006:3). This is quite a burden for Christians to carry, especially if they are unable to rejoice continually in the face of death and the dying of their own relatives as well as their patients, certainly in the case of most of the caregivers interviewed for this research. Many Christians have ‘confessed’ to the incredible pain expressed during illness, dying and following death of their loved ones. Despite theology there remains the sadness of loss. This does not, however, discount the value of faith and hope in the resurrection. In fact caregivers need to ensure that they receive spiritual care, and that includes asking
religious leaders for help especially when trying to make sense of death, dying and the grief process.

“I’ve become more comfortable with sitting with people when they die, by reading my Bible, where God speaks of preparing a place for us. We are nursing patients and seeing that there is no way that we can, you know, help them to live longer, when we see now that person has reached the end and that it is, would be best for that person to go rather. That helped me to get used to the idea that people have to die, you know”.

Another caregiver describes how her faith in God helps her with death and dying:

“Yes I believe my faith is strong and is really something that I can depend on. I believe in God”.

Discussing death and dying with a spiritual leader is also beneficial as mentioned previously; and one of the caregivers agrees:

“It does help me if I speak to somebody. I usually speak to one of our Reverends at my church and he always, um, shows me, I mean shows me what to think or to say: don’t be like this, be calm because you’re going to make yourself sick, don’t worry about this patient. He was sick now he’s resting”.

Bereavement is one of life’s greatest stresses, and the more bereavement people face, the higher the stress; therefore caregivers need to learn how to de-stress, so that they are in a position to help their patients and not the other way around. In one of the interviews, a caregiver expressly speaks of preferring to work with adult patients because then she can tell them her problems, and get advice from them. These are dying patients, with whom she bonds in her own way; but one has to query the kind of support they are receiving from this troubled person:
“So I do talk with them, sometimes when I have a problem at home I want to talk to anyone: ‘Oh I’m worried today, you know my daughter today is doing this and that and this’. Then the patient says ‘no, man, (caregiver’s name), don’t talk like this, you are doing this and this and this and your child will take, your child will put down at home about him, you know’; that’s why I like the patients, sometimes they help me so much”.

Because caregivers are there to support and help dying patients, they need to be supportive to their patients, available to listen to their patients’ hopes, fears, pain and dreams so that spiritual care can be added appropriately to the physical care offered. This would presuppose that the caregivers are in a position to offer such spiritual care. The caregiver quoted above buried two brothers in 2005, both of whom died of AIDS, and her sister is HIV positive. This caregiver has marital problems and often appears depressed, possibly due to abuse at home. This woman is trying to work as well as possible with her patients, and probably feels that she is achieving this goal, but when correlating her interview with field notes, it is not difficult to pick up on her immense spiritual pain and her own incredible need for emotional and spiritual support. HIV/AIDS has a disproportionate effect on the lives of women, since women are carrying the major share of the burden physically and emotionally when AIDS affects a household. The women are the caregivers, as well as being the breadwinners for the families, as is the case in this place of work ((Kelly, 2006:6). There is no doubt whatsoever that what those living with AIDS and their caregivers need above all, is hope, and the deepest roots of this hope lie in the death and resurrection of Jesus Christ as many of the caregivers attested to in their own way:

“Ja, the other side is right because I am going to rest and wait for my God, my Jesus”

“...and that dying is not the end, it’s just the door to another life”.

“Oh, its stressful, it’s a stress, it’s a stress, death is not a thing you can say you get used to. You know you can’t, it’s a stress thing to see people going, you know, one after another, after another, you know. But, because I am a
believer, some people are going, you know, you say thank you Lord to take that person because you did see how was the pain to that person”.

There is no doubt that faith in God helps the caregivers to cope with the death of their patients. They also combine their faith to help one another; and this support of one another plus the support of family and friends enhances this faith base.

“Everybody takes everybody important here, it’s nice to work here, although you do get ah, the death thing, that does mean that we must take as a challenge as, to go nearer to God and help, help more people; we are alright, people here can help us to grow”.

Studies have shown that those who attend church were quite likely to have a religious commitment, which is further hypothesised to lead to improved stress- control mechanisms, rich social support and the strength of personal values (Puchalski, 2001:2). This further supports the premise that faith and hope in God would strengthen the caregivers at this place of work.

4.2 Caregivers experience death as a reality of life:

There is no doubting the reality of death. The caregivers who were interviewed for this research can readily attest to this fact. They have all seen enough dead people to be sure of the reality of this which abounds in this caregiver’s comments.

“It does make me sad, when they die. I'm even worse with the children, I don't know how I will cope when a child dies while I'm working in the nursery, but with the adults, it does make me sad”.

In this crisis of AIDS everyone needs faith to cope with the magnitude of death. It is tempting to ask where God is in all of this suffering and death; and reassurance that AIDS is not a punishment from God is some help especially in the face of so many judgmental and stigmatising attitudes (discussed previously). “Perhaps an incident that occurred in one of the concentration
camps in Nazi Germany can help. The story is told by Eli Weisel, an inmate in one of the camps, who described what happened when the camp authorities hanged two Jewish men and a youth in front of all the assembled prisoners: the men died quickly, but the death throes of the youth lasted for half an hour. ‘Where is God? Where is He?’ someone asked behind me. As the youth still hung in torment in the noose after a long time, I heard the man call again, ‘Where is God now?’ And I heard a voice within myself answer, ‘Where is He? He is there, He is hanging there on the gallows” (Kelly, 2006:4).

In the crisis of HIV/AIDS, that is the faith that we need, that the caregivers interviewed for this study need, to have the vision to be able to see and say, God is here, in this suffering person, this suffering child, God is present.

“It’s not an easy thing to see, especially when the funeral parlour comes to fetch them; you feel heart sore, okay, I was so bonded with this patient, now he’s gone I will never see him again”.

“You know, with the death...coping with the death, I am a very emotional person, but I started becoming like death. It’s like there’s something that gets to me, I think. I can’t walk away from it. I have to face it, it needs to happen”.

That AIDS causes immeasurable suffering is undisputed, but God is present with those who are suffering is equally clear, to both the patients and staff at this place of work. God works with those who care for the infected to enable them to overcome the suffering that is being experienced. Pain and suffering in a dying person is terrible and tears the heart out of us, leaving us numb, desperate, and frustrated (Kelly, 2006:5).

“I feel very painful when I see the young ones suffer with pains, sometimes the babies can’t say it sore or Mama my mouth is sore. I feel very bad especially for the babies. The adults they say, ‘oh my arm is sore,’ then you can help, but the babies don’t know what is sore.”

“When he had fits of pain that no amount of morphine could control, he screamed out ‘momma’ with such intensity, such anger that I felt totally
inadequate; here was a five-year-old boy, orphaned, abandoned, abused, in pain, and dying of AIDS”.

It doesn’t get more real than this, but somewhere in all the suffering, it is important to believe that the person eventually passes to a new stage of peace and acceptance. They may not be able to put the words to it; but deep within themselves they are confident that their Redeemer lives, and that they shall see God (Kelly, 2006:5).

4.3 Caregivers experience prayer as an integral measure of strength:

Prayer is our communion with God, whether it be a petition made to God, worship, repentance, praise or thanksgiving. It doesn’t have to be a laid-out prayer, but words from the heart. God wants all of us to talk to Him as if He already knows the situation (Sanders, 2001:2). All the caregivers interviewed spoke of prayer as being the one thing that got them through the day, the only way that they could cope with the work that they do:

“I pray. Even here when I go to the toilet, I always pray. God gives strength, this place it very, very bad place, so He give me strength. It’s a dying place, this place”

In answer to how she coped with all the death and dying, one caregiver answered:

“Crying and then praying, I go to a place alone in my room, I always call it my quiet place, to pray about it. Somehow or other, you do get peace”.

Scientists are currently studying the power of prayer and in particular its role in healing people who are sick. Most researchers look at how sick people are affected by their own spiritual beliefs and practices. In general these studies have suggested that religious people seem to heal faster, or cope with illness better than those who are not devout (Rauch, 2000:1). In a study of cardiac patients conducted in Missouri, scientists decided to investigate if patients
could be helped by praying for them without their knowledge. One thousand patients were divided into two groups: half received daily prayer and the other half no prayer in conjunction with the study. The group receiving the prayers fared 11 percent better than the group that didn’t, a number considered statistically significant to the researcher. At the very least the results validate the need for extended research to bolster the evidence that prayer works (Rauch, 2000:2).

Prayer is a powerful force that asks for and welcomes God’s help. God is present to aid us in the healing process, to support us in our time of illness, crisis or need. Prayer helps us to overcome fear and anxiety as we seek understanding, forgiveness and love (Rauch, 2000:3).

“I have peace because I do keep everybody in prayer all the time, and to me prayer is not only sitting here on my knee or so, it’s praying all the time, when I see there is something happening that I can’t handle, you know, then I pray. That’s what really helps me to cope. Even in my own life, if there are things that I don’t understand, even with my children, then I pray. I feel bad, I feel sad, but I pray and that gives me joy, because I trust and give everything to the Lord because I know I can’t handle nothing, it’s only by His grace and strength that I can handle things”.

“You know, I pray, oh please God give me strength and love to look after the patient more and give me the courage to do what is the best thing I must do, give me strength and love, everyday I pray, even as I came here in the door”

There is no doubt as to the power of prayer in the lives of Christians, indeed, in any religion. Everyone prays, some fast too and pray at set times; therefore prayer has to be acknowledged as an integral part of most people’s lives and there has to be a reason for this. Obviously the belief in a higher power is the start of this process, but in the research being done to highlight the power of prayer, the oft-mentioned ‘autosuggestion’ is ruled out. Prayer changes things and people which has been said often and in the case of these caregivers it certainly appears to be true:
“You know, I became so stressed, I used to, when I go home, to lock, to go in, go straight to my room and lock and take a pillow and, you know, and shut my face and cry, and cry and cry. And after I become relieved I pray, I pray to God, and I pray hard and thereafter, I become alright”

“And then I say sister, so and so to me looks like is on the way, can’t we just go and pray? Then we do, the sisters say, okay, let’s go, and we pray for that person and then we make that person to be in peace, you know”.

Belief in the power of prayer, along with faith and the strength received from God through prayer are clearly of immeasurable help and comfort to the caregivers who are working in this place with dying adults and children.
Sub-theme 5: Caregivers experience caring for patients as fulfilling and meaningful despite the sadness of death and dying:

**Figure 3.6 Diagrammatic Representation of Sub-theme Five**

There is undoubtedly a sadness linked to death and dying (discussed previously) which can certainly predispose caregivers to compassion fatigue/caregiver stress. A study performed by Prabha, Jairim and Anila (2004:48-54) showed that there was a lack of data on the prevalence of burnout syndrome amongst AIDS caregivers in developing countries, but studies done have highlighted extensive depression, anxiety, overwork and fear of death in caregivers who are working with AIDS patients in developed countries. Burnout is further related to age, communication, role ambiguity, team problems and lack of staff support (Prabha et al, 2004:49). These issues have been mentioned by the caregivers in this study, and will be discussed in the three sub-themes that follow. The severity of the stress suffered by AIDS caregivers is linked to the fact that so many young people, children and babies, are dying from this disease (Prabha et al, 2004:49), another factor verified by the caregivers in this study (see previous sub-theme relating to death of children). When the stress reaction is activated too often, it can lead to severe discouragement, a process which happens over time as opposed to being instantaneous. Burnout has been described in this context as being ‘a
syndrome of emotional exhaustion, a depersonalisation and reduced personal accomplishment as a result of chronic emotional strain of working extensively with other human beings, particularly when they are troubled’. In the palliative care setting burnout is also viewed as a coping mechanism used by caregivers to distance themselves emotionally from the patients, to enable them to be able to continue working in the field, which implies that burnout could be a state of being rather than a process (O’Neill & Mckinney, 2003:6).

Many of the caregivers interviewed for this study indicated to the fieldworker that they coped well with the constant death and dying that they dealt with; however, the researcher is aware (as stated previously) that at least five of these caregivers have recently started taking anti-depressant medication, following referrals after the previously mentioned counselling:

“Yes, for that matter I got many, more than five, counselling’s from the Matron, Matron Maggie, she gave me the counselling, you know. She helped me a lot on that because I’ve been crying and depressed”.

“But Matron is there to talk to when you are full, the doors are always open for her, to come and talk to her, and it helps”.

Caring for dying patients is a difficult task, and the fact that there are so many deaths of young adults, children and babies, magnifies the difficulties experienced by these caregivers. Most people choose to go into palliative/hospice care for a reason, and many people drawn to this type of work have the right motivation, experience, personality, or all three, to cope with the demands of this field. However, over sensitivity to the problems of others, caused by empathy, compassion or training, can heighten the awareness of others’ pain and could end up being more of a burden than a positive factor for the caregivers (O’Neill & Mckinney, 2003:8).

“I feel helpless. Sometimes they will, they like to talk to you and they don’t want to be alone, they will always call you. And sometimes you can’t be there 24/7, because you got other things to do, but they feel so alone, they need company, and you can’t give your whole, ummm, say 100% to the one, there’s a lot, so it’s actually, you feel torn”
“Especially when you deal more especially with the very sick ones then that I wish I can help, I wish I can, I wish I can take that pain to me but you can’t, you can’t, that’s why you feel so emotional and…and stressed out, because you can’t just help that particular person”.

There are many reasons why the caregivers feel stressed; and chronic anticipatory grief, (discussed previously), loss, a need to grieve and to come to closure consistently, are all potentially stressful, as are inappropriate motivations for choosing this field of work (O’Neill & McKinney, 2003:8).

“I think that bottling it up doesn’t really work because tomorrow you come back and somebody else dies and you haven’t yet had closure of the previous one”

In the place of work where this study was done, the researcher remains of the opinion that most of the workers are there through a need for a job, therefore the reasons for taking this job are largely financial. Despite this, many of these workers have found, in themselves, strength to continue and have managed to overcome many of the challenges this field offers. Despite the enormity of their task and the obvious emotional toll that it takes on the caregivers, the workers still manage to succeed in feeling positive (most of the time), and thus coping with the death and dying that they deal with constantly. Despite the negative factors and the potential for burnout, there are rewards to caregiving, which are listed below:

- Providing mission and a sense of purpose to one’s life
- Development of empathy and self-knowledge
- Gaining a sense of personal effectiveness by demonstrating competence under very difficult circumstances
- Experiencing the positive feelings associated with loving, caring and feeling needed (O’Neill & McKinney, 2003:6).

These factors will be included in the discussions of the following three sub-themes.
5.1 Caring so much for the patients emotionally and physically that there are no regrets when the patient dies:

Caregivers in other studies have stated that they find working with AIDS patients rewarding and that such work gives them a sense of fulfilment. Making patients comfortable and supporting a patient emotionally, especially at the time of death, also enhances the work experience for these caregivers (Stajduhar, 1998:14).

“But when she dies it helps to me because I feel proud. I saw her suffer and then I help in so many things, you know, with love and caring”.

“And if you do what you must do while you around a person then it gives you that satisfaction you did what you could”.

What is important is that when caregivers know that they have done a good job caring for their patients by giving respectful, compassionate care, the mourning process is eased for them. AIDS has compelled many people to face their own mortality, many have died, many live on infected, and all who work on the frontlines have learnt about the temporary nature of life. The threat of becoming overwhelmed and demoralised is a real danger (Goldblum & Erikson, 1999:2), yet the lessons to be learnt, although hard, are also a growth area for all who confront this disease; and all people dealing with its losses must find their own strength to face its burdens, and to find meaning within the struggle (Goldblum & Erickson, 1999:4).

“I like to work with the work of God, help Him with the people, and I feel relieved when that person can see the difference, that’s when He’s helping me, even I can help by just reporting that this person has a problem here, I’ve helped”.

Caring for dying children is exceptionally stressful, especially observing them suffering. Although advances have been made in understanding the impact of death and loss, too little has been done to apply this knowledge in preparing health care workers for the challenges of paediatric palliative care (Contro, Larson, Schofield, Sourkes & Cohen: 2004:3). Despite this many caregivers
interviewed for this study felt fulfilled by ensuring that the emotional needs of the children were met prior to death, which left them with no regrets:

“I feel all right because at least in his last time (before he died) I did do the thing he want, like he say to me, let me feed myself the porridge, and then I give him and then he sat and eat, just feel that I, I did do something that he wants before he goes”

This does not mean that there is no sadness or unresolved issues. Perhaps it’s like taking a stoic view of accepting the good with the bad or staying in denial. What is clear is that most of the staff are not particularly comfortable about discussing death and dying and many of them become acutely distressed, especially when children die. The researcher was called out at night on numerous occasions to assist the staff when a child had died because the staff member was unable to cope.

The researcher also noted that the staff were unable to tell the other children when one of their friends had died. Bearing in mind that these children live together like siblings this is an area of concern to the researcher. When five-year-old Khaya died, nine-year-old Bohlali was in the same room, but the caregivers moved him to another room after the death. The next morning, when Bohlali enquired as to Khaya’s whereabouts, he was told that Khaya had gone to hospital. The researcher counselled the caregiver and attempted to find out why she could not tell the child the truth. She said that she felt distressed and did not know how to tell him as she had not expected the question. She never discusses death with any of the children and felt ill-equipped to do so. This is in keeping with other studies done in palliative care institutions for children where staff reportedly “felt inexperienced, reported feeling distressed and inadequate in their communications with patients and families about the dying child” (Contro et al, 2004:5).

While caregivers voiced feeling more comfortable with adults dying than children (see sub-theme 2), it was clear that this was rather a qualification of terms: that it was hard to watch children suffer and die, but that did not detract from feelings of sadness and all other emotions when adults died. Accordingly the caregivers were equally fulfilled by ensuring that all the needs for the dying adult patients were met; and felt
comfortable knowing that they had done all that they could to ensure a “good” death for their patients.

“I like to look after the patient, I know what’s happened to the patient whence they are adults. I like to help the peoples, you know, the sick people”.

“You know, my philosophy in life is helping people, help people, really, so, when you help a person, you must only know that you are helping for that specific reasons but that you must meet his scriptural need and emotional need as well, you know. This is the most difficult part; sometimes the patients feel like crying inside, they miss their relatives, then you as the health care worker have to step in to give that spiritual need to the patient”.

This comment from one of the younger caregivers showed tremendous insight into the needs of the patients and an attempt at reaching patients at their point of need, which is of utmost importance in palliative care. These caregivers are doing their best to cope with the pain of death, especially with the amount of death, but despite the insight shown above a lot of pain emerged from these statements. The study mentioned above highlighted the need for adequate support for staff working with dying patients, and the caregivers who were interviewed for this study did state that support was not adequate at the place where they were working; that debriefings did not occur; counselling was only done by the Matron; and that many of the staff voiced feeling depressed, sad and hopeless (see previous themes). The staff needs to be reassured that they really are doing their best, and that they’ve done all that they can for the patients (Contro, 2004:7). This study has also highlighted the fact that staff dealing with dying patients often feel that they are being left to deal with things on their own and that they feel isolated in their grief (Contro, 2004:7).

“I always feel sorry for the patients that is dying, especially when we cannot do anything for the patient, nothing to do for the patients in the last stage, there is nothing you can do for the patient”
From the above quote it does appear as though these caregivers feel as overwhelmed as those interviewed for the study described and as hopeless. The repetition by this caregiver is particularly poignant as she tries to describe her feelings; and simply can’t get past the fact that there is nothing that can be done to help these patients. The need for debriefing is clear; and that these caregivers need the reassurance that they are doing their job well, that they are seen to be doing their best for their patients. They were saying that to help the patients enabled them to avoid regrets, so that at the end of their work day they could say that they have helped the patients; yet, equally, some of the caregivers spoke of the workload and that they could not always get to the patients as required which perhaps did lead to some guilt. Either way, the caregivers need to be supported to cope with accepting their limitations, having some peace with knowing that they have done a good day’s work and that more than this they cannot do:

“Did we do enough? I started to think like that and that makes me feel bad, you know, we always had that guiltiness that maybe there is something that I didn’t do. Is there anything that wasn’t enough?”

“When you are not able to help somebody sometimes you are working alone on the adults side and there also another person that wants help, so you will feel angry that eh, I wish that there was somebody who can help that one, because I am still busy here with this one”.

This caregiver described her frustration at not being able to get to all her patients and to help them as she’d like to have, which could also lead to feelings of not having done enough. This was not one of the caregivers who said that she felt no regrets when the patients passed on: she certainly appeared to have a contrary opinion to the one expressed in this theme, due to feeling that there was too much work and she could not get to all her patients.

5.2 The caregivers experienced that working with terminal PWA’s provided a positive contribution towards the patient’s last days:
Although there is no doubt that all care provided at the place where the caregivers work is better than the care these particular patients would receive at home in most cases there is still plenty of evidence that the caregivers are struggling to cope with the enormity of the burden that they carry, linked to all the death and dying they have to deal with especially of children. In the study mentioned in the previous theme, staff members said that they felt obliged to put aside their grief and return to work immediately; and they felt that they had no place to talk about their experiences and were plagued by painful memories (Contro, 2004:8).

“Working here is very difficult at times, not always. Sometimes you feel sad, hopeless, angry emotionally. Those things can be caused by the stress that you come across of not coping to help your patients, and generally everybody that you can’t get to”

This caregiver would like to do more, but is struggling with the workload. Other caregivers have a more positive outlook than hers:

“If you must leave this place or you go somewhere else, you can with a positive thought and mind and tell them, listen, this is where I worked, this people with whom I worked and the patients whom I cared for while there, it really is a marvelous place, really”

One of the caregivers spoke about the need for support, which was mentioned previously:

“It makes it very hard for me to cope within this working place that thereby they will get stress, and all those things. Whereby we need also to have these eh, eh, mentors, we need to alternate the hard jobs with the nice jobs. We
need to take two to five minutes of non-working activities so that we can breathe, voice out, you see. And we need mentors whereby you full, you have to talk to that particular person”

This caregiver was aware of the need to have structured debriefing, some time out and stress release, which is a positive outlook and would help these caregivers to continue to contribute positively to their patients’ last days. If these caregivers were supported adequately, they would be in a strong position to help their patients achieve a “good” death. The caregivers in this study were trying to give the best care possible, but as described throughout this study, they had so many needs of their own, which were largely unmet, that it was hard to see just how effective they really could be with their patients.

However, for the purposes of this study, it is important that the caregivers believe that they are effective, since this appears to be part of their coping mechanism: tending to fall between denial of their pain and lack of support, and bargaining for that support. Sometimes the relationship between caregiver and patient becomes blurred and boundary issues (rules that regulate the social interactions between the caregiver and patient) need to be imposed to protect the worker who might blur the lines due to a growing attachment to the patient (Fox, 2006:954). Again the need for support is evident:

“For instance I really got deep friends with one of the patients here and I thought to myself, listen here, you did not set your boundaries walls, that’s the most difficult part, as a nurse you don’t set your boundaries walls”.

Taking care of someone close to death is a sacred act, in which certain boundaries are often dissolved, and each person, patient and caregiver, is
affected by the other (Fox, 2006:955), which is certainly often the case at the place where these caregivers are working:

“Because that’s why I said I am worried the patient really, but, but those I took like a brother or like a sister and sometimes they shared my problems, you know, that’s why I’m prayed when she is died, you know?”

Neither of these caregivers spoke of caring optimally for the patients in so many words; yet in their own way they had bonded to such an extent with their patients, taken them as friends, that the patients could only have benefited immensely from such care, bonding and love given by the caregivers. Therefore the caregivers need not feel guilty about not doing enough for their patients, although many do, since they are trying to the best of their ability to ensure adequate care for their patients. Of some concern to the researcher is the possibility that the support these caregivers require is coming from the patients themselves, as discussed previously, rather than from mentors, structured debriefing or adequate management structures.

Some of the caregivers bond with their patients to such an extent that they attend their funerals, which, according to literature, is not actually a bad thing. Caregivers develop varying degrees of concern, depending on the circumstances and relationship they have with the patient; so attendance at memorial services indicates that detachment is not the necessary and natural response to death and dying. In fact caregivers often cope best having worked through the grief that bereavement causes by attending the funeral; but it does depend on the caregiver:

“It painful it someone who is closer to me and someone who I saw almost every day, you know, it like my friend and my relative. Because I saw every day chat with them, share jokes, everything, you know. So I lose somebody that why when it her funeral, I going all the time, you see me there. The other lady who was in place Kwazakhele, I went to funeral”
“At least if you there you will tell yourself when the Reverend take the soil and then he say in the soil, at least you see that person for the last time go down and all that, fact, if you go to the funeral you like, you tell yourself you see him for the last time and then you bury him and then the last time you tell yourself he is not there again”.

In these instances, the caregivers clearly needed the closure that a funeral generally brings; for they both stated that it helped them tremendously in coping with death and dying and it also seemed to help with the feeling that they had done all that they could for their patient, right up to honouring the patient by attending the funeral, therefore alleviating any guilt feelings and feeling that they had, indeed, made a positive contribution to the patient’s last days.

5.3 Being in constant contact with death and dying reaffirms an appreciation for being alive:

When caregivers were able to really help their patients they felt a sense of pride in what they had accomplished, found meaning in their experiences and made sense of the loss of patients. For many, their experiences helped them to learn new things about themselves and to view their work differently (Stajduhar, 1998:20). This new worldview often included a renewed sense of inner strength, spirituality and a strong belief in life after death (Stajduhar, 1998:20). Many of the caregivers interviewed for this study also spoke of a belief in life after death:

“As a Christian I believe there is a life after this”
“I think people when they die go to heaven and sing, eh, sing and praise and eh that how I feel now that now when I go to heaven, you are going to sing and praise”

Many caregivers assimilate their experiences and often make constructive changes in other aspects of their lives, life changes or a change in how they view life (Stajduhar, 1998:20).

“I personally, it has changed my outlook on life, it has changed, I would say some, some it makes you think that, you know, if somebody in my family dies I become, you know, I just think of what happens to Mr. so and so, you sort of correlate the two, you know, and then though they haven’t died of the same illness but you think of your heartache you had then, and then, I find that I grieve more when a relative dies, now, than before. I think it’s due to all the death that we see here”

“I now talk to my friends and tell them like, you know, life is so short, that I see so many people dying, and then some of them come over to my side, they say I’m more mature, I’ve grown, but there are some that will wonder if this is really true. Is this a really true person that I knew before?”

In the study quoted in this sub-theme, AIDS caregivers found that caregiving demanded considerable time, energy and commitment that often went unrecognised and unsupported (as mentioned previously). Caregivers said that caring for those with AIDS was an intense emotional experience filled with pride and enrichment and conversely with anger and disillusionment (Stajduhar, 1998:20). Kubler-Ross (in Ahmed, 1992:158-159), mentions that the care of AIDS patients has some psychological benefits for the caregiver, that the caregivers have a sense of usefulness, compassion and fulfilment, which could be as a result of the satisfaction and/or gratification anyone achieves when offering care and service to others. Caregivers interviewed for
this research have reported a newly-found clarity in their lives as a result of their caregiving experiences:

“Um, you know, life is too short, I just take it that way, life is really too short, still to argue about nitty gritty things around you, and you really at that time and that moment when the person argue with another person, you just think, okay, why must I still pity myself about this person, and there’s a sick patient busy dying inside? I can rather spend that quality time with that person than standing here and argue about nonsense, you understand?”

“It’s just that what I want to get through to others is like don’t always stare at one picture. There’s many pictures around you, and that pictures, especially at this place, actually mean something for you. If you look at patients it’s like a story that the patient is telling you, and you have to start learning to read that story, understand that story, and really you have to leave your fights and strife from home at the door and step into a more calm, peaceful environment, understand?”

An indirect benefit of working with AIDS patients is coming to terms with the inevitability of death, a realisation that enables the appreciation of the benefits of death (Stajduhar, 1998:17). One of these benefits was stated as helping the caregivers to savour life and really appreciate being alive (Stajduhar, 1998:17).

“It makes me treat people better, changed the way I see relationships, like you know, arguments between my family, like, having little differences and I will come in and ask them, do you know how short life is? And they will stare at me and say ja, and I tell them remember where I am working, and I get frustrated that they don’t see how fleeting life is”.
“I’ve grown in this place, I embrace life more because of all the death that I’ve seen”

“I would say it has made me more compassionate because you have that idea that you are here today and gone tomorrow and it also makes you a better Christian or a better person to get along with people you haven’t gotten along with, because that person might not be there forever, or you might not be there forever, I think that is the impact that death has on me, that I am trying to live a better life because I feel that life is so short”

So despite the fact that death is sad and causes grief and bereavement, those working in the field of palliative care often feel that they grow through death that they witness. Certainly in Kubler-Ross’s book (1975) the value of death is recorded, as is the immense growth of those who witness and assist those dying. A dying person often drops roles, takes off masks and strips down to what really matters; so those assisting or witnessing this process have to be influenced by the sheer honesty of this time in a person’s life (Funk, 2005:1). Those working with the dying may be prompted to note that death might not be the worst thing that can happen to us, since by doing that we become locked into fear and denial, as many of the caregivers in this study just might be (Demmer, 2002:2). Denial of death leaves us feeling lost and alone because death is the defining element of the human experience (Funk, 2005:4). In order to keep our passion for life, to enable us to savour it daily and to give us the ability to live in the moment, in community with our fellow mortals, we need to have an awareness of death, but not the fear and denial (Demmer, 2002:2).

“I don’t fear death, if it’s my turn, I will go, and if I have to die in an accident or whatever then that is maar just, it’s just maar how I must die. It doesn’t worry me”
“I don’t know, I think it’s God’s will, if it’s your time. I think it’s God’ will, don’t argue. Sometimes you want to bargain with Him, like if, or I would be better or, but I think its His will, it’s His will, I’m not afraid of dying, but I don’t want to suffer”

The caregivers working at this place appear to have grown positively in many ways from their experiences of death and dying, although the suffering of their patients has had an impact on them too, as mentioned previously. Certainly, dealing constantly with death and dying has given them an awareness of death that most people do not have. Emotional detachment is not an inevitable response to working with the dying, and although some of the caregivers interviewed are detached and unable to cope with helping the patients who are dying, many are able to attend funerals, develop friendships with patients that they know are dying and feel able to be sad at the death of their patients and grieve for them, which is a healthy response. There is certainly room in this place of work for workers to be allowed to be concerned about their patients and to have legitimate emotional responses to patients’ deaths. (Fox, 2006:960).

“Fortunately we are allowed to grieve for them, which is good, and grieve with each other because we’ve seen the children grow up here, we’ve nursed them and then they die, it’s quite traumatic for us”.

Many caregivers are happy to be making a difference in their patient’s lives when working with dying patients, and are definitely appreciative of being alive, as seen above. There is no doubt that working in this field (HIV/AIDS) is very hard on these caregivers, especially due to the ages of their patients; therefore adequate and timely support is definitely essential to assist these workers.
3.4 CONCLUSION

In this chapter the experiences of caregivers working with patients dying from AIDS was described in detail, based on data generated from thirteen in-depth phenomenological interviews. The participants were all caregivers working at an institution offering palliative care for patients dying of AIDS.

The uniqueness of the challenges facing these caregivers emerged clearly from the interviews and were described in this chapter under specific identified themes. Since the aim of this study is to describe the uniqueness of the challenges faced by workers in the AIDS field, emphasis was placed on how these caregivers experienced and reacted to their environment, an institution offering palliative care to patients dying of AIDS.

Research findings were placed within the context of the broader body of scientific knowledge as found in literature. It was shown that the field of HIV/AIDS manifested its own multi-faceted structure and dynamics that did not lend themselves to easy explanation by means of existing models. This important finding will be addressed in the next chapter under research recommendations. Broad guidelines to enable the mentors of the caregivers to provide support for the caregivers, so that they can optimise nursing care of patients dying of AIDS, as well as limitations, will be also be dealt with in chapter four.
CHAPTER FOUR

GUIDELINES, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

“There is within each of us a potential for goodness beyond our imagining; for giving which seeks no reward; for listening without judgement; for loving unconditionally.”
(Kubler-Ross, 1998:242)

4.1 INTRODUCTION

In the introductory chapter an overview of the research study was presented and the problem statement was described. Chapter two incorporated the research design and method. In Chapter three, data that was gathered during interviews with caregivers was analysed and themes were identified, reflecting caregivers’ experiences whilst working with AIDS patients in a formal setting. In this chapter these experiences as reflected in the themes and the transcribed interviews form the baseline for the development of broad guidelines, the purpose of which would be to provide support for the caregivers. The guidelines will be brought to the attention of the management board of the institution where the caregivers are working. In addition to the formulated guidelines, this chapter includes the summary of findings, limitations, recommendations and the conclusion to the study.

The objectives of the study were to:

a. explore and describe how caregivers in the formal setting (an institution) experience caring for their patients dying of AIDS, and
b. to develop broad guidelines that would enable mentors of the caregivers to provide support to the caregivers, so that they could optimise nursing care for the patients dying of AIDS.

In order to attain the first objective, the researcher posed the following question:

“Can you tell me about your experiences of working with patients with AIDS?”
In order to attain the second objective, the following question was formulated:

“How can the caregivers in this study be supported, to enable them to optimise nursing care for patients dying of AIDS?”

In the opinion of the researcher, the aforementioned objectives were reached on completion of this study.

4.2 SUMMARY OF FINDINGS

The study emanated from the researcher’s own experiences as a Professional Nurse working with patients dying of AIDS. The researcher noticed signs and symptoms of burnout/caregiver fatigue, as mentioned in chapter three. During the research process, the caregivers who formed the target population for the study were interviewed, and voiced their lived experiences to the fieldworker. Information-rich data was generated by the unstructured in-depth, individual interviews. The data was analysed and reported on under one central theme and associated sub-themes (see Table 3.1).

Although many experiences, both positive and negative, were shared with the fieldworker, one central theme emerged, namely that “in their daily duties (at their place of work) caregivers experience various challenges as a result of having to deal with the death and dying of their patients suffering from AIDS”. This was the common thread that permeated the sub-themes, highlighting the difficulties that these caregivers faced daily as they worked, cared for and supported, the patients dying of this disease. It was the experience of the researcher and, in particular, the participants, that caring for those dying was a complex type of work, requiring physical, emotional and spiritual reserves that many people would find it hard to sustain, particularly if unsupported. The sub-themes highlighted the experiences of the caregivers in their place of work.

In Sub-theme one the focus was on the participants’ emotional challenges in caring for patients that incorporated difficulty in accepting death; sadness at the plight of their patients; anger at the fact that relatives did not visit the patients; and feelings of
helplessness when patients were dying. The caregivers appeared to be aware of the fact that the patients required love, care and emotional support and many of the caregivers went out of their way to provide this, but with consequences to themselves, emotionally, physically and spiritually. There is a strong feeling of helplessness in the face of this dramatic disease, which the caregivers described, wishing that they could do more for their patients, knowing they could not and feeling frustrated because of this.

In Sub-theme two the differences in death and dying for adults as opposed to children was discussed, with the emphasis on the caregivers’ distress at having to watch babies and children suffer and die. No matter how emotionally mature the caregivers were or how long they had worked at the institution, and therefore supposedly became ‘used to’ the death and dying, the death of children was undoubtedly a very traumatic experience which evoked reactions and emotions that many participants had never experienced before. All participants agreed that the hardest part of this job was the death of children, and voiced the need to come to terms with this aspect, develop coping skills and establish support systems, namely colleagues, family, friends and the Christian faith. On a negative level, many of the caregivers attempted to avoid bonding with babies and children once they have had to deal with the death of little ones, due to the pain that grief caused, and tried to blunt themselves emotionally so as to avoid repetition of this grief. The other aspect covered in this theme was the feeling that adults played a role in acquiring this disease whereas children were innocent and had the disease passed on to them by adults; yet there was still compassion towards the adults, which was voiced by most of the caregivers, combined with feelings of anger that this disease continued to spread.

In Sub-theme three the participants’ rationalisation of death was discussed, with caregivers differing in their understanding of death and what happened to the person when they died. Included in this theme was the description of death as God’s will, that some caregivers found death fascinating or intriguing, and that caregivers considered their experiences of working with patients dying of AIDS as enabling them to grow emotionally and spiritually. The caregivers definitely found comfort in the concept of death being God’s will, and “if it is your time to go, you go” rationale. This made it easier to accept the death of young people, as well as children and babies. Some appeared to find death fascinating or intriguing, but this could be a form of rationalisation and a way of coping with death, namely, focusing on the physical
aspects instead of the emotional, thus helping the grief process in themselves by
intellectualising the death in order to avoid the associated feelings. Putting up
emotional barriers in this way is not considered negative, but rather a positive way of
allowing the person to continue to function, rather than becoming so emotionally
overwhelmed from the pain evoked by repeated contact with dying patients that
caregivers would become unable to continue with their work, as mentioned in chapter
three.

In Sub-theme 4 the participants’ feeling that faith in God gave them strength to
cope with death and dying was discussed, which incorporated the feeling that
God provided hope and faith, that caregivers experienced death as a reality of
life, as well as their experience that prayer provided an integral measure of
strength. Mostly this was a positive feeling, that when in doubt, the caregivers
prayed, and prayer was cited as being used at all times in all places. The
negative component of this sub-theme was the expressed helplessness and
hopelessness the caregivers experienced as they watched the suffering of
their patients, which was indicative of spiritual pain. In some respects it
appeared as though the caregivers were hopeful that prayer would help them,
and they believed it would, and yet as the hopeless feelings persisted they
questioned, and wondered. As stated in chapter three, bereavement remains
one of life’s greatest stresses and constant bereavement increases that stress
incrementally. The caregivers appeared to require help and support to deal
with this stress, as signified by the quotes in chapter three.

In Sub-theme five the participants’ experiences that caring for patients was fulfilling
and comforting despite the sadness of death and dying was highlighted. The
negative aspect of dealing with constant death and dying was the despondency
which resulted from the fact that 95% of the adult patients admitted would die in the
following months, increasing stress levels and the potential for caregiver burnout. On
a positive side, the caregivers did acknowledge personal growth, linked particularly to
being in the unique position of helping another person at a time of great need.
Feeling useful and needed appeared to enhance the self-esteem of most of the
caregivers, although constantly giving of themselves without receiving something
back equally appeared to be draining on them, a factor which was noticeable in the
fact that so many of the participants complained about the workload, linked to feeling
tired and stressed.
From the researcher’s experience, based on the data as well as the fieldnotes, and as highlighted by the participants through the depicted central and sub-themes, the above-mentioned aspects related to the caregivers’ experiences, are prevalent. The study was undertaken to reflect on and to understand the lived experiences of caregivers who are caring for patients dying of AIDS, as well as to determine how they can be assisted in order to develop broad guidelines to enhance support for these workers.

4.3 BROAD GUIDELINES THAT WOULD ENABLE MENTORS OF THE CAREGIVERS TO PROVIDE SUPPORT TO THE CAREGIVERS, SO THAT THEY CAN OPTIMISE NURSING CARE OF PATIENTS DYING OF AIDS.

By describing the lived experiences of caregivers based on the research interviews the researcher could paint a clear picture of the palliative care environment for patients dying of AIDS. The caregivers functioning in this world painted the picture, as it was their voices that were heard in this study. This is a unique world, inhabited by unique people with unique characteristics and needs.

Since this study focuses on the caregivers who are dealing with death and dying of terminal AIDS patients, the proposed guidelines are aimed at improving their life-world. The guidelines are based on:
- information gathered through the interviews
- relevant literature
- the experience of the researcher, based on the research data and field notes and
- discussions with relevant experts familiar with this context.

Broad guidelines that would enable mentors of the caregivers to provide support to the caregivers, so that they can optimise nursing care for patients dying of AIDS, centre on the fostering of a work environment conducive to the caregivers’ needs. The guidelines will focus on the physical and supportive working environment of caregivers in a palliative care setting. These guidelines represent broad and general thoughts around which a refined and
specific support programme for caregivers should be developed. It is important that this particular organisation creates the opportunity for ongoing support and that caregivers are given the time to attend support sessions. This may consist of support through team meetings, access to counsellors, the opportunity to debrief after incidents and access to in-service training (Ferryl & Coyle, 2001:657). Table 4.1 presents a summary of the guidelines, in tabular form.
Table 4.1  **Broad Guidelines that will enable mentors of the caregivers to provide support to the caregivers, to enable them to optimise nursing care for their patients dying of AIDS**

<table>
<thead>
<tr>
<th>Principle guidelines</th>
<th>Sub-guidelines</th>
</tr>
</thead>
</table>
| 1. Create a work environment conducive to being supportive to the caregivers          | 1.1 *Create a physical environment conducive to optimal palliative care.*  
   i. Provide an exclusive restroom as a place of safety and silence for use by the caregivers.  
   1.2 *Create a supportive occupational environment conducive to enabling the caregivers to provide optimal palliative care for their patients.*  
   i. Enhance and facilitate understanding, insight and empathic support from management.  
   ii. Institute 3-monthly counselling/debriefing sessions.  
   iii. Ensure that caregivers are kept updated regarding patient treatment and prognosis.  
   1.3 *Create an educational environment to enable the caregivers to provide optimal care for their patients who are dying of AIDS.*  
   i. Provide in-service training for the caregivers.  
   ii. Develop a library in the ward.                                                                                                                                                                                                                                           |
| 2. Identify and enhance areas where care for caregivers can be instituted which could help to prevent caregiver fatigue/burnout | 2.1 Description of caregiver fatigue/burnout.  
  2.2 Strategies for preventing burnout and promoting self-care.                                                                                                           |

In the next section the principal guidelines will be described using the format of naming the guidelines, the rationale for them and the operational implications or actions pertaining to each guideline.
4.3.1 PRINCIPAL GUIDELINE 1: CREATE A WORK ENVIRONMENT CONDUCIVE TO BEING SUPPORTIVE TO THE CAREGIVERS

In order for caregivers to be able to provide optimal nursing care to their patients who are dying of AIDS, it is necessary to create a working environment that is conducive to rendering such optimal nursing care.

4.3.1.1 Create a physical environment conducive to optimal palliative care.

A physical work environment that lacks comfort and safety will not enhance work performance or general feelings of well-being. It is also assumed that, in instances where the job environment does not incorporate access to necessary and acceptable interpersonal contact (in other words, time to interact with co-workers in a meaningful way), emotional and mental health are likely to be compromised, which in turn affects the physical health of the caregivers (WHO, 1993:7).

i. Provide an exclusive restroom as a place of safety and silence for use by the caregivers.

Rationale:

- The caregivers in this facility currently share the patients' dining room or the patients' lounge area, which means that they do not have a private place to sit and chat or be peaceful. At most break times there are patients and their visitors sharing these facilities and/or children and babies. The caregivers are therefore not given the time to 'switch off', or rest adequately in order to 'recharge', which would enable them to carry on with their tasks in a positive manner.
- Staff working in palliative care settings with dying patients have a strong need for a rest place that encourages safety and quietness (Hector & Whitfield, 1982:103).
Operational implications:

- Obtain staff input to assess specific needs regarding a restroom
- Ensure that the restroom is for the exclusive use of the caregivers
- Ensure that it is as private and quiet as possible
- Have it decorated and equipped by means of a staff project

4.3.1.2 Create a supportive environment conducive to enabling the caregivers to provide optimal palliative care for their patients.

Creating a supportive and healthy work environment contributes to the well-being of employees, while at the same time contributing to the development of skills and attributes which are essential for personal and professional optimalisation (Gerber, Nel & van Dyk, 1987:101).

i. Enhance and facilitate understanding, insight and empathic support from management

Rationale:

- It is essential to provide the management board with insight into the unique dynamics of a palliative care unit, specialising in the care of patients dying of AIDS.
- Presentations to the management board regarding the needs of the caregivers would gradually lead to an insight into the needs of those caring for patients who are dying of AIDS.
- Deepened understanding would hopefully lead to improved working conditions and incentives for the staff, which could result in a decrease in caregiver stress levels.
- Meeting between staff and management should help to prevent the build-up of negative emotions and misunderstandings.
- The value of peer support in reducing occupational stress has been documented in literature (Gerber, et al, 1987:114-116).
Operational implications:

- Arrange for a member of the management board to be present at the monthly staff meeting. By working on a rotational basis, with each board member taking a turn, it should be possible to accommodate both board members and staff.
- Plan monthly meeting dates on a rotational basis to accommodate both shifts.
- Ensure that there is an agenda, prepared timeously, for each meeting, and that all concerns from staff members are added to the agenda. A notice board or issue-box could be utilised where topics to be discussed can be proposed anonymously before meetings.
- Establish a time frame for the meeting long enough to ensure that all members have time to voice their feelings adequately, but not so drawn out that staff are away from their work duties too long, to the detriment of the service to the patients.
- After the meeting with management, staff could meet on their own for another 20 minutes to deal with their own ‘housekeeping’-type matters.
- Encourage open sharing of feelings at all meetings, ensuring no risk of repercussions for any staff member.
- Organise a really comprehensive workshop or advocacy group on a quarterly basis.

ii. Institute 3-monthly counselling/debriefing sessions

Rationale:

- Caregivers will feel really free to open up with an ‘outside’ counsellor
- There is increased confidentiality when the counsellor is not an employee of the institution
- Regular debriefing prevents build-up of negative emotions that could lead to burnout (O’Neill & McKinney, 2003; Prabha, et al, 2004; Smit, 2003)
Operational implications:

- Negotiate with the management board to acquire the services of an ‘outside’ psychologist or counsellor.
- Organise adequate time for staff to consult with the counselor, for instance, just before or after hand-over, to accommodate day and night shifts.
- Encourage members of other shifts to attend these sessions by stressing the therapeutic benefits thereof.
- Hold these meetings on alternative shifts every time so that all staff are required to attend, bi-monthly, on their day off.
- Experiment with levels of openness in mixed versus category-specific meetings, in other words the caregivers need to be able to vocalise their thoughts and ideas honestly and with confidence when senior management are present.

iii. Ensure that caregivers are kept updated regarding patient treatment and prognosis

Rationale:

- Because of close relationships, patients often feel freer to put questions to the caregivers, rather than to the Registered Nurses.
- Adequate information is necessary for the caregiver to feel safe in her life-world of caring for patients dying of AIDS (compare Kotze, 1998:6).
- The more information caregivers have about this disease and the particular diagnosis of each patient, the easier it will be for them to answer questions raised by the patient and family which would serve to enhance their trust relationship.
- The Registered Nurses may make decisions regarding patient care, but by sharing this information with the caregivers, ensuring that it is transferred so that the caregivers can understand it, will ensure that the caregivers have the confidence that they need to nurse their patients optimally.
Operational implications:

- Establish a system of keeping a confidential file with information on every patient.
- Have the registered nurse on duty keep the patient’s records up to date, adding all new information following visits of the doctor, social worker and a record of attendance of patients at clinics and hospitals; and communicate this information to all staff.
- Keep all information updated in a structured manner, and use a standardised format, which should be communicated to all staff members.
- Communicate new treatments for patients to staff members, and exactly how these treatments should be administered to ensure consistency and effectiveness of the treatment regimen.

4.3.1.3 Create an educational environment to enable the caregivers to provide optimal care for their patients who are dying of AIDS

Education refers to activities aimed at developing knowledge, moral values and understanding. Its purpose is to develop people intellectually and provide them with a basis for further learning. Education is considered to be basic knowledge rather than applied skills; is required in all walks of life; and is of value throughout life (Gerber, et al, 1998:184).

i. Provide in-service education for the caregivers

Rationale:

- The caregivers and nurses require regular updating regarding HIV/AIDS and new treatment regimens.
- In-service education ensures that the employees function efficiently through the increase in their knowledge base (Mellish, 1985:174).
- In-service education assists the employer’s needs by upgrading quality of care, prevention of medico-legal hazards and allowing for the introduction of new methods (Mellish, 1985:174-175).
Operational implications:

- Institute monthly in-service education for both shifts.
- Registered Nurses can take turns to present a relevant topic, for example: side effects of Anti-retroviral drugs, details about skin conditions specific to AIDS and so on.
- ‘Outside’ speakers can be arranged for specialised subjects and to ensure that the staff’s educational needs are met.
- Topics can be chosen by the staff themselves, who can place suggestions on the notice board or give them to the registered nurse in charge of the shift.
- Management could add topics related to observed needs or apparent gaps in knowledge.

ii. Develop a library in the ward

Rationale:

- Availability of educational material in the ward encourages personal responsibility for self-development.
- Treatment regimes in HIV/AIDS are changing rapidly as the disease evolves, and it is important to be aware of new symptoms plus the suggested treatment.
- Availability of resources encourages the Registered Nurses to assist caregivers in learning, which will have the added benefit of improving nursing care through increased knowledge.

Operational implications:

- Books and articles on:
  - Disease signs and symptoms
  - Treatment modalities, including Department of Health booklets
Appoint a staff member to be responsible for updating the library with new articles and treatment regimes.

4.3.2 PRINCIPAL GUIDELINE 2: IDENTIFY AND ENHANCE AREAS WHERE SUPPORT FOR CAREGIVERS CAN BE INSTITUTED, WHICH COULD HELP TO PREVENT CAREGIVER FATIGUE/BURNOUT

Most participants in this study felt that they were ‘called’ to nurse patients with AIDS, which meant that they were, for the most part, comfortable with their chosen field of work. Owing to a strong religious affiliation in most participants, and the fact that the facility itself is supported by a church in Port Elizabeth, there is an underlying faith-based component, which appears to provide considerable support to the caregivers. The fact that many of the participants in this study voiced their need for someone to talk to, and especially the need for debriefing, is evidence that adequate support has not been provided. During the interviews, it became clear to the fieldworker that many of the participants were struggling to come to terms with:

- death and dying, and how it made them feel;
- the type of suffering prior to death that their patients had to endure;
- the fact that such young people and children were dying;
- the number of deaths that the caregivers had to cope with weekly;
- the stigma surrounding HIV/AIDS and how this affected the caregivers;
- the anger that these caregivers felt towards the adult patients who they thought should have tried to avoid contracting this disease, and
• feeling ‘worn out’ and tired but not being sure why they felt this way.

4.3.2.1 Description of Caregiver fatigue/burnout

Rationale:

q Conflicts regarding terminal illness and death must be recognised in order to enlarge caregivers’ capacity to care adequately for their patients and enable them to express empathy and compassion (O’Neill & McKinney, 2003:5).

Operational implications:

q Ensure that the management board is made aware of the consequences of caregiver burden.
q Educate the caregivers and other staff categories about the causes of caregiver burden.
q Causes of caregiver burden are:
  ° fear of exposure to HIV;
  ° lack of support from friends and family due to concerns about contagion;
  ° stigma by association;
  ° emotional distress at not being able to ‘cure’ the disease;
  ° repeated exposure to the death of young patients;
  ° having to be supportive to informal caregivers and family members of their patients and
  ° workplace-related stressors, such as work overload, unrealistic expectations of what can be accomplished, communication problems, role conflicts, inadequate medical resources and referral arrangements (O’Neill & Mckinney, 2003:5).

q Consequences of caregiver burden include:
little time left or energy for self-care; and
° being prone to high levels of chronic stress, which the literature divides into two types of stress, namely primary and secondary stressors:-

- Primary stressors arise from the actual tasks of caregiving and include:
  - number and intensity of caregiving activities
  - role overload and
  - sense of being coerced into caregiving due to needing work/money

- Secondary stressors are influenced by the caregiving role and include:
  - exacerbation of family conflicts, which often increases friction at work due to transference of emotions and
  - reduction of social contacts owing to work demands, and due to fear on the part of friends and family that the caregiver is a ‘carrier’ of AIDS, as mentioned above (O’Neill & McKinney, 2003:5)

Management and staff members need to be informed as to what burnout actually is and the signs and symptoms of caregiver burnout:

° The term “burnout” is used to describe the process in which everyday stressors that are not addressed gradually undermine caregivers’ mental and physical health. Finding rewards in caregiving does not necessarily make these activities less stressful; and a high degree of involvement, whether positive or negative, can produce stress (O’Neill & Mckinney, 2003:6). Burnout is defined in terms of three components:
  - emotional exhaustion, which represents the basic stress dimension of burnout;
  - depersonalisation, which represents the interpersonal dimension of burnout; and manifests as cynicism, apathy, withdrawal and detachment; and
  - reduced personal accomplishment, which is evident in decreased efficiency at work, difficulty concentrating and increased irritation with colleagues (O’Neill & McKinney, 2003:6).
4.3.2.2 Strategies for preventing burnout and promoting self-care

Rationale:

The literature on caregiving describes a wide variety of strategies for preventing and managing burnout. Most of these strategies focus on ways of managing the caregiving situation, rather than on eliminating or reducing stressors in the caregiving environment. Caregivers should rather re-evaluate caregiving demands and resources, clarify values and priorities and adopt coping strategies that match the nature of the stressors in order to provide optimal care for their patients.

Operational implications:

O’Neill & Mckinney (2003:9-10) mention various approaches to counteract burnout and promote self-care, which will be mentioned here as a way of implementing coping strategies:

° Use problem-focused strategies to cope with stress, which include gathering information, planning and taking direct action. This is preferable to using emotion-based strategies which include efforts to avoid problems, emotional outbursts and self-accusation;

° Change caregiving patterns – Caregivers may get so involved with their work that they lose perspective and burn out quickly. Caregiver patterns can be changed by breaking down tasks into small acts of care; learning how to adjust the pace of caregiving; asking others to help with caregiving tasks; encouraging the care recipient/patient to help with tasks and to continue self-care for as long as possible.

° Adopt relaxation techniques – these include yoga, exercising, going for a walk, reading a book, and having a bath. Include visualization in these chosen activities, imagining a scene of beauty and tranquility. Having a ten-minute worry break is also therapeutic, the idea being to consolidate all worries into this period and then set them aside until the next day.
° Strive for good health – which involves eating three balanced meals a day, having regular physical activity, sleeping 7-9 hours per day and developing a spiritual focus. All are beneficial and improve the person’s ability to avoid burnout.

° Maintain a life outside of the caregiving role: – a response to stress is often an over-involvement in work and caregiving, which then leads to neglect of friends and family. Caregivers need to be encouraged to maintain hobbies and take regular breaks.

° Build a support network: – social resources can provide emotional comfort, practical support, reduce social isolation and be an encouragement. Caregiver support groups are a useful resource enabling caregivers to share their feelings and experiences and learn from one another.

° Set realistic work targets for all caregivers.

° Request training on HIV management, and effective ways to communicate with patients and family members

° Allow caregivers to attend memorial services of patients that they have bonded with, and allow them to grieve for these patients.

° Ensure regular time off for caregivers and appropriate rewards to encourage them in their work.

° Minimise conflict in the work-place, which could be achieved by scheduling regular forums for case discussions, so that caregivers could share approaches to care and receive support in eliminating stressors, and in this way build team spirit, and genuine caring for one another.

4.3 LIMITATIONS OF THE STUDY

As with all qualitative studies, it is recognised that the sample size and specific nature of the sample and research context prohibit generalisations. However, the richness of data provided an abundance of insight into the experiential world of these caregivers. The envisaged benefits of a phenomenological approach were, therefore, achieved.
Specific limitations that are acknowledged are:

- Interviews were conducted in one palliative care facility only. The study does not include experiences of caregivers in out-patient settings such as clinics, home-based care groups, hospice settings or state hospitals
- Although confidentiality was ensured as far as possible, the fact that only one facility was involved could impair anonymity, leading to participants being careful and even inhibited when sharing experiences. This did not appear to occur in this research study.

4.4 RECOMMENDATIONS

In the light of the research findings, and indicated limitations, the following recommendations for nursing practice, education and research were formulated:

4.5.1 Recommendations For Nursing Practice

- The broad guidelines need to be made available to all hospitals, clinics and hospice home based caregivers
- Management of institutions where patients with AIDS are being cared for need to be sensitised regarding the unique needs and challenges for caregivers within the field of HIV/AIDS, to enable them to recognise it as a specialisation area with scarce skills
- Guidelines need to be refined to develop a detailed support programme for caregivers working in the HIV/AIDS field.

4.5.2 Recommendations For Nursing Education

- In-service education courses and workshops need to be developed to enhance the life-skills of caregivers working with patients who are dying of AIDS. Palliative care is a specialised field, where research into the effects of working with terminally ill patients is current and ongoing. It is clear that anyone working in this field requires specific skills to cope with the arduous task of dealing with the death of their patients and then to be able to support the family and friends left behind. This is difficult enough
in Oncology wards; but in areas where HIV/AIDS patients are being cared for it is even more so, due to the rapidity with which the patients are dying, and the number of patients succumbing to this disease. Education, therefore, is crucial, to enable caregivers to be empowered physically, emotionally and spiritually to cope with the death and dying of their patients.

4.5.3 Recommendations For Nursing Research

- A questionnaire, based on the themes identified in the interviews, could be developed for use in a quantitative study, thereby testing the generality of the research findings of this study.
- A model for explaining and predicting job satisfaction in HIV/AIDS nursing needs to be developed.
- A model for predicting stress-response and coping mechanism in caregivers working with patients who are dying of AIDS needs to be developed.

4.6 CONCLUSION

The study provided evidence that the field of HIV/AIDS, and the caregivers working with patients dying of AIDS, is unique and differs in many respects from other areas of nursing/caregiving. Very little understanding of this uniqueness exists outside this field.

Understanding the necessity to support, retain and recruit caregivers was enhanced by this study; but much still needs to be done, specifically to address the unique needs of the caregivers working in this field.

Finally, the researcher would like to conclude this study with a simple quote from one of the participants:

“It is nice to work here, except that the people die”. 
BIBLIOGRAPHY


Goldblum, P. and Erickson, S. 1999. Working with Aids bereavement: A comprehensive approach for mental health providers. Retrieved on 4 October


ANNEXURE A

LETTER REQUESTING CONSENT FROM MANAGEMENT OF INSTITUTION.
The Chairperson  
Executive Committee  
The House of Resurrection Haven (AIDS Haven)  
83 Adams Street  
Salsoneville  
6058

Dear Madam,

Regarding Interviews for research

I am a student at Nelson Mandela Metropolitan University and I am currently enrolled to complete a treatise as part of a Masters Degree in Primary Health Care.

The title of the treatise is “The experiences of caregivers in formal institutions caring for patients with AIDS.”

I hereby request you permission to interview staff members at your institution for the purposes of completing the abovementioned research topic.

I will explain the requirements to all participants, and they may decide for themselves whether or not they wish to participate, there is no obligation to assist with this research.

Your permission to work with the staff at your institution will be greatly appreciated.

Thanking you in anticipation.

M. WILLIAMS
ANNEXURE B

CONSENT FORM FOR PARTICIPANTS
**CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** The experiences of caregivers in formal institutions caring for terminal AIDS patients

**REFERENCE NUMBER:** 202343812

**PRINCIPAL INVESTIGATOR:** Margaret Williams

**ADDRESS:**
12 Aliwal Street
Tulbach
Port Elizabeth
6025.

**CONTACT TELEPHONE NUMBER:** 041-3607114 (H) 0845105789 (Cell)

**UNIVERSITY OF REGISTRATION:** Nelson Mandela Metropolitan University

---

**Declaration by or on Behalf of Participant**

I, THE UNDERSIGNED ………………………………………………….(Name)

(Identity Number: ………………………………..) Participant.

(Address :) …………………………………………………

……………………………………………………………………

……………………………………………………………………

A. Hereby Confirms as follows:

I, I was invited to participate in the above mentioned research project, which is being undertaken by Margaret Williams at The Department of Nursing Science in the faculty of Health Science at Nelson Mandela Metropolitan University.

2. The following aspects have been explained to me, the participant. Initial

| 2.1 Aim: To explore and describe the experiences of caregivers, in formal institutions, caring for patients with AIDS. To develop guidelines which will educated and support caregivers, enabling them to optimize nursing care for patients dying from AIDS. Initial |
| 2.2 Possible risks: I will not be exposed to any form of risk or harm. Initial |
2.3 Possible benefits: As a result of my participation new insights might be gained regarding the experiences of caregivers in nursing patients with AIDS.

2.4 Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigator.

2.5 Access to findings: Any new information/or benefit that develops during the course of study will be shared with me.

2.6 Voluntary Participation: My decision whether or not to participate will in no way affect my present or future working relationship with the researcher.

3. The information above was explained to me the participant by Margaret Williams in Afrikaans/English/Xhosa/Other ……………………………
…………………………………………………………………………………………
by ……………………………………………… (Name of translator)

I was given the opportunity to ask questions and all these questions were answered satisfactorily.

4. No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalization.

5. Participation in this study will not result in any additional cost to me or my place of employment.

B. I hereby consent voluntarily to participate in the abovementioned project.

Signed/ confirmed at …………………………………………… … (place)
on ………………… 20….
(date)
………………………………………… ………………………
Signature of consenting ………………………
Participant……………………………… Signature of Witness
ANNEXURE C

CONSENT FROM FACULTY OF HEALTH SCIENCES
ANNEXURE D

TRANSCRIPTION OF INTERVIEW
The Experiences of Caregivers in Institutions Caring for Patient with AIDS Interview with

Caregiver = Respondent two on the 2nd November 2005

Student: M. Williams

I = Interviewer
R = Respondent

I: How long have you been working here now

R: I now here, a couple of months started here the 1st June 2004.

I: Enjoying it?

R: A pleasure a beautiful place, ja. Sometime the place do get rough for you but you get through it, you get through it.

I: What best part about working here?

R: The best part about working here is to see some patients do improve, so patients don't. So patients do get discharge, some don't. The wellness management here, the nursing care here is excellent. Although some people don't see it but really like if I take the bedridden patients no bedsores or bed wounds are under our care. Even the children is well. With 24-hour care, no injury nothing or no breaking of bones, no emergency medical nothing of that, the medical care is excellent here. The food that the patients do get it is well prepared although the patients won't like sometimes won't like the food where my chicken, where my fish and stuff like that but really the food is well prepared. The staff does it well. The hygiene of the place is quite well so you know. The staff sometimes you know you do get a lot of stuff sometimes you don't get a lot stuff that mortal thing. The friendliness around this place, sometimes you get your up- and downs but you do get through it.

I: Mm, OK. Generally it very positive.

R: Exactly it very positive, if you feel like it negative but then you have to search within yourself You have to look deep into yourself are this place really negative or is the negatively here. Even starting from The Matron right through to the last carer here. It really reasonable, even the night duty here as well it very comfortable, no serious stuff that that worming or emergency midnight procedures Fourteen days and working hours it quite nice. The money is quite good because it comes from awarded situation a instituted like, the Diocesan whatever. And the funding what they do here, how they proposal for money it just extras you know. Ja, great guy provides. Ja.

I: Ja. Cool. How much death have you see since you been here?

R: You, know I can't even take, I can't even even starting to record. When I started working in June. I started go through eight deaths, you know. End of 2004 December I started running eighteen. The children was five which I can record but in 2005 it like I can't keep record. But some patients do die at hospital when they get transfer and stuff like that. (Caregiver sneezes) Excuse me?

I: Bless you. As you were saying?

R: As I was saying, really the deaths that I went through like it hardened me, I had to stand in front of patient, the patient passed away and you have to prepare it for the undertakers and you just ag like to do this. So you slap you mind out of it ag, you imagine yourself that it not a death person, you just working like you do or something and you just get over it. With the children really um starting with Sombili. He was, death quite amazingly just giving the high five whole the day and suddenly the child passed away. Even Thando, her death was also traumatic for me. Kahili the one with the invention tube the feeding tube it was quite, you know. From nursing the child and loving the child it was just something that you just need to tell
yourself that the child has passed away. There nothing that you can do. You can't take the Lord's - work out his hand, you have to go on with life. You know. The mother that so young and also HIV positive and it even hard for her as well. The realizing that the child actually passed away. There was something that we did it positive health care that we gave her and there was no negativity in it. On the long run, you really think that sometimes you wish can change the clock. Why HIV started? Why can it stop but you can't ask those questions because it all the Lord's hand. You must just tell yourself. One day, one day, it going that it going to stop eventually. But who knows when. Really the new staff that were appointed here after me, really I got well along with them. And they even ask me "Craig where did you work before?" I said "Grand Bazaar, Mothwa Haven, Mercantile, I done clerk a lot of private patients and where I went it was also with a positive mind. I never went with the negatively, even if you come into this place. On the they won't look so well to you, just need to you if my workplace I need to get on with it and when the day ends just debrief yourself to where did I went wrong, what was it that I did do, is there something that I come nave done better, did I go that extra mile, you know, as a young person like me I do stay on the premises. There are witty gritty things that I like to do, like popping in here and um just checking ag there a hand that I can give. Like, watering the garden last night. It was fun for me. Not only doing it for patients but keeping this establishment in place, you know. And really that goes alongs with your reference one day if you must leave this place or you go somewhere else, you can with a positive thought and mind and tell them. Listen is the House of Resurrection Haven, this is The AIDS Haven, this is where I worked, this people with whom I worked and the patients whom I cared for while there. It really a marvellous place, really. Home of positive living, as it says.

I: What the hardest part of working here?

R: You know the hardest part of working here, is coping with the workload that is being set out for you. Sometimes, you know, sometimes you system is off, like you don't well or then you have to pull through and it when there a little problem that needs to be solve. You know that you done wrong and yet you want to co rectify yourself and the people around you will always put a negative thought or point at you. But really, like when you start the day and something not right or you forgot the following day to what for the night staff or leave something. You know, and and they ask you "Why didn't you do this?" This is what the hardest part for me because you knew that you could of done it but yet you didn't do it. You know. And the hardest part is when you done something and need to come in and be asked why did you do it, why did, you know that is the hardest part. Because who wants to be called in for disciplinary and stuff Eke that. You know, my philology in life is helping people help people, really. So. When you help a person, you must only know that you are helping for that specific reasons but you his scriptural need and emotional need as well. You know. There a lot of patients that comes heres with a social problems, like for instances I really got- deep friend ah with one of the patients here and I thought to myself listen here you did not set your boundaries walls. And that the most difficult part and and as a male nurse and you don't set you boundaries walls and this person comes to you and tell you. Listen here about my family this one did that, this one did that and you as a non social worker can't do the work of a social worker, you don't have the guts to tell the person but I am not a social worker. You have to tell him you are sorry here a shoulder lean on me but yet you must not take his. But you must have listening skills as well and when he talks to you, you must actually reflect back. He must be like a mirror for him because he must listen to his own words and solve his own problems. You know. This is the most difficult part. Sometimes the patients feel like crying inside, they miss their relatives so their priest must come in. You know. That also the because here a health care worker. You have to step in that a spiritual need that patient wants now and you know, it from guidance of from above that you need to ask the Lord. Give me that strength to actually counsel this patient spiritual. Open your bible, read your favourite text or pray for him. You know. But sometimes the patients doesn't want that, they want actually the relatives or priest or father, whatever. Wants to be next to him, you know. The most difficult part is when they know know when they going pass away and yet then that last minute when they call for help. You know, it like your hands have been chopped off. You don't know how to go further now, you know that the most difficult part. So (silence)

I: You were saying that a couple of children early, that there deaths were pretty hard for you?

R: Ja, it was pretty hard for me, as a youngest to know that one day that must have children and who knows they can also be positive or negative or disabled. You know Denver Witbooi, that in the wheelchair the little boy, you know, I give more attention to him as the others, you
know. Not for reasons, I favour him, it because that he specially that, he feels that like does has legs, he want to use them but he can't you know. That the most difficult part in now day the child you tell him sorry Denver but you remain in your wheelchair but yet he will know that he does has legs. He can still move them around, he won't understand why he can't, you know. For a five year child it really difficult and you as adult to help to him. That doesn't have children have children yet, it quite amazing, ja (long silence)

I: What was hardest thing about the death of the children here?

R: You know thing about the death of children here, was when nursing to when you know this child is going to past away. You actually see death in their eyes, you know like Thando, she was quite frighten. She was screaming, she was crying it was like you don't know what do you want to grab the thing from her and actually keep it in your hand but you can't. And at that moment in that in the few moments then the child pass away. It like the child stares in your eyes. When you held him your arms and you look at him it direct staring in your eyes and you know that you can't do - anything because the child needs to go now. And at the moment that the child pass away that like standing in that room everything freeze next to you and it just that - moment that this child as actually pass away now. Were there something that I could to prevent it, you know, it feels like that. Why must the patient the dies and why must the little children go, you know, even though in the bible the Lord said " Do not prevent the children to come me" but yet I know it his prophet and we were only borrow on earth and the lives were set for them like that. But I look at the children in the nursery that are well, like Kwanale, Nelson when their walk around. I really image myself. I just see these children like social workers, doctors, psychiatrists, you know nurses, whatever. But will their achieve that age yet. Who know? You know. It really, (sigh) for me to break through.

I: Have you even been with any of the adults, when they passed away?

R: Yes. I been with a few. Standing next to their beds, nursing them for the last time. You know, the adults it really other way of death, when their die it like grasping and their breaths you know. : You just sit next to them and they like. Like Thelma Kramer, when she passed away it like she knew that her time has come. She knew that she could feel that really, I am going now. And she was frighten to go, she was screaming, she was crying, she was moaning and we just need to calm herself and that she goes in peace. When she passed away it was like, very quiet next to her you know, that moment she always they all they look at you they grasp off. It like something amazing see it. How a patient actually pass away. That you knew that ok the patient has gone, the virus has done he work wants to achieve but life must go on. You know.

I: Anything else you wanted to say about that?

R: And even the relatives, when they when we phone them or inform them that the patient's health didn't look like this. It like, next to or even you phone them sorry but you relative has passed away that screaming, moaning and crying over the phone. And just say sorry but you know, you know how the emotions of the relatives on that side of the phone. You know, I had one patient when I started here, I have to phone the relatives and tell sorry that the patient had pass away and that women went ballistic. She screamed in my ears and she banged the phone. And I was sitting with the phone and I sorry ma but she has passed away. But you are lying and the women denied. I said you come in a have look the body is still with us, before the undertaker and she actually came in. And when she came, the undertaker the just went pass her with the bakkie. And she said that was the undertaker now she realises she wants to she want to, seeing is believing she said. She could not believe that when I told her that her child had passed away. It was the hardest thing for that and we on this side you don't know how was if the patient had a social problem. Though the patient pass away you don't even how will they buried that person. Will it be in a dignified manner? Will they be ag they had HIV it passed away. What must we do? It things like that. Like for instance Samantha when she passed away that day the family actually the stepmother the father actually argue in the passage while the body was on the way to the to the undertakers and she knew that the child had passed away. Because there was also social problems like there was actually she didn't have no emotion what so ever, even the father as well no emotions and you know you just ask yourself how is this child going to be buried. For a twenty-one year old who didn't have a future, how is she going to be buried in a dignified manner or undignified manner, you know that the question you ask yourself. And I always tell myself if I must win the Lotto. To extend this place really I should I will really donate money to
I: Are you afraid of dying?

R: You at know mm at first yes, but as life goes on I just told myself that if I have to die, I have to die. The Lord knows why, we don't know, our life have not been set by ourselves but only by him. Who knows will be able to reach thirty-one day. Will I be able to have children, one day, you know, you don't know even I can just walk out of this office and I collapse and pass away, you know. Things like that, so being scared of dying really you need to search yourself deeply and ask why you actually scared of dying. How was your life on earth? Did you actually do what the Lord wants you to do? Did you fulfill his commands that he set out for you? You know, because that a person scared of dying I really think that the Devil is really running next to you. You know, the negatively in your body. You know, brain is overwhelmed with negatively that I think that why a patient person will be scared of dying because you are running walking with negative thoughts. Everything in life is negative that how you will die negative. You know. But (silence)

I: Is there a specific event or any specific that has changed your mind?

R: You know, when I started work, I started work here mm (silence) At night when I was appointed here through nursing services. When I started working it was my first time with direct HIV patients because I come from Greenacres hospital and it was just something that something told me Craig you are in a place where you mindset is really going to change drastically. You'll maturity going to change drastically. You going to see things in reality, you know and when I started working here my mindset wow this is reality that I am standing here I never knew because I was outside reality, you know. Now I am inside reality some of my ex colleagues I do tell them. Mm, other hospitals like the private hospitals you don't stand in reality you have to be in reality to accept the things that you cannot change. You know, that the how it works, you know change. And if I if I would become HIV positive or AIDS whatever you know as I told you before my life has been set out by our reverend father. He knew why, he knew when and he knew how long its going to be, you know, for me as a nurse, if a person come to me claiming "I'm HIV+", you know at that moment, you just stare at him. You don't know if you must say "I am sorry", because these words you can't actually change you know. He has been diagnosed with HIV. You must just tell him positively. You must just tell him: "sorry but there's a life out there. It's not like you are locked in a wall of how many centimetres of bricks. Life is still going on. You can still go into jobs. You can still have a family. But you know, there is precautions following with that." You know, if a person comes in here and you say, freshly diagnosed with HIV/AIDS and sometimes they don't know how did they get it. Like for instance we have one patient when we admit him we asked him "do you know what is HIV?" He said "no". I asked him, "did you know that how do you receive it?" "No, I think from the leaves, from the grass." Because I think he was uneducated for being sick and didn't go to a health clinic or what ever. And I explained to him and he still didn't understand until later on; so, couple of months, when he was here weeks. When we asked him "Do you know how did you get it?" "Ja I think through women, you know." His mindset is also still negative. Although he has HIV, but he doesn't know that he's in reality yet, things like that, ja.

I: You mentioned earlier that, when you were talking about not being there for Thando and some of them, that once they had passed away you were thinking things like, "Could I have done anything more?" What are those things you were thinking you could have done?

R: You know, um, giving only for himself, like that specific child to involve your single. Loving the child singly, or not giving attention to other children, but only him, you know because he's the weakest. You only sit with him, you only nurse him, you know, stuff like that. You only feed him, you only love him, really it will be easy for you but actually difficult of dealing with the death, not really. After a child's death, I'm deep breathing quickly. I just need to tell myself the child has passed away. He's in safe arms where he is now. Because I mean, for a one year
old child will never ' know of what is HIV, so they are free. They are actually. And as for a
twelve year old child started being naughty and also doesn't know what naughty is actually.
That's quite, you know the age groups in a child's death, you know. Like now, there's this one
baby that passed away in the nursery. The day before I just told the carer that worked with
him. This child's not going to last. Something is just telling me that this child is not going to be
with us any more. The following morning when I walked in this child was gasping, you know.
And the education that they started receiving here of knowing how to look at a child and knew
that the child is going and the condition how the child is just improving, is just amazing.
Because I could have told the carer that sorry, but this man is... what we have done we have
done. You know. And that I could have dealt with, you know, because I knew. I told myself that
evening: Lord, you knew why you were taking that little boy now. Keep him safe. Guide his
mother where she is today. : Guide the father, the grandmother, you know, whoever, if they
are still... the mother is positive. Guide her safe, that she can also continue her future, if its in
your hands, not ours, you know. You just say that prayer at the time of death and then when
they died. The services that we give here for the children, you know, its deeply emotional. The
time you're sitting in the chapel and you look at the little white coffin and its like, wow. I am
already 24 and the Lord have really spared my life. It could have been me, you know, that
could have passed away, it could have been someone else. But we are, we have to be
thankful for him, the grace that he gives us.

I: Obviously your relationship with God is something that is important?

R: Exactly, exactly.

I: Do you have any other ways of coping?

R: You know, with the death, ... coping with the death... I am a very emotional person, but I
started becoming like death, is like, there's something that gets to me, I think. I can't walk away
from it. I have to face it. At first, before I started working here, I just hear a person passed away
then I start crying you know. But here it started changing, you know. If I see a patient passed
away, or if I go to a funeral, its like: It needs to happen. It's not like I don't have emotion. I do
have emotions, but I know, you know, it has educated me, really, that you need to pass away.
Its just how's life; the circle of life is. At first I need to ask, I like to ask myself "This person is
now actually passed away?" You don't see him. Its as if he moved from PE to Cape Town, you
know, I started doing that. As if the child has been transferred out of the Haven into other
home, you know. Its very easy, its like walking around with the mindset that the child has
passed 'away, shame; man. 1 am still heart-sore. • Like even, Marilyn, one of the silicone
sisters, she was now in Die Son. What they wrote there, she had a beautiful life, but yet her life
ended with HIV and AIDS, you know? She knew that she was HIV and AIDS, she had HIV, but
what did she do? None positive life she lived. She still continued with her negativity, you know.
Things like that and, um Then she came to us and she discharged back to hospital. It was like,
ag, when the sister phoned the family to ask how's her condition this auntie said: Its going
down. I just told myself she has to go. Her life has been set out in front of us; it's the end of her
life. The Lord knows why. Her family must also realize why. Life goes on. You know I only are
here for a few years or minutes on this Earth, who knows? Ja. If you reach eighty, you are
lucky, you are really lucky.

I: Anything else you want to say about death and dying?

R: You know, death and dying, its like... to educate a patient as well. When the patient needs
to be admitted here, you need to sit with that person and tell him that you are in reality now.
We don't know and you don't know how long you going to be with us. We need to explain to
them that there is going to be one day that they are going to pass away. Its not like they are
sick and its like Livingstone they are walking in, you know? Anything can happen. With HIV
and AIDS, anything can happen. You need to educate them, person, and have that person
also realise: Sorry, but I've stepped into reality now. Hello I'm really here. You know, we need
to tell that person. We have tell that person, strictly counsel them, you know. And tell him that
sorry this is reality. One day is the longest that you can depend on.

I: Have you ever received counselling for...

R: No, I haven't yet, I haven't yet. The only time when I received counselling was from the
sister's husband that's a pastor. Spiritual counselling, I went for spiritual counselling because I
really felt like my spiritual need is now lying on the rock and I just explained to him its not like I'm discouraged, but when I go to church, its like: Why am I still sitting here? You know, it's those type of things, and: Why doesn't the Lord take me, quickly? Why do I still need to face these people and stuff like that, you know? You just ask the Lord: Why, why, why? And that's why.

I: Thanks.

R: Okay, it's a pleasure.