Experiences of HIV and AIDS
patients and families
regarding palliative care
in an urban care centre in Buffalo City

by

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EXECUTIVE SUMMARY

Background

The South African Constitution (South Africa, 1996) states that access to healthcare services is a basic human right. The Patients' Rights Charter (HPCSA, 2008: 6) stipulates that the provision for "special needs in the case of persons living with HIV or AIDS" and palliative care be "affordable and effective". The need for palliative care in South Africa today continues to increase. Khan and Sayed (2011[2]) found that five years after commencement of antiretrovirals, twenty five percent of their patients had passed away.

This study was performed in the Eastern Cape which is one of the poorest provinces with the second highest HIV prevalence rate. Since 2008, Sophumelela Centre Incorporated has offered palliative care for HIV and AIDS patients in Buffalo City. Some of these patients and their families were interviewed about their experiences in this care centre.

Problem Statement

Palliative care is fundamentally about bringing comfort to the patient and, according to Doyle (2008), "the essence of palliative care is the relief of suffering". Yet little research has been carried out to explore the experiences of persons terminally ill with HIV and AIDS and their families, or how role players can be assisted to best provide care for these patients.

Research Question

What are the experiences of HIV and AIDS patients and families regarding palliative care in an urban care centre in Buffalo City?

Significance of the Study

This research gives an in depth understanding into palliative care experiences of HIV patients and their family in Buffalo City. It provides insight into how to better

care for these patients. The researcher formulated guidelines for role players to care for persons and their families, in a palliative care centre.

Research Objectives

Explore and describe the lived experiences of HIV and AIDS patients and their families regarding a palliative care in an urban care centre in Buffalo City.

Formulate guidelines for role players to care for persons and their families, being cared for in a palliative care centre.

Methodology

Phenomenological interviews were performed, recorded and data transcribed verbatim. The data was analyzed, identifying themes and sub-themes.

Conclusions

The most important aspects of palliative care named by the patients and their families were good care, hospitality, autonomy and spiritual care. Symptom management was seldom mentioned but rather the relational care that helped patients feel at home was repeatedly mentioned.They were treated with dignity and their traditions and cultural practices were respected. Patients were cared for spiritually and experienced positive interaction with the multi-disciplinary team. The patients and their families were allowed to participate in their own healthcare and were encouraged to exercise choices. Availability of staff and communication were also crucial factors. Families expressed their sense of hopelessness, aloneness and stress at having to care for their loved one at home. A repetitive theme was the lack of proper communication and basic care previously experienced in the healthcare system.

Key Words: palliative care, HIV / AIDS, patients' and families' experiences

Declaration

I declare that EXPERIENCES OF HIV AND AIDS PATIENTS AND FAMILIES REGARDING PALLIATIVE CARE IN AN URBAN CARE CENTRE IN BUFFALO CITY is my own work and that all sources that I have used or quoted have been acknowledged by means of complete references and that this work has not been submitted for any other degree at this or any other institution.

Helen Bunt   Student number: 2011 07713

Date: October, 2012

DEDICATION

To Pumza

who died caring for those whom she loved.

You taught my heart to see and love beyond the brokenness and grime: to seek out the person inside.

To those unable to speak for themselves

"Unfortunately in end of life care we don't have a vocal constituency: the dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak" (Chochinov, 2000).

And to my team at Dignity House

because of your dedication and hard work – thanks for walking with me.

You are the present and future advocates for those who cannot speak for themselves.

ACKNOWLEDGEMENTS

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CHAPTER 1:

INTRODUCTION

1.1 Introduction and Background to the Study

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Narrative

The elderly mother slipped into the clinic. It took great courage to ask for help. Last month community members had beaten a neighbour because he was human immunodeficiency virus (HIV) positive. Now she had to reveal her well-kept secret – her daughter was dying from that same dreaded disease. Her desperation made her risk the consequences. She had already nursed her infected son until he died and now cared for his young child. At her age she could hardly cope with either situation. The burden was just too much. When this daughter, Nomthandazo* was admitted to a care centre, her filthy body smelled putrid. Her rigid limbs were doubled over in pain, skin thick with fungus. After several weeks of intensive palliative care - pain control, anti-fungal treatment and antiretrovirals (ARVs), the patient was learning to get herself into her wheel chair. The family was planning for her home-coming, not her funeral! But soon the celebration of the home-coming will be replaced with the harsh reality of continual caring for a terminally ill family member. Like Nomthandazo there are many …

*not her real name
**meaning of name: *prayer*.

</div>

In South Africa, palliative care has traditionally been given in hospices or care centres. According to Wright, Wood, Lynch and Clark (2008: 13), palliative care in South Africa is well established. By 2006, around 80 member organisations had enrolled in the South African Hospice Palliative Care Association (HPCA) and between 2003 and 2004, data returned to HPCA indicated that 24,613 patients

were cared for, of whom 12,413 had an acquired immune deficiency syndrome (AIDS) diagnosis (Wright *et al.*, 2008: 14). By 2010, UNAIDS estimated that AIDS claimed 310,000 lives in South Africa in 2009 - almost 850 deaths every day (UNAIDS, 2010: 185).

The national HIV prevalence rate in 2009 was calculated to be 29.4%, according to the South African Department of Health's study of antenatal attendees. This study showed the Eastern Cape prevalence in 2001 to be 21.7% and in 2010 to be 29.9%. According to the South African National HIV Survey of 2008, the national prevalence average is 10.9%. The number of deaths between 1997 and 2006, nationally, rose 93%. Among those aged 25-49 years, the rise was 173% in the same nine-year period (AVERT, 2012a). According to Groenewald, Nannan, Bourne, Laubscher and Bradshaw (2005: 193–201), there is much controversy about identifying the number of deaths caused by HIV and AIDS.

The antiretroviral (ARV) role-out program hopes to reduce the AIDS mortality numbers and initial assessments by the Actuarial Society of South Africa (van der Merwe, 2011[1]) indicate a significant decline in AIDS mortality due to the ARVs being more widely available. However, UNAIDS (Opie, 2012: 465) estimate that only 40-59% of clients eligible for ARV's in South Africa, receive them. In a recent study in Durban, it was found that five years after commencement of ARVs, twenty five percent of their patients had passed away and the majority of the deaths occurred in the first six months (Khan and Sayed, 2011[2]). The number of deaths

may even be higher than reported due to inaccurate diagnosis's on notifications of death. Consequently, it is very difficult to estimate a true mortality rate. Despite the difficulty in obtaining true statistics, it is evident that the hospitals and current palliative care centres in South Africa are severely burdened by the increasing numbers of HIV infected clients.

Stjernswärd, Foley and Ferris (2007: 487) note that there is a very significant unmet need for palliative care: globally 58 million people die annually (45 million in developing countries, 13 million in developed countries). Sixty percent of them will have a prolonged advanced illness and would benefit from palliative care. If at least two family members were involved in each patient's care, palliative care could improve the quality of life of more than 100 million people annually worldwide. Palliative care is particularly important for patients with cancer and AIDS, as the burden of issues that cause suffering is particularly high for these patients. Already, three million patients die annually from AIDS (Stjernswärd *et al.*, 2007: 486).

Previous to the ARV role out in South Africa researchers stated that there would still be a great need for palliative care after the advent of ARVs. Selwyn and Rivard (2003: 475–487) stated that although there are fewer deaths than before antiretroviral therapy, palliative care is now becoming more important and complex. Pain and symptom control are just as necessary. In 2003, Selwyn and Forstein (2003: 290) wrote that there was an increase in the need for palliative care as

patients survive for longer in latter stages of progressive HIV. For this reason, more comprehensive care and support are needed for patient and family.

The principles of palliative care, as given by the World Health Organisation (WHO, 2012), are clearly stated as:

- ❖ Provides relief from pain and other distressing symptoms;

- ❖ Affirms life and regards dying as a normal process;

- ❖ Intends neither to hasten nor postpone death;

- ❖ Integrates the psychological and spiritual aspects of patient care;

- ❖ Offers a support system to help patients live as actively as possible until death;

- ❖ Offers a support system to help the family cope during the patient's illness and in their own bereavement;

- ❖ Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;

- ❖ Will enhance quality of life, and may also positively influence the course of illness.

 Much work has been done both by the International and South African Hospice Palliative Care Association to provide guidelines for the implementation of the above mentioned principles. Yet it is unclear what terminal clients and their families want in order to die with dignity. Kikule (2003: 192–194) writes that, in Uganda, a "good death" occurs at home, in the absence of pain and other distressing

symptoms, without stigma or a sense of dependence, and with adequate finances for the basic needs. The home was the preferred site for care because of the financial implications regarding travel. In addition, terminal patients feel safer surrounded by their family in the privacy of their own homes.

By making use of home base care (HBC), many more patients can be cared for than could be attended to in a care centre or hospital (Gwyther and Cohen, 2009: 2). Home based care of the terminal person is becoming imperative. Gysels *et al.* (2011: 1–10) conclude from their literature review that there is a need for further research into the role of the extended family in Africa and whether they prefer to care for their sick at home. In 2011 in Uganda, despite their decreased infection rate, the need for palliative care was escalating (Jack *et al.*, 2011: 4). In 2005, Harding and Higginson (2005: 1971) wrote that home based care had been largely successful, but community capacity, resources and clinical supervision were lacking. As indicated by Stjernswärd *et al.* (2007: 486), the current health care facilities are already overburdened and terminal patients are often left to die unattended.

It is clear that a HBC programme is a lot less costly to run than in-patient care and that it is a way of multiplying the effects of scarce professional health workers. However according to Ama and Seloilwe (2010: 14) much of this cost is simply incurred by the family caring for the patient and often the family care-giver does not have the knowledge nor capacity to care for the patient. In a study of the needs of

rural persons living with HIV, Majumdar and Mazaleni (2010: 4–8) found many needs were unmet. Medical/ physical needs were often not met at the clinic which was short of staff and medicines. Many patients and their family care givers were despressed and did not know where to turn. Stigma isolated many of the participants and this prevented them from receiving help. Financially they struggled even more than usual as the sick person could no longer help to provide for the family and expenditure was higher due to transport to hospital or buying medicines that were not available at the clinic. It would seem that despite the apparent success of HBC, families and patients alike struggle and do not cope with caring or being cared for at home. It would therefore be important to understand how best patients and families can be cared for and supported during this difficult process. For this reason this study embarked upon exploring the experiences of those who were cared for in a care centre.

In the Eastern Cape, palliative care is offered at Sophumelela Centre Incorporated. It is a faith-based non-governmental organisation which serves HIV infected and affected people in Buffalo City. It is funded principally by the President's Emergency Plan For AIDS Relief (PEPFAR). Sophumelela offers health, enterprise development and education programmes. It was founded in 2005 as one of the first ARV clinics in the city and each year has expanded to include another service. As stated in the organisation's strategic plan 2010-2015 their purpose is to restore hope, health and dignity. The health programme includes ARV treatment and care, tuberculosis (TB) testing and treatment, HIV counselling and testing and palliative

care consisting of home based care (HBC) and a care centre. In 2008 the organisation built the nine bedded palliative care centre called Dignity House and two years later established a HBC programme for over a hundred patients.

The care centre has seen average annual bed occupancy of 60% in the first year of operation and this increased to 82% from the third year. It has served a total of 348 patients over four years with a death rate of 28%. Nurses are regarded as the primary care givers in this unit, but they work in close collaboration with medical practitioners and other members of the interdisciplinary team who share the same philosophy of palliative care. Low-technology care is provided for HIV and AIDS patients in a homely and relaxed atmosphere. The staff consists of three professional nurses, two enrolled nurses and six care givers.

The discipline of palliative care is relatively new and minimal research was found on the needs of the terminal South African patient. Harding *et al.* (2003: 33) were unable to find research studies that describe the activities and challenges of established end of life or palliative care services in Sub-Saharan Africa. Jameson (2008: 1–6) found that out of some eight thousand abstracts accepted for the International AIDS Conference in Barcelona in 2002, only 53 were on palliative or home-based care and none were from South Africa. The researcher herself found only two palliative care topics presented out of the 137 presentations at the fifth Southern African AIDS Conference in 2011.

Jameson (2008: 6) indicates that there is a great need for deeper and more formal research to be conducted in the area of palliative care as this is a relatively new discipline. Kikule (2003: 192–194) of Hospice Africa closes his article by saying that further investigation needs to be carried out around the issues of "a good death" to further establish patient and family needs regarding palliative care. This statement was reinforced by the findings of a needs-assessment performed in 2006, in which the clients at Sophumelela stated that one of their needs was "a place to die with dignity".

1.2 Problem Statement

The South African Constitution (South Africa, 1996) enshrines the rights of all people living in South Africa and affirms the democratic value of human dignity, equality and freedom. No person may unfairly discriminate directly or indirectly against any one. Furthermore, everyone has inherent dignity and the right to have their dignity respected and protected, the right to bodily and psychological integrity, which includes the right to make decisions concerning one's own body, the right to an environment that is not harmful to their health or well being, the right to have access to health services, including terminal care. It also states that access to health care services is a basic human right. The Patients Rights Charter (HPCSA, 2008: 6) stipulates the provision for "special needs in the case of persons living with HIV or AIDS patients" and palliative care that is "affordable and effective".

Over the past eleven years, the researcher has been involved in palliative care and has personally witnessed the suffering of both patients and their families caused by the HIV and AIDS pandemic. The researcher interacts daily with clients facing life-threatening illness and their families and listens to their stories. From personal, unstructured observation and informal discussions with clients and their families it became clear to the researcher that they all face similar situations during terminal illness.

The following questions arise:

What are the experiences of persons terminally ill with HIV and AIDS and their families?

How can role players be assisted to best provide care for these patients?

1.3 Research Question

The following research question was formulated:

What are the experiences of HIV and AIDS patients and families regarding palliative care in an urban care centre in Buffalo City?

1.4 Significance of the Study

The body of knowledge gained by this research will give an in depth understanding into palliative care needs of HIV patients and their family in Buffalo City. It will provide insight into ways in which these needs might be fulfilled. The researcher will formulate guidelines for role players (nurses, care givers and managers of such a facility) to care for persons and their families, in a palliative care centre.

1.5   Definition of Concepts

- ❖ **ARVs/ ART/ HAART** – Antiretrovirals/ antiretroviral therapy/ highly active antiretroviral therapy – all refer interchangeably to the medication used to suppress HIV in the body.

- ❖ **End of life care** (also called **terminal care**) – in the context of this study means the care needed in the last days of life that would not necessarily prolong the patient's life but keep him/ her comfortable.

- ❖ **HIV status** – whether or not human immunodeficiency virus is detectable in a person's body.

- ❖ **Home Based Care –** in the context of this study, refers to nursing care and support given to the patient and family in their home. In some cases, the community care giver is supervised and supported by a multidisciplinary team.

- ❖ **Hospice** – usually refers to an end of life care centre, but may be more broadly used to mean the philosophy relating to this kind of care.

- ❖ **Palliative care** – in this study the definition of The World Health Organisation (2012) will be used. Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- ❖ **Stigma** – the discriminatory, negative attitude often displayed towards people because of their HIV positive status.

1.6 Research Objectives

The objectives of this study were to:

❖ Explore and describe the HIV and AIDS persons and their family's lived experiences of being cared for in a palliative care centre in Buffalo City.

❖ Formulate guidelines for role players (nurses, care givers and managers of such a facility) to care for persons and their families, being cared for in a palliative care centre.

1.7 Delineation of Chapters

Chapter 1	Overview of the study
Chapter 2	Research design and methodology will be discussed. Details of the interviews as well as the population and sampling will be described. Details of data collection will also be given. Ethical considerations and trustworthiness will be explained.
Chapter 3	Data analysis, interpretation and literature control will be discussed according to the themes identified.
Chapter 4	Conclusions, guidelines, recommendations and limitations will be portrayed.

CHAPTER 2:

RESEARCH DESIGN AND METHODOLOGY

2.1 Introduction

The purpose of this research study was to investigate the experiences of HIV patients and their families regarding palliative care and to bring about a comprehensive understanding of palliative care needs of the terminal patient and their family. In this chapter, the researcher will describe the research design and methodology used in the study.

2.2 Research Design

The research design was qualitative and phenomenological in nature as it dealt with the patients' and families' lived experiences. It was exploratory, descriptive and contextual. This design was selected because it allowed patients and their families to explain their experiences in depth. This enabled the researcher to obtain the best answers to the research question and thereby fulfil the research goals. In analysing the data a clear correlation emerged between the themes and the concept of the whole person described in the nursing theory of the whole person developed by the Oral Roberts University: Anna Vaughn School of Nursing (1990:

136–142). It has a holistic focus and describes a person in terms of internal and external environments. Internal environment consists of body, spirit and mind. The mind is described as intellect, emotion and volition. The external environment is defined as physical, social and spiritual. Each of these areas is inter-related in the same way as the data from the participants were inter-related and overlapped. For clarity in presentation, they are explained separately.

Qualitative research is a systematic, interactive, subjective approach used to describe life experiences and their meanings (Leininger, 1985; Munhall, 1989 and Boyd, 1999 cited by Burns and Grove, 2009: 507). Qualitative research is by nature descriptive and seeks to explain, illustrate and give vivid expression to a reality. According to Babbie and Mouton (2000: 53), the paradigm of qualitative research is to study humans from the insider's perspective and to bring about understanding, rather than explanation or prediction. In this study the aim was to "stay close" to the research subject in order to understand the experience of palliative care as offered in an urban care centre. It is for this reason that it was helpful for the researcher to be an "insider" in terms of one who knew and understood the context of the patients and their families.

A phenomenological approach is an approach to human enquiry that emphasizes the complexity of human experience, and the need to study the experience holistically as it is lived (Burns and Grove, 2005: 61–80; Creswell, 1994: 51). The foundation of phenomenology is to focus on the "lived experiences" (Morse and

Field, 1995: 124) of the clients cared for in the palliative care centre and that of their families.

Husserl, Moran and Gibson (2012) write of *intersubjectivity* as a condition somewhere between subjectivity and objectivity – something personally experienced by more than one subject. This study was based on the systematic reflection and analysis of experiences taken from a highly modified first person view point. This enables subjective consciousness to be studied, not from "my" perspective, but from any consciousness whatsoever (Husserl *et al.*, 2012). Other important concepts in a phenomenological study are bracketing and intuiting (Brink, 1996: 113). *Bracketing* is the concept of the researcher putting aside any preconceived notions so as to be free to embrace those of the subjects in the research. This was achieved by the researcher deliberately concentrating on the subject in the interview, rather than the patient she remembered nursing or her own opinions and biases about the subject. *Intuiting* is the process whereby the researcher develops an awareness of the lived experience by immersing him/herself in the data until there is a common understanding (Brink, 1996: 114). The researcher transcribed each interview herself, listened to it several times, before reading each one over and again, until themes and patterns emerged.

This research was also *exploratory* because it involved listening and analyzing the experiences of HIV and AIDS patients cared for in a palliative care centre during the terminal phase of life and the experiences of their families. This enabled the

researcher to gain a richer understanding of this phenomenon (Babbie and Mouton, 2000: 76–79; Brink, 1996: 11; Mouton and Marais, 1988: 43–45).

The data generated in qualitative studies is *descriptive* in nature (Creswell, 1994: 51–57; Mouton, 1996: 102). The purpose is to provide an in-depth picture of situations as they naturally occur. This enabled the researcher to describe the experiences of HIV and AIDS patients being cared for in a palliative care centre and depict the experiences of their families.

This research was a *contextual* study by nature, focusing on the experiences of HIV and AIDS patients and their families cared for in a specific palliative care centre in Buffalo City. Guidelines for the role players were described in this specific context (Mouton, 1996: 133). It was not the aim of this research to generalize the findings, but rather to explore and describe within the specific context.

The researcher chose a contextual study so as to give a deeper understanding of a specific experience – that of being cared for in that particular palliative care centre. To separate the events from the background of the whole context would detract from the meaning of the whole (Mouton and Babbie, 2001: 272). The methodology was described in detail to enable reproduction in another context for further research if desired.

The study was conducted in two phases:

- ❖ PHASE 1: During this phase the researcher explored and described the experiences of HIV and AIDS diagnosed terminal persons who are cared for in a palliative care centre and that of families whose family member is being cared for in a palliative care centre.

- ❖ PHASE 2: During this phase, the researcher formulated guidelines for role players (nurses, care givers and managers of such a facility) to provide palliative care for persons and their families in an urban care centre.

2.3 Research Method

In order to achieve the best results in this exploratory study, it was decided to conduct phenomenological one-on-one interviews with patients and family members of patients who had been cared for in a care centre in Buffalo City. The interviews were audio-taped (Morse and Field, 1995: 77) and field-notes were taken during and immediately after the interview so as not to lose the richness of the data. The interviews were carried out by the researcher. The researcher utilized the following techniques: probing and paraphrasing, responsive listening, minimal verbal response, reflecting, summarizing, open-ended phrases, stating observed gestures communication and silences to elicit information from the patients and families. Time for questions was allowed. The researcher aimed at being empathetic and understanding while keeping the participants focused during the interview.

To gain experience in phenomenological interviewing technique, the researcher conducted several interviews which were analysed and critiqued before conducting the actual research. It was found that the researcher's knowledge of the care centre and the relationship she had with the patients contributed to their willingness to participate.

Privacy and confidentiality were ensured by using the patient's private ward or a nearby office at the care centre. Interviews were held in a comfortable environment familiar to the participants. A time of greeting and introduction was used to help the participants to relax. The interview was finalized by asking if there was anything more the participant would like to add. Participants were thanked and reminded of the agreed upon confidentiality and where and when they could expect to see the results.

2.4   Population and Sampling

The term population refers to the entire group of persons or objects that is of interest to the researcher (Brink and Wood, 1998). The population for this study was all the patients cared for in a palliative care centre in Buffalo City and their families who were willing to participate in the interviews. The researcher used a purposive sampling technique (Burns and Grove, 2005: 61–80; De Vos, 1998: 191). Terminally ill HIV positive clients and their families who were cared for, for at

least 3 weeks in the centre, who met the inclusion criteria, were invited to participate in the study. The researcher met with them in the convenience of the care centre, where the research goals and objectives were explained, informed written consent obtained and appointments for interviews booked.

Inclusion criteria were:

❖ Patients admitted in the care centre for longer than 3 weeks. This was an average length of stay and long enough to form opinions about the experience and to be cared for by the full rotation of staff.

❖ Family members of patients who had difficult situations or prognoses or who were no longer available to share their experiences e.g. due to their passing or moving away.

❖ Proficient in English (due to the researcher's inability to conduct interviews in other indigenous languages.)

2.5   Data collection

The phenomenological interview was used as a method of data collection to achieve a better understanding of the patients and families and to increase the credibility of the findings.

2.5.1 Preparation

Potential participants were given an invitation letter (Annexure A) explaining the process and purpose of the study. This was either done in person while the patient was admitted in the care centre or the letter was given to the patient on their return visit to the adjacent ARV clinic. Some potential participants were telephoned and invited to participate and the letter delivered if a potential participant was interested. The willing participants then made an appointment with the researcher for a time agreeable to both. A written, informed consent to conduct the interview, and to audio-tape it, was obtained from the participant. The venue was prepared ahead of time to help the participant to feel comfortable and welcomed. The participants were served a beverage to demonstrate hospitality. The tape recorder was placed close enough to capture the voices well, but inconspicuously, out of direct view. A new tape marked with the participant's identification code was used for each interview and batteries fitted in case of a break of electrical supply.

The researcher tested her interviewing skills with preliminary interviews that were not included in the study. This also proved the clarity of the questions. The questions were easily understood and facilitated the research well. The skills of the researcher were further improved by involving a coach. Further reading on the subject was done and "practise" interviews performed on non-participatory individuals.

2.5.2   Interviews

The interview was structured in such a way that safer topics such as the demographic data or contents of the consent letter were discussed before the one central question was asked of patients, **"*How was being cared for in Dignity House for you?*"** and to family members, **"*How did you experience the care given to your family member in Dignity House?*"**. The recorder was switched on during the introductory phase and then ignored until the participant had left the room at the end of the interview.

After the central question was asked, the researcher listened carefully to the participant's response and probed deeper. Often reflecting or paraphrasing what the participant had said brought out further meaning to the actual words used. Stating the observed gestures or repetitions made by the participant elicited further information. Pausing to allow time to think was important. The researcher aimed at being empathetic and understanding while keeping the participants focused during the interview.

Some of the respondents poured out their hearts in telling their experiences while others were not that open. However, the researcher utilized her training and experience to observe all-important matters concerning interview interaction including verbal and non-verbal communication between her and the participants, such as, contact and facial expression, a relaxed natural posture. She encouraged

communication by leaning slightly forward, probing, reflecting, clarifying, summarizing, silence, nodding agreement and using minimal utterances such as "umm", "hmm" or "yes". After transcription of the audio tapes, the researcher met with some of the respondents to provide feedback, to clarify issues and to confirm if the researcher had captured what they meant.

2.5.3 Collecting Data

All interviews were tape recorded on separate tapes and stored in a safe place. Each tape was labelled according to the researcher's code for each participant. The interviews were transcribed verbatim and stored electronically as well as in hard copy. The data of each patient were assigned a number and a list of patients' names and numbers kept only by the researcher and destroyed once the data were analysed. The researcher observed the participants' non-verbal responses that could indicate discomfort, irritability or stress (hesitation, laughing or other non-verbal cues). These observations were noted during and after the interview. The researcher kept personal notes, which included her own reflections and experiences during the course of the interviews.

Each interview was read and initial analysis done. Observations were written in the margin. Where it was clear that the researcher did not probe deep enough or further information was needed for clarity, the researcher contacted the participant again by telephone. The information obtained from second interactions was noted in a different colour for easy identification during analysis.

2.6 Ethical Considerations

Ethical standards by the Democratic Nursing Association of South Africa (DENOSA, 1998: 1–7) and the University of Fort Hare, East London were followed to ensure that appropriate steps and measures of ethics in research were adhered to. Ethical clearance was obtained from the University of Fort Hare (Reference number UFH/UREC, 19 – REC-270710-028. Annexure B). Written permission to perform research at Dignity House, Sophumelela was obtained from the manager (Annexure C). Informed consent (Annexure A) was obtained from the respondents with utmost care to avoid emotional assault as they were already traumatized by their terminal diagnoses. The following ethical measures included:

2.6.1 Confidentiality and anonymity

Face-to-face interviews were done and audio-taped by the researcher. All participants already knew the researcher from being cared for in the care centre and their identity was not revealed to any other person. Informed written consent was obtained, and all information that could link the interview to a particular person was removed. None of the participants in the study were expected to reveal information they didn't want to share. The causes of infection with HIV were not identified or revealed during the interviews.

2.6.2 Fair treatment

The clients were not coerced to participate in the study. Hence, the clients were invited to participate in the research voluntarily and they could withdraw from the project at any time without obligation. The interviews were all conducted after the patient had been discharged from care at the care centre so that what was said in the interview could not influence further care received. The purpose and extent of the study was explained to the participants and all information gathered during the study was used only for its intended purposes.

2.6.3 Beneficence and Non-maleficence

No deliberate attempt was made to cause emotional discomfort or harm. The participants were free to withdraw from the study at any given time. If the researcher had sensed that the participants were experiencing any emotional difficulty or trauma caused by the questions, the interview would have been ended and follow up counselling by the spiritual workers of the care centre, would have been offered to the participant. There were unintended benefits to the clients and their families as they were able to ventilate their feelings and obtain emotional comfort. Further benefits could include that there may be changes in the care given to the terminally ill client and their families once the findings of this study are communicated to care centres. Informed written consent was obtained from the clients and their families before data collection.

2.6.4 Privacy

The interviews were conducted in the privacy of the client's room or a nearby office where he/she was able to behave and think without interference. The use, safekeeping and subsequent destroying of the audio-recording were explained to the clients and their families. All records of interviews and information related to the study will be stored for at least three years and in such a way that only the researcher and persons directly related to the study could have access to it. After this period the tapes and related papers will be destroyed by shredding paper and burning tapes.

2.7 Trustworthiness

The researcher ensured trustworthiness of the study by using the model of Lincoln and Guba (1985: 290–300) which sets criteria for trustworthiness of a study. The following criteria of credibility, transferability, dependability and conformability was also utilized (Polit, Beck and Hungler, 2001: 715–720).

- ❖ *Credibility* was aimed at ensuring an authentic picture. Techniques such as triangulation of data, peer debriefing to identify researcher's biases, were used.

- ❖ *Transferability* is the ability to reproduce such a study in another setting. To promote this, the researcher has given a detailed description of how the research was conducted.

❖ *Dependability* was ensured by peer review auditing the processes used by the researcher to determine whether they were acceptable.

❖ *Confirmability* was also achieved by an audit of internal agreement between the researcher's interpretation of data and the actual evidence.

2.7.1 Trustworthiness during Phenomenological Interviews

To ensure trustworthiness during the phenomenological interviews, the researcher:

❖ Invested sufficient time in data-collection activities to ensure in-depth understanding of the participants' views and experiences.

Since the researcher had worked in the palliative care centre for a period of three years before data collection, rapport and trust was already established.

❖ Conducted interviews herself.

❖ Maintained close observation during the interviews to determine non-verbal cues.

❖ Audio-taped each interview with the participant's consent on a new tape that was identified and dated.

❖ Kept field notes during and directly after each interview.

❖ Maintained interviews until saturation of data was obtained.

2.7.2 Trustworthiness during Data Analysis

The researcher transcribed the audio tapes of the phenomenological interviews verbatim before analysis. Grammar and repetition used by the participants was left unchanged, thereby prohibiting the possibility of losing any information.

A method of open coding was used and the data analyzed according to Tesch's data analysis method (Creswell, 1994: 155). Data were organised into themes and sub-themes. The researcher and an independent coder analysed the data separately. Themes were identified during and after the interviews using Tesch's (Creswell, 1994: 188) eight steps of analysis.

In order to complete these steps more efficiently and in detail, the computer program _Atlas.ti 6.1_ (Annexure E) was also used. After the researcher had carried out her own analysis manually, the program was utilized to do automatic coding to confirm the analysis already conducted. Additional information and any discrepancies were noted.

The expertise of a person with a master's degree in psychiatric nursing and who has extensive experience in qualitative research analysis was utilised as an external co-coder. Consensus on the findings was obtained between the co-coder, the researcher and the supervisor of the study. They then agreed on the themes and sub themes identified in the transcription and the field notes.

The researcher undertook an extensive literature control to triangulate the findings. The data of the interviews guided the literature control. Information obtained from the literature and similar research was disclosed for each theme to gain a comprehensive picture of the topic under investigation. The findings were discussed in light of all relevant literature (Creswell, 1994: 154; Morse and Field, 1995: 103).

2.8   Conclusion

In this chapter a comprehensive outline of the method of data collection was provided. The ethical considerations were explained and a description was given of how these principles were followed in this study. The efforts of the researcher to comply with trustworthiness were examined. This was followed by a full description of how the data was analysed. In the next chapter the results will be discussed in conjunction with the literature control.

CHAPTER 3:

DATA ANALYSIS, INTERPRETATION AND LITERATURE CONTROL

3.1 Introduction

The purpose of this research study was to explore and describe the lived experiences of HIV patients and their families regarding the palliative care given in a care centre in Buffalo City. The experience of palliative care is central to a person's life. Families are able to recall accurately the details of their feelings when a family member goes through the process of being diagnosed with a terminal illness and the subsequent death evolves. This, in turn, affects how the person will approach the final phase of their life. When patients suffered, whether humiliation as a result of pain, lack of care or injury, or through being the passive instrument of physical processes, they could not understand; it is not only they who are affected.

In Chapter Two, a description of the research design and method was detailed. Chapter Three will present a narrative account, as well as a discussion of the results of the in-depth, unstructured phenomenological interviews with clients and families on their experiences of palliative care in a small care centre in Buffalo City. The objective of this chapter is to discuss the results of the conducted study and to review the literature control.

3.2 Data Analysis

Data collection and analysis were implemented as follows: Individual phenomenological interviews were conducted with each participant and recorded to allow verbatim transcription. The researcher obtained the participant's written consent to conduct and audio-tape the interview. Six ex-patients and four family members of other patients participated in the study. All the interviews were conducted in English and took place at the care centre. One central question was asked of patients, **"*How was being cared for in Dignity House for you?*"** and of family members, **"*How did you experience the care given to your family member in Dignity House?*"** The researcher then invited the participant to explain and/ or expand on what they had said.

3.3 Description of the Results and Literature Control

Table 1 presents a brief summary of the themes and sub themes identified during the study of the experiences of HIV and AIDS patients and families regarding palliative care in an urban care centre in Buffalo City. All these themes and sub themes are interrelated.

Table 1: SUMMARY OF THEMES AND SUBTHEMES

Themes	Sub-themes

Experienced the care they received as holistic in nature:	**The clients experienced that they were cared for as a unique person with a body, soul and spirit:**
	Body
	   ➢ **Treated with care and compassion**
	   ➢ **Treated with respect**
	Soul
	   ➢ **Experienced encouragement hope and support**
	   ➢ **Experienced the right to exercise choices and autonomy**
	   ➢ **Treated with dignity**
	   ➢ **Experienced the right to be educated and receive relevant information**
	Spirit
	   ➢ **Experienced spiritual support through prayers, counselling and religious meetings**

The clients experienced that they were cared for as a holistic unique person within a unique environment	**Physical external environment**
	   ➢ **Physical hygiene**
	   ➢ **Availability of staff**
	   ➢ **Medical competence**
	
	Emotional external environment
	   ➢ **Experienced the relationship with the staff members positively**
	   ➢ **Caring and loving relationship with staff**
	   ➢ **Experienced understanding from the staff**
	
	External social environment
	   ➢ **Experienced the social environment as being positive**
	   ➢ **Experienced hospitality**
	   ➢ **The relationship between the family members were encouraged**

Experienced traumatic recollections of previous hospitalizations and nursing care	
Experienced sense of fear, hopelessness and a spiritual void before admission	
Family experienced relief when the patient was admitted in the care centre	**Family were stressed, felt alone and hopeless, didn't have the adequate knowledge to care for the patient at home**

3.3.1 THEME 1: Experienced the care they received as _holistic_ in nature

In this study the researcher found that most of the respondents commented on the care they had received as holistic. Palliative care is known to be holistic in nature and Chochinov (2006: 84) asserts that the goal of palliative care is to provide comfort, not just to be made to feel more comfortable. This means much more than just the technically competence of symptom management. It is a holistic approach to end of life care that includes the psychosocial, existential, and spiritual aspects of the patient's experience. One patient spoke about the pain control she had received and summed it up by saying:

> _"Number one the people here have a holistic approach … When you need healing from any disease you need prayers, good care, love and people who understand" (Interview 7 paragraph 2 & 49)1._

SUB-THEME 1.1 **Body**: Treated with care and compassion

All of the respondents in this study described the care as an aspect, if not the most important part of their experience, in Dignity House. This was in line with the literature which suggests that the interaction between a professional care giver and a patient is considered to be the key element in the terminal phase of life.

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[1] Reference to paragraph means the numeration assigned in Atlas.ti 6.1

Chochinov (2007: 184–187) states compassion is a vital part of palliative care. This can only come about in relation with the patient – as the care giver establishes contact, understands, feels and allows that to shape their approach to care. Broyard (1992) poignantly describes his experiences of being terminally ill, "To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I just wish he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way. I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness." This very vivid description adds potency to the time-honoured concept that care is so much more than the treatment of the illness (Peabody, 1927: 82).

In this study some patients mentioned the good diet and one mentioned pain control as signs of caring.

"The way they treated me was the most important thing," (Interview 4 paragraph 4).

"The care, I did get that care," (Interview 4 paragraph 1).

"…I know the people was gonna help me…" (Interview 2 paragraph 7).

"Here you stand in front of me; you are wait in front of me with water. So I can't even throw [the pills]. Because you want me to be well" (Interview 4 paragraph 58).

"... So it was that close, close care that I wanted" (Interview 6 paragraph 14).

Caring is often seen as the hallmark of the nursing profession, and it is the essential indicator of quality health care. Different communities, groups and individuals may have different opinions about this. "It can be argued that caring is what makes us human, that it is an innate human attribute" (Pera and Van Tonder, 1996: 11). Van der Wal (in Pera and Van Tonder, 2005: 16) identifies words associated with the term caring, namely inter alia *acceptance, accompaniment, affection, attitude, compassion, confidence, empathy, fairness, healing and helping.* In this study, the nurses are perceived as observant, empathetic, supportive, with good listening and communication skills and that their experience with them lead to the development of a therapeutic relationship (Cortis and Kendrick, 2003: 8–9).

SUB-THEME 1.2 **Body:** Treated with respect

Searle (1999: 69–72) argues that the nurse made a commitment to the public's right to safe nursing practice. A commitment to the ethical values such as *caring, respect* and *beneficence was thus made.* In particular, these fundamental ethical concepts are directed to the preservation of human life at all stages of its existence from conception to death: respect for the human being; protection of his dignity and privacy, his personal values, beliefs and cultural traditions; protection of his right to make decisions regarding his health and his rights as a person; protection of the vulnerable when they do not have the strength, the will or the knowledge to protect themselves. This is furthermore supported by the Constitution of South Africa

(South Africa, 1996). It enshrines the rights of all people and affirms the democratic values of *human dignity, equality and freedom* from birth to death.

All the participants in this study felt that they were respected as human beings. There was one patient, however, who spoke about a nurse disrespecting her right to choose and forced her to eat certain foods. Nevertheless, she spoke of other ways in which she was respected in the care centre:

> "*Nobody was shouting at me… Nobody was saying, 'Why do you do this?' So I was feeling at home" (Interview 6 paragraph 38 & 40).*

Dignity and respect are closely related and both are named as general principles of palliative nursing (Ferrell and Coyle, 2005: 16–18). In this study, participants were reported feeling that they had been treated with dignity and respect; that they had had the right to make decisions and that their beliefs and cultural practices were acknowledged. The staff members demonstrated empathic concern:

> "*... a sister would ask if you need to chat about anything?" (Interview 3 paragraph 46).*

Nursing care across cultural boundaries is a reality in South Africa today. Airhihenbuwa (1995: 6) argues that culture embodies moral, ethical and aesthetic values through which people come to view themselves and their place in the universe. Culture in a broad sense may be viewed as the way of life of a group of people.

In this study, none of the participants experienced nursing staff to be culturally insensitive or disrespectful. None of them experienced prejudice. This was supported by direct quotes such as:

"…and they don't discriminate ... they treated the other patients the same ... whatever background you are from they make you feel at home" (Interview 7 paragraph 5 & 7).

"It was like family, like somebody looking after me at home nicely" (Interview 6 paragraph 18).

"...that was very nice to be treated like a queen" (Interview 5 paragraph 44).

SUB-THEME 1.3 **Soul:** Experienced encouragement, hope and support

When a palliative care patient enters a hospice type system, he or she is most vulnerable, as in many instances, this is seen as the last phase before passing away. They need to be welcomed into the strange environment and given comfort, care and information. The care that palliative clients receive during the last phase of life should not only help them cope with the effort, stress and pain; it should promote physical and mental well-being. Support includes praise and encouragement. The nurse can help ensure that the palliative care patient understands the purpose of every procedure and the result of every examination. When the patient increases in weight or their CD4 count increases, when they

swallow their pills or recognise their medication, there is cause for celebration. Often patients who develop an immune reconstructive inflammatory syndrome become discouraged and think that ARVs are making them sick. These patients, in particular, need the relevant information and support in order to go on. One patient told how the sister had explained about the effects of her very low CD4 count and how that helped her to continue the struggle to take her medication (Interview 3 paragraph 24).

In this study, the palliative patients were under the supervision of the care givers throughout their stay in the palliative care centre where the nurses observed the physical condition and mental capacity of the client. Most of the patients stated that they received sufficient support, as indicated by this direct quote:

"…a good support. It just shows how do they care" (Interview 6 paragraph 12).

Families also felt that they did receive enough support from the nursing staff:

"They would encourage him. That is a part of the care. To reassure the patient is very important" (Interview 11 paragraph 24).

"But the nurses here they care. They are smiling and they give hope every time" (Interview 11 paragraph 52).

"Giving that support. Each and every one that is here is giving that support" (Interview 9 paragraph 18).

"They also motivate. They encourage the patients to hold on and to know that they are living with HIV" (Interview 9 paragraph 38).

SUB-THEME 1.4 **Soul:** Experienced the right to exercise choices and autonomy

Autonomy and choice is highly valued in most societies today.

In South Africa, it is a human right to choose one's health provider and to choose to refuse treatment (South Africa, 1996; HPCSA, 2008). In ethics, personal autonomy and the protection of the vulnerable patient is a key concern (Entwistle *et al.*, 2010: 741–750). This is founded on the understanding that we all need to be our own person and shape our own lives. Running our own lives and making our own choices are basic to meaningful living (Horst, 2012). This is particularly true in palliative care, where the patient may need assistance with many daily bodily functions, the choices they can make, are very important to them. Ferrell and Coyle (2005: 16–18) cite autonomy and choice a general principle of palliative nursing.

In this study, the importance of choices and autonomy was mentioned by four of the six patients and is evidenced by the following:

> *"We are asked, 'What would you like to eat?' What do you like?" (Interview 6 paragraph 58).*
>
> *"It's you that decide if you want more" (Interview 2 paragraph 47).*
>
> *"… I could have any food I wanted and the care was wonderful because I could get up and go to the toilet whenever ... I was not bound by [their routine] and being in my bed however long it didn't matter. It was much more relaxing and I could do my own thing. It was fantastic here" (Interview 5 paragraph 8,10).*

Levinson, Lesser and Epstein (2010: 1310–1311) affirm the importance of respecting and responding to patients' preferences and needs. It is seen as part of building the physician-patient relationship. In this study, there was a case of a nurse who insisted that a patient should eat food that she does not like. It was clear that the nurse-patient relationship was affected.

"No, no I was given no choice, because it was said that is what you are going to eat in the evening. Then I was saying I don't want to eat Mpoqoqo. They would say we are not going to listen to you. You are going to eat Mpoqoqo. Even ... taking the spoon to your mouth. Sometimes I would fight. Sometimes I didn't want to swallow because I know if I swallow it would make me vomit everything. So that is what made me to feel uncomfortable and scared" (Interview 6 paragraph 90-92).

"…I didn't want to be forced but I was supposed to (eat) even if I didn't want … so the cruelty was nothing because I was to be healed" (Interview 6 paragraph 122).

This was clearly upsetting to the patient. Choice is an important element of control since it encourages the terminal patient to express their individuality. These choices should be available to all terminal patients and professionals should be able to provide for those in a realistic way (McCrea and Wright, 2001: 877–884).

Cassell (2004: 33–35) suggests that the more an individual's sense of self and personhood is threatened or undergoes disintegration, the greater his/ her suffering. Often due to the pressure of the work load in the health field, it is very

difficult for medical staff to uphold and respect the patient's wishes. The dying patient is particularly vulnerable, as they are often faced with many losses and severely limiting disease. Chochinov (2006: 91) summarizes it by stating that personal autonomy is often integrated with the idea of being a whole person and so conversely, a lack of choice or dependency can be experienced as a threat to personhood itself. The importance of this individualized autonomy is clearly noted in palliative care.

SUB-THEME 1.5 **Soul:** Treated with dignity

In a case study of hospital patients, they defined dignity as feeling comfortable, in control and valued. Environment, staff behaviour and patient factors impacted on it. Staff being abrupt, authoritarian or breaching privacy threatened dignity (Baillie, 2009: 29–30). In this study, most families implied that they and their family member had been treated with dignity:

> *"... this place is so dignified as the word says, 'Dignity House'" (Interview 11 paragraph 60).*
>
> *"(The patients) are comfortable and they are warm. They feel at home here" (Interview 8 paragraph 41).*

The patients also spoke about being treated with dignity:

> *"But the nighties that we wear here, today you are wearing pink and tomorrow you are wearing blue ... It made me to feel fresh and comfortable. (It was important) for my health so that maybe I would get quickly recovered and also feel accepted" (Interview 6 paragraph 22).*

Dignity and respect is a general principle of palliative nursing (Ferrell and Coyle, 2005: 16–18). The more health care providers affirm the patient's value by seeing them as a person rather than a disease or diagnosis the more a patient feels treated with dignity. The patient's own self perception is also an important factor in the patient feeling dignified (Chochinov, 2007: 184–187). This was shown to be particularly important for patients in this study where many of them had previously been stigmatised and ill-treated because of their HIV status. One patient stated,

> *"maybe they [family] don't accept me because I was HIV positive …the stigma of the HIV positive, and also the problem of being accepted by the community… they don't know what to do with us" (Interview 6 paragraph 36 & 37).*

SUB-THEME 1.6 **Soul:** Experienced the right to be educated and receive all relevant information

It was clear during the literature control that many authors are of the opinion that information and education are vital to help the palliative care patient to make

informed choices. Grant *et al.* (2011: 8) name education as one of the four most important palliative care needs of HIV patients. Harding *et al.* (2012) agree that one of the most burdensome problems was that patients had inadequate information to plan for the future. They concluded that insufficient *communication* with health care professionals was a major contributing factor.

It is often claimed that poor *communication* is a serious problem in the health services (Mandla, 2009: 7; de Villiers and Tjale, 2004: 112-114). In all interaction between the nursing staff, health visitors, doctors and others who care for the terminal patient, it is vital to listen and learn, instead of telling and hoping that those at the receiving end are absorbing the teaching. Communication of information and facts must be appropriate, adequate and accurate for it to be effective.

In this study the nursing staff fostered a relationship with the patients and their families, evidenced by the following statements by patients:

> *"The way the staff look after you here. They don't shout at you but they explain things. You see those were the nicest things. The way they chat with you" (Interview 3 paragraph 72)*
>
> *"...it's the approach, even they talk with you" (Interview 2 paragraph 47).*

Health education depends on relationship, information and understanding between the parties communicating. As the parties grow to understand one another better, so their communication improves. Part of communication is the feedback and

questions that are asked between communicators (de Villiers and Tjale, 2004: 109). The patients were not afraid to ask questions and found well-illustrated information about palliative care and their conditions:

"If you want to ask something no one is changing" (Interview 4 paragraph 24).

"…I learnt a lot here at Dignity House…" (Interview 2 paragraph 125).

Families also felt free to ask questions and could see that their family member was given education about their illness:

"You feel free to ask any question" (Interview 8 paragraph 33).

"She [the patient] was getting education through the educators - all things about HIV and what is happening with ARV's" (Interview 9 paragraph 18).

One patient had stopped taking her treatment previously because she said that she never understood why she was taking treatment. Even though she was feeling much better, the nurses continued to give her more packets of pills to swallow. Sometimes they were white and other times they were pink, but she was just told to take them. It is agreed (Mandla, 2009: 95; Morgan, 2000: 302–303) that adherence is directly linked to information being relayed through an appropriate relationship and good communication. She told how thankful she was for the way she had been taught about HIV and how ARVs function:

> *"…now I even know the names of all my pills and everything" (Interview 4 paragraph 8).*

The provision of accurate information relieved some of the anxieties and fears people living with HIV experience. Communication allowed them to realize that what they are experiencing is normal and does not signal that something is wrong (Mandla, 2009: 107). The fears of this patient were allayed.

> *"I saw the people [staff] treat me different [accepting me] …When I'm asking too much questions or too wanting too much things or always complaining" (Interview 2 paragraph 42 &44).*

SUB-THEME 1.7 **Spirit:** Experienced spiritual support through prayers, counselling and religious meetings

Although Jameson (2008: 6) found few of the terminal patients in her study mentioned psychosocial / spiritual needs as important in the face of the severe symptoms they suffered, others (Grant *et al.*, 2004: 8; R. Harding *et al.*, 2012: 5–13) state that this is a profound need in palliative care patients. Selman *et al.* (2011: 66) reported 25% of patients in their study had not felt at peace (existential, social, religious and physical). In a recent study carried out in Dignity House by

Phutu (2011: 16–28), 80% of patients felt angry with, and had not forgiven, the person who had infected them with HIV. They also reported feeling guilty and not forgiven by God. This would seem to indicate a great need for psychosocial and spiritual care.

Spirituality/ religion has been shown to be very important to palliative care patients (Cotton *et al.*, 2006: 5–13; Edwards *et al.*, 2010: 767). Viktor Frankl (1985: 50–51) in his classic writings explores how facing even the most difficult of situations, and having a positive attitude, could bring fulfilment and make meaning in and of itself. Research has shown that many patients not only cope with a diagnosis of HIV, but grow to the extent that they find their life to be better than before being diagnosed with HIV (Szaflarski *et al.*, 2006: 38). This shows the major importance of spiritual care in the lives of patients living with HIV.

In Buffalo City, the researcher found that half (2/4) the family members and all but one (5/6) patients mentioned some aspect of spiritual care as being important to them. The three areas of spiritual care mentioned were prayer, religious meetings and spiritual counselling.

The following direct quotes confirmed the arguments of Dijoseph and Cavendish (2005: 153) that prayer is the most frequently used spiritual practice. Participants described it as a participatory activity, where patients were prayed *with* as well as being prayed *for*. This was done by the spiritual workers, staff members and even

fellow patients. The majority of participants who mentioned spiritual care spoke about the importance of prayer.

> *"We get prayed for because we are visited by the pastor ... And even the staff, they pray... for and ... with you - meaning that you get looked after spiritually, emotionally and physically" (Interview 7 paragraph 13).*
>
> *"and they[(the nurses] could pray with me" (Interview 5 paragraph 22).*

One family member told of her non-religious relative:

> *"Even he was saying that they are praying for us here every day. It was nice to know that here they are praying" (Interview 11 paragraph 60).*

Half of the patients (3/6) mentioned their belief that prayer is important and brings healing:

> *"...I would feel the pain in me going away, I would feel a strength coming to me, whilst I was busy praying..." (Interview 7 paragraph 8).*

Half of the patients (3/6) who spoke about spiritual care mentioned attending the nearby church or prayer meetings. Often patients are too ill to leave the care centre, but those who are well enough were invited. This was particularly important to the following two patients:

> *[Smiling and bright she said,] "I was excited every Sunday, just the fact that I am getting out of this place, I'm going to be with everyone in the church ... talking and talking" and " ...the older people they just make you comfortable"(Interview 6 paragraph 126 and 130).*
>
> *"No, people, they [staff] gave me good care. Cos I went to prayer meetings on Wednesday nights and church on Sundays" (Interview 2 paragraph 99).*

It appears that attending religious meetings helps the patient spiritually and assists in making them feel part of normal society. Being able to leave the care centre and talk to the people showed one patient that she could go back to having a "normal" life. The acceptance shown by others helped to overcome stigmatisation. This supports the research results of Ironson, Stuetzle and Fletcher (2006: 62–68) that showed that forty-five percent of people increased their spirituality/ religiousness after being diagnosed with HIV, forty-two percent stayed the same and thirteen percent decreased. The researcher furthermore compared the relevance of these findings on the CD4 counts and viral loads after four years. There is consensus that an increase in spirituality, religious behaviour (e.g. rituals, prayer or attending services) has a positive effect on both CD4 and viral load counts (Dalmida *et al.*, 2009: 119–143; Ironson *et al.*, 2006: 62–68).

Collins (1980: 4–15) states that spiritual counselling is all about change. It is about listening, reflecting and sharing about difficulties the patient may have, particularly in dealing with or making life changes. Most palliative care patients are facing

constant changes in their condition: dealing with loss or the change in life style that is required to accommodate the taking of ARV's. Grant *et al.* (2004: 371–378) assert that enabling patients to deal with their spiritual needs through affirmative relationships with health professionals improves quality of life and may reduce use of health resources. In this study, many of the participants (4/10) spoke positively of this kind of spiritual support. One patient spoke nervously with trembling voice, of working through the experience of her mother's death and the consequent fears of her own death:

> *"I was scared that I would die … I would leave my brother alone … I could see in his eyes that he was also scared" (Interview 3 paragraph 16 & 20).*
>
> *"Mm, a sister would come next to your bed and ask if you need anything, do you need to pray? Do you need to chat about anything?"... "[the chaplain] here always comes to talk and pray with us, she helped a lot" (Interview 3 paragraph 46 & 58).*

One family member stated:

> *"The patients are being taken care … even to the side of … that they can know God ... and that is why I want my sister to come here" (Interview 9 paragraph 5).*

3.3.2 THEME 2: The clients experienced that they were cared for as a holistic unique person within a <u>unique environment</u>

The therapeutic environment of a patient is part of what facilitates healing. Participants in this study experienced a unique environment of care through their physically clean and pleasing surroundings, the competence, understanding and caring of the staff. The participants described a unique environment but not one that cannot be emulated.

SUB-THEME 2.1 Physical external environment: Physical hygiene

Just as personal hygiene is important for good health, confidence and self esteem, environmental physical hygiene is of great importance (Basavanthappa, 2003: 8). Good physical hygiene is the basis for ordering one's mind and good mental hygiene. In palliative care where there is much emotional and spiritual work to be done, this was seen as particularly important. Many (4/6) patients emphasised the importance of cleanliness in the care centre.

> *"But here it was so much better, smell, the atmosphere and everything"* (Interview 5 paragraph 6).
>
> *"... the cleanliness of the place especially the bathrooms. You know places like this, especially when it is for people who have nothing you see mos from public clinics and hospitals it's not that clean. But [here] it's number one."* (Interview 7 paragraph 9).
>
> *"always with nice clean clothes and I was feeling fresh everyday"* (Interview 6 paragraph 18).

Kozier *et al.* (1995: 57) wrote of the importance of a healthy and hygienic environment. An unpleasant odour or a dirty environment gives a message of ill-health and patients feel undignified. Not only does this influence physical health, but a person's self concept can easily be threatened by an unhealthy or unhygienic environment (Brunner *et al.*, 2008: 69–71). Cleanliness and healing environments are claimed to have beneficial effects on patients (Dijkstra *et al.*, 2006: 167).

SUB-THEME 2.2 **Physical external environment:** Availability of staff

Elisabeth Kübler -Ross in her classic book, "On Death and Dying," states that what a dying person needs is simply for the carer "to be with them when their end comes close. Sit with them - you don't even have to talk. You don't have to do anything but really be there with them" (Kübler-Ross, 1973). Edwards *et al.* (2010: 753–770) write about the importance of focusing on presence and journeying in palliative care. Some of the barriers to achieving this are lack of continuity of staff and their workload. The availability of staff builds a trusting relationship and allows the patient and family to tentatively share some of their journey. Most (4/6) of the patients in this study made mention of how staff had been available to them:

> *"The staff were not so busy that they did not have time for me"* (Interview 5 paragraph 21).
>
> *"…a sister would come next to your bed and ask if you need anything"* (Interview 3 paragraph 46).
>
> *"There was somebody with me all the time"* (Interview 4 paragraph 8).

Doyle (1983) described death as one of the most solitary or lonely experiences of life. It is a time that we desperately want to be accompanied, not just by a stranger, but by a person with whom we can share the intimate secret of our death. According to Grau Abalo *et al.* (2008: 37–38) when a person is faced with a terminally ill patient they are to some extent confronted by their own mortality. If the person fears death, a barrier is formed between them and the patient. This tends to emphasise the loneliness of the patient. At times, health care providers fear their own death and so become "very busy", avoid the patient or a break-down in communication occurs. This prevents the patient from being able to share intimately about his/ her death and work through the grief and losses that s/he is facing.

SUB-THEME 2.3 **Physical external environment:** Medical competence

Searle (1999: 75) is of the opinion that nurses and care givers have to be committed in maintaining standards of quality of nursing. This aspect of commitment is reflected in the way the patient receives care: caring, protective,

supportive and technically competent, knowledgeable, legal and ethical. In this research study, the family members expressed gratitude for the professional conduct of all members of Dignity House:

> *"They [nurses] will treat him the way we would and even better because they have all the knowledge" (Interview 8 paragraph 45).*
>
> *"The treatment is good. If the patient is sick he or she will have the treatment at the exact times ... here really it was superb" (Interview 11 paragraph 13).*

It is widely accepted (Chochinov, 2006: 84–85; R. Harding *et al.*, 2011: 553–554; Jameson 2008, 6–10) that medical competence in palliative care is holistic, includes impeccable assessment and good pain and symptom control. Patients spoke at length about the holistic care they had received, the pain control and the detailed assessment. One patient shared how she had been in a lot of pain before being admitted and was given medication, but it did not help. When she arrived she was prayed for and given the correct combination of medications to control her pain:

> *"Plus the medication and they knew what to do … it helped me, it saved my life, really" (Interview 7 paragraph 11).*
>
> *"Even if it is a small thing that you feel it is itching here you get the medication and everything ...that close close care, checking up on you all the time" (Interview 6 paragraph 10 & 14).*
>
> *"The nurses were there checking on us" (Interview 4 paragraph 8).*

Ferrell and Coyle (2005: 7) state that palliative nursing involves three broad areas: approaching care from patient-based and family-based inter-dimensional care focus; expertise in end-stage disease; applying nursing process as part of the inter-disciplinary team. It becomes the responsibility of every nurse to gain specific knowledge and competence for the area in which they work (Ferrell and Coyle, 2005: 29–31).

SUB-THEME 2.4 **Emotional external environment**: Experienced the relationship with the staff members positively

Dying is by definition a lonely process as each of us faces the experience for ourselves and individually (Ferrell and Coyle, 2005: 23). So it is in this situation that patient and family most need positive relationships with medical staff. Chichonov (2007: 184–187) names *dialogue* as a crucial part of palliative care and defines this as "acknowledging personhood beyond a pathology". Without a positive relationship, patients and families are unable to ask for even the most basic of needs to be fulfilled. All the participants of this study spoke of the relationships they had built with staff. Patients said:

> *"a wonderful experience! Everyone was just so friendly"* (Interview 3 paragraph 8).

> *"They make you feel that they own you, you are theirs. You belong to them. … as a result, I told myself that I must not mess up anything because I want to keep that understanding, that love, I didn't want to tire them. But they would say, no, don't, if you are about to vomit and there is no one here just ring the bell or … don't worry if you mess, we are here for that" (Interview 7 paragraph 21).*
>
> *"But beside to have medicines, when I saw nurses I would just be ok" (Interview 4 paragraph 1).*

A family member said:

> *"They are always greeting you with smiles" (Interview 8 paragraph 33).*

Ferrell and Coyle (2005: 7) state that the nurse's individual relationship with the patient and family is seen as crucial. This relationship, together with knowledge and skills is the essence of palliative nursing and sets it apart from other areas of nursing practice. If that relationship of trust and respect is not built, the patient and family will not be able to share more intimate issues related to loss and dying.

SUB-THEME 2.5 **Emotional external environment:** Caring and loving relationship with staff

The relationship between the staff and the terminal patient is important in modulating the experience of dying and subsequent death. The patient and family

look for respect, trust, alliance, warmth, care and understanding, as well as encouragement from their caregivers and not only physical support (Kübler-Ross, 1973: 10–11; Chochinov, 2007: 184–187). In this research, the researcher found patients preferred a home-like environment and care givers with whom they are personally acquainted or with whom they could easily build a relationship. Patients showed this in the following comments:

> *"If someone loves you, you get well, even before you get a treatment. That is the thing that is happening here – firstly I got love" (Interview 4 paragraph 30).*
>
> *"The [staff] are warm hearted, the love that you get here and hmm ... they treat you well. They make you to feel that you are ok ... They give you love. They make you feel that they own you, you are theirs. You belong to them. That's what I felt." (Interview 7 paragraph 9 & 21).*
>
> *"The care that you get from the sisters" (Interview 3 paragraph 16).*

Even the family members could see the staff's caring attitude to the patients:

> "The staff, here are very loving, kind to the patient and everyone who is coming here" (Interview 8 paragraph 33-34).

This relationship is the foundation for basic communication, assessment and intervention. Stridh and Svensson (2011: 18) affirm that a relationship based on trust is required if nurses are to be able to identify a patient's spiritual and existential needs. This can also be applied to other areas in the life of the dying patient.

SUB-THEME 2.6 **Emotional external environment:** Understanding from staff

In this study, the researcher made the deduction that staff showed understanding to patients as the participants repetitively referred back to previous negative experiences in different settings. Lack of understanding between the nursing staff and terminal patient and their families has a very negative impact on the quality of palliative care. Ferrell and Coyle (2005: 7) state that in palliative nursing the "individual" is recognized as a very important part of the healing relationship. If patients are not seen as individuals, they do not feel understood and their personhood is diminished. This prevents a deeper sharing of the issues of dying. Most of the participants were apprehensive about not finding understanding and commented on their experiences of being incontinent in the care centre:

> *"Eeh, nobody was shouting at me. Here, if I'm wet, ok I was wet, it was a mistake and the sisters would just cover that thing and changed the bed without shouting at me" (Interview 6 paragraph 46).*
>
> *"Even if you just maybe wee wee no one will shout at you. Nurses they will help you about that" (Interview 4 paragraph 30).*

It is obvious from these statements that previous experiences within the hospital system influenced patients' initial fears on admission. Others shared their experiences of staff at the care centre:

> *"I was scared of people [especially the nurses]... As time went on I saw there is actually nothing wrong" (Interview 2 paragraph 22-24).*
>
> *"I felt like I could talk to everyone" (Interview 5 paragraph 20)*
>
> *"…people who understand…" (Interview 7 paragraph 25).*

Another patient shared her experience of learning how to use a colostomy bag and the understanding of nurses in the care centre:

> *"You mess up, you do things and they would come as if nothing has happened and clean you up. And if you feel shy or embarrassed by what you have done, they will make you feel comfortable and tell you that these things they do happen, it's not your fault, you are sick. We are here to look after you" (Interview 7 paragraph 21).*

Being incontinent can be a very degrading and undignified experience. Kozier *et al.* (1995: 472) cite elimination of waste as a very personal, private and independent act. When a patient has problems in this area of their lives, it causes great embarrassment and discomfort. The nurse's reaction to the patient being incontinent affects how the patient is able to cope with it. Frequently in palliative care, a person's physical and functional dimensions decline. During this time quality of life can be enhanced by paying attention to their interpersonal well-being and transcendent dimensions (Ferrell and Coyle, 2005: 23).

SUB-THEME 2.7 **External social environment:** Experienced the social environment as being positive

It is generally agreed (Chochinov, 2006: 84–103; Gysels *et al.*, 2011: 6; Kikule, 2003: 192–194; Harding and Higginson, 2005: 1971–1977) that the social aspects of palliative care are very important. If there is a tense or frenetic atmosphere, it is difficult for patients to relax and concentrate on the work of their own healing and/ or dying process. In this study the researcher found the respondents were impressed with their interactions with the nursing staff and found the social environment to be positive. Most (8/10) participants felt welcome, taken care of and nurtured. This was reiterated by patients' statements such as:

> *"…it was like family, like I was at home" (Interview 6 paragraph 4).*
>
> *"I feel accepted. I was feeling that I was home" (Interview 6 paragraph 26).*
>
> *"…the atmosphere and everything. It was so much better here ... it was much more relaxing" (Interview 5 paragraph 6, 14 & 40).*
>
> *"It is a pleasant place here." (Interview 6 paragraph 146).*

SUB-THEME 2.8 **External social environment:** Experienced hospitality

It is commonly agreed that persons living with HIV and AIDS experience stigma on a regular basis (Campbell *et al.*, 2011: 1204–1219; Visser *et al.*, 2009: 197–206). For many patients, they are not shown hospitality in their communities nor even

welcomed in their own homes. For some this has become a deeply entrenched part of their self image (Kalichman *et al.*, 2009: 87–93) and so it is most important, when a person living with HIV enters a hospital or unit for palliative care for the first time, that they are treated with respect and acceptance. On admission palliative care patients often experience fear and uncertainty about the care, treatment and inevitable death. This is the time when they feel and are most vulnerable. These patients need to be welcomed from the moment they arrive into the strange environment and given comfort and care. The word "*hospice*" comes from the Latin word "*hospes*" meaning to host a guest or stranger (Amitabha Hospice, 2012). Most participants shared about the hospitality they were shown in the care centre and patients expressed it this way:

"Well, I was afraid at first. I didn't even want to come because there is this thing that when you are admitted in a hospice you are about to die… And hmm, the staff they treat you well. They make you to feel that you are ok. Even if you are about to die, they make you to forget ... Yes, they welcome you. They make you feel at home" (Interview 7 paragraph 1,2 & 5).

"Oh, I was feeling like I was being at home – with good hands, love, faith, honesty" (Interview 4 paragraph 8).

"Everything even the bedding, the linen, it is so welcoming" [holding her arms as if to hug herself] (Interview 6 paragraph 146).

"It was the hospitality of the staff" (Interview 2 paragraph 38).

"It was like family, like I was at home, somebody looking after me at home nicely" (Interview 6 paragraph 18).

SUB-THEME 2.9 **External social environment:** The relationships between the family members were encouraged

For many patients and their families the last moments they spend together are at a hospice or palliative care centre. Thus it would seem imperative that such a place promotes communication, reconciliation, planning for the future and strengthening of relationships. According to Chochinov (2006: 85), one of the fundamental principles of palliative care and patient wishes is to bolster or enhance these relationships. Ferrell and Coyle (2005: 705) state that it is important to encourage open communication between the patient and family so that they can work toward reconciliation and completion of any unfinished business. Some patients mentioned this aspect of care:

> *"Even my husband said it was better coming to visit me here because he could come any time of day. Also my son preferred it here. He could sit with me and hold my hand" (Interview 5 paragraph 34).*

Because a death affects the whole family, palliative nursing focuses on care from a patient and family perspective (Ferrell and Coyle, 2005: 14). According to Penson *et al.* (2005: 160–169) patients can use their illness as an opportunity to prepare for the end of life, to close old conflicts, to say goodbye and seek forgiveness. Clearly, this requires that the loved ones are near and that there are little to no communication barriers between them.

The researcher found that most family members spoke of the way in which the care centre facilitated their interaction with their families. For some it was that they were relieved of the huge stress of physical care so that they had energy to interact with their loved one:

> *"I had to go [to the hospital] frequently to change him. He was wet, wet. But here it was nice to him. When I came to visit there was nothing I had to do because he was dry" (Interview 11 paragraph 5).*

3.3.3 THEME 3: Experienced traumatic recollections of previous hospitalizations and nursing care

In several studies (AVERT, 2012b; Makoae and Jubber, 2008: 40–44) from different continents, many patients report stigmatisation and describe health providers as unkind, rude, brusque, unsympathetic and uncaring. Relations in terminal settings are sometimes so tense that the patients and families are afraid to call for help. Cassell (1999: 531–534) wrote about how being labeled as "dying" affects how others behave towards that person and how they behave towards self and others. For health care professionals, there can be a "disengaging" which leaves the patient isolated and uncared for. The participants in this study

remembered well the treatment and care they received in other health settings: verbal abuse, rough treatment, threats, scolding, shouting and intentional humiliation and physical neglect. One of the participants in this study reported negatively on this care centre. Patients revealed previous experiences with vivid recollection:

"Sometimes if you are in hospital the nurses just leave you with your medication, they don't care. They will just ignore you even when you leave the medication there. And they don't change you most of the time. If you wet yourself they shout at you..." (Interview 6 paragraph 14).

"They [nurses] don't even care if you take [your medicines] or not, it is your trouble, they don't mind. They didn't look after you. So you get sick all the time" (Interview 4 paragraph 58).

"... they just let you wear those open gowns and you are always feeling that you are cold and open ..." (Interview 6 paragraph 22).

"it was such a horrible urine smell ..." (Interview 5 paragraph 6).

"They told now you must go to the toilet or now you must do this ... it was horrible" (Interview 5 paragraph 14).

"I couldn't talk to anyone. They were always busy doing other things" (Interview 5 paragraph 20 & 22).

And one family member shared her experiences:

"The [ARV treatment times] were haphazard" (Interview 11 paragraph 13).

"There he was left" (Interview 11 paragraph 52).

The lack of compassionate care in South Africa health care settings is often reported. There are regularly reports of patient abuse and nurse negligence, especially in the government settings (Khuthala, 2012: 1).

It is not unusual that burn out and feelings of hopelessness lead to hostility. Health care providers today in South Africa face deaths on a frequent if not daily basis due to HIV. Coping with cumulative loss is never easy. The challenges of working in palliative care with HIV and AIDS patients is widely acknowledged (Chandra *et al.*, 2004: 48–54; de Saxe Zerden *et al.*, 2009: 38–43; Singh *et al.*, 2011: 1–7; van Rooyen *et al.*, 2009: 1–11). Those health care providers who are not able to process these losses through appropriate grief and personal death awareness may begin to distance themselves from emotional involvement with patients and families. This withdrawal negatively affects not only the coping ability of the professional, but also the quality of compassionate delivery of care and the ability to meet the needs of the dying patient and their families during the terminal phase of illness (Ferrell and Coyle, 2005: 37). According to Chochinov (2007: 184–187) a lack of curative options should not influence the amount of contact health professionals have with the terminal patient. If palliative care is really understood, professional caregivers would know the importance of care and not be disappointed and frustrated by the low cure rate.

3.3.4 THEME 4: Experienced a sense of fear, hopelessness and a spiritual void before admission

Penson *et al.* (2005: 160–169) wrote that to fear death is a rational response and in health care, this primeval fear should not be ignored. The fact that we cannot fully comprehend death, makes it all the more fearful (Mermann, 1992: 137–142). The fears are many: fear of the moment of death itself, or of the process of dying, of isolation, loss of control or of pain and physical suffering (Penson *et al.*, 2005: 160–169). It would appear that this is the moment in which patients most need care and support, but many of the patients in this research reported their experience of difficulty accessing effective treatment and the feelings of fear, hopelessness and spiritual void in previous health care settings.

"…before I came here, the doctor gave me a letter to see the social worker but she was on leave. And those were the days that I was very, very sick. I would have died. I asked my brother to phone [our friend] to help because I feel now I'm about to go home. And my brother was so scared. So I have a belief that I would have died. Because the waiting period was too long. Because there was absolutely nothing they could do before I see the social worker in order to start me on treatment … So that was a very long time, sitting at home with TB being around other people and a CD4 count of 34" (Interview 3 paragraph 14).

"I was very dizzy, I can't even see what was going on with me and eeh, I was just feeling down [after returning to the clinic several times]" (Interview 4 paragraph 2).

"Well, I was afraid at first. I didn't even want to come because there is this thing that when you are admitted in a hospice you are about to die. So I was afraid" (Interview 7 paragraph 1).

"I was scared that I would die, because I saw that I was on the verge of my deathbed" (Interview 3 paragraph 16).

Penson *et al.* (2005: 162) wrote that in the United States of America one strategy is to provide empathy by finding out what the patient is most afraid of, what it is that is hard for them, and allow them to think it out loud and express their true emotions. It seems, however, that in Buffalo City, often times the terminally ill person battles to access care and is left alone with his/ her fears and with little hope.

"But because what people here did, I need you to see that what you are doing here changes lives, their perception of this place called hospice. I'm sure it is not me alone that thinks these things about a hospice that you go there to die. But by what you did, I got healed ... in that Dignity House people get healed, people get saved. What you did here it is making us want to get better. It's an encouragement. By closing this place many people will suffer especially those who are HIV positive. I tell them that at that place they will help you ... They help you until you are better" (Interview 7 paragraph 23).

3.3.5 THEME 5: Family experienced relief when the patient was admitted in the care centre

Family members carry the burden of caring for their loved one at home even with the presence of a HBC programme. The task of caring for a terminally ill person with HIV and AIDS at home "is over-whelming and the effects devastating." (UNAIDS/UNFPA/UNIFEM, 2004). Several authors report on these severe effects (HelpAge International, 2006; Ogden *et al.*, 2006: 333–342). A family member must stay at home, leave employment or studies and assume the role of carer (Kikule, 2003: 192–194). The family is often affected emotionally, not only with the difficult

task of grieving, but the added stress of not knowing how to care. According to Bachmann and Booysen (2003: 14 & 2006: 1861–1867), the physical and severe economic strain causes malnutrition and even more illness in the family.

In this study, families caring for patients at home were stressed, felt alone and hopeless. They felt they didn't have the adequate knowledge to care for their patient at home. This is evidenced by the following direct family member's quotes:

"The other thing is that when your family is sick you lose that hope when you are staying with him or her. You just give up everything. You just feel alone, you don't have that support" (Interview 8 paragraph 5).

"[We didn't know]…how to treat them and how to love them" (Interview 8 paragraph 3).

Orner (2006: 236–240) reported that care giving placed considerable demands on families which was exacerbated by insufficient support and dire poverty. Lack of support was extremely stressful and often debilitating.

In this study, one family member told tearfully how her sister had been looked after in the care centre, but had gone back to drinking and had stopped taking her treatment:

> *"I don't know what I can do. Maybe I'm not doing it right ... It is so difficult ... It's hurting me, it's hurting me. Really it is hurting me"*
> *(Interview 9 paragraph 2, 4 & 7).*

Even with all that the care centre offers, there is still significant strain on the family. Akntola (2008: 1) affirms that families are unable to cope with providing care in their homes. This is attributed to the often long drawn out nature of HIV disease, the financial burden and the frequent lack of necessary skills and support for providing adequate care.

The researcher found that all the family participants shared how relieved and grateful they were that their patient could be cared for in the care centre:

> *"Since then I haven't been stressing like I was stressing then"* (Interview 10 paragraph 1).
>
> *"For me it was firstly a relief…"* (Interview 8 paragraph 1).
>
> *"So this place helped out a lot"* (Interview 10 paragraph 2).
>
> *"…we are glad that we found this place."* (Interview 8 paragraph 12).
>
> *"I was so blessed. I know that there is care here"* (Interview 11 paragraph 1).

3.4   Conclusion

This chapter gave an account of the analysis of the data gathered from the interviews with palliative care patients and their families as they recount their lived experiences of the care and treatment they received in an urban care centre in Buffalo City. The patients and family members tended to agree on their experiences and what they shared as their needs. Themes and sub themes that emerged were discussed and supporting literature on the subject was given. There was one instance where a patient shared about being made to eat something she did not like and autonomy was not respected, but this was the only contradiction shared by participants.

The next chapter will contain the conclusions, guidelines, recommendations and limitations of this study.

CHAPTER 4:

CONCLUSIONS, GUIDELINES, RECOMMENDATIONS AND LIMITATIONS

4.1   Introduction

In this study, the researcher investigated the palliative care experiences of HIV and AIDS patients. The purpose of this research study was to explore and describe the lived experiences of HIV patients and their families regarding the palliative care given in a care centre in Buffalo City. When the researcher asked participants about their experiences, they spoke freely about both their experiences and their needs. The understanding of their experiences and needs will lead to a better education and guidance of nurses caring for patients facing a life-threatening illness such as HIV.

In the previous chapter, the data analysis was summarised and the results of the study were discussed as related to relevant literature in order to re-contextualise the findings. In this chapter, conclusions will be drawn from the data and analysis, and this will lead to providing guidelines for a small urban palliative care centre. Thereafter the recommendations and limitations of the study will be discussed.

4.2   Conclusions

The death of a significant person is the most difficult loss most families face in their lifetime. This may be in part because "Most of us fear the thought of death" and "In

our culture we continually avoid looking at the reality of change and death" (Richo, 2008: 5, 17). According to Kübler-Ross (1997) it is difficult to accept death in this society because it is unfamiliar and mostly hidden. While this may still be the case in Europe, it may not be so in South Africa today. The high rate of HIV infections means that many people die of Aids-related conditions. It is thus inevitable that health care professionals will come into contact on a daily basis with patients and their families going through the process of bereavement, in most of the healthcare settings. The bereavement process can be a lengthy one and can be influenced by numerous events and personal experiences.

Caring for people at the end of life is challenging for both families and health care professionals. Death is still a fearful, frightening happening, and the fear of death is a universal fear even if we think we have mastered it on many levels (Kübler-Ross, 1973: 7). The dying person must be supported through illness and accompanied during the phases of dealing with loss and grief. As life ends, the patient must be guided through the end stages and the family supported and cared for in their bereavement.

> *Palliative care is seen by the WHO (2012) as care that improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.*

Palliative care focuses on symptom relief without curing the illness which is causing the problem but also encompasses much more than just symptom control. "The essence of palliative care is the relief of suffering" (D. Doyle in Gwyther and Cohen, 2009: 2). Due to the complexity of palliative care, a multi disciplinary approach is followed but the nurse is central in caring for these patients and their families.

Caring should be the hallmark of the nursing profession and the quality of care given is reflected by the caring attitude of the nursing practitioner. The nurse caring for the terminal patient and his family has a legal obligation to render safe and competent care. The Constitution of South Africa (1996) further states the importance of delivering care to vulnerable persons, throughout the life-span, to ensure a dignified death.

Most of the themes and the sub themes in this study were interrelated and it is actually difficult to separate one from the other. Nevertheless, for the sake of simplicity and understanding, these themes and sub themes were discussed separately, though interrelated with one another as seen in the previous chapter.

In palliative care, special emphasis must be placed on the collaborative relationship between the nurse and the dying person. In order to care for this vulnerable person, the aspect of respect, empathy, support and compassion should be embraced. The ethics of care enables the nurse to respond to others as

worthy, with no expectation or reciprocity. Moral behaviour arises from a natural impulse to care and incorporate compassion, benevolence, honesty and kindness.

Many of the themes identified in this study are reflected in the principles of palliative care of the World Health Organisation. For ease of order and continuity of thought the conclusions from this study will be presented according to the following principles that underpin the approach to palliative care as formulated by the World Health Organisation.

4.2.1 Palliative care: Affirms life and regards dying as a normal process (WHO, 2012).

- ❖ The researcher found that the health professionals caring for HIV and AIDS clients in Buffalo City promoted quality of life and comfort regardless of the client's stage of the illness.

- ❖ All but one of the patients felt physically cared for in a clean environment and supported during meals and the taking of medication. They experienced this care to be part of the privilege of being alive.

- ❖ Patients experienced the care they received to affirm life.

4.2.2 Palliative care: Provides relief from pain and other distressing symptoms (WHO, 2012).

- ❖ In this study, few patients spoke of the importance of pain and symptom control but _care_ seemed to be of major importance to all. Patients appreciated being comfortable and noted that the nurses had the necessary knowledge to bring relief.

❖ The relationships between the patient and family and the caregivers were positive and considered to be the key element in the quality of care they received.

4.2.3 Palliative care: Integrates the psychological, cultural and spiritual aspects of patient care (WHO, 2012).

Any person who approaches a health service for assistance has the right to expect treatment and care. The nurse thus accepts full responsibility for the terminally ill and dying person and is guided by their personal and professional codes of conduct. The principle of respect for persons furthermore implies that the dying person has the right to respect, dignity and the absence of discrimination where s/he has the freedom to participate in decisions regarding their health.

The relationship between the nurse and the person and family during the end-phase of life, is important in modulating the experience of bereavement and death. The patients and their families during these phases look for respect, trust, alliance, warmth, care and understanding, as well as encouragement and not only physical support.

❖ The researcher found in this study that the patients had a positive experience in their interaction with the nurses during admission into the palliative care centre. They felt very welcome, and were treated with dignity and respect.

❖ The relationship between the patient and family and the caregivers were positive and considered to be the key element in the quality of care they received.

❖ The nurses were empathic, kind and caring and staff were available to both patients and family members.

- ❖ The patients and family members alike emphasized the importance of holistic care they had received.

- ❖ Patients were cared for spiritually and experienced positive interaction with the multi-disciplinary team. They felt strengthened and encouraged in their spirituality by the treatment they received.

4.2.4 Palliative care: offers a support system to help patients live as actively as possible until death (WHO, 2012).

- ❖ The researcher found that the patient and their families were allowed to participate in their own health care and were encouraged to exercise choices – thus enforcing the principle of self-determination.

- ❖ Participants appreciated being able to be with their family whenever they wanted to be, encouraging family relationships.

- ❖ Others mentioned being able to attend church services or meetings had been encouraging to them.

- ❖ The researcher found that communication with the health care professionals was a crucial factor for the terminal patient and their families. The patients wanted to have more information regarding their illness and treatment and felt empowered by gaining that knowledge. The central focus seemed to be the need for information, being cared for and being supported.

4.2.5 Palliative care: offers a support system to help the patients and the families to cope during the patient's illness and in their own bereavement (WHO, 2012).

- ❖ The researcher found that the multidisciplinary approach to address the needs of the patient and the family was experienced to be most effective.

- ❖ The patients and their families felt that they were treated with dignity and respect, with consideration of traditional and cultural practices. The family could be present at any given time.

- ❖ The families expressed their sense of hopelessness, aloneness and stress at having to care for their loved one at home. This was contrasted by the support and knowledge that they received in the care centre.

- ❖ While none of the participants discussed working through losses or grief in detail, they felt supported and enabled to talk through issues.

- ❖ A repetitive theme was the patients' recollection of how information was withheld from them in previous health care settings; the rudeness they experienced and the disempowerment they felt.

- ❖ The palliative care patients in this study expressed extreme vulnerability by the lack of proper communication and verbal assaults in the ordinary health care system. This was a repetitive theme, where they reiterated the lack of basic care and treatment they experienced previously. This had made them initially fearful of being admitted into the palliative care centre.

4.3 Guidelines

The researcher compiled the following guidelines that can assist any health care professional in any given setting; providing palliative care to the terminally ill patient and their families. They are presented according the principles of palliative care.

4.3.1 Affirm life and regard dying as a normal process

- ❖ Nurses should render high quality palliative care. Compassionate care and availability of staff are paramount.

- ❖ Care is often shown in the details of our approach. Participants of this study told how a clean, hospitable environment had been important to them. The care shown by waiting in front of the patient while they took their medication affirmed life for another. The staff and the environment should be welcoming and bright to the people they serve.

- ❖ Participants all spoke of how important the ethos of dignity was to them. Staff must have a clear understanding of the vision, mission and values of the organisation as well as the principles of palliative care. Best practice in palliative care should be discussed and systems developed to best implement them.

- ❖ Patients shared what it meant to them that no one was discriminated against and that staff were open to them. Staff should also be made aware of their own feelings about HIV, dying and the grief process. The extent to which one has faced one's own death is the extent to which one has freedom in working with dying patients.

- ❖ Management must support nurses in caring for the dying patient and their families, recognizing that the emotional burden of caring is high and that burn out is common in hospices. It is clear that quality care cannot be given by emotionally exhausted or burnt out staff. Staff should be coached on how to prevent burn out. One way of doing this can be to increase staff awareness of the purpose and meaning of their work and by increasing their curiosity and resilience. An implication of this is for staff to understand that palliative care is, "to cure sometimes, to relieve often, to comfort always" (Edward Livingston Trudeau, 1800s) and that the expected death rate is estimated at around 25% (Khan and Sayed, 2011). Participants of this study all told of their experience of the caring and loving staff. It is important that staff are able to work through the issues they face in their work in order to be able to care for the next patient and family.

- ❖ Staff should be provided with debriefing and group work. This should incorporate spiritual counselling, self-awareness and personal growth. It is important that staff understand principles of self care and see this as their responsibility which is facilitated by their managers.

4.3.2 Pain and Symptom relief

❖ Patients in this study told of their experiences of staff be able to manage their pain and symptoms. Medical staff should be trained in principles and skills of pain and symptom control and the relevant medication and equipment made available e.g. syringe driver, morphine (both oral and injectable), foot spa, heat pads, massage oils.

❖ Pain charts can be a useful tool in assisting with pain assessment, communication with patient and amongst the staff members.

❖ Participants all spoke of their relationship with the staff and how important it was for them to feel understood and that they could talk openly with staff. Nurses should be coached in how to develop good relationships with patients and families. The nurse-patient relationship must be well developed in order to build trust and communicate around the issues of pain and symptoms.

❖ The nurse must see the patient holistically and understand them as a person and not an illness. Pain is not just physical and must be treated as such.

❖ Trust must be developed in the relationship with the patient and family. They must be confident that the nurses know how to help them deal with their symptoms.

❖ Staff should be trained in communication and especially listening skills. Dying patients often speak using metaphors and cues to test out how much the listener is comfortable with the subject of death or pain. Good communication must be established with the patient and family in order to understand the patient's needs, to discuss his/her pain and also to give the necessary information for them to understand what is happening and how they can best work together to ensure relief of suffering.

4.3.3 Palliative care: Integrates the psychological, cultural and spiritual aspects of patient care

❖ Nurses should render care from a framework of caring irrespective of colour, creed, health diagnosis or any other discriminatory factor. Nurses need the knowledge, skills, experience and values to implement this.

❖ Staff must see care as holistic and their patients and family as an integrated whole. Family members and patients alike told how they had developed a good relationship with the staff.

❖ Professional development programs should be used to support staff. These programs should emphasise basic human needs; human rights issues; respectful of the client with open communication; inclusion of family and relative; provision of unbiased accurate information. The inclusion of rights to decision-making; explanation of procedures and support persons are also important issues. Patients in this study emphasised the importance of autonomy and respect.

❖ Another important issue in South Africa is the cultural aspects of care; how to sensitively deal with different languages, beliefs, foods and customs. It is helpful to have staff of different cultures to explain, and give insight into, the thinking of the other person. Yet the underlying attitude of expecting and respecting differences is perhaps of more importance.

❖ Because palliative care is holistic in nature there is a particular need for staff to improve their communication skills. This requires emotional and cognitive development and is more than just a set of skills.

❖ Spiritual care and spirituality is an area that is often neglected or less developed but is a very necessary part of palliative care. Participants of this study made frequent mention of the benefit of spiritual support through prayer, counselling and religious meetings. Although this work is often left to the spiritual worker on the team it is important for all members to be aware of the spiritual needs of patients and how to care. Nurses should be trained in how to give spiritual care and to grow and remain refreshed in their own spirituality.

4.3.4 Palliative care: offers a support system to help patients live as actively as possible until death

❖ The multidisciplinary team needs to include the patient and family actively in the developing of each individual care plan for each patient.

❖ When patients in this study experienced the right to exercise choices and autonomy, they said it helped to make them feel "special" or "respected". The patient should be given as many choices as possible – treatment, food, clothing, daily routine and bed linen. This strengthens the principle of self determination and helps the person to live actively until death.

❖ Communication with both family and patient is a crucial element. Sharing the truth and information about the patient's condition and prognosis is vital. Without this information the patient cannot make wise decisions about how to live her or his life.

❖ Patients should be encouraged to be as active as their condition allows them. Some patients spoke about how much it meant to go to church. Families should be encouraged to include patients even though they may be bedridden at the time and going home for the day or a few hours can be very important.

4.3.5 Palliative care: offers a support system to help the patients and the families to cope during the patient's illness and in their own bereavement

❖ The team should always be available to both the patient and the family and should be encouraged to ask questions and discuss their thoughts and emotions. Participants of this study told how open communication with staff had helped them to feel at home and supported.

❖ There should be open visiting with only restrictions that protect the patient and family e.g. in the case of TB infection or patient privacy for hygiene routines.

❖ The relationship established with patient and family must be one of trust, openness and honesty to enable free communication and support.

4.3.6 Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

❖ For effective palliative care there should be a multidisciplinary team or strong links and networking with other organisations to provide this care. Linking with other organisations for mutual benefit also brings a richness of service.

❖ Multidisciplinary rounds are a useful tool to enhance good communication in the team and ensure that all the components of care are rendered.

❖ In order for a team and therefore an organisation to function optimally there needs to be a clear vision, mission and values which would be based on an agreed theoretical framework. Every organisation is set within its own context and attention should be paid to stake-holder and networking partners. For effective co-ordination of services, it is important for management to collaborate and partner with other organisation.

❖ One such partnership could be to work in association with a training institution for financial sustainability and promotion of best practice. Often this sort of experience is beyond the textbook and the best way to kindle a passion for nursing is generating a reflexive sense of relaxation and spiritual connection with individuals who need care and who are deeply appreciative of personal involvement.

4.3.7 Will enhance the quality of life, and will also positively influence the course of illness

❖ Staff should learn to see the patients for the individual people they are, to understand the multidimensional aspects of each person and his/ her situation. This is in sharp contrast to knowing only the diagnosis and treatment for "bed number 5" that often occurs in busy curative settings.

❖ One patient described her stay in the care centre as, "so much better". Her quality of life and condition were vastly improved by staff recognising her needs, respecting her autonomy and individuality. Staff should be trained in the skill of assessment and every effort made to treat illness where appropriate. In the field of HIV palliative care there is much debate and confusion around what is curative and what is palliative. It has been the experience of the researcher that there are difficult decisions to face but that team discussion and seeking the good of the patient has served to guide action.

4.4 Recommendations

Further research is recommended in the following areas:

❖ It was not the intention of this study to generalise the findings but it would be important to extend this investigation to a broader population.

❖ A satisfaction survey of patients would also help to generalise these data.

❖ Determine the needs of the practising palliative care nurses.

❖ Determine the knowledge and skills of nurses working in palliative care settings.

❖ Develop a model for culturally sensitive palliative nursing care.

❖ Explore HIV palliative care to better understand the needs of patients in relation to the dying process and grieving.

❖ Explore the effects of caring for an HIV and AIDS patient on the family caregivers and other members of the family.

4.5   Limitations

The research was conducted in English only. Some of the patients may have withheld information because of a lack of English language proficiency.

Participants focused primarily on the care they received and did not delve deeper into their own bereavement process. The language used during the interviews could have influenced this process.

4.6   Conclusion

In conclusion this study has explored and described the experiences of HIV and AIDS patients and their families regarding palliative care in an urban care centre in Buffalo City. It appears that the most important experiences of participants were the care (dignity and respect) and hospitality given to them in the care centre. The HIV patients and their families who participated in this study want holistic care in a clean, friendly environment where they can exercise choices about their treatment, care and lives.

4.7 Epilogue

Due to a lack of funding, Dignity House was forced to close its doors on the 30 September 2012.

Most of the clients were sent home to be cared for by their families, two were referred to networking partners and one was so ill that she was admitted to the local hospital. Another patient passed away the following week.

The staff were all retrenched. Each one will need to work through the personal loss of employment, but perhaps most difficult is thinking of what will happen to those whom Dignity House would have served.

More patients will now die of HIV and AIDS. Others will survive but the effects on their families may leave scars for always. All those very ill patients will pass through some of their darkest hours of being HIV positive with little or no access to care.

There will be an even greater burden on the state health facilities and the few non-governmental institutions that try to serve persons with HIV and AIDS. The economic cost to the state facilities will increase greatly as many opportunistic infections will go undetected and more patients will need more medication and longer hospitalisation.

On completion of this study the researcher is left with the following soul-searching questions:

Are we to ignore those who are unable to speak for themselves?

Who will speak for these, some of the most vulnerable in our society?

How will they be cared for in the future?

Who will care for the care givers?

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LIST OF ANNEXURE

A. Letter to participants requesting consent:

Researcher: HELEN BUNT   Student Number: 201107713

Dear Participant,

I am registered for a masters' programme at the University of Fort Hare. I am inviting patients who have been cared for at Dignity House for more than three weeks to participate in a research study. The title of my study is THE EXPERIENCES OF PALLIATIVE CARE IN AN URBAN CARE CENTRE BY HIV/AIDS PATIENTS AND THEIR FAMILIES IN BUFFALO CITY. The purpose of the study is to understand better what you and /or your family experienced during your stay in Dignity House and then to be able to formulate guidelines for care in such a centre.

Your participation in this study is completely voluntary. You are under no obligation at all to participate and may withdraw at any time along the process without any consequences at all.

Although there will be no direct benefit to you, it may improve the service offered at the care centre and may influence other care centres. The only risk involved is that it may be painful for you to remember the time that you were so sick and admitted in the care centre.

I would like to interview you privately, and ask you about your experiences. This interview will last about 45-60 minutes. Your real name will not be published. The information you share about your experience will be reported on but any names of staff members or personal details you tell will be omitted.

This study and its processes have been approved by the ethics committee and thesis Board of the University of Fort Hare. If you have any questions about participating or anything linked to this study, please contact me, Helen Bunt 043-722 9283.

__ I agree to be interviewed for the purpose of this research

__ I consent for the interview to be audio taped

__ I understand that I can stop at any time with no pressure to go on or any other consequences.

__ I understand that my name will not be used and the information I share will be used in such a way as to guard my anonymity.

__ I consent to the tape and written form of my interview to be kept for three years.

_____   _____   _____

   Signature of witness   Signature of subject   Date

B. Letter granting permission to conduct research by Ethics Committee, University of Fort Hare

OFFICE OF THE DEPUTY VICE-CHANCELLOR:
ACADEMIC AFFAIRS AND RESEARCH
Private Bag X1314,   Alice 5700
Tel: 04060 22403
Fax: 0866282944
tsnyders@ufh.ac.za

University of Fort Hare
Together in Excellence

UFH/UREC, 19 - REC-270710-028

Application for clearance from the University of Fort Hare's Ethics Committee

Project title: **Experiences of HIV and AIDS patients and families regarding palliative care in an urban care centre in Buffalo City**

Chief Researcher: Helen Bunt

Supervisor/Co-supervisor: Dr DW Du Plessis

Date of application: 29 March 2012

Having consulted the Dean of Research, I hereby grant permission to conduct the research.

Professor G de Wet
Deputy Vice-Chancellor
Chairperson of the interim Ethics Committee

10 April 2012

C. Letter of consent to conduct research in Dignity House, Sophumelela

P.O. Box 11126, 1-10 Belgravia Crescent, Southernwood, East London, 5213, South Africa
Tel: +27 43 722 2261; Fax:+27 86 219 5776
E-mail: info.sci@firstcity.co.za
Reg No: 2005/001831/08
VAT No: 4820233890

Sophumelela
CENTRE
Restoring Hope, Health & Dignity

24 February, 2012

Mrs. Helen Bunt,
P.O. Box 366,
Gonubie
5256 Eastern Cape

Request to conduct research in Dignity House, Sophumelela by Mrs. Helen Bunt (Fort Hare University Student Number 201107713)

Dear Helen,

I have considered your request to conduct research in our institution and as discussed, am willing for you to conduct you research in our institution. Of course, you must have approval from the Ethics Committee of your university prior to your investigations and we expect you to abide by all the norms of ethical conduct. You must have informed written consent from each participant and ensure privacy and confidentiality.

Your topic is interesting and the guidelines will be of use to our staff. I look forward to reading the results.

I, hereby grant permission for you to conduct interviews with willing participants who have been served by Dignity House. You may make use of facilities like a ward, office or classrooms at Sophumelela, should the need arise.

Yours Faithfully,

Andre Bezuidenhout

General Manager

Directors: G Berndt, E Buchner, J Benn, S Nana
General Manager: André Bezuidenhout
Visit us on the Web at www.fightingaidsinafrica.co.za

D. Verbatim transcript of patient interview

The questions and comments of the researcher are in bold print and the interviewee in regular print. Observations are in brackets. All names have been assigned a letter to protect anonymity of patient and any staff member or institutions mentioned.

Interview 7

How was it for you being cared for in Dignity House?

Well, I was afraid at first. I didn't even want to come because there is this thing that when you are admitted in a hospice you are about to die. So I was afraid. Christian as I am, but it was because I didn't want to die (she laughs) at that moment! You see. Otherwise when I decided to come I found that I had been fearing something that was not there (she laughs).

Ja. So what was it like being cared for here?

Number one the people here have a holistic approach and number two I would say they are warm hearted, the love that you get here, the cleanliness of the place especially the bathrooms. You know places like this, especially when it is for people who have nothing you see mos from public clinics and hospitals it's not that clean. But Sophumelela and Dignity House it's number one. And hmm, the staff they treat you well. They make you to feel that you are ok. Even if you are about to die, they make you to forget.

Wow. P you talked about the care being holistic, what do you mean by that?

It's a Christian based situation where we get prayed for because we are visited by the pastor here who is in the situation here. He comes to see us. And even the staff, they pray. So you get prayed for. Meaning that you get looked after spiritually, emotionally and physically. You get prayed for, they pray with you, that's what I mean.

Ja. Why was that important to you?

It is important because I know (emphatically pointing finger) that if you are a believer but even if you are not, prayers they do something to you. It is my belief that when you pray something happens. The heavens open, and knowing very well that Jesus Christ died and rose up again for us to be healed. In fact we were healed by His stripes you see, that is my belief. So, prayer for me is very important. And in fact I have seen even to the other patients that were there with me. For instance I used to pray in my room where I had about two other patients with me I prayed and they were so blessed by that. And when they asked me to also pray I would feel the pain in me going away, I would feel a strength coming to me, whilst I was busy praying for her.

Wow, that's wonderful. You were saying that Dignity House is warm …

Yes, they welcome you. They make you feel at home. As I have mentioned that it is a clean place, even your beds sometimes for instances I was affected by cancer. At first I didn't even know what was wrong to me besides HIV. Sometimes you

mess up, you do things and they would come as if nothing has happened and clean you up. And if you feel shy or embarrassed by what you have done. They will make you feel comfortable and tell you that these things they do happen, it's not your fault, you are sick. We are here to look after you. They give you love. They make you feel that they own you, you are theirs. You belong to them. That's what I felt. And if you sleep more than 2 hours they will wake you to ask is there something wrong, how are you feeling because I'm sure when you sleep for several hours they panic and want to see if there's nothing wrong. If you don't sleep they ask why are you not sleeping? Is there something wrong? Do you feel pain? They will ask you such questions and you feel loved. And they don't discriminate, they don't make you feel like you've got something they will easily catch themselves, no, no. I've been to the public places and if you accidentally wet your bed, man! You are shouted at you are made to feel small and terrible about what you have done. But I never experienced that here as a result, I told myself that I must not mess up anything because I want to keep that understanding, that love, I didn't want to tire them. But they would say, no, P. don't, if you are about to vomit and there is no one here just ring the bell or … don't worry if you mess, we are here for that.

Wow, how did you feel with their response?

Oh, I just thought, these people, they are not working here. It is their calling. They are following their calling because there is a difference when they are employed and you are an employer or they have come to serve their people, that is all.

Wow, those are very big words.

Yes, that is what I observed when I was here. All of them, the nightshift ones, the dayshift ones, they are all the same. And it was not because it was me, no, I observed they treated the other patients the same. Even if, whatever background you are from they make you feel at home. And the diet too is good. It is a good diet cooked well by people who are doing their job with love, knowing that these people they can't even swallow food but you will be given what is proper for you - a balanced diet.

So what you are telling me is, the important things for you were that you were received warmly here, the cleanliness … how did the cleanliness make you feel?

It quickened my healing. Within two days of my being admitted I felt the strength. For instance, if I can remember correctly, when I came here my stomach was bloated and it was painful. And thinking that I because I am on ARV's I shouldn't be in pain because my viral load will go up. I was given something to ease off … because no one knew then what was wrong with me. So I was given a drug that will ease off the pain that was given four hourly. My stomach was bloated and I couldn't go to the bathroom to relieve myself. So I was given a purgative that was very mild but it helped me. So eventually my stomach go down and the pain was controlled by the medication that I was given. As a result I never had any viral load going up or a CD4 going down. No, everything was normal and the pain was

controlled that make me to have strength the medication, the care medically that I had from here, the love, and the care.

That's wonderful …

Those things they make you … by the time I was referred back to the hospital for surgery I felt better already I didn't even have pain then and my stomach was normal. But I was needing the surgery. But the help I got was from Dignity. That's why I actually say it is no longer Dignity House to me, it is Dignity Home (we laugh). Because, really, I felt at home. (We laugh).

Brings tears to your eyes, hey?

I have never felt a pain like that pain that I had but you had to give me that pain relief drug four hourly and it helped.

So if I can summarise again - So you're saying it was the warmth and the love that you received, the care was holistic, the cleanliness of the place were all things that helped you to get better.

Plus the medication and they knew what to do to. When I was in Hospital F, they didn't give me those things. I was left with that bloated stomach – it was so painful. Day and night. I couldn't even sleep at night. That's why I was admitted here, despite my fear. Because during the night I would just cry in pain not knowing what to do and my adult children didn't know what to do. So I realized I was damaging them psychologically and physically because they needed to go to work the next

day. So I decided to come here. And it was a good decision because it helped me, it saved my life, really.

That's amazing. P. I don't think I have anything else to ask. Is there anything else you'd like to say?

It is just clear that really, when you need healing from any disease you need prayers, good care, love and people who understand - people who would give their all for you. It makes you to feel I must not disappoint these people by not wanting to get better. Because by not accepting their efforts and wanting to get better, what they are doing would be in vain. But because what people here did, I need you to see that what you are doing here changes lives, their perception of this place called hospice. I'm sure it is not me alone that thinks these things about a hospice that you go there to die. But by what you did, I got healed. You get your ego back and you want to tell people, in that Dignity House people get healed, people get saved even those who were not saved. The other patients they asked me and I told them I am a believer in Jesus Christ and that is what is happening here. He is using doctors and nurses for ones' healing. What you did here it is making us want to get better. It's an encouragement. By closing this place many people will suffer especially those who are HIV positive. I tell them that at that place they will help you. They are not going to ask you questions that you cannot answer. They help you until you are better.

E. _Atlas.ti 6.1_ computer program – a brief explanation of functions

ATLAS.ti 6.1 is a Computer-Assisted Qualitative Data Analysis (CAQDA) program similar to e.g. NVivo and NUDIST. Its name is derived from the German "Archiv fur Technik, Lebenswelt und Alltagssprache" which can be translated as: "archive for technology, the life world and everyday language". The extension "ti" stands for text interpretation. The first version of this software was developed at the Technical University of Berlin in 1989.

Data is imported to the program and is easily coded. Thematic labels and "memos" can be attached to segments of data. These can then be used to search and retrieve coded data. It can also perform analytic tasks; define concepts; map the range, nature and dynamics of phenomena; create typologies; find associations; seek explanations; develop new ideas, theories or strategies.

In this study, it was used by the researcher to discover repeated words and ideas and to identify themes and sub-themes. The program was useful in finding quotes on any particular theme which could be used in the text of the thesis. The programme numbers the data by paragraphs and this was used to identify the quotes given in the text of this research. A final analysis of all the data was done by the program to confirm analysis that had been done manually by the co-coder, supervisor and researcher.