

# **NURSES' PREPAREDNESS TO CARE FOR PATIENTS WITH TERMINAL DISEASES IN A SELECTED HOSPITAL IN ANGOLA**

by

**ARÃO CATOMBELA**

submitted in partial fulfilment of the requirements

for the degree of

**MASTER OF ARTS**

in the subject

**HEALTH STUDIES**

at the

**UNIVERSITY OF SOUTH AFRICA**

**SUPERVISOR: PROF MC BEZUIDENHOUT**

**JOINT SUPERVISORS:  
MRS JE TJALLINKS AND MRS MFCC DE ALMEIDA**

**JUNE 2007**

Student number: 3378-207-5

## DECLARATION

I declare that the study on **NURSES' PREPAREDNESS TO CARE FOR PATIENTS WITH TERMINAL DISEASES IN A SELECTED HOSPITAL IN ANGOLA** is my own work and that all the sources consulted, used or quoted are reliable sources and that this work has not been submitted previously in any other institution.

**SIGNATURE**

(Arão Catombela)

**DATE** .....

# NURSES' PREPAREDNESS TO CARE FOR PATIENTS WITH TERMINAL DISEASES IN A SELECTED HOSPITAL IN ANGOLA

STUDENT NUMBER: 3378-207-5  
STUDENT: ARÃO CATOMBELA  
DEGREE: MASTER OF ARTS  
DEPARTMENT: HEALTH STUDIES, UNIVERSITY OF SOUTH AFRICA  
SUPERVISOR: PROF MC BEZUIDENHOUT  
JOINT SUPERVISORS: MRS JE TJALLINKS AND MRS MFCC DE ALMEIDA

## ABSTRACT

The impression existed that nurses were not always compassionate and caring when they had to nurse terminally ill patients and the question arose whether they were adequately trained for this task. This study focused on the most frequent diseases that cause the death of patients in a province of Angola, and set out to determine what preparation nurses in a specific hospital received to equip them to care for terminally ill patients. A quantitative approach was adopted, using an exploratory and descriptive design, and a self-developed questionnaire was applied as data-collection instrument for a sample of 100 medium- and basic level nurses in a specific hospital in a province of Angola.

From the results of the study it was evident that the nurse respondents were well informed as to what it entailed to be terminally ill, which factors affected the patient's comfort, safety and self image needs but only half of the respondents indicated that they received training pertaining to palliative care. Recommendations were made in view of better preparing nurses to care for the terminally ill patient.

### KEY TERMS:

Nurse training; palliative care; terminal illness.

## **ACKNOWLEDGEMENTS**

I thank all those who gave me courage not to desist from this study, mainly my translators **Mónica de Almeida and Elizabete Soares** who always assisted me to acquire the didactic material necessary to enable me to reach the anticipated goal. They were always very kind towards me. I would also like to thank my supervisors, **Mrs JE TJALLINKS** and **Prof MC BEZUIDENHOUT**, and also my colleague **Paulo Santos Chivango Sicato**, who tirelessly assisted me throughout this study.

**SANTED**, for providing financial assistance to this project.

**Mrs I Cooper**, for editing the manuscript.

**Mrs R Coetzer**, for the technical assistance and professional layout of the manuscript.

My profound thanks also to those who made this work possible, by giving of their time without any monetary gain or personal reward.

## *Dedication*

*With my readers' permission I would like to dedicate this work to Ester Nachova Catombela my dearest wife who passed away on 02 August 2005, and who used to help me a lot during my Kuito/Luanda and Luanda/Kuito trips, always encouraging me to continue my studies.*

*Unfortunately she can no longer enjoy the fruits of this work as she is no longer amongst the living.*

## Chapter 1

### Context and orientation to the study

|         |   |    |
|---------|---|----|
| 1.1     | INTRODUCTION .....                            | 1  |
| 1.2     | CONTEXT AND BACKGROUND .....                  | 1  |
| 1.3     | PROBLEM STATEMENT AND RESEARCH QUESTION ..... | 3  |
| 1.4     | OBJECTIVES .....                              | 3  |
| 1.5     | ASSUMPTION .....                              | 4  |
| 1.6     | SIGNIFICANCE OF THE STUDY .....               | 4  |
| 1.7     | LIMITATION OF THE STUDY FIELD .....           | 4  |
| 1.8     | RESEARCH METHODOLOGY .....                    | 4  |
| 1.8.1   | Research design.....                          | 5  |
| 1.8.2   | Population.....                               | 6  |
| 1.8.3   | Sample .....                                  | 6  |
| 1.8.4   | Data-collection instrument .....              | 6  |
| 1.8.4.1 | Validity.....                                 | 7  |
| 1.8.4.2 | Reliability .....                             | 7  |
| 1.9     | PRE-TEST OF THE INSTRUMENT .....              | 8  |
| 1.10    | ETHICAL CONSIDERATIONS .....                  | 8  |
| 1.11    | DEFINITIONS OF TERMS .....                    | 8  |
| 1.12    | ABBREVIATIONS USED.....                       | 10 |
| 1.13    | OUTLINE OF THE STUDY.....                     | 10 |
| 1.14    | CONCLUSION.....                               | 11 |

## Chapter 2

### Literature review

|       |  |    |
|-------|--|----|
| 2.1   | INTRODUCTION .....   | 12 |
| 2.2   | TERMINAL DISEASES .....  | 12 |
| 2.2.1 | Definition.....  | 13 |
| 2.2.2 | Main causes of death amongst patients at a provincial hospital in Bié..... | 13 |

| <b>Table of contents</b> |   | <b>Page</b> |
|--------------------------|---|-------------|
| 2.3                      | THE TERMINAL PATIENT AND PALLIATIVE CARE.....           | 14          |
| 2.3.1                    | Stages of death .....                                   | 14          |
| 2.3.2                    | Palliative care .....                                   | 16          |
| 2.4                      | NEEDS OF TERMINALLY ILL PATIENTS .....                  | 16          |
| 2.5                      | CARING FOR THE TERMINALLY ILL .....                     | 17          |
| 2.6                      | CATEGORIES OF NURSES IN ANGOLA AND THEIR TRAINING ..... | 18          |
| 2.6.1                    | Basic level nurse or nursing assistant .....            | 19          |
| 2.6.1.1                  | Competencies of the basic level nurse .....             | 19          |
| 2.6.1.2                  | Curricular content for basic level nurses.....          | 19          |
| 2.6.2                    | Medium level nurses.....                                | 20          |
| 2.6.2.1                  | Competencies of the medium level nurse.....             | 20          |
| 2.6.2.2                  | Curriculum for medium level nurses .....                | 21          |
| 2.6.3                    | Graduate/qualified nurses.....                          | 22          |
| 2.6.3.1                  | Competencies of graduate/qualified nurses .....         | 22          |
| 2.6.3.2                  | Curriculum for graduate/qualified nurses.....           | 23          |
| 2.6.4                    | Experiential learning .....                             | 25          |
| 2.6.5                    | Supervision.....  | 25          |
| 2.6.6                    | Role modelling.....                                     | 25          |
| 2.7                      | CONCLUSION.....   | 25          |

## Chapter 3

### Research methodology

|       |                      |    |
|-------|----------------------|----|
| 3.1   | INTRODUCTION .....   | 26 |
| 3.2   | OBJECTIVES .....     | 26 |
| 3.3   | RESEARCH DESIGN..... | 26 |
| 3.3.1 | Quantitative .....   | 26 |
| 3.3.2 | Exploratory .....    | 27 |
| 3.3.3 | Descriptive.....     | 27 |
| 3.4   | ASSUMPTION.....      | 27 |
| 3.5   | POPULATION .....     | 27 |
| 3.6   | SAMPLE .....         | 27 |

| <b>Table of contents</b> |  | <b>Page</b> |
|--------------------------|--|-------------|
| 3.7                      | DATA-COLLECTION INSTRUMENT .....                 | 28          |
| 3.7.1                    | Validity.....                                    | 29          |
| 3.7.2                    | Reliability .....                                | 29          |
| 3.8                      | DATA COLLECTION .....                            | 30          |
| 3.9                      | DATA ANALYSIS .....                              | 30          |
| 3.10                     | PRE-TESTING THE DATA COLLECTION INSTRUMENT ..... | 30          |
| 3.11                     | PERMISSION TO CONDUCT THE STUDY.....             | 31          |
| 3.12                     | ETHICAL CONSIDERATIONS .....                     | 31          |
| 3.13                     | CONCLUSION.....                                  | 32          |

## Chapter 4

### Data analysis and interpretation of findings

|         |   |    |
|---------|---|----|
| 4.1     | INTRODUCTION .....  | 33 |
| 4.2     | DATA ANALYSIS .....   | 33 |
| 4.3     | DATA PRESENTATION .....   | 34 |
| 4.3.1   | Biographical information .....  | 34 |
| 4.3.1.1 | Current position in the hospital .....  | 34 |
| 4.3.1.2 | Duration of position held.....  | 34 |
| 4.3.1.3 | Age .....   | 35 |
| 4.3.1.4 | Gender.....   | 37 |
| 4.3.2   | Nursing care of the terminally ill patient.....                                     | 37 |
| 4.3.2.1 | The terminally ill patient.....   | 38 |
| 4.3.2.2 | Safety and comfort needs of the terminally ill patient .....                        | 38 |
| 4.3.2.3 | Comforting the terminally ill patient.....  | 40 |
| 4.3.2.4 | Factors affecting the self-esteem and self-image of the terminally ill patient..... | 41 |
| 4.3.2.5 | The terminally ill patient's need for love and belonging .....                      | 42 |
| 4.3.2.6 | Handling physical discomfort.....   | 43 |
| 4.3.2.7 | Alleviate the patient's fear.....   | 44 |
| 4.3.2.8 | Signs and symptoms when death is imminent.....                                      | 44 |
| 4.3.3   | Training of nurses taking care of the terminally ill patient.....                   | 45 |
| 4.3.3.1 | Curriculum content on palliative care.....  | 45 |
| 4.3.3.2 | Specific curriculum content pertaining to the terminally ill patient.....           | 46 |
| 4.3.3.3 | Guidance in caring for the terminally ill patient .....                             | 47 |
| 4.3.3.4 | Caring for the dying patient .....  | 48 |
| 4.3.3.5 | Phases in the grieving process according to Kübler-Ross.....                        | 51 |



---

|     |                 |    |
|-----|-----------------|----|
| 4.4 | CONCLUSION..... | 51 |
|-----|-----------------|----|

## Chapter 5

### Findings, conclusions and recommendations

|       |   |    |
|-------|---|----|
| 5.1   | INTRODUCTION.....   | 52 |
| 5.2   | OBJECTIVES.....   | 52 |
| 5.3   | RESULTS.....  | 52 |
| 5.3.1 | Section A: Biographical information.....                              | 53 |
| 5.3.2 | Section B: Nursing care for terminally ill patients.....              | 53 |
| 5.3.3 | Section C: Nurses' training to deal with terminally ill patients..... | 55 |
| 5.4   | CONCLUSIONS.....  | 56 |
| 5.4.1 | Section B: Nursing care for terminally ill patients.....              | 56 |
| 5.4.2 | Section C: Nurses' training to deal with terminally ill patients..... | 57 |
| 5.5   | RECOMMENDATIONS.....  | 57 |
| 5.5.1 | Nursing education and policy.....                                     | 58 |
| 5.5.2 | Further research.....   | 59 |
| 5.6   | LIMITATIONS OF THE STUDY.....   | 59 |
| 5.7   | CONCLUSION.....   | 60 |
|       | BIBLIOGRAPHY.....   | 61 |

---

|            |  |    |
|------------|--|----|
| Table 1.1  | Most common diseases resulting in death during the period 2004-2006 in the Hospital of Biè ..... | 2  |
| Table 4.1  | Current position in the hospital (n=100) .....   | 34 |
| Table 4.2  | Respondents' age distribution (n=93) .....   | 36 |
| Table 4.3  | Curriculum content on caring for the terminally ill (n=70) .....                                 | 46 |
| Table 4.4  | It's like working with any other patient (n=71) .....  | 48 |
| Table 4.5  | Feel uncomfortable (n=70) .....  | 48 |
| Table 4.6  | Anxiety because I don't know what to do (n=69) .....   | 48 |
| Table 4.7  | Felt scared to care for the dying patient (n=69) .....   | 49 |
| Table 4.8  | Do not like caring for the dying patient (n=71) .....  | 49 |
| Table 4.9  | It's a privilege to be there for the patient (n=65) .....  | 49 |
| Table 4.10 | Do not want to be alone with the patient (n=64) .....  | 50 |
| Table 4.11 | Do not have enough knowledge to deal with terminal patients (n=67) .....                         | 50 |
| Table 4.12 | Do not have practice in psychological counselling (n=68) .....                                   | 50 |
| Table 4.13 | Emotions in terms of the grieving process (n=100) .....  | 51 |

## List of figures

Page

---

|             |   |    |
|-------------|---|----|
| Figure 4.1  | Respondents' years in current position (n=92).....  | 35 |
| Figure 4.2  | Respondents' age categories (n=93).....   | 36 |
| Figure 4.3  | Respondents' gender (n=89).....   | 37 |
| Figure 4.4  | Aspects related to terminally ill patients (n=100).....   | 38 |
| Figure 4.5  | Aspects that have a negative bearing on the safety and comfort of a terminally ill patient (n=100)..... | 39 |
| Figure 4.6  | Means to comfort a terminally ill patient (n=100).....  | 40 |
| Figure 4.7  | Factors affecting the terminally ill patient's self-esteem and self-image (n=100).....                  | 41 |
| Figure 4.8  | Factors affecting the terminally ill patient's need for love and belonging (n=100).....                 | 42 |
| Figure 4.9  | Actions in handling physical discomfort of terminally ill patients (n=100).....                         | 43 |
| Figure 4.10 | Actions to alleviate the patient's fears (n=100).....   | 44 |
| Figure 4.11 | Signs and symptoms of imminent death (n=100).....   | 45 |
| Figure 4.12 | Curriculum content on caring for the terminally ill patient (n=100).....                                | 46 |
| Figure 4.13 | Guidance on caring for the terminally ill patient (n=100).....  | 47 |

## List of annexures

---

Annexure A            Permission requested

Annexure B            Permission granted

Annexure C            Consent form

Annexure D            Questionnaire

Annexure E            Clearance certificate

# Chapter 1

## Context and orientation to the study

### 1.1 INTRODUCTION

Patients with terminal diseases generally have no hope of recovering from their illnesses and are in the final phase of their lives, requiring comfort and care. These patients have the right to die in peace and with dignity. When admitted to a health care facility such as a hospital, it is the responsibility of the nursing staff to care for and nurture the dying patient, assisting with the activities of daily living and providing a calm and peaceful environment.

This study deals with the preparation of nurses at basic and medium levels to care for patients with terminal diseases at a provincial hospital of Bié, in Angola. This chapter covers the context, problem statement, objectives, assumption, as well as the significance of the study, and the research methodology.

### 1.2 CONTEXT AND BACKGROUND

Angola is a country situated on the western coast of Southern Africa, bordered in the North by the Democratic Republic of Congo, in the Northeast by the Republic of Congo, in the East by Zambia, in the South by Namibia and in the West by the Atlantic Ocean, and has an area 1 2760.700 square kilometres. It has a population of 13,5 million inhabitants, of whom 44,4% live in an urban environment and 63,6% are younger than 20 years of age. Given the situation created by the prolonged war of more than 30 years, the country has 4,2 million displaced people <http://pt.wikipedia.org>. The province of Bié is situated in central Angola and has a population of 2,3 million inhabitants who basically work in agriculture. It has an abundance of mineral resources such as diamonds, iron, gold and oil.

The provincial hospital of Bié, which forms part of this study, operates with basic and medium level nurses. Table 1.1 represents the number of deaths at the hospital for the period 2004 to 2006 according to the hospital records.

**Table 1.1 Most common diseases resulting in death during the period 2004-2006 in the Hospital of Biè**

| Disease                     | Mortalities per year |      |                                  |
|-----------------------------|----------------------|------|----------------------------------|
|                             | 2004                 | 2005 | 2006<br>1 <sup>st</sup> semester |
| Malaria                     | 299                  | 297  | 188                              |
| Meningitis                  | 15                   | 11   | 1                                |
| Severe diarrhoeal diseases  | 9                    | 9    | 9                                |
| Severe respiratory diseases | 91                   | 111  | 34                               |
| Pulmonary tuberculosis      | 28                   | 47   | 26                               |
| Cholera                     |                      |      | 1                                |

Complaints from terminally ill patients as well as their family members and friends about the care provided by nursing professionals indicated that nurses were not equipped to care for patients with terminal diseases. In the researcher's view, then, there was a need to prepare and train nursing professionals at Biè to enable them to deal with terminally ill patients and situations of imminent death, both for the sake of patients and their family members. In other words, they need to be able to offer the psychological and physical comfort that these patients need, and to guide and support the family members at the time of loss.

Palliative care requires a multi-professional approach, which encompasses patients, their families, service providers, and social and health services, thus taking into account the individual's holistic needs. A terminally ill patient requires multi-professional care given the needs of these patients and their family members. Therefore, a quality response must always be based on a true interdisciplinary team effort, where doctors, nurses and social workers represent the basic elements, although other professionals might be useful and necessary (Programa Nacional de Cuidados Paliativos [PNCP] 2004:2).

Palliative care seeks to attend to the physical, psychological, social and spiritual needs of the patient and to extend support to the family during mourning (PNCP 2004:2). The objective of nursing care must be to improve the quality of life during that terminal phase, alleviating the symptoms and allowing the patient to die with comfort and dignity.

### **1.3 PROBLEM STATEMENT AND RESEARCH QUESTION**

The provincial hospital of Bié, where the study was conducted, shelters patients who are carriers of diverse pathologies such as malaria, tuberculosis (TB), cancer, patients suspected of being HIV/AIDS positive (“suspected” as the hospital does not have an adequately equipped laboratory to analyse and determine with efficiency the HIV/AIDS status and the only test available is the screening test), as well as patients with other diseases. According to hospital records, during the first semester of 2006, there were 188 deaths caused by malaria, 31 deaths due to acute respiratory diseases and 26 deaths due to pulmonary tuberculosis. This alarmed patients and their families to such an extent that many left the hospital to seek traditional treatment. Family members felt the hospital was not equipped to meet patients’ needs.

Ideally, nursing staff should be able to offer psychological, moral and spiritual comfort to patients, family members and loved ones, faced with a distressful situation. In practice, however, nurses lack the competency, attitude and empathy required by the terminally ill. Patients are ill-treated and often neglected, without access to the pain relief and tranquillity they so desperately need at this difficult time. This, in turn, increases the suffering and agony of patients and their family members.

This situation led the researcher to formulate and investigate the following research question:

- Are professional nurses equipped during their training to care for terminally ill patients?

### **1.4 OBJECTIVES**

The objectives of this study were to

- determine whether the training received by nurses enabled them to care for terminally ill patients
- make recommendations for the training and development of nurses to care for patients with terminal diseases

## **1.5 ASSUMPTION**

According to LoBiondo-Wood and Haber (2001:321), an assumption is “a basic principle assumed to be true without the need for scientific proof”. The assumption that guided this study was that knowledge could lead to a change in behaviour.

## **1.6 SIGNIFICANCE OF THE STUDY**

Patients with a terminal disease require assistance with their basic daily living activities, relief from pain, and a calm and peaceful environment. Their family members and loved ones need guidance and information to better understand and cope with the situation.

This study attempted to show that individuals who deal with patients with terminal diseases must show empathy when performing their professional duties. The study aimed to promote a higher level of responsibility on the part of nurses for their actions. In practical terms, this implied that nurses should have a better understanding of terminal diseases and their effect on patients and their loved ones. This, in turn, would enable better preparation of nursing professionals to care for this type of patient.

## **1.7 LIMITATION OF THE STUDY FIELD**

The study involved the nursing staff in one public hospital in the province of Bié, and focused on the competency of basic and medium level nurses to care for patients with terminal diseases.

## **1.8 RESEARCH METHODOLOGY**

Research methodology involves the stages, procedures and strategies to collect data during a research project. According to Oliveira (1995:43), scientific research methodology refers to the process, the pace of the research, the use of instruments and techniques to achieve the best standard of quality, with the best logic/reasoning, the least cost and the least effort and time. Thus, methodology relates to the way of thinking, of guiding researchers' thoughts to clarify a specific unclear issue. Technique has to do with the instruments chosen by researchers to enable the adequate



development and optimal unfolding of their thinking. Inadequately chosen instruments do not develop thinking properly and might even confuse it.

### 1.8.1 Research design

Research design refers to the strategy best suited to meet the objectives of the study, and can be descriptive, exploratory or phenomenological. The aim of the research design is to provide a plan that meets the research problems (LoBiondo-Wood & Haber 2001:89).

For this study, the researcher adopted a quantitative approach, using an exploratory and descriptive design to determine to what extent nurses are trained to care for patients with terminal diseases.

- **A quantitative approach** aims to utilise methods to describe variables in terms of their core tendency or medium, median or modal dispersion or is divided into categories and described in terms of frequencies and percentages (Victoria, Knauth & Hassen 2000:37).
- **Exploratory research** aims to examine a relatively unknown research area in order to acquire knowledge about the phenomenon that constitutes the study object (Mouton & Marais 1991:43). Exploratory research seeks to explore the dimensions of a phenomenon and the way in which it is manifested and the other factors with which it is related. In this study, the nurses' knowledge about the terminally ill was explored in terms of the training they received.
- The aim of **descriptive research** is to describe and summarise the collected data. According to Polit, Beck and Hungler (2004:437-438), descriptive research has as its main objective to accurately describe and portray the individual characteristics, situations or groups and the frequency with which specific phenomena occur.

## **1.8.2 Population**

LoBiondo-Wood and Haber (2001:41) describe a population as “a well-defined set of people, animals, objects or events that have certain special characteristics, which are appropriate for a study”. In this study, the population in question were the nurses of a provincial hospital in Bié, Angola. Of the nurses, 200 had basic training, and 400 had medium level training, which provided a total of 600 nursing professionals employed at the specific hospital.

## **1.8.3 Sample**

In research, sampling refers to “the process of selecting a part of the population to be studied. The sample is the subset of this population” (Polit et al 2004:225). In this study, the sample consisted of 100 nurses from a population of 600 basic and medium level nurses.

## **1.8.4 Data-collection instrument**

A data-collection instrument comprises the techniques used by the researcher to collect data, and can be in the form of questionnaires, tests, observations or interviews (Polit et al 2004:436). For this study, the researcher decided to use a questionnaire to collect data, as this was a quantitative study that encompassed a large number of research subjects.

The questionnaire has the following advantages:

- It is less costly and requires less time and effort to manage.
- It offers the possibility of total anonymity, which is crucial to obtain information on illegal or deviant behaviours, or about embarrassing characteristics.
- The absence of an interviewer ensures no bias in terms of how the respondent would react to the interviewer, more than to the actual questions.

The questionnaire has the following disadvantages:

- Not all the questionnaires distributed or posted to a target group may be returned.
- The respondents can ignore a questionnaire that is posted. The low rate of replies can lead to partiality, because the respondents rarely constitute a random subset of those the researcher intended to include in the study.
- Many people simply cannot complete a questionnaire; for example, small children, visually impaired and the elderly (Polit et al 2004:256).

#### **1.8.4.1 Validity**

The validity of a measuring instrument refers to whether it measures, in reality, what it is intended to measure. The instrument is considered valid if it reflects the concept that it is supposed to measure (LoBiondo-Wood & Haber 2001:187). Various types of validity can be used to test an instrument.

For this study, *content* and *face* validity were used. According to LoBiondo-Wood and Haber (2001:321), *content validity* is the level to which the instrument represents the universe of the content being studied. *Face validity* is an intuitive type of validity, where it is determined whether the instrument apparently measures what it is intended to measure (LoBiondo-Wood & Haber 2001:189).

#### **1.8.4.2 Reliability**

Reliability relates to “the consistency with which the instrument measures the attribute at different times. An instrument is reliable if what it measures accurately reflects the true measurements of the attribute” (Polit et al 2004:288). If an instrument is used on more than one occasion to measure constant behaviours, similar results are expected, if it is reliable. Reliability relates to “coherence, precision, stability and homogeneity” (LoBiondo-Wood & Haber 2001:193).

## 1.9 PRE-TEST OF THE INSTRUMENT

A pilot study is a small-scale version of the main study, which is used to obtain information with a view to improving the project or to evaluate its feasibility (Polit & Hungler 1995:35). For the purposes of this study a complete pilot study was not done but the instrument was pre-tested on a small group of five nurses from a different hospital to determine its validity and reliability.

## 1.10 ETHICAL CONSIDERATIONS

When people are used as subjects in scientific investigations, as they usually are in nursing research, great care must be exercised to ensure that their rights are protected (Polit & Hungler 1993:353). The respondents' anonymity and confidentiality of the data were ensured and the respondents' rights respected.

## 1.11 DEFINITION OF TERMS

For the purposes of this study, the following terms were used as defined below:

- **Care** means precaution, caution, attention (Novo Dicionário Aurélio de Língua Portuguesa 1986:507). In healthcare settings and the nursing profession, care refers to the attention, caring, nurturing and empathy bestowed on patients by their carers, which in this case are the nurses.
- **Centre for palliative care.** This is a hospice with a philosophy of treatment aimed at providing comfort, due to the fact that cure is not anticipated. The hospice can be set up at home or in a hospital, provided some facilities are ensured aimed at providing palliative care to patients, with regard to signs of pain, psychological support to the patient and family, support from the medical team, for example, fast means of transportation and, whenever necessary, spiritual and other support (Aspectos da humanização no tratamento de crianças na fase terminal – Hospital do câncer [Aspects of humanization in the treatment of children in a terminal phase – Cancer Hospital] <http://www.hcanc.org.br/outrasinfs/ensaios/huml.html>)

- **Death** is the end of existence of any and all beings that have a body, that breathe, move, have sense and feelings, sensation and emotions. <http://pt.wikipedia.org>.
- **Empathy** demonstrates the ability to understand and identify oneself with the feelings, thoughts and experiences of other people (Concise Oxford Dictionary 1964:397).
- **Hospice** means a nursing home that specialises in caring for the terminally ill (*Concise Oxford Dictionary* 1964:588).
- **Hospital** refers to a facility and institution where patients are admitted and treated for health-related problems (Novo Dicionário Aurélio de Língua Portuguesa 1986:908).
- **Humanisation** refers to the effect of humanising; in other words, respecting individuals' human nature and rights (Novo Dicionário Aurélio de Língua Portuguesa 1986:908).
- **Need** means that which is absolutely necessary or a requirement (Novo Dicionário Aurélio de Língua Portuguesa 1986:1185). In this study, need referred to the needs experienced by terminally ill patients, including basic needs, such as sleep, nutrition and excretion, and psychological and emotional needs.
- **Nurse** means a person qualified in nursing; the person who cares for sick people (Novo Dicionário Aurélio de Língua Portuguesa 1986:1192). This study focused on basic and medium level nurses.
- **Provincial hospital** refers to a tertiary level health care centre, which accepts referrals from other health care facilities and is able to provide specialised care and treatment.
- **Responsibility** means the condition of being responsible (Novo Dicionário Aurélio de Língua Portuguesa 1986:1496). Taking responsibility for doing and completing allocated tasks to the satisfaction of all parties.

- **Terminal** means related to the end or conclusion of a disease or patient (Novo Dicionário Aurélio de Língua Portuguesa 1986:1967).
- **Terminal disease** means the improper designation of the final stage of a disease, which leads to death (Novo Dicionário Aurélio de Língua Portuguesa 1986:605).

## 1.12 ABBREVIATIONS USED

The following abbreviations were used in this study:

|          |   |  |
|----------|---|--|
| HIV/AIDS | – | Human immune virus/Acquired immune deficiency syndrome |
| PNCP     | – | Programa Nacional de Cuidados Paliativos               |
| TB       | – | Tuberculosis   |
| WHO      | – | World Health Organization                              |

## 1.13 OUTLINE OF THE STUDY

Chapter 1 introduced the study, outlined the problem, the purpose, objectives and significance of the study, and the research design and methodology, defined terms, and listed abbreviations.

Chapter 2 covers the literature review conducted for the study.

Chapter 3 discusses the research methodology.

Chapter 4 discusses the data analysis and interpretation.

Chapter 5 presents the findings and conclusions, and makes recommendations for practice and further research.

## **1.14 CONCLUSION**

This chapter provided an overview of the study, its background and context, the most frequent diseases which cause the death of patients at the specific hospital, the research problem and objectives, the research methodology, definition of terms as well as an outline of the dissertation.

Chapter 2 discusses the literature review undertaken for the study.

## **CHAPTER 2**

### **Literature review**

#### **2.1 INTRODUCTION**

This chapter covers the literature review conducted on the care of terminally ill patients. The researcher wished to define the concept of terminal disease, its effects on patients and family members, and determine the causes of death in the province of Bié. The chapter discusses palliative care, the needs of terminally ill patients and the preparation of nurses who deal with these patients, and presents a framework of nursing categories in Angola and their basic curriculum training.

LoBiondo-Wood and Haber (2001:71) define a literature review as “a wide, encompassing, profound, systematic and critical review of specialized publications, specialized printed and non-published materials, audiovisual materials and personal communications”. Burns and Grove (2005:93) point out that a literature review is traditionally considered a systematic and critical review of the most important published literature related to a specific topic.

#### **2.2 TERMINAL DISEASES**

The most frequent or common terminal diseases in the province of Bié are malaria, TB and acute respiratory diseases. With regard to TB, it should be pointed out that patients frequently only seek medical care at an advanced stage of the disease, having first tried home treatment, namely self-medication, and ignoring the disease and its prognosis. Given their usual poor nutritional state when placed under medical care, many of these patients do not recover but die. Early detection of the disease and the accompanying medication would substantially reduce the rate of mortality in this situation. Deaths due to malaria are widespread because in many regions malaria has acquired resistance to the common medications. The Ministry of Health has introduced health education, and the distribution of mosquito nets and essential medication against malaria.



### **2.2.1 Definition**

Terminal diseases do not have a cure, and cause the death of the patient. To say that a patient is terminal implies that the patient is dying. According to Brandão (2006:4), a disease is considered terminal when:

- There is diagnostic confirmation of malignant progressive disease.
- It is recognised that death is near.
- All therapeutic alternatives have been exhausted.

Faced with a terminally ill patient, when “there is nothing else to do”, many health professionals (doctors and nurses) show a mixture of inability, compassion and disappointment. They do not see that there is a difference between caring for and curing, and that in reality “the limitations of caring for are wider than those of curing” (Lopes, Camargo & Furrer 1999) [[www.mulheres.org.br/parto/doutorado\\_6.html](http://www.mulheres.org.br/parto/doutorado_6.html) -].

It is always possible to care for a patient although it might not always be possible to cure the disease. Within that reality, so-called palliative care comes to the fore. Degenerative neurological diseases, such as multiple sclerosis, or chronic insufficiency, such as emphysema, or diseases such as cancer, malaria and AIDS usually cause premature death and therefore form part of the list of terminal diseases in this area.

### **2.2.2 Main causes of death amongst patients at a provincial hospital in Bié**

The provincial hospital of Bié, which was the site of this study, has assisted patients with various pathologies that cause death. The main causes of death at the specified hospital between 2004 and 2006 were malaria, meningitis, severe diarrhoeal and severe respiratory diseases, pulmonary TB and cholera (see table 1.1, chapter 1). The highest percentage of mortalities occurred amongst children, mainly due to malaria and acute respiratory diseases.

## 2.3 THE TERMINAL PATIENT AND PALLIATIVE CARE

The last phase of life can be traumatic both for patients as well as their families. Terminally ill patients have lost the battle against the disease and therefore they and the family experience feelings of despair and helplessness when faced with fatality.

### 2.3.1 Stages of death

The Swiss psychologist, Elizabeth Kübler-Ross describes the stages experienced by patients about to die, from when they receive the malignant diagnosis to the time when they accept it. People who are dying go through specific stages in this grieving process: from denial to anger, from negotiation to depression and finally acceptance (Sorensen & Luckmann 1998:1859).

- **Denial:** This serves as a protection for the person who is constantly confronted with a very painful reality. Denial allows patients to continue living their life. During the stage of denial, health care must be provided assuming that the individual must come out of the denial phase for the various anticipated phases.
- **Anger:** Very often anger is expressed more directly towards family members and care providers. Religious beliefs can be another area at which the dying direct their anger and frustration. During this stage, the nurse might see an individual who was normally kind, cooperative and polite treat his wife with cruel words. The wife can feel very confused at this sudden explosion of anger. Anger can also be expressed against God or the priest (especially people who have lived a religious life, may feel a deep anger because God allowed this to happen). The dying must be able to express their anger without running the risk of losing those who are important, and it is up to the nurse to ensure that they are able to express it, but to also explain this stage to the family members (Sorenson & Luckmann 1998:1859).
- **Negotiation:** This is a way of trying to postpone the inevitable. Negotiation can be done in various forms such as repeatedly asking for medical treatment. The patients can look for a doctor or a treatment, which, in essence, enables them to better negotiate life. They can negotiate with care providers with regard to

controlling the timing of medication or the promise to cooperate in the type of treatment if they are allowed to go home for the weekend. This can be noticed this in individuals who ask God to have more time in life. According to Kübler-Ross (Sorensen & Luckmann 1998:1859-1860), they reach the point where they understand that the unavoidable cannot be postponed, which takes them to the next phase, which is depression.

- **Depression:** Depression is a very realistic period of suffering, due to everything that is almost lost and also for the losses that have, in fact, already occurred. During this period, individuals have a tendency to give up the world. Their appetite tends to reduce and there can be changes in the sleeping patterns. It is not uncommon to see them lying down or sitting with their backs to the door, avoiding the family members and the care providers, distancing themselves from them. The nurse can assist patients going through that period, by providing the physical care with kindness and observing them frequently without demanding a verbal answer in exchange (Sorensen & Luckmann 1998:1860).
- **Acceptance:** Acceptance is seen as a peaceful letting go. This can, in fact, be disturbing for the care providers, the family and other professionals because the individuals might show very little emotional expression and start giving up living. This can be interpreted as giving up the fight. During that period, the patients become aware and fully accept the implications of their prognosis. There is a feeling of satisfaction towards the life lived. Incomplete issues have been finalised and this is the time to say the final goodbyes. Acceptance is illustrated by the individuals accepting that the time remaining is short, they take a decision to leave the hospital and go home to spend that time at home in peace, in meditation and leaving those who are dear to them a legacy of warmth and peace (Sorensen & Luckmann 1998:1860).

Terminal patients must be given the opportunity to speak about death, so that they can reach the phase of acceptance. It is the responsibility of health professionals to ensure that that happens. As palliative care is the active holistic care of patients with advanced progressive illness, nurses should take care and allow the patient to verbalise and interact about his or her feelings, fears and anxieties [[http://en.wikipedia.org/wiki/Kübler-Ross\\_model](http://en.wikipedia.org/wiki/Kübler-Ross_model)] [Kübler Ross's model on grieving].

### 2.3.2 Palliative care

If nothing else is left in terms of cure, all that is left for terminally ill patients is the right to die with dignity and tranquillity. They have the right to “die properly”. For that to happen they must feel comfortable and the family must be supported. The ideal care pattern for patients in the final stage of life is called palliative care. Palliative care is comprehensive and active care provided by health professionals to patients and their family members in a situation of advanced and incurable disease (Gandra, Costa & Barbosa 2006:2). For many people, the term “palliative” has a negative meaning “of inefficient treatment”, as this is only postponing the unavoidable, that is death. However, palliative comes from the Latin *palliare* to cloak, and means to alleviate (a disease) without curing. Human life even without any possibility of cure and when limited, will always have great value and dignity, and must receive the best possible treatment and palliative treatment (Lopes, Camargo & Furrer 1999:3). Palliative care must guarantee relief from pain or suffering, attending to the physical, psychological, social and spiritual needs of the patient and extend to support of the family.

### 2.4 NEEDS OF TERMINALLY ILL PATIENTS

Terminally ill patients have a series of physical, psychological and emotional needs that change according to the disease and the stage of the disease (**Factores da vida** [factors of life] [<http://eutanasia.aaldeia.net/cuidadospaliativos.htm>]; (Sorensen & Luckmann 1998:1825):

- **Physical needs** occur mainly due to the bodily limitations caused by the advancement of the disease (constipation, dry skin, bedsores) and particularly to the pain. Pain occurs mainly in the case of cancer, as 80% of terminally ill patients are affected by it. With adequate treatment, up to approximately 95% of the pain can be controlled.
- **Psychological needs** refer to the patients’ need to feel safe, to trust the team of professionals who are treating him, and to feel safe that people will not abandon them. They need to love and be loved.

- Terminally ill patients' **social needs** are no less important in times of physical suffering. The terminal disease consumes the patient, affects the family and can cause family disagreements. Often all the attention and resources of the family are concentrated on the patient while other family members and their needs are neglected.
- **Spiritual needs** are focused on discovering the meaning and aim of life and disease, and for situations in life, to give and receive love, the feeling of relating to others and the experience of life's patterns.

## 2.5 CARING FOR THE TERMINALLY ILL

According to the Associação Brasileira de Cuidados Paliativos [Brazilian Association for Palliative Care 2004] [[www.cuidadospaliativos.com.br/artigo.php?cd](http://www.cuidadospaliativos.com.br/artigo.php?cd)] the palliative model is centred on the actual patients, and essentially taking care not only of their physical, but also their psychological and spiritual needs. According to the WHO [[www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)] palliative care constitutes an approach aimed at improving the quality of life of the patients and their family members when faced with a disease that threatens life, through the prevention and alleviation of suffering, through early identification and impeccable evaluation, treating pain and other physical, psychological and spiritual problems..

A programme for palliative care aimed at caring for the patients' physical, psychological, social and spiritual needs has to promote a careful study of the aspects that could facilitate their quality of life. One of the main aims of palliative care is to provide comfort for the patients so that despite their terminal disease, they can feel comfortable.

Nursing staff must therefore be trained to enable them to determine individuals' level of physical discomfort. Signs of discomfort include nausea, fatigue, itchiness, and constipation, stiffness of joints and muscles, and pain. Knowledge about the course of the disease and treatment of the patient should be taken into account when evaluating individuals' level of comfort.

By understanding the physical-pathological course of the disease, as well as the physiological and biochemical effects of the various circumstances used to treat a

specific diagnosis, the trained nurse is better able to anticipate the potential sources of discomfort. This knowledge also makes the nurse better equipped to provide some prior guidance to the patient and the family members. Observing the patient can provide an indication of any type of discomfort (Sorensen & Luckmann 1998:1866).

In considering the comfort of patients, it is important to regulate the bodily temperature, control symptoms such as pain, maintain a colon routine to prevent constipation, ensure that the patient is hydrated, attention is given to mouth hygiene and moisturizing of the skin, constant change of position so as to prevent bedsores, and to keep the bed dry. For that purpose, it may be necessary to insert a bladder catheter and, when necessary, a faecal incontinence device (such as nappies) should be applied to prevent unpleasant odours in the environment causing distress to the patient and others. Empathetic nursing care of an acceptable quality aimed at alleviating the pain, the suffering and stress of terminally ill patients and their family members is thus required.

Equally important is the emotional and psychological support provided to the terminally ill person, treating the patient with dignity, patience, a caring attitude and respecting him or her as a person who has feelings and rights [<http://www.hsm.min-saúde.pt/Default.aspx?tabid=1506> & Menu Active=cuid].

In view of the above, the researcher examined the level of preparedness of nurses in Angola, especially in the Bié province, to care for patients with terminal diseases.

## **2.6 CATEGORIES OF NURSES IN ANGOLA AND THEIR TRAINING**

To evaluate the preparedness of nurses to treat terminally ill patients at the provincial hospital of Bié required considering the training framework for nurses in Angola. In Angola there are three categories of nurses, namely, basic, medium and higher levels. These nurses have different training programmes and different roles in the provision of health care. The relevant curriculums were consulted to ascertain the content taught at the different levels.

## **2.6.1 Basic level nurse or nursing assistant**

These are the holders of certificates as nursing assistants or basic level nurses awarded by a teaching institution registered, in terms of the law, within the relevant structure of the Angolan Nurses' Association.

### **2.6.1.1 Competencies of the basic level nurse**

The following competencies are required of the nursing assistant: To

- fulfil nursing activities at the level of promotion of health
- assist in the recovery and rehabilitation of the health of individuals and/or social groups
- provide care as required by patients in a serious state under the guidance of the graduate/qualified nurse
- provide nursing assistance in collective health to the individual in the various phases of the life cycle, to the family, groups, community, by means of health education, aimed at improving the quality of life
- select and use specific techniques in the treatment of patients/environment/materials and equipment with the aim of controlling infections

This specific hospital has 200 nurses belonging to this group.

### **2.6.1.2 Curricular content for basic level nurses**

The curriculum for basic level nurses covers the following (19) topics:

- 1 Orientation to the ethics and norms of the school
- 2 Introduction to health and nursing
- 3 Psychology I
- 4 Anatomy and physiology
- 5 Maternal assistance I
- 6 Child assistance (first half)
- 7 Adult assistance
- 8 Nutrition I

- 9 Nursing techniques (first half)
- 10 Pharmacology
- 11 Notions on epidemiology and extended vaccination programme
- 12 Maternal assistance II
- 13 Child assistance (second half)
- 14 Education for health
- 15 Management in nursing and health statistics
- 16 Community nursing
- 17 More frequent diseases
- 18 Nursing techniques (second half)
- 19 Environmental health.

The basic level nurse is educated and trained to provide basic nursing care in different contexts.

## **2.6.2 Medium level nurses**

Medium level nurses are holders of Diplomas or Certificates as medium level nurses issued in accordance with the legislation and registered by the relevant structure (Angolan Nurses' Association).

### ***2.6.2.1 Competencies of the medium level nurse***

Medium level nurses are required to:

- Recognise and act in the various scenarios within professional practice.
- Identify the determining and conditioning factors of the health-disease process.
- Identify the structure and organisation of the health system in force with a critical discernment of the situation with regard to public health.
- Identify functions and responsibilities of the members of the work team.
- Plan and organise the work within the framework of integral and quality attendance.
- Interpret and apply norms and ethical principles of professional practice, fully complying with the code of ethics of the profession.



- Perform in a responsible and humane manner all activities pertaining to the function under the supervision of the graduate/qualified nurse.
- Provide nursing assistance to clients in a serious or agonising situation, at home, at the emergency or intensive treatment units, and provide physical, mental and spiritual comfort.
- Register occurrences and services rendered in accordance with the demands of their professional field.

### **2.6.2.2 Curriculum for medium level nurses**

Mid-level nurse training covers the following (29) modules:

- 1 Portuguese language
- 2 English language
- 3 Biology
- 4 Chemistry
- 5 Physics
- 6 Mathematics
- 7 Physical Education
- 8 Sociology
- 9 Psychology
- 10 Nursing and professional ethics
- 11 Strategy for primary health care
- 12 Hygiene and sanitation
- 13 Anatomy and physiology
- 14 Chronic diarrhoeal diseases
- 15 Nutrition
- 16 Education for health
- 17 Maternal assistance
- 18 Child assistance
- 19 Medical-surgical nursing
- 20 Pathology and pharmacology of current diseases
- 21 Introduction to nursing techniques
- 22 Techniques of hospital nursing
- 23 Nursing in emergency pathologies

- 24 Theatre nursing
- 25 Obstetrics and gynaecology
- 26 Nursing in paediatric pathologies
- 27 Administration and management
- 28 Human parasitology
- 29 Nursing practice.

Medium level nurses are trained in more complex topics than basic level nurses.

### **2.6.3 Graduate/qualified nurses**

Graduate nurses are holders of a diploma awarded by higher education institutions in the Republic of Angola.

#### **2.6.3.1 Competencies of graduate/qualified nurses**

Graduate nurses are required to have competencies in three components:

##### ➤ **Management of health institutions**

Their management task encompasses to

- Participate in the definition of national health policies.
- Manage health services, coordinating the assistance in the institution to which they are attached.
- Manage nursing assistance to patients in need of differentiated care.
- Manage the work process in health care with ethical principles and resolve at both individual as well as collective level in all areas of professional activity.
- Manage human resources of health institutions within the scope of planning, recruiting, selection, allocation and distribution of personnel, continued education, performance evaluation, leadership, supervision and professional career.

##### ➤ **Management of health programmes**

In managing health programmes they are expected to

- Manage health programmes ensuring the human, physical, material and financial resources essential for the development of these programmes.
- Promote and evaluate community participation in all phases of programme development.

➤ **Management of schools and nursing teaching programmes**

In terms of the schools and nursing programmes, graduate nurses are required to

- Participate in the development and/or review of nursing curricula for the country in accordance with the health needs of the population and the norms from the Ministry of Health and Education.
- Participate in the definition of educational policies for nursing within the national level, and at the level of PALOP and SADECC (Nurses Order of Angola).

**2.6.3.2 Curriculum for graduate/qualified nurses**

Training this category of nurses entails the following (44) modules:

- 1 Nursing and obstetrics
- 2 Introduction to public health and community health
- 3 History and legislation in nursing
- 4 Integration of the nursing student in school and within the profession
- 5 Cellular biology, histology and embryology
- 6 Human anatomy
- 7 Microbiology
- 8 Basic instruments for nursing
- 9 Introduction to computer science applied to health
- 10 Health and health vigilance
- 11 General psychology
- 12 Sociology
- 13 Parasitology
- 14 Ethics in nursing
- 15 Genetics

- 16 Psychology II
- 17 Introduction to statistics applied to health
- 18 Didactics I
- 19 Physiology
- 20 Introduction to nursing
- 21 Nutrition
- 22 Pharmacology
- 23 Didactics II
- 24 Pathology
- 25 Child health
- 26 Women's health
- 27 Adult health
- 28 Epidemiology and epidemiologic vigilance
- 29 Introduction to mental health
- 30 Development psychology
- 31 Paediatric nursing
- 32 Medical nursing
- 33 Introduction to management applied to nursing
- 34 Nursing in transmissible diseases
- 35 Diet-therapy
- 36 Fundamental ethics
- 37 Dynamics of the group relations in nursing
- 38 Obstetric and gynaecological nursing
- 39 Introduction to work nursing
- 40 Surgical nursing
- 41 Psychiatric nursing
- 42 Hospital nursing
- 43 Nursing management in a public health unit
- 44 Management applied to hospital nursing

As the senior category, the graduate/qualified nurse is more comprehensively trained with a significant component allocated to different forms of management. It is not clear from the curricula of all three groups, however, whether their training actually includes topics on palliative care.

#### **2.6.4 Experiential learning**

Experiential learning enables student nurses to apply the theory they learn in the class situation in the practical field of health care. During these sessions student nurses learn the hands-on skills of patient care. To consolidate and improve the training, experienced professionals accompany students during practice. At the end of the course, depending on their area of professional training and competencies, students are placed in primary, secondary or tertiary health care in the area for which they were trained.

#### **2.6.5 Supervision**

Supervision is an act by which trained and experienced staff lead, guide, support and correct the actions of subordinates (Novo Dicionário Aurélio de Língua Portuguesa 1986:412). In health care settings, the people who supervise are the most professionally experienced ones who follow up the work done by their subordinates with the aim of detecting errors and their subsequent correction. In Angola, graduate/qualified nurses supervise basic and medium level nurses.

#### **2.6.6 Role modelling**

Role modelling implies that leaders, managers or seniors subtly influence others' behaviour by their example (Jooste 2003:93). This presupposes that the example being modelled is always positive.

The most experienced nurses are appointed to share their competencies with those who are inexperienced and those who have just graduated, in the theoretical and practical areas, enabling them to learn by example and to grow professionally.

### **2.7 CONCLUSION**

This chapter discussed the literature review, which dealt with terminal diseases, the effect of being terminally ill on a person, and the family members and loved ones, Kubler-Ross's stages of death, and the needs of patients who find themselves in this situation. The different categories of nurses in Angola and their training were also described.

Chapter 3 discusses the research methodology.

## **CHAPTER 3**

### **Research methodology**

#### **3.1 INTRODUCTION**

Research methodology refers to the stages, procedures and strategies used to structure the process and to collect and analyse data in research. This chapter discusses the research methodology of this study, including the research design, population, sample, data-collection instrument, obtaining permission, pilot study, data collection and ethical considerations.

#### **3.2 OBJECTIVES**

The objectives of this study were to

- determine whether the training received by nurses enabled them to care for terminally ill patients
- make recommendations for the training and development of nurses to care for patients with terminal diseases

#### **3.3 RESEARCH DESIGN**

The research design refers to the strategies adopted by the researcher to acquire precise and objective information, which can be interpreted (Polit & Hungler 1999:109). The research design is a researcher's general plan to answer the research questions or to test the hypotheses (Polit et al 2004:164-165). For this study, a quantitative approach with an exploratory and descriptive design was adopted.

##### **3.3.1 Quantitative**

Quantitative research is the study of a phenomenon suitable to be measured with precision and to be quantified, often involving a rigorous and controlled design (Polit et al 2004:439). The quantitative approach was suitable for this study as specific knowledge and training content was being measured.

### **3.3.2 Exploratory**

Exploratory research starts with a phenomenon of interest and, besides observing and describing it, investigates its complex nature and the other factors with which it is related (Polit et al 2004:34). This study aimed to explore the preparedness of nurses to care for terminally ill patients.

### **3.3.3 Descriptive**

Descriptive research entails studies that have as their main objective the precise portraying of the characteristics of the individuals, situations or groups as well as the frequency with which specific phenomena occur (Polit et al 2004:439). The researcher also described the current situation in a province of Angola pertaining to the capability of nurses to adequately look after and care for dying patients.

## **3.4 ASSUMPTION**

An assumption is “a basic principle assumed to be true without the need for scientific proof” (LoBiondo-Wood & Haber 2001:321; Polit et al 2004:27). The assumption guiding this study was that knowledge could lead to a change in behaviour.

## **3.5 POPULATION**

A population is “a well-defined set of people, animals, objects or events that have certain special characteristics, which are appropriate for a study” (LoBiondo-Wood & Haber 2001:41). In this study, the population were the nurses of a provincial hospital in Bié, Angola. Of the nurses, 200 had basic and 400 had medium level training, which provided a total of 600 nursing professionals employed at the hospital.

## **3.6 SAMPLE**

A sample is a subset of a population used to study certain characteristics within the target population (LoBiondo-Wood & Haber 2001:316). Sampling refers to “the process of selecting a part of the population to be studied. The sample is the subset of this population” (Polit et al 2004:225). The researcher used simple random sampling,

according to which each person or element within a population has an equal chance of being selected for the study. Simple random sampling is a probabilistic sampling strategy through which the population is defined, a sampling structure is numbered and a subset is selected from which a sample was chosen (LoBiondo-Wood & Haber 2001:145). In this study, the sample consisted of 100 nurses from a population of 600 basic and medium level nurses. The respondents were randomly selected as they arrived on duty.

To participate in this study, nurses had to be

- basic or medium level nurses
- working at the specific provincial hospital in Biè

### **3.7 DATA-COLLECTION INSTRUMENT**

The instrument is the element or techniques that a researcher uses to collect data; for example, a questionnaire, tests, observation or interviews (Polit et al 2004:436). The instrument used to collect data for this study was a questionnaire developed by the researcher for the purposes of this study (refer to Annexure D).

Polit et al (2004:256) point out that questionnaire has the following advantages:

- It costs less and requires less time and effort to manage.
- It offers the possibility for complete anonymity.
- The absence of an interviewer ensures impartiality, leaving participants at ease to respond freely to the questions.

At the same time, a questionnaire has disadvantages (Polit et al 2004:256), including

- It must not be very long so as not to tire the respondents.
- There can be mistakes when filling in the questionnaire due to the lack of attention by the researcher.
- Participants can fill in the questionnaire not to cooperate with researchers, but rather to get rid of them.



The questionnaire comprised the following three sections:

Section A: Biographical information

Section B: Nursing care of terminally ill patients

Section C: Training of nurses to care for terminally ill patients

### **3.7.1 Validity**

Validity means to determine whether a measuring instrument really measures what it intends to measure. It is the degree to which the instrument measures what it is supposed to measure and whether it measures the concept correctly (LoBiondo-Wood & Haber 2001:321).

There are different types of validity: face, concurrent, construct, content, external, internal, and criterion-related validity (Polit et al 2004:441). However, the types of validity appropriate for this study were face and content validity. Content validity seeks to ensure that the questions contained in the questionnaire are relevant to the topic, represent the universe of the content and will obtain the data related to the variables of the study. Content validity was supported by the literature review. Face validity refers to the appearance of the questionnaire and whether it appears to measure the intended variables. Face validity was achieved by submitting the questionnaire to academics at the University of South Africa (UNISA) for perusal and comment.

### **3.7.2 Reliability**

Reliability refers to the consistency with which the instrument measures the attribute. An instrument is reliable if its measurements reflect exactly the true measures of the attribute (Polit et al 2004:288). The attribute can be measured by three aspects of reliability namely, stability, internal consistency and equivalence (Polit et al 2004:288).

For this study, reliability through internal consistency was sought by doing a pre-test of the instrument.

### **3.8 DATA COLLECTION**

Data collection is the actual method employed to collect information from the respondents by means of the instrument for data collection, which in this case was a questionnaire. The questionnaire was randomly distributed amongst the target group at the provincial hospital of Bié. The questionnaires were handed to nurses as they came on duty on a specific day for a day shift and the remainder of the questionnaires were given to the Head Nurse to distribute amongst the night duty personnel. As the nurses came on duty they were approached and given a brief orientation of the study, were requested to sign the consent form if they were willing to participate, after which the questionnaires were distributed. One hundred questionnaires were distributed and all 100 were returned.

### **3.9 DATA ANALYSIS**

Data analysis is the process of organising and managing the data in such a way that the research questions can be answered and the hypothesis can be tested (Polit et al 2004:430). In this study, a statistician analysed the data by means of descriptive analysis, which calculated the frequencies and percentages. The data was analysed using the Statistical Package for Social Sciences (SPSS) program. Once the data was processed, the results were presented in the form of tables, graphs and diagrams.

### **3.10 PRE-TESTING THE DATA COLLECTION INSTRUMENT**

A pilot study is a small-scale version of the main study, which is used to obtain information on how to improve the project or to evaluate its feasibility (Polit & Hungler 1999:35). However, in this study, a pilot study was not done but the questionnaire was pre-tested to ensure its clarity and user friendliness (Polit et al 2004:54). The pre-testing was done at a different hospital from the one used in the main study, five nurses were asked to complete the questionnaire compiled by the researcher. The pre-test indicated that the questionnaire was clear and specific. No corrections were necessary.

### 3.11 PERMISSION TO CONDUCT THE STUDY

Written permission was obtained from the relevant authorities to conduct the study. A letter requesting permission was addressed to the Clinical Director and General Director of the provincial hospital of Bié, together with the research proposal and a questionnaire (see Annexure A). A positive reply, granting permission, was received (see Annexure B).

### 3.12 ETHICAL CONSIDERATIONS

Ethical considerations are basic principles relevant to conduct research. They are necessary when human beings are involved because people have the right to self-determination and treatment as autonomous agents. They have the freedom to participate or not in a research project (Polit & Hungler 1999:159).

In order to respect the respondents' basic human rights, the researcher took into account the principles of respect, beneficence, justice, anonymity and confidentiality.

- **Respect for people:** People have the right to self-determination and to be treated as autonomous agents (Polit & Hungler 2001:159). This was achieved by respecting human rights, their privacy and dignity. The respondents had the freedom to participate in the study or not.
- **Beneficence:** This is the obligation not to cause any harm and to maximise potential benefits (Polit & Hungler 2001:159). In this study, the respondents were treated in an ethical manner, their decisions were respected, they were protected from harm and efforts were made to make the process as easy as possible for them.
- **Justice:** People who participate as research subjects must be treated with fairness (Polit & Hungler 2001:159).
- **Right to anonymity:** Based on the principle of respect, anonymity exists when the identity of the research subjects cannot be linked, even by the researcher, to their individual reactions (Polit & Hungler 2001:163). In this study, the researcher

respected the respondents' right to anonymity by asking them not to fill in their names on the questionnaires.

- **Confidentiality:** Confidentiality means that the individual identities of the research subjects cannot be linked to the information provided by them and will not be publicly disclosed (Polit & Hungler 2001:163). In this study, confidentiality was ensured, as respondents did not identify themselves.

### **3.13 CONCLUSION**

This chapter discussed the research methodology used in this study aimed at determining the preparedness of basic and medium level nurses to care for terminally ill patients. The research design, population, sampling method, instrument, data collection and analysis, permission and ethical considerations were described.

Chapter 4 discusses the data analysis.

## **CHAPTER 4**

### **Data analysis and interpretation of findings**

#### **4.1 INTRODUCTION**

The overall purpose of this study was to determine whether nurses were adequately prepared to nurse and care for terminally ill patients in a selected provincial hospital in Bié, Angola. Data was collected from the respondents by means of questionnaires. One hundred questionnaires were distributed and all were returned, giving a response rate of 100 percent.

The completed questionnaires were submitted to a statistician at the University of South Africa (UNISA) for data processing and analysis. The questionnaire consisted of three sections, namely biographical information, nursing care of the terminally ill patient, and training of nurses to care for the terminally ill.

#### **4.2 DATA ANALYSIS**

The computer program used for the analysis was the SPSS version 13. The questions in the questionnaire consisted of categorical responses, which led to categorical variables.

The statistician reduced the data acquired from the responses to each question to frequencies, that is, counts of how many respondents selected a particular response. These frequencies were illustrated by means of pie charts or bar charts. Bar charts are particularly useful in questions that offer alternatives and where the respondents are allowed to mark more than one choice (the “Yes/No” options) where the bar chart compares the frequencies of the different choices. Pie charts are used when the respondents are allowed to choose only one alternative, and the pie chart then illustrates the share of the total respondents opting for each choice.

### 4.3 DATA PRESENTATION

The information was presented in tables, pie graphs and bar graphs. As the frequency of the 100 respondents equalled the percentage of 100 percent, percentage is mostly used in the discussion of the results. It should be noted that the percentages in the tables were calculated on the number of respondents who answered the particular question and therefore do not always correspond with the total frequency of 100.

#### 4.3.1 Biographical information

This section dealt with aspects such as position, years experience, age and gender.

##### 4.3.1.1 *Current position in the hospital*

The respondents were asked to indicate their current position in the hospital where they worked.

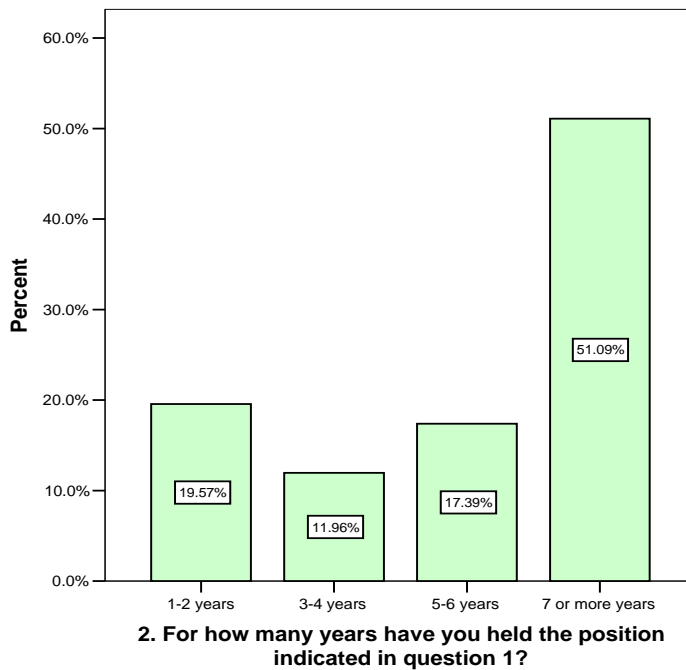
**Table 4.1 Current position in the hospital (n=100)**

| <b>CURRENT POSITION IN THE HOSPITAL</b> | <b>FREQUENCY</b> | <b>PERCENT</b> |
|---|------------------|----------------|
| Medium level nurse                      | 47               | 47,0           |
| Basic level nurse                       | 46               | 46,0           |
| Medium level student                    | 3                | 3,0            |
| Basic level student                     | 4                | 4,0            |

From table 4.1 it is evident that medium level (47) and basic level nurses (46) were evenly represented in the sample.

##### 4.3.1.2 *Duration of position held*

The respondents were asked to indicate how long they had been employed in their current position.



**Figure 4.1**  
**Respondents' years in current position (n=92)**

The category *7 or more years* was the largest category. Figure 4.1 is based on the respondents who answered the question. Of the respondents, 51% had held their positions for seven years or longer, while 17% had held them for at least five to six years. This confirmed the tendency of nurses in rural areas to remain in their positions and place of work, as there is limited opportunity for change or advancement.

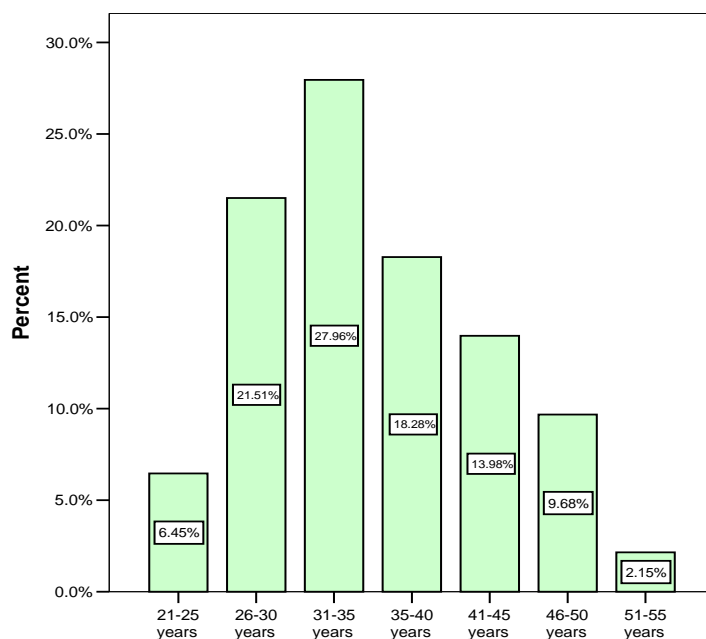
#### **4.3.1.3 Age**

The respondents were required to select one of the age categories to indicate their age (see table 4.2).

**Table 4.2 Respondents' age distribution (n=93)**

| AGE CATEGORY | FREQUENCY  | PERCENT      |
|--------------|------------|--------------|
| 21-25 years  | 6          | 6,0          |
| 26-30 years  | 20         | 20,0         |
| 31-35 years  | 26         | 26,0         |
| 36-40 years  | 17         | 17,0         |
| 41-45 years  | 13         | 18,0         |
| 46-50 years  | 9          | 9,0          |
| 51-55 years  | 2          | 2,0          |
| No answer    | 7          | 7,0          |
| <b>TOTAL</b> | <b>100</b> | <b>100,0</b> |

The largest category was 31-35 years. Figure 4.2 indicates the number of respondents who answered the question. Of the respondents, 82% were aged between 26 and 45, indicating that they were mature individuals, of whom 68% had five and more years' experience in their current positions. Figure 4.2 illustrates the age distribution.



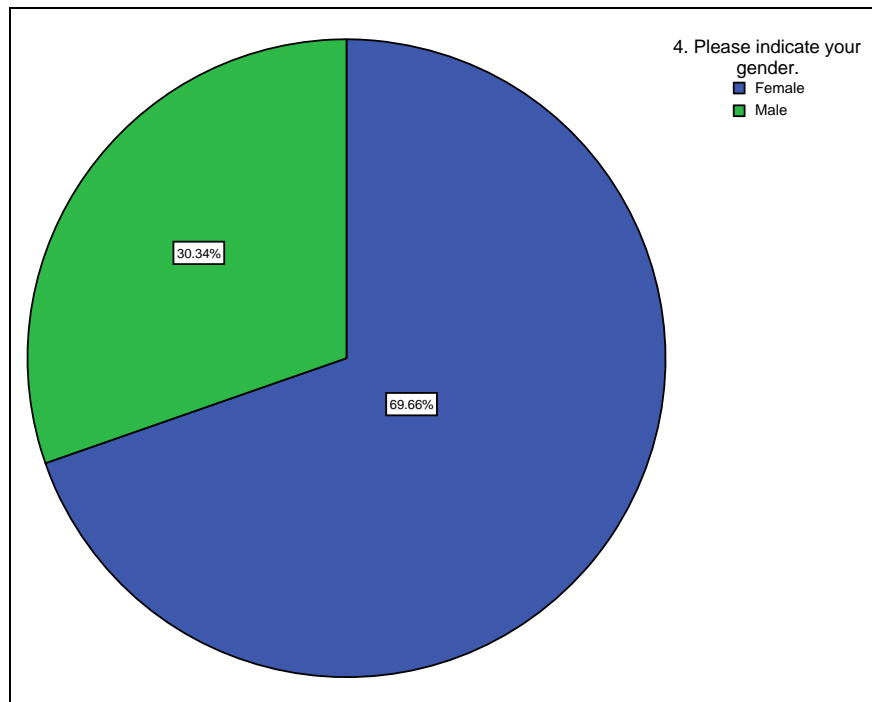
3. Indicate in which age category you are.

**Figure 4.2**  
**Respondents' age categories (n=93)**



#### 4.3.1.4 Gender

It was considered important to establish the respondents' gender, as nursing is usually considered a female-oriented profession.



**Figure 4.3**  
**Respondents' gender (n=89)**

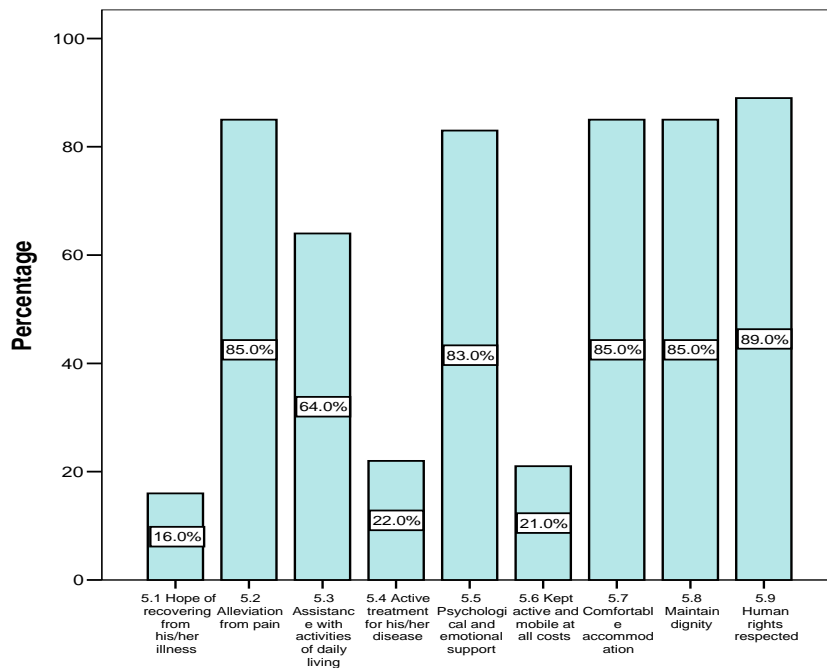
Figure 4.3 indicates that of the respondents, most (n=62) were female, and one third (n=27) were males.

#### 4.3.2 Nursing care of the terminally ill patient

This section wished to determine the respondents' understanding of what it implied to be terminally ill.

### 4.3.2.1 The terminally ill patient

The respondents were asked nine questions pertaining to the terminally ill patient, and had to respond by choosing one of the following response alternatives *always*, *often*, *seldom* and *never* (see figure 4.4).



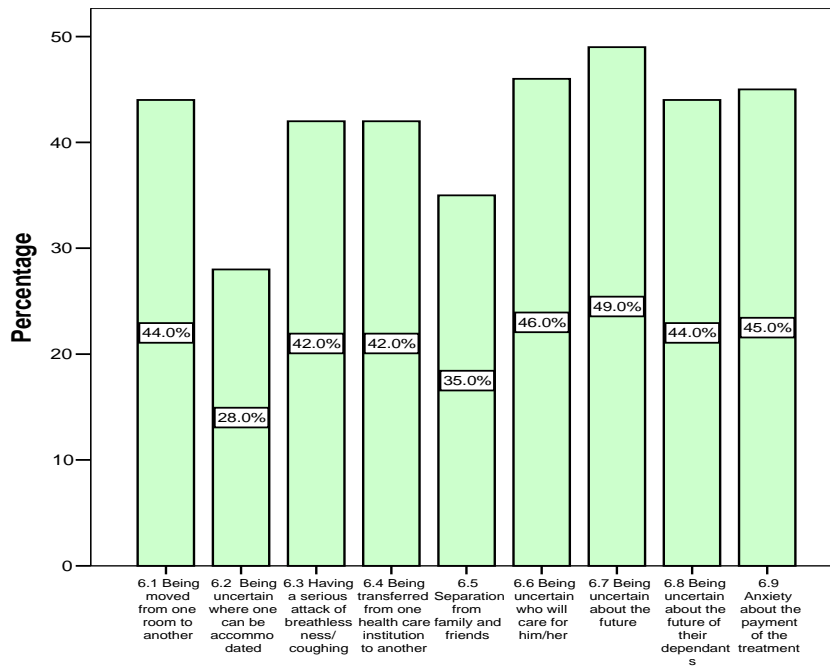
**Figure 4.4**

**Aspects related to terminally ill patients (n=100)**

Figure 4.4 indicates the percentage of the respondents who answered *always* or *often* to each question. Of the respondents, between 83% and 89% knew the circumstances of terminally ill patients as they indicated that these patients required alleviation from pain (85%), psychological and emotional support (83%), comfortable accommodation (85%), that their dignity be maintained (85%) and that their human rights be respected (89%).

### 4.3.2.2 Safety and comfort needs of the terminally ill patient

The respondents were asked to indicate which of the following safety/comfort aspects had a negative influence on the terminally ill patient (see figure 4.5).



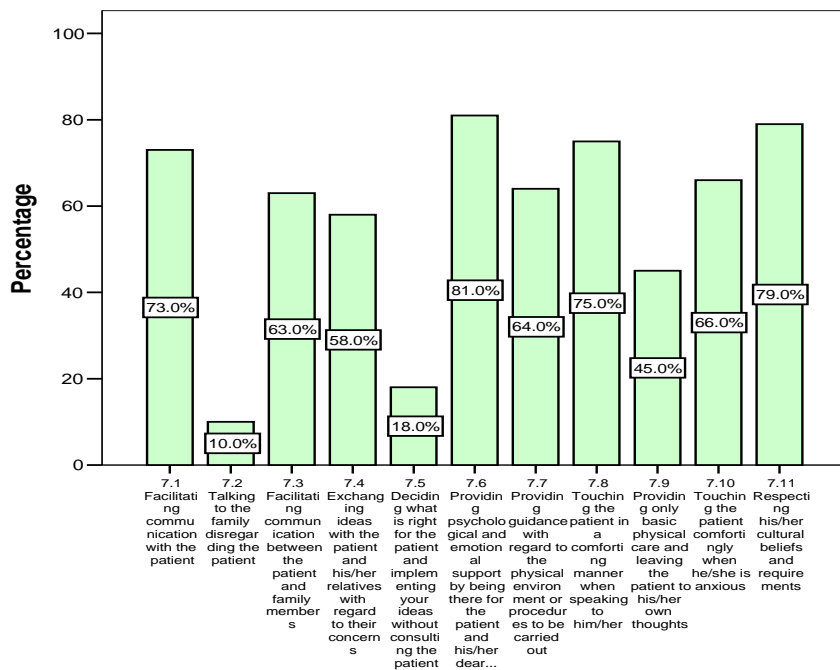
**Figure 4.5**  
**Aspects that have a negative bearing on the safety and comfort of**  
**a terminally ill patient (n=100)**

The bar chart indicates the percentage of all respondents who answered yes to the nine posed questions. The number of responses to these questions was incomplete in most cases varying between 14 and 26 respondents who did not answer all or some of the questions.

Factors which affect the safety and comfort of terminally ill patients were identified by a third to half of the respondents (35 to 49%) as being moved from one room to another (44%), having a serious attack of breathlessness (42%), being transferred from one health care centre to another (42%), separation from family and friends (35%), being uncertain who will care for him or her (46%), being uncertain about the future (49%) and the future of their dependents (44%), and anxiety about the payment of the treatment (45%). It thus appears as if half of the nurse respondents are aware of the disconcerting factors which affect the dying patient.

### 4.3.2.3 Comforting the terminally ill patient

The respondents were required to indicate how they would comfort a terminally ill patient who was anxious and disturbed about his/her accommodation and care, by selecting from 11 alternatives (see figure 4.6).



**Figure 4.6**  
**Means to comfort a terminally ill patient (n=100)**

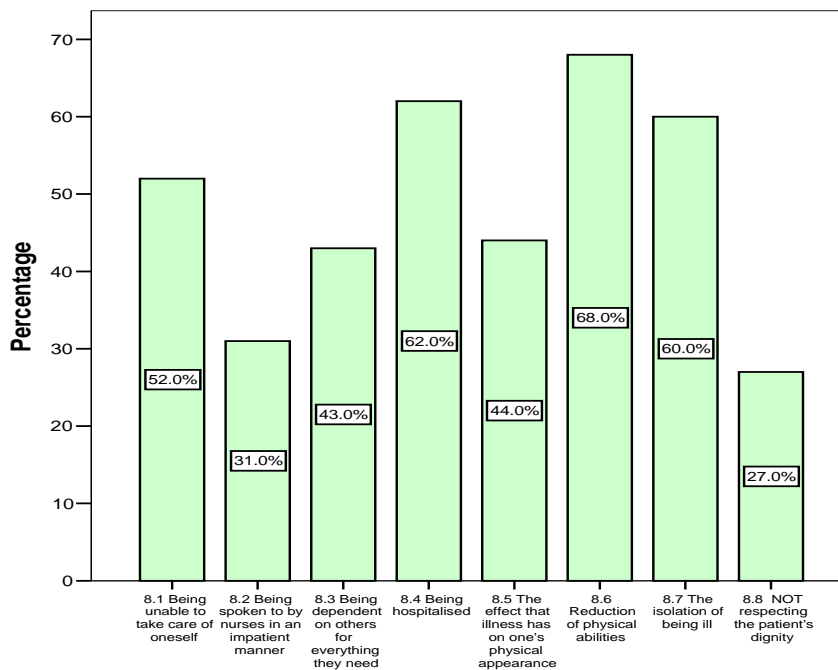
Figure 4.6 illustrates the respondents who replied *always* to these questions. The response rate to these 11 questions was slightly higher than the previous set of questions, but there were still between 11 and 21 missing values for the respective questions.

Of the respondents, between 45% and 81% indicated that they would comfort a terminally ill patient by facilitating communication with the patient (73%), facilitating communication with the family (63%), exchanging ideas with the patient and family members with regard to his/her concerns (58%), being there for the patient (81%), providing guidance with regard to the physical environment or procedures to be carried out (64%), touching the patient in a comforting manner when speaking to him/her (75%), or touching the patient comfortably when he/she was anxious (66%), and respecting his/her cultural beliefs and requirements (79%).

However, some of the respondents felt that they could talk to the family disregarding the patient (10%) and decide what was right for patient and implement such ideas without consulting with the patient (18%).

#### **4.3.2.4 Factors affecting the self-esteem and self-image of the terminally ill patient**

The respondents were asked to indicate the factors they thought could affect the self-esteem or self-image of the terminally ill patient adversely from a list of eight alternatives (see figure 4.7).



**Figure 4.7**  
**Factors affecting the terminally ill patient's self-esteem and self-image (n=100)**

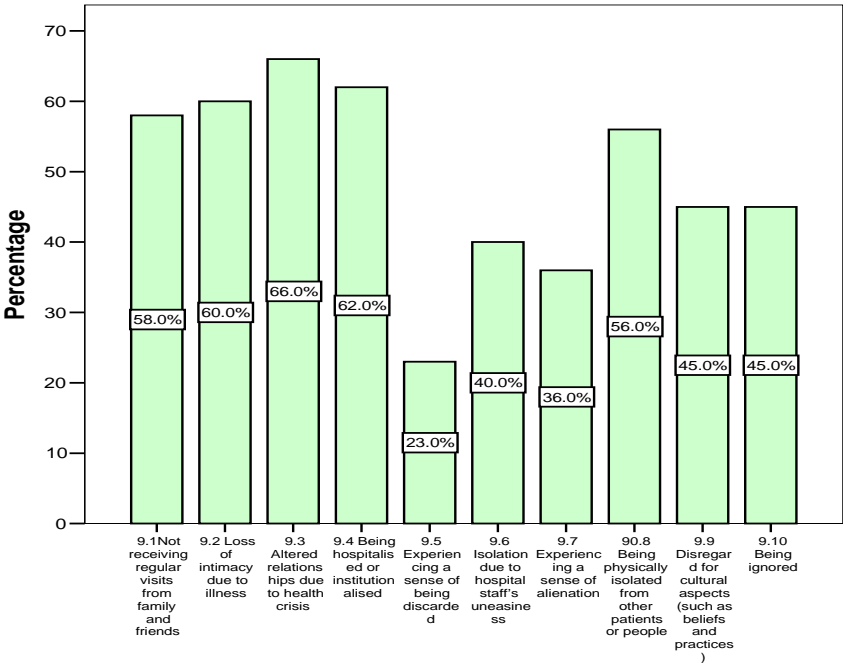
Figure 4.7 illustrates that between one third and two thirds of the respondents indicated that each of these factors would affect the self-esteem or self-image of the terminally ill patient.

With regard to aspects adversely affecting the self-esteem and self-image of the terminally ill patient, the respondents indicated that reduction in physical abilities (68%),

being hospitalised (62%), the isolation of being ill (60%), being unable to take care of themselves (52%), the effect illness had on their physical appearance (44%), being dependent on others for everything they need (43%), being spoken to by nurses in an impatient manner (31%), and not respecting the patient’s dignity (27%), all contributed to the patient’s poor self-esteem and self-image.

**4.3.2.5 The terminally ill patient’s need for love and belonging**

It is human nature to want to be with loved ones when ill or subject to trauma. The respondents were thus required to indicate which factors could affect the terminally ill patient’s need for love and belonging (see figure 4.8).

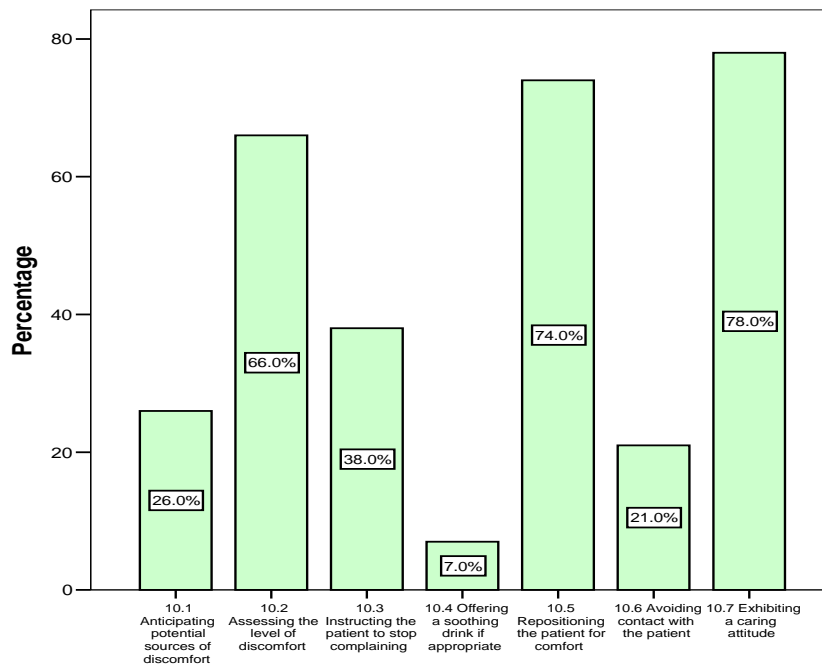


**Figure 4.8**  
**Factors affecting the terminally ill patient’s need for love and belonging (n=100)**

Figure 4.8 illustrates the percentages of the respondents who said yes to each of these statements. The most important factors affecting the terminally ill patient’s need for love and belonging were altered relationships due to the health crisis (66%), being hospitalised or institutionalised (62%), loss of intimacy due to illness (60%), not receiving regular visits from family and friends (58%), and being physically isolated from other patients or people (56%).

### 4.3.2.6 Handling physical discomfort

As the disease progressed, there was usually an increase in physical discomfort, thus the respondents were asked to indicate how they would handle this situation (see figure 4.9).



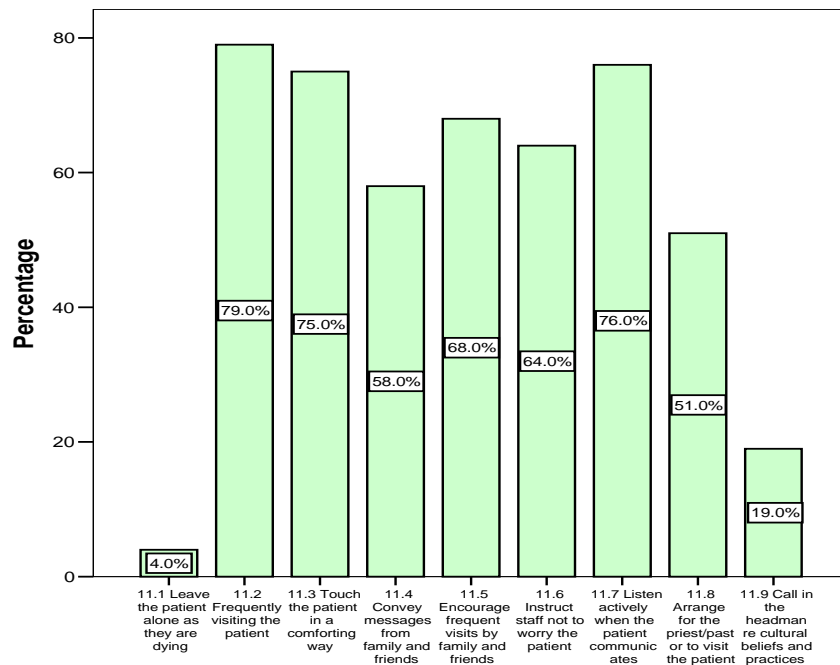
**Figure 4.9**

#### ***Actions in handling physical discomfort of terminally ill patients (n=100)***

Figure 4.9 illustrates the percentage of all respondents who said yes to each of the statements. The respondents appropriately noted that it was important to exhibit a caring attitude (78%), to reposition the patient (74%), and to assess the level of discomfort (66%). However, some of the respondents noted that they would instruct the patient to stop complaining (38%) and would avoid the patient (21%).

#### 4.3.2.7 Alleviate the patient's fear

Terminally ill patients can fear isolation and loneliness. The respondents were asked to indicate what they would do to alleviate a patient's fear (see figure 4.10).



**Figure 4.10**

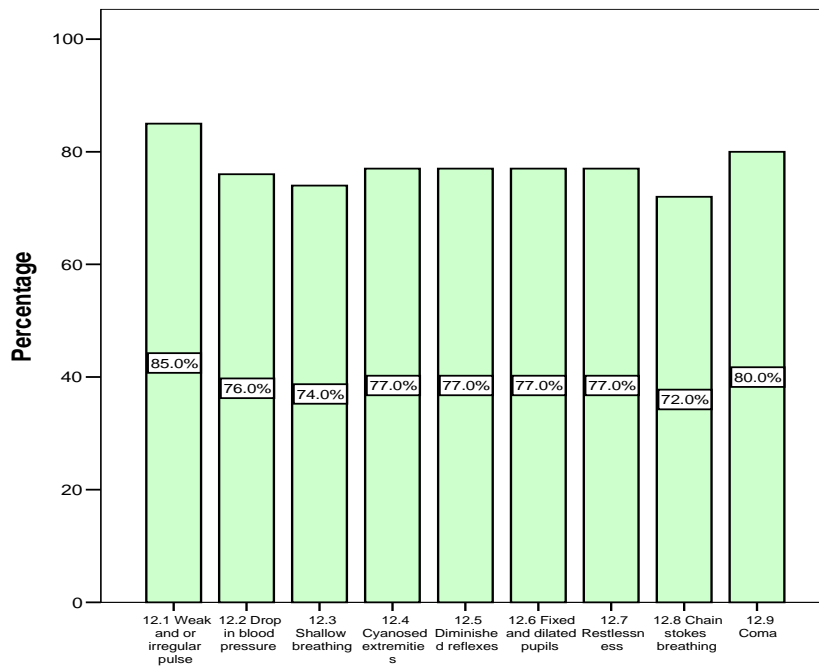
#### **Actions to alleviate the patient's fears (n=100)**

Figure 4.10 illustrates the percentage of the respondents who said they would *always* take such action. The respondents appeared to be empathetic in their actions to alleviate patients' fear by frequently visiting the patient (79%), by actively listening when the patient communicates (76%), by touching the patient in a comforting manner (75%), by encouraging frequent visits by family and friends (68%), by instructing the staff not to worry the patient (64%), and by conveying messages from family and friends (58%).

#### 4.3.2.8 Signs and symptoms when death is imminent

The respondents were asked to indicate the signs and symptoms that might be evident when the death of a terminally ill patient was imminent (see figure 4.11).





**Figure 4.11**  
**Signs and symptoms of imminent death (n=100)**

Figure 4.11 illustrates the percentage of the respondents who said yes to each of the listed symptoms. Between 85% and 72% of the respondents affirmed that a weak and irregular pulse (85%), coma (80%), cyanosed extremities (77%), diminished reflexes (77%), fixed and dilated pupils (77%), restlessness (77%), drop in blood pressure (76%), shallow breathing (74%) and chain-strokes breathing (72%) might be evident when the patient was dying. The majority of the respondents thus had the necessary knowledge to identify a dying patient.

### **4.3.3 Training of nurses taking care of the terminally ill patient**

In this section specific questions examined the training the respondents had received on the care of the terminally ill patient, or palliative care.

#### **4.3.3.1 Curriculum content on palliative care**

The respondents were asked to indicate whether their curriculum contained a section on caring for the terminally ill (see table 4.3).

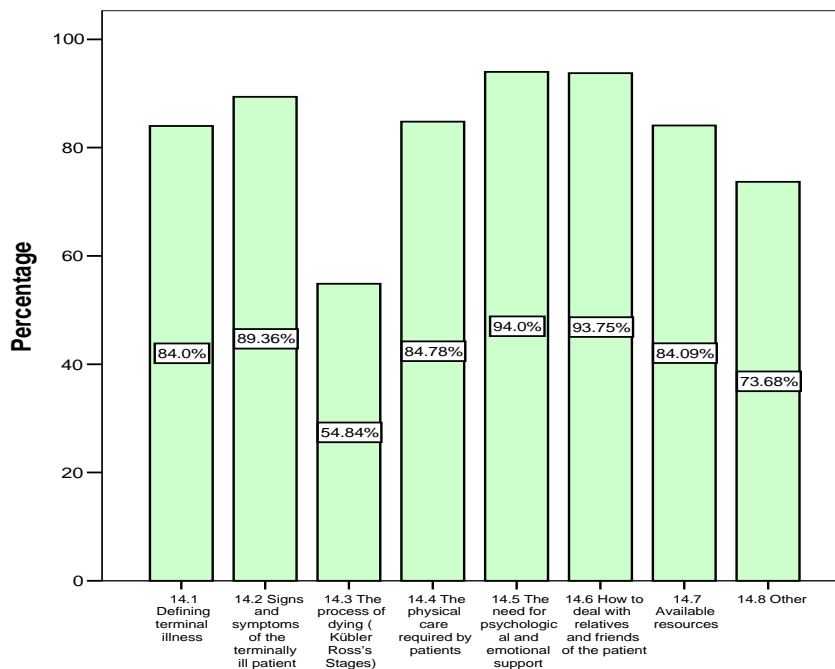
**Table 4.3 Curriculum content on caring for the terminally ill (n=70)**

|              | FREQUENCY  | PERCENT      |
|--------------|------------|--------------|
| Yes          | 44         | 63,0         |
| No           | 26         | 37,0         |
| No answer    | 30         | -            |
| <b>TOTAL</b> | <b>100</b> | <b>100,0</b> |

Of the 70 respondents who answered this question, 63% indicated that their curriculum did contain a section on caring for the terminally ill, while 37% responded negatively in this regard. It was thus not clear what the true state of affairs was, as it can be assumed that nurse training in a country should be guided by a standard curriculum.

**4.3.3.2 Specific curriculum content pertaining to the terminally ill patient**

Following the previous question, the respondents were asked to indicate which of the following aspects regarding the terminally ill patient were included in their curriculum allowing them to receive training in this regard (see figure 4.12).



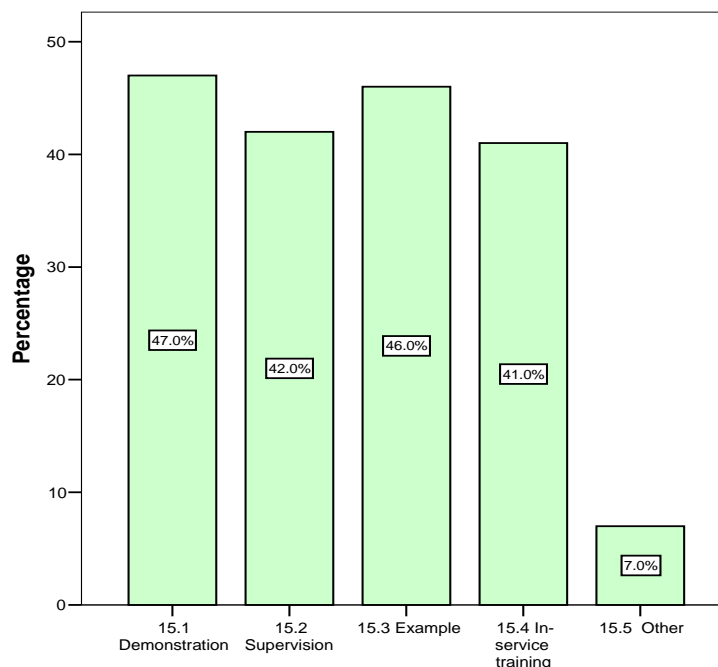
**Figure 4.12**

**Curriculum content on caring for the terminally ill patient (n=100)**

Figure 4.12 shows the percentage of the respondents who confirmed that these topics were included in their curriculum: the need for psychological and emotional support (94%), how to deal with family and friends of the patient (94%), signs and symptoms of the terminally ill patient (89%), the physical care required by patients (85%), available resources (84%), defining terminal illness (84%), and just over half (55%) of the respondents indicated that they learned about Kübler-Ross's stages of grieving.

#### 4.3.3.3 *Guidance in caring for the terminally ill patient*

The respondents were asked to indicate in what way they were guided in the practical situation to take care of the terminally ill patient (see figure 4.13).



**Figure 4.13**

***Guidance on caring for the terminally ill patient (n=100)***

It should be noted that this question was poorly answered, as 38 to 43 respondents did not respond to the first four alternatives. Figure 4.13 shows the percentage of the respondents (between 41% and 47%) who had experienced the listed forms of training and guidance. It appeared that demonstration (47%), learning by example (46%), supervision (42%) and in-service training (41%) were applied in practice. These results indicated that guidance in the practical field did not receive much attention.

#### 4.3.3.4 *Caring for the dying patient*

It is human nature to shy away from dying and death therefore the respondents were asked to explain how they experienced caring for a dying patient (see tables 4.4.to 4.12). This question was poorly answered as the non-responses for the nine alternatives varied between 29 and 36. A brief analysis was given of the data pertaining to the response alternatives in the following nine tables. For the sake of clarity, the questions were slightly adjusted to serve as table headings.

**Table 4.4 It's like working with any other patient (n=71)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 28               | 39,0           |
| No           | 43               | 61,0           |
| No answer    | 29               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Even though 39% of the respondents in table 4.4 stated that they did not mind caring for the dying patient, 61% indicated that it was not like caring for other patients. Twenty-nine respondents did not answer this question.

**Table 4.5 Feel uncomfortable (n=70)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 13               | 19,0           |
| No           | 57               | 81,0           |
| No answer    | 30               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Only 19% of the respondents felt uncomfortable caring for a dying patient, while 81% did not. There were 30 missing responses. The fact that most nurses did not feel uncomfortable to work with these patients indicated that they would probably not avoid the patients.

**Table 4.6 Anxiety because I don't know what to do (n=69)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 27               | 39,0           |
| No           | 42               | 61,0           |
| No answer    | 31               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

In table 4.6, 39% of the respondents noted that they felt uncomfortable to care for the dying patient, while 61% did not. There were 30 missing responses.

**Table 4.7 Felt scared to care for the dying patient (n=69)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 7                | 10,0           |
| No           | 62               | 90,0           |
| No answer    | 31               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Of the 69 respondents who answered this question, 90% indicated that they did not feel scared to care for the dying patient.

**Table 4.8 Do not like caring for the dying patient (n=71)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 8                | 11,0           |
| No           | 63               | 89,0           |
| No answer    | 29               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Only 11% of the 71 respondents who answered this question stated that they did not like caring for the dying patient, while 89% indicated the opposite (see table 4.8).

**Table 4.9 It's a privilege to be there for the patient (n=65)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 49               | 75,0           |
| No           | 16               | 25,0           |
| No answer    | 35               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Of the 65 respondents who answered this question, 75% indicated that it was a privilege to care for the dying patient.

**Table 4.10 Do not want to be alone with the patient (n=64)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 19               | 30,0           |
| No           | 45               | 70,0           |
| No answer    | 36               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Of the 64 respondents who answered this question, 70% did not mind being alone with a dying patient whereas 30% indicated that they did not want to be alone with a person who was dying (see table 4.10).

**Table 4.11 Do not have enough knowledge to deal with terminal patients (n=67)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 26               | 39,0           |
| No           | 41               | 61,0           |
| No answer    | 33               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

Almost two thirds (61%) of the 67 respondents who answered this question noted that they did not have enough knowledge to deal with terminal patients, while 39% did not agree (see table 4.11).

**Table 4.12 Do not have practice in psychological counselling (n=68)**

|              | <b>FREQUENCY</b> | <b>PERCENT</b> |
|--------------|------------------|----------------|
| Yes          | 13               | 19,0           |
| No           | 55               | 81,0           |
| No answer    | 32               | -              |
| <b>TOTAL</b> | <b>100</b>       | <b>100,0</b>   |

The greater majority (81%) of the respondents in table 4.12 were of the opinion that they had practical experience in psychological counselling and could thus support the patients and their relatives.

### 4.3.3.5 Phases in the grieving process according to Kübler-Ross

The respondents were required to select from the following alternatives the stages of adjustment in the grieving process described by Kübler-Ross as a means to test their knowledge in this regard (see table 4.13).

**Table 4.13 Emotions in terms of the grieving process (n=100)**

| EMOTION          | INITIAL STAGE | MIDDLE STAGE | FINAL STAGE | NO ANSWER |
|------------------|---------------|--------------|-------------|-----------|
| 17.1 Denial      | 22            | 4            | 14          | 60        |
| 17.2 Anger       | 11            | 7            | 8           | 74        |
| 17.3 Acceptance  | 7             | 7            | 18          | 68        |
| 17.4 Rage        | 12            | 10           | 10          | 68        |
| 17.5 Complacency | 5             | 8            | 4           | 83        |
| 17.6 Envy        | 9             | 7            | 7           | 77        |
| 17.7 Resentment  | 10            | 7            | 4           | 79        |
| 17.8 Excitement  | 5             | 2            | 11          | 82        |
| 17.9 Anxiety     | 10            | 8            | 10          | 72        |
| 17.10 Pleasure   | 8             | 9            | 9           | 74        |

It is clear from table 4.13 that the majority of the respondents had no idea what this topic was about. The respondents who did answer the questions disagreed about what the correct answer should be. This contradicted the findings from figure 4.12 where 55% of the respondents indicated that they had received training on Kübler-Ross's stages of grieving.

## 4.4 CONCLUSION

This chapter discussed the data analysis and interpretation. The three main components of the questionnaire dealt with biographical information, nursing care of the terminally ill patient, and training of nurses to care for the terminally ill. Chapter 5 presents the findings, conclusions and recommendations.

## **CHAPTER 5**

### **Findings, conclusions and recommendations**

#### **5.1 INTRODUCTION**

A quantitative, exploratory and descriptive research design was applied in this study to investigate the preparedness of nurses to care for terminally ill patients, and to make recommendations, if necessary.

Based on the data analysis and findings, this chapter discusses the objectives, results, conclusions, recommendations and limitations of the study.

#### **5.2 OBJECTIVES**

The objectives of this study were to

- determine whether the training received by nurses enabled them to care for terminally ill patients
- make recommendations with regard to the training and development of nurses to care for patients with terminal diseases

#### **5.3 RESULTS**

Data was collected by means of a questionnaire comprising the following three sections:

Section A: Biographical Information

Section B: Nursing care for terminally ill patients

Section C: Nurses' training to deal with terminally ill patients



### 5.3.1 Section A: Biographical information

The sample consisted of one hundred respondents, from two groups of nurses, evenly represented in the sample. There were 47 medium level nurses plus 3 medium level students and 46 basic level nurses plus 4 basic level students.

Most of the respondents fell into the age group of 26 years and higher with the main representation being in the age group 31 to 40 years (43%). Two thirds of the respondents were female and one third was males.

Of the respondents, 68% had been in their position for at least six years, of whom 51% had been in them for seven years or longer.

### 5.3.2 Section B: Nursing care for terminally ill patients

Of the respondents, between 83% and 89% knew the **circumstances of terminally ill patients**, as they indicated that these patients required alleviation from pain (85%), psychological and emotional support (83%), comfortable accommodation (85%), that their dignity be maintained (85%) and that their human rights be respected (89%).

Of the respondents, 35% to 49% identified factors that affect the **safety and comfort of terminally ill patients adversely** as being moved from one room to another (44%), having a serious attack of breathlessness (42%), being transferred from one health care centre to another (42%), separation from family and friends (35%), being uncertain who would care for them (46%), being uncertain about the future (49%) and the future of their dependants (44%), and anxiety about the payment of the treatment (45%). Half of the respondents thus appeared to be aware of the negative factors that affect dying patients.

Between 45% and 81% of the respondents pointed out that they would **comfort a terminally ill patient** by facilitating communication with the patient (73%), and facilitating communication with the family (63%), exchanging ideas with the patient and family members with regard to his/her concerns (58%), by being there for the patient (81%), by providing guidance with regard to the physical environment or procedures to be carried out (64%), by touching the patient in a comforting manner when speaking to

him/her (75%), or touching the patient comfortingly when he/she is anxious (66%), and by respecting his/her cultural beliefs and requirements (79%).

According to the respondents, the most important factors affecting the **terminally ill patient's need for love and belonging** were altered relationships due to the health crisis (66%), being hospitalised or institutionalised (62%), loss of intimacy due to illness (60%), not receiving regular visits from family and friends (58%), and being physically isolated from other patients or people (56%).

In dealing with the **physical discomfort of the terminally ill patient**, more than half of the respondents noted that it was important to exhibit a caring attitude (78%), to reposition the patient (74%), and to assess the level of discomfort (66%). However, it was of concern that 38% of the respondents noted that they would instruct the patient to stop complaining and 21% indicated that they would avoid the patient.

In dealing with the **terminally ill patient's fears of isolation and loneliness**, the respondents appeared to be empathetic in their actions to alleviate the patient's fear by frequently visiting the patient (79%), by actively listening when the patient communicates (76%), by touching the patient in a comforting manner (75%), by encouraging frequent visits by family and friends (68%), by instructing the staff not to worry the patient (64%), and by conveying messages from family and friends (58%).

With regard to the **signs and symptoms of imminent death**, the majority of the respondents exhibited knowledge of how to identify a dying patient. Between 85% and 72% of the respondents indicated that a weak and irregular pulse (85%), coma (80%), cyanosed extremities (77%), diminished reflexes (77%), fixed and dilated pupils (77%), restlessness (77%), drop in blood pressure (76%), shallow breathing (74%) and chain-strokes breathing (72%) might be evident when patients were dying.

### 5.3.3 Section C: Nurses' training to deal with terminally ill patients

Of the 70 respondents who answered this question, 63% indicated that their **curriculum** contained content on the care of the terminally ill, in response to which they were required to indicate the relevant content. The following was noted: need for psychological and emotional support (94%), how to deal with family and friends of the patient (94%), signs and symptoms of the terminally ill patient (89%), the physical care required by patients (85%), available resources (84%), defining terminal illness (84%), and just over half (55%) of the respondents indicated that they learned about Kübler-Ross's stages of grieving.

The question on the **forms of guidance received in the practical situation** on how they should care for the terminally ill patient was poorly answered as 38 to 43 respondents did not answer it. The responses indicated that demonstration (47%), learning by example (46%), supervision (42%) and in-service training (41%) were applied in practice. These results indicated that guidance in the practical field was not given much attention.

In **caring for the dying patient**, the respondents generally did not experience it in a negative way: 81% did not feel uncomfortable in caring for dying patients; 90% did not feel afraid to care for them; only 11% stated that they did not like caring for them, while the greater majority (89%) indicated the opposite; 75% indicated that it was a privilege to care for them, 70% did not mind being alone with them and 30% indicated that they did not want to be alone with a person who was dying. Of the 67 respondents, 61% indicated that they had enough knowledge to deal with terminal patients. The majority (81%) of the respondents indicated that they had practical experience in psychological counselling and could thus support the patient and his/her relatives.

Regarding Kübler-Ross's stages of grieving, the responses indicated that the majority had no knowledge of the topic. The respondents who did answer the questions disagreed on the correct answer. This contradicted the findings emanating from figure 4.12 where 55% of the respondents indicated that they had received training on Kübler-Ross's stages of grieving.

## 5.4 CONCLUSIONS

The conclusions were drawn from the findings. It should be noted, however, that in most cases there were substantial missing values due to respondents not answering the questions, which in itself could imply that they did not know how to respond or did not have the knowledge to do so.

### 5.4.1 Section B: Nursing care for terminally ill patients

- The respondents knew what it meant to be terminally ill in terms of psychological and emotional support, being treated with dignity and respect and the need for alleviation of pain.
- They were able to identify the safety and comfort aspects that have a negative influence on the terminally ill patient, such as being insecure about accommodation and payment for treatment, and their as well as their dependant's future.
- They knew how to comfort a terminally ill patient who is anxious and disturbed, this can be done by providing psychological and emotional support, adhering to cultural beliefs, and facilitating communication.
- They were able to identify, to a moderate degree, the factors that could affect the terminally ill patient's self-esteem and self-image, including reduction of physical abilities, and the effect of disease on one's appearance, being hospitalised and being unable to take care of oneself.
- They could identify the factors that affect the terminally ill patient's need for love and belonging in a negative way, such as altered relationships due to the health crisis, being hospitalised, loss of intimacy, not receiving regular visits and isolation.
- In handling physical discomfort, the respondents noted that a caring attitude and assessment of the level of discomfort were essential, after which positioning was emphasised.

- To alleviate the patients' feelings and fear of isolation and loneliness, the respondents indicated that frequent contact with the patient, listening actively and touching the patient were important actions.
- They were able to identify the signs and symptoms of imminent death such as shallow breathing, drop in blood pressure, cyanosed extremities, and fixed and dilated pupils.

#### **5.4.2 Section C: Nurses' training to deal with terminally ill patients**

- More than half of the respondents indicated that their curriculum contained content on the care of the terminally ill patient, but the fact that the remaining respondents denied this led to uncertainty about the true content of the curricula. Content said to be included in the curriculum incorporated aspects such as signs and symptoms of the terminally ill patient, the dying process, the need for emotional and psychological support and the physical care required by these patients.
- Guidance on how terminally ill patients should be cared for mostly took place by means of demonstration, learning by example, supervision and in-service training. However, low frequencies were evident for all these methods, which was indicative of a need for better guidance, support and training.
- In caring for the terminally ill, most of the respondents did not appear to have serious reservations although some indicated that they did not want to be alone with the patient, and felt uncomfortable and anxious because they did not know what to do.
- The respondents were not able to select Kübler-Ross's stages of the grieving process even though some indicated that this was included in their curriculum.

### **5.5 RECOMMENDATIONS**

Based on the findings and conclusions of the study, the researcher makes the following recommendations.

### 5.5.1 Nursing education and policy

These recommendations should enable the authorities to make the necessary adjustments with regard to the preparation of Angolan nurses to care for the terminally ill patient.

- The curriculum should be reviewed to determine to what extent palliative care is dealt with and whether the topic is sufficiently covered, to ensure that adequate attention is given to the teaching and learning of the topic as an important issue in the current health care scenario.
- Adequate integration of theory and practice in terms of palliative care, in this instance, is essential and should be purposefully realised. Therefore adequate support, guidance, role modelling and supervision should be provided by the professional nurses under whom the medium and basic level nurses function.
- As a means to create and maintain an empathetic attitude amongst the nurses, and to obtain their commitment in providing safe, caring and holistic care, a focused in-service training programme should be developed, to be presented on an on-going basis so that all the nurses within the institution have an opportunity to attend all the sessions in the programme. Content for this in-service training programme should include the following topics:
  - Professional behaviour and conduct
  - Ethics and ethical codes
  - The principles of palliative care
  - Compassion and empathy
  - Interpersonal relations
  - Dealing with the needs of terminal patients
  - Dealing with anxiety and fear in the patient
  - Pain management
  - Involving patients in their care regime
  - Emotional and psychological support
  - Counselling skills

- Creating a therapeutic care environment
- Interactive communication skills
- Resources available for terminally ill or lonely patients
- Dying with dignity

### **5.5.2 Further research**

Future studies should be conducted into the following topics to contribute to enhancing the care of all patients, especially the terminally ill:

- The behaviour of nurses when dealing with a terminally ill patient
- Coping behaviours of family members who mourn for a deceased
- The role of culture in dealing with a terminally ill patient
- The role of the traditional healer with regard to caring for terminally ill patients

### **5.6 LIMITATIONS OF THE STUDY**

A number of limitations affected the outcomes of this study.

First, it was difficult to reach the aims because the study was done by means of distance and not campus-based tuition. The supervisors travelled from South Africa to Angola and were not fluent in the Portuguese language. This made it difficult when the researcher wanted to communicate directly but had to do so through interpreters.

Secondly, the questionnaires had to be distributed twice as some respondents received but did not return the questionnaires therefore the anticipated number did not correspond to the requirements. Consequently, new questionnaires had to be distributed to other respondents.

Thirdly, the questionnaires were not comprehensively completed because many of the respondents ignored several variables, which made the data analysis and interpretation of data difficult.

## **5.7 CONCLUSION**

This study focused on the most frequent diseases that cause the death of patients in Angola, and set out to determine what preparation nurses in a specific hospital received to prepare them to care for terminally ill patients. A quantitative approach was adopted, using an exploratory and descriptive design, and a self-developed questionnaire was used as the data-collection instrument.

This chapter discussed the findings, conclusions and recommendations of the study. The findings and recommendations of this study should contribute to enhancing the preparation of nurses to better care for terminally ill patients.



## BIBLIOGRAPHY

Associação Brasileira de Cuidados Paliativos (Brazilian Association for Palliative Care) 2004. *The palliative carers in Brazil*. [www.cuidadospaliativos.com.br/artigo.php?](http://www.cuidadospaliativos.com.br/artigo.php?)

Brandão, C. 2006. *Cancer and palliative care*. [www.cuidadospaliativos.com.br](http://www.cuidadospaliativos.com.br). (Internet site of Brazilian Association for Palliative Care).

Burns, N & Grove, SK. 2005. *The practice of nursing research*. 5<sup>th</sup> edition. St Louis: Elsevier.

*Concise Oxford Dictionary*. 1964. Oxford: Clarendon Press.

*Electronic Dictionary Michaellis English Portuguese/Portuguese Portuguese*.1986.

Factors da vida [factors of life], number 13; “Eutanásia”, edição São Paulo, Lisboa. 1994. Euthanasia. <http://eutanásia.aaldeia.net/cuidadospaliativos.htm> São Paulo editors, Lisboa, 1999 [Internet site – euthanasia]

Gandra, CMGB, Costa, ACR & Barbosa,MGC. 2006. 23/03/2006. What is palliative care. Intrahospital team of support in palliative care from HSM Page 1 of 2 <http://www.hsm.min-saúde.pt/Default.aspx?tabid=1506> & Menu Active=cuid. 09/06/2006.

Jooste, K (ed). 2003. *Leadership in health services management*. Landsdowne: Juta.

LoBiondo-Wood, G & Haber, WJ. 2001. *Research in nursing*. 4<sup>th</sup> edition. Rio de Janeiro: Mosby.

Lopes, LF, Camargo, B & Furrer, AA. 1999. *Aspects of humanization in the treatment of terminally ill children*. Cancer Hospital. Department of Paediatrics. Page 1 of 11. <http://www.hcanc.org.br/outrasinfs/ensaios/huml.html.09/06/2006>.

Mouton, J & Marais, HC. 1991. *Basic concepts in methodology for the human sciences*. Pretoria: Human Sciences Research Council.

NOVO DICIONÁRIO Aurélio de Língua Portuguesa 1986. 2<sup>nd</sup> edition. Ferreira Buarque: de Holanda Aurélio.

Oliveira, TFR. 1995. *Biomedic research*. São Paulo: Mosby.

Polit, BF, Beck, CT & Hungler, BP. 2004. *Research in nursing*. 5<sup>th</sup> edition. Philadelphia: Lippincott.

Programa Nacional de Cuidados Paliativos (PNCP) [National Programme for Palliative Care] 2004.

Sorensen, KC & Luckmann, J. 1998. *Basic nursing: psycho-physiological approach*. [www.calgaryhealthregion.ca/ftp/Publicationsandmultimedia.htm](http://www.calgaryhealthregion.ca/ftp/Publicationsandmultimedia.htm).

Victora, CG, Knauth, DR & Hassen, MNA. 2000. *Qualitative research in health*. Porto Alegre.

World Health Organisation (WHO).  
[www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)

## **WEBSITES DIRECTLY ACCESSED AND REFERRED TO**

[http://www.cuidadospaliativos.com.br/artigo.php?cdTexto=305\(câncer e cuidados paliativos\)](http://www.cuidadospaliativos.com.br/artigo.php?cdTexto=305(câncer e cuidados paliativos)) [Internet site - palliative care – cancer and palliative care].

[http://www.scielo.br/scielo.php?=&script=sci-artx & pid=so104-11692005000600006&lng=pt&nrm=iso&...](http://www.scielo.br/scielo.php?=&script=sci-artx&pid=so104-11692005000600006&lng=pt&nrm=iso&...) [Internet site - the provision of care in the dying process according to the perception of women with cancer].

<http://www.cuidadospaliativos.com.br/artigo.php?cdTexto=215> [Internet site – the nurse with regard to managing cancer pain].

<http://www.hcanc.org.br/outrasinfs/ensaios/huml.html> [Internet site – aspects of humanization in treating children in a terminal phase].

<http://eutanásia.aaldeia.net/cuidadospaliativos.htm> São Paulo editores, Lisboa, 1999

<http://www.hsm.min-saúde.pt/Default.aspx?tabid=1506 & Menu Active=cuid>. [Internet site - What is palliative care?].

<http://www.patriarcado-lisboa.pt/vidacatólica/vcnum21/3-01-11-conferência-10-NOV.doc> [Internet Site – Death, the last taboo and the rebirth of hope].

<http://www.scielo.br/scielo.php?script=sci-artx & pid=s0104=11691999000500014> [Internet site - Death within a hospital context – teams for reanimation in cardiac arrest].

<http://www.hsm.min-saúde pt2006> [Internet site – Intra-hospital support team in palliative care].

<http://pt.wikipedia.org>.

<http://en.wikipedia.org/wiki/Kübler-Rossmode> [Kübler Ross's model on grieving].

To:  
Dr. Luís Miguel Cabaça

### **AUTHORIZATION TO CONDUCT RESEARCH**

We herewith would like to request your permission to conduct research (indicate institution/place) for a project of dissertation on the topic.....

I am presently registered at the University of South Africa where I am completing the Master's degree in Health Sciences. The research project is part of the requirements to complete the referred Master's degree.

My research proposal has already been approved by the Department of Health Studies of the University of South Africa.

The aim of the research project is to prepare nurses to care for terminally ill patients at the Provincial Hospital of Bié and for such it is necessary to fill in a questionnaire so as to enable the researcher to collect the necessary data for the research. Therefore I would request that you grant me permission to distribute the questionnaire to potential participants in the research.

The researcher undertakes to rigorously adhere to all ethical considerations and measures in conducting the research so as to prevent any potential damage and in order to protect the confidentiality of participants.

Annexed please find a copy of the research proposal as well as the questionnaire that will be used for the research.

I would be very grateful if you would grant me permission to conduct the research. We thank you for your cooperation in this regard.

KUITO, 04 July 06

Yours truly,  
(Signed)  
Arão Catombela

*Tomou conhecimento  
Autorizamos a feitura  
do trabalho proposto e desejamos-lhe  
bons sucessos.  
V. Excelência  
27-07-06*

À  
SUA EXCELÊNCIA Dr. LUÍS MIGUEL  
CABAÇA

### AUTORIZAÇÃO PARA A REALIZAÇÃO DE PESQUISA

Solicita-se, pela presente autorização de V. Excelência para se efectuar pesquisa (indicar instituição/lugar) para um projecto de dissertação sobre o tópico.....

Encontro-me presentemente matriculado na Universidade da África do Sul onde estou a finalizar o grau de Mestrado em Ciências de Saúde. o projecto de pesquisa integra-se nos requisitos para o referido grau de Mestrado.

A minha proposta para o projecto de pesquisa foi já aprovada pelo Departamento de estudos de Saúde da Universidade da África do Sul.

O objectivo do projecto de pesquisa é preparação dos enfermeiros(as) para cuidarem pacientes terminais em Hospital Provincial do Bié para tal é necessário o preenchimento de um questionário, de forma a proporcionar ao pesquisador a recolha dos dados necessários para a pesquisa. Assim, solicitava a V. Excelência autorização para ( distribuir o referido questionário a possíveis participantes na pesquisa).

O pesquisador assegura que o cumprimento rigoroso de todas as considerações e medidas éticas na realização da pesquisa, e de modo a evitar quaisquer danos e a proteger a confidencialidade dos participantes.

Junto anexo uma copia da proposta de pesquisa bem como do questionário a ser utilizado para a pesquisa.

Muito agradecia a cooperação e apoio de V.Excia neste sentido, conferindo-me autorização para realizar a pesquisa.

Kuito, aos 04 de Julho de 06

SUBSCREVO-ME ATENCIOSAMENTE

*Dr. João Catumbela*  
Dr. João Catumbela

## Consent to Partake in Research

I, the undersigned, .....  
herewith agree to:

- partake in the research on the (topic)  
PREPAREDNESS OF MEDIUM AND BASIC LEVEL NURSES TO CARE FOR  
TERMINALLY ILL PATIENTS
- fill in the relevant questionnaire
- authorize the researcher, to use, at his discretion, the data that I have provided in the questionnaire, for purposes of writing the researcher's report on the research that was carried out.

Furthermore I also state that it is my understanding that

- I may, at any time, discontinue my involvement in this research or withdraw my consent to partake in this research;
- the information that I have provided until such time as I withdraw my participation in this research can, however, still be used by the researcher;
- the researcher will, at all times, maintain strict confidentiality and that the identity of the participant will never be linked to the information provided;
- I will not receive any financial reward or payment for the information herewith provided or for my involvement in this project;
- I have the option to refuse to answer any question(s) should I feel that this/these question(s) constitute a violation of my own privacy;
- when signing this consent form to partake in the research I undertake to answer in an honest manner to all reasonable questions and not to provide any false information or in any other way purposely mislead the researcher
- I will be provided with a signed original copy of this consent form

I herewith declare that the researcher

- has explained to me the objective of this research
- has informed and explained to me the content of this consent to partake in the research
- has elucidated me on the implications of signing this consent to partake in the research

By co-signing this consent to partake in the research, the researcher undertakes to

- maintain confidential and private the identity of the participant and the information provided in the research
- organized, beforehand, an appropriate venue and time for me to partake in this project
- to keep in a safe place the duplicate of this consent to partake in the research

Signed in ....., on ..... 2006.

.....  
PARTICIPANT'S Signature

.....  
RESEARCHER'S Signature

.....  
Signature of Father/Mother/Legal Guardian  
(in the case of a minor participant)

## Consentimento de Participação em Pesquisa

1

Eu, abaixo-assinado, .....,  
Concordo pelo presente documento a:

- Participar no estudo de pesquisa sobre o (tópico)

Conhecimentos das adolescentes sobre as implicações da gravidez

Preencher o questionário relevante.

- Autorizar o pesquisador a utilizar, a sua discricção, os dados por mim proporcionados no referido questionário, para fins de elaboração do relatório do pesquisador sobre a pesquisa realizada.

Afirmo também ser o meu entendimento que

- Posso, em qualquer altura, terminar o meu envolvimento nesta pesquisa ou rescindir o meu consentimento para participar na mesma.
- A informação por mim providenciada ate a altura em que rescindir a minha participação nesta pesquisa pode, no entanto, continuar a ser utilizada pelo pesquisador.
- O pesquisador manterá sempre, rigorosa confidencialidade e que a identidade do participante não será nunca ligada a informação providenciada,
- Não receberei qualquer recompensa ou compensação financeira pela informação aqui providenciada ou pelo meu envolvimento neste projecto.
- Tenho a opção de me recusar a responder a (quaisquer) pergunta (s) caso considere que esta (s) constitua/constituam violação da minha própria privacidade.
- Ao assinar o presente consentimento de participação comprometo-me a responder honestamente a todas as perguntas razoáveis e a não providenciar informação errónea ou de qualquer outra forma induzir, propositadamente, em erro o pesquisador
- Ser-me-á providenciada uma copia original deste consentimento de participação após a minha assinatura do mesmo.

Declaro pelo presente que o pesquisador

- Me explicou em detalhes o objectivo deste projecto de pesquisa
- Me informou e explicou-me o conteúdo deste consentimento de participação
- Me esclareceu sobre a implicação da assinatura deste consentimento de participação

Ao co-assinar este consentimento de participação, o pesquisador compromete-se a

- manter confidencialidade e privacidade relativamente à identidade do participante e à informação proporcionada pelo participante na pesquisa

- organizar, antecipadamente, um local e hora apropriada para a realização da minha participação neste projecto

- a guardar em seguro o duplicado do presente consentimento de participação

Assinado em \_\_\_\_\_, aos \_\_\_\_\_ de \_\_\_\_\_ 2006

\_\_\_\_\_

Assinatura do Participante

\_\_\_\_\_

Assinatura do Pesquisador

\_\_\_\_\_

Assinatura do Pai/ Mãe/ Encarregado de Educação



## Consent to Partake in Research

I, the undersigned, (*Generosa Ngueve*) .....  
herewith agree to:

- partake in the research on the (topic)  
To ascertain the knowledge of Nurses with regards to caring for terminally ill patients;
- fill in the relevant questionnaire
- authorize the researcher, to use, at his discretion, the data that I have provided in the questionnaire, for purposes of writing the researcher's report on the research that was carried out.

Furthermore I also state that it is my understanding that

- I may, at any time, discontinue my involvement in this research or withdraw my consent to partake in this research;
- the information that I have provided until such time as I withdraw my participation in this research can, however, still be used by the researcher;
- the researcher will, at all times, maintain strict confidentiality and that the identity of the participant will never be linked to the information provided;
- I will not receive any financial reward or payment for the information herewith provided or for my involvement in this project;
- I have the option to refuse to answer (any) question(s) should I feel that this/these question(s) constitute a violation of my own privacy;
- when signing this consent form to partake in the research I undertake to answer in an honest manner to all reasonable questions and not to provide any false information or in any other way purposely mislead the researcher
- I will be provided with a signed original copy of this consent form

I herewith declare that the researcher

- has explained to me the objective of this research
- has informed and explained to me the content of this consent to partake in the research
- has elucidated me on the implications of signing this consent to partake in the research

By co-signing this consent to partake in the research, the researcher undertakes to

- maintain confidential and private the identity of the participant and the information provided in the research
- organized, beforehand, an appropriate venue and time for me to partake in this project
- to keep in a safe place the duplicate of this consent to partake in the research

Signed in ..... on 12 / 08/ 2006.

.....  
PARTICIPANT'S Signature

Signed) *Arão Catombela*  
RESEARCHER'S Signature

**Mr A Catombela**

|   |   |   |
|---|---|---|
|   |   |   |
| 1 | 2 | 3 |

**QUESTIONNAIRE FOR VERIFYING THE KNOWLEDGE OF NURSES ABOUT  
CARING FOR TERMINALLY ILL PATIENTS**

**1. THE OBJECTIVE IS**

To determine the preparedness of nurses to care for terminally ill patients.

**2. UNDERTAKING**

All information provided will be treated in confidence. You are not required to provide your name on the questionnaire.

**3. INSTRUCTIONS**

- 3.1 Please answer all the questions.
- 3.2 Complete questions by providing an x in the appropriate box or by providing the information requested.
- 3.3 Please complete the questions as honestly, frankly and objectively as possible.
- 3.4 Please answer the questions as they apply to you personally.
- 3.5 Please return the questionnaire by the end of August 2006.

**SECTION A: BIOGRAPHICAL INFORMATION**

Please answer the questions by placing an x in the appropriate box

1. Please indicate your current position in the hospital

For office use

| Position                 | Answer |
|--------------------------|--------|
| 1.1 Medium Level Nurse   | 1      |
| 1.2 Basic Level Nurse    | 2      |
| 1.3 Medium Level Student | 3      |
| 1.4 Basic Level Student  | 4      |
|                          |        |
|                          |        |
|                          |        |

|  |   |
|--|---|
|  | 4 |
|--|---|

2. For how many years have you held the position indicated in question 1?

For office use

| Years in current position | Answer |
|---------------------------|--------|
| 2.1 1 - 2 years           | 1      |
| 2.2 3 - 4 years           | 2      |
| 2.3 5 - 6 years           | 3      |
| 2.4 7 years or longer     | 4      |

|  |   |
|--|---|
|  | 5 |
|--|---|

3. Indicate in which age category you are.

For office use

| Your age in years      | Answer |
|------------------------|--------|
| 3.1 15 – 20 years      | 1      |
| 3.2 21 – 25 years      | 2      |
| 3.3 26 – 30 years      | 3      |
| 3.4 31 – 35 years      | 4      |
| 3.5 36 – 40 years      | 5      |
| 3.6 41 – 45 years      | 6      |
| 3.7 46 – 50 years      | 7      |
| 3.8 51 – 55 years      | 8      |
| 3.9 56 years and older | 9      |

|  |   |
|--|---|
|  | 6 |
|--|---|

4. Please indicate your gender.

|            | Answer |
|------------|--------|
| 4.1 Female | 1      |
| 4.2 Male   | 2      |

|  |   |
|--|---|
|  | 7 |
|--|---|

**SECTION B: NURSING CARE OF THE TERMINALLY ILL PATIENT**

5. Which of the following statements are relevant to a terminally ill patient? Please respond by indicating the frequency which you think is applicable.

For office use

| <b>The terminally ill patient</b>                       | <b>Always</b> | <b>Often</b> | <b>Seldom</b> | <b>Never</b> |  |    |
|---|---------------|--------------|---------------|--------------|--|----|
| 5.1 Has hope of recovering from his/her illness         | 1             | 2            | 3             | 4            |  | 8  |
| 5.2 Requires alleviation from pain                      | 1             | 2            | 3             | 4            |  | 9  |
| 5.3 Requires assistance with activities of daily living | 1             | 2            | 3             | 4            |  | 10 |
| 5.4 Requires active treatment for his/her disease       | 1             | 2            | 3             | 4            |  | 11 |
| 5.5 Requires psychological and emotional support        | 1             | 2            | 3             | 4            |  | 12 |
| 5.6 Must be kept active and mobile at all costs         | 1             | 2            | 3             | 4            |  | 13 |
| 5.7 Requires comfortable accommodation                  | 1             | 2            | 3             | 4            |  | 14 |
| 5.8 Desires his/ her dignity to be maintained           | 1             | 2            | 3             | 4            |  | 15 |
| 5.9 Is entitled to have his/her human rights respected  | 1             | 2            | 3             | 4            |  | 16 |

6. According to your view, which of the following safety/comfort aspects have a negative influence on the terminally ill patient?

Answer either NO (1), DO NOT KNOW (2) or YES (3) for each of the following aspects.

| <b>Safety needs of terminally ill patients</b>                    | <b>Answer</b>   |                          |                  |  |    |
|---|-----------------|--------------------------|------------------|--|----|
|   | <b>No<br/>1</b> | <b>Do not know<br/>2</b> | <b>Yes<br/>3</b> |  |    |
| 6.1 Being moved from one room to another                          | 1               | 2                        | 3                |  | 17 |
| 6.2 Being uncertain where one can be accommodated                 | 1               | 2                        | 3                |  | 18 |
| 6.3 Having a serious attack of breathlessness/ coughing           | 1               | 2                        | 3                |  | 19 |
| 6.4 Being transferred from one health care institution to another | 1               | 2                        | 3                |  | 20 |
| 6.5 Separation from family and friends                            | 1               | 2                        | 3                |  | 21 |
| 6.6 Being uncertain who will care for him/her                     | 1               | 2                        | 3                |  | 22 |
| 6.7 Being uncertain about the future                              | 1               | 2                        | 3                |  | 23 |
| 6.8 Being uncertain about the future of their dependants          | 1               | 2                        | 3                |  | 24 |
| 6.9 Anxiety about the payment of the treatment                    | 1               | 2                        | 3                |  | 25 |

7. How would you comfort a terminally ill patient who is anxious and disturbed about his/her accommodation and care? Select from the following alternatives which you feel is appropriate.

For office use

| <b>Comforting the terminally ill patient</b>   | <b>Always</b> | <b>It depends</b> | <b>Never</b> |
|--|---------------|-------------------|--------------|
| 7.1 Facilitating communication with the patient  | 1             | 2                 | 3            |
| 7.2 Talking to the family disregarding the patient   | 1             | 2                 | 3            |
| 7.3 Facilitating communication between the patient and family members                                  | 1             | 2                 | 3            |
| 7.4 Exchanging ideas with the patient and his/her relatives with regard to their concerns              | 1             | 2                 | 3            |
| 7.5 Deciding what is right for the patient and implementing your ideas without consulting the patient  | 1             | 2                 | 3            |
| 7.6 Providing psychological and emotional support by being there for the patient and his/her dear ones | 1             | 2                 | 3            |
| 7.7 Providing guidance with regard to the physical environment or procedures to be carried out         | 1             | 2                 | 3            |
| 7.8 Touching the patient in a comforting manner when speaking to him/her                               | 1             | 2                 | 3            |
| 7.9 Providing only basic physical care and leaving the patient to his/her own thoughts                 | 1             | 2                 | 3            |
| 7.10 Touching the patient comfortably when he/she is anxious   | 1             | 2                 | 3            |
| 7.11 Respecting his/her cultural beliefs and requirements  | 1             | 2                 | 3            |

|  |    |
|--|----|
|  | 26 |
|  | 27 |
|  | 28 |
|  | 29 |
|  | 30 |
|  | 31 |
|  | 32 |
|  | 33 |
|  | 34 |
|  | 35 |
|  | 36 |

8. Which of the following factors do you think can affect the self-esteem or self-image of the terminally ill patient adversely?

Answer either NO (1), DO NOT KNOW (2) or YES (3) for each of the following aspects:

For office use

| Factors affecting terminally ill patients' self-esteem or self-image | Answer  |                  |          |
|--|---------|------------------|----------|
|  | No<br>1 | Do not know<br>2 | Yes<br>3 |
| 8.1 Being unable to take care of oneself                             | 1       | 2                | 3        |
| 8.2 Being spoken to by nurses in an impatient manner                 | 1       | 2                | 3        |
| 8.3 Being dependent on others for everything they need               | 1       | 2                | 3        |
| 8.4 Being hospitalised   | 1       | 2                | 3        |
| 8.5 The effect that illness has on one's physical appearance         | 1       | 2                | 3        |
| 8.6 Reduction of physical abilities                                  | 1       | 2                | 3        |
| 8.7 The isolation of being ill                                       | 1       | 2                | 3        |
| 8.8 NOT respecting the patient's dignity                             | 1       | 2                | 3        |

|  |    |
|--|----|
|  | 37 |
|  | 38 |
|  | 39 |
|  | 40 |
|  | 41 |
|  | 42 |
|  | 43 |
|  | 44 |

9. Which of the following factors do you think can affect the terminally ill patient's need for love and belonging?

Answer either NO (1), DO NOT KNOW (2) or YES (3) for each of the following aspects:

For office use

| Factors affecting terminally ill patients' need for love and belonging | Answer  |                  |          |
|--|---------|------------------|----------|
|  | No<br>1 | Do not know<br>2 | Yes<br>3 |
| 9.1 Not receiving regular visits from family and friends               | 1       | 2                | 3        |
| 9.2 Loss of intimacy due to illness                                    | 1       | 2                | 3        |
| 9.3 Altered relationships due to health crisis                         | 1       | 2                | 3        |
| 9.4 Being hospitalised or institutionalised                            | 1       | 2                | 3        |
| 9.5 Experiencing a sense of being discarded                            | 1       | 2                | 3        |
| 9.6 Isolation due to hospital staff's uneasiness                       | 1       | 2                | 3        |
| 9.7 Experiencing a sense of alienation                                 | 1       | 2                | 3        |
| 9.8 Being physically isolated from other patients or people            | 1       | 2                | 3        |
| 9.9 Disregard for cultural aspects (such as beliefs and practices)     | 1       | 2                | 3        |
| 9.10 Being ignored   | 1       | 2                | 3        |

|  |    |
|--|----|
|  | 45 |
|  | 46 |
|  | 47 |
|  | 48 |
|  | 49 |
|  | 50 |
|  | 51 |
|  | 52 |
|  | 53 |
|  | 54 |

10. As the disease progresses there is usually an increase in physical discomfort. How should the nurse handle this situation?

Answer either NO (1), DO NOT KNOW (2) or YES (3) for each of the following possibilities:

For office use

| Handling physical discomfort   | Answer  |                  |          |
|--|---------|------------------|----------|
|  | No<br>1 | Do not know<br>2 | Yes<br>3 |
| 10.1 Anticipating potential sources of discomfort  | 1       | 2                | 3        |
| 10.2 Assessing the level of discomfort   | 1       | 2                | 3        |
| 10.3 Instructing the patient to stop complaining   | 1       | 2                | 3        |
| 10.4 Offering a soothing drink if appropriate  | 1       | 2                | 3        |
| 10.5 Repositioning the patient for comfort   | 1       | 2                | 3        |
| 10.6 Avoiding contact with the patient   | 1       | 2                | 3        |
| 10.7 Exhibiting a caring attitude (by actively listening and speaking in an empathetic manner) | 1       | 2                | 3        |

|  |    |
|--|----|
|  | 55 |
|  | 56 |
|  | 57 |
|  | 58 |
|  | 59 |
|  | 60 |
|  | 61 |

11. Isolation and loneliness can be feared by the terminally ill patient. What can you as a nurse do to alleviate the patient's fear?

For office use

| Dealing with fears of isolation and loneliness             | Always | It depends | Never |
|--|--------|------------|-------|
| 11.1 Leave the patient alone as they are dying             | 1      | 2          | 3     |
| 11.2 Frequently visiting the patient                       | 1      | 2          | 3     |
| 11.3 Touch the patient in a comforting way                 | 1      | 2          | 3     |
| 11.4 Convey messages from family and friends               | 1      | 2          | 3     |
| 11.5 Encourage frequent visits by family and friends       | 1      | 2          | 3     |
| 11.6 Instruct staff not to worry the patient               | 1      | 2          | 3     |
| 11.7 Listen actively when the patient communicates         | 1      | 2          | 3     |
| 11.8 Arrange for the priest/pastor to visit the patient    | 1      | 2          | 3     |
| 11.9 Call in the headman re cultural beliefs and practices | 1      | 2          | 3     |

|  |    |
|--|----|
|  | 62 |
|  | 63 |
|  | 64 |
|  | 65 |
|  | 66 |
|  | 67 |
|  | 68 |
|  | 69 |
|  | 70 |
|  | 71 |



12. Which of the following signs and symptoms may be evident when the death of a terminally ill patient is imminent?  
 Answer either NO (1), DO NOT KNOW (2) or YES (3) for each of the following signs:

For office use

| Signs of a dying patient         | Answer  |                  |          |  |    |
|----------------------------------|---------|------------------|----------|--|----|
|                                  | No<br>1 | Do not know<br>2 | Yes<br>3 |  |    |
| 12.1 Weak and or irregular pulse | 1       | 2                | 3        |  | 72 |
| 12.2 Drop in blood pressure      | 1       | 2                | 3        |  | 73 |
| 12.3 Shallow breathing           | 1       | 2                | 3        |  | 74 |
| 12.4 Cyanosed extremities        | 1       | 2                | 3        |  | 75 |
| 12.5 Diminished reflexes         | 1       | 2                | 3        |  | 76 |
| 12.6 Fixed and dilated pupils    | 1       | 2                | 3        |  | 77 |
| 12.7 Restlessness                | 1       | 2                | 3        |  | 78 |
| 12.8 Chain-stokes breathing      | 1       | 2                | 3        |  | 79 |
| 12.9 Coma                        | 1       | 2                | 3        |  | 80 |

**SECTION C: TRAINING OF NURSES TO CARE FOR THE TERMINALLY ILL**

13. Did your curriculum contain a section on caring for the terminally ill ?

For office use

|      |     | <b>Answer</b> |  |    |
|------|-----|---------------|--|----|
| 13.1 | Yes | 1             |  |    |
| 13.2 | No  | 2             |  | 81 |

14. If your answer to question 13 was YES, could you please indicate which of the following aspects regarding the terminally ill patient was included in your curriculum allowing you to receive training in this regard.

For office use

|  |   | <b>Answer</b> |           |  |    |
|--|---|---------------|-----------|--|----|
| <b>Factors included in your curriculum YES/NO?</b> |   | <b>Yes</b>    | <b>No</b> |  |    |
| 14.1   | Defining terminal illness                             | 1             | 2         |  | 82 |
| 14.2   | Signs and symptoms of the terminally ill patient      | 1             | 2         |  | 83 |
| 14.3   | The process of dying ( Kübler Ross's Stages)          | 1             | 2         |  | 84 |
| 14.4   | The physical care required by patients                | 1             | 2         |  | 85 |
| 14.5   | The need for psychological and emotional support      | 1             | 2         |  | 86 |
| 14.6   | How to deal with relatives and friends of the patient | 1             | 2         |  | 87 |
| 14.7   | Available resources                                   | 1             | 2         |  | 88 |
| 14.8   | Other, please specify                                 | 1             | 2         |  | 89 |
|  | .....   |               |           |  | 90 |
|  | .....   |               |           |  |    |
|  | .....   |               |           |  |    |

15. In what way were you guided in the practical situation to take care of the terminally ill patient, by means of:

For office use

| <b>Guidance in the practical field</b> |                       | <b>YES</b> | <b>NO</b> |  |    |
|--|-----------------------|------------|-----------|--|----|
| 15.1                                   | Demonstration         | 1          | 2         |  | 91 |
| 15.2                                   | Supervision           | 1          | 2         |  | 92 |
| 15.3                                   | Example               | 1          | 2         |  | 93 |
| 15.4                                   | In-service training   | 1          | 2         |  | 94 |
| 15.5                                   | Other, please specify | 1          | 2         |  | 95 |
|  | .....                 |            |           |  |    |
|  | .....                 |            |           |  |    |
|  | .....                 |            |           |  |    |

16. How do you experience caring for a dying patient? Select YES or NO for each of the questions below.

| <b>Personal experience</b>  | <b>YES</b> | <b>NO</b> |
|---|------------|-----------|
| 16.1 I don't mind, its like working with any other patient        | 1          | 2         |
| 16.2 I feel uncomfortable   | 1          | 2         |
| 16.3 I feel anxious because I don't know what to do               | 1          | 2         |
| 16.4 I am scared  | 1          | 2         |
| 16.5 I don't like caring for the dying patient                    | 1          | 2         |
| 16.6 I experience it as a privilege to be there for the patient   | 1          | 2         |
| 16.7 I don't want to be alone with the patient                    | 1          | 2         |
| 16.8 I don't have enough knowledge to deal with terminal patients | 1          | 2         |
| 16.9 I don't have practice in psychological counselling           | 1          | 2         |
| 16.10 Other, please specify<br>.....<br>.....<br>.....            | 1          | 2         |

For office use

|  |     |
|--|-----|
|  |     |
|  | 96  |
|  | 97  |
|  | 98  |
|  | 99  |
|  | 100 |
|  | 101 |
|  | 102 |
|  | 103 |
|  | 104 |
|  | 105 |

17. Select from the following alternatives the stages of adjustment in the grieving process as described by Kübler Ross.

| <b>Personal experience</b> | <b>Initial stage</b> | <b>Middle stage</b> | <b>Final stage</b> |
|----------------------------|----------------------|---------------------|--------------------|
| 17.1 Denial                | 1                    | 2                   | 3                  |
| 17.2 Anger                 | 1                    | 2                   | 3                  |
| 17.3 Acceptance            | 1                    | 2                   | 3                  |
| 17.4 Rage                  | 1                    | 2                   | 3                  |
| 17.5 Complacency           | 1                    | 2                   | 3                  |
| 17.6 Envy                  | 1                    | 2                   | 3                  |
| 17.7 Resentment            | 1                    | 2                   | 3                  |
| 17.8 Excitement            | 1                    | 2                   | 3                  |
| 17.9 Anxiety               | 1                    | 2                   | 3                  |
| 17.10 Pleasure             | 1                    | 2                   | 3                  |

For office use

|  |     |
|--|-----|
|  |     |
|  | 106 |
|  | 107 |
|  | 108 |
|  | 109 |
|  | 110 |
|  | 111 |
|  | 112 |
|  | 113 |
|  | 114 |
|  | 115 |

18. Is there any other information you would like to provide on nursing the terminally ill patient?

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

**Thank you for your time and inputs.**