UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

THE MANAGEMENT OF DYSPHAGIA IN NEURODEGENERATIVE DISORDERS: HOSPICE CAREGIVERS' PERCEPTIONS AND PRACTICES

by

ANGELIQUE ROBERTSON

Submitted in fulfilment of the requirements for the degree

MCOMMUNICATION PATHOLOGY

in the Faculty of Humanities
in the Department of Communication Pathology
at the

UNIVERSITY OF PRETORIA

SUPERVISOR: MS AM STIPINOVICH
Co-supervisor: Prof AM Kritzinger

August 2008

ACKNOWLEDGEMENTS

I would like to express my sincere thanks and appreciation to the following:

§ To my mom and dad. For always believing in me and supporting me regardless of the challenge. I could not have completed this study without you.

§ To my husband. For being so understanding and encouraging throughout my studies. I love you.

§ To my girls, Sarah and Leila. For changing the way I see the world. I love you two.

§ To my aunt, Linda. For always being there to lend a helping hand. I appreciate it more than you know.

§ To Alex, my research supervisor. For your continual guidance and patience through-out the study.

§ To Dr Kritzinger, my co-supervisor. For your support and insightful comments.

§ To my friends and family. For your love and encouragement

§ To the hospice caregivers who took the time to complete the questionnaires, without whom this research would not have been possible.

SUMMARY

The aim of this study is to describe hospice caregivers' perceptions and practices in the management of dysphagia in neurodegenerative disorders. In South Africa, hospices provide support and care for people with neurodegenerative disorders and have been offering palliative care to patients and their families facing life-threatening illnesses since 1989. Detailing the management practices of hospice caregivers may assist in determining whether there is a need for the services of a speech-language therapist in the transdisciplinary model.

A non-experimental, descriptive survey research design was selected for the purpose of this study as it allowed the researcher to describe the characteristics of a large number of respondents. Information was gathered by means of mail-distributed, self-administered questionnaires. The collected data was descriptively analysed and graphs and figures were used to summarise and display the frequency distribution and associations within the data.

It was evident from the findings that dysphagic patients with neurodegenerative disorders form part of the hospice caregivers' caseloads. However, there appears to be limited specialist involvement in the management of neurodegenerative dysphagia within the hospice setting. Furthermore, caregivers' perceptions of the subtle symptoms of dysphagia, the positions that facilitate safe swallowing and the consistencies that are most easily swallowed by people with dysphagia were found to be inadequate.

The results obtained have numerous significant clinical and theoretical implications regarding current dysphagia management in the South African hospice setting. Recommendations are made to hospices, speech-language therapists and future researchers.

Key words: swallowing, dysphagia, neurodegenerative disorders, management, hospice, palliative care, caregivers, perceptions, practices, speech-language therapist

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

CHAPTER 2: THE ASSESSMENT AND MANAGEMENT OF DYSPHAGIA ASSOCIATED WITH NEURODEGENERATIVE DISORDERS WITHIN PALLIATIVE CARE

CHAPTER 3: METHODOLOGY

CHAPTER 4: RESULTS AND DISCUSSION

CHAPTER 5: CONCLUSION AND IMPLICATIONS

LIST OF APPENDICES

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Aim: The aim of the chapter is to orientate the reader by providing a statement of the research problem and a rationale for the study. This discussion highlights the occurrence of dysphagia in neurodegenerative disorders and the need for the effective management thereof. Additionally an outline of the chapters included in this dissertation and definitions of the terminology used within the dissertation are provided.

1.1 INTRODUCTION

The term dysphagia originates from the Greek words ‘dys’ meaning ‘bad’ and ‘phago’ meaning ‘to eat’. Although there are many definitions for dysphagia, it is frequently defined as a difficulty in swallowing or in the process of transporting food and liquid from the oral cavity into the stomach (Logemann, 1998).

The act of swallowing is a complex process that depends on the coordinated movement of numerous structures in the oral cavity, pharynx, larynx and oesophagus. A successful swallow involves a sequence of voluntary and involuntary muscular contractions in the head and neck region that are carefully regulated by sensory input from the muscles involved. Therefore, a disorder in the sensory, muscular or structural integrity of the oral cavity, pharynx or larynx will result in dysphagia (Leonard & Kendall, 2007).

Swallowing disorders are associated with numerous medical diagnoses and can affect people of all ages, from premature infants to geriatric adults. In the paediatric population, dysphagia can occur as a result of prematurity, neurological conditions, complex medical conditions, craniofacial anomalies or developmental disabilities (ASHA, 2002). In adults, however, swallowing disorders are usually acquired and develop either as a result of anatomic anomalies or neuromuscular disorders. Anatomical disorders that may result in adult dysphagia include – but are not limited to – head and neck cancer, injury or surgery involving the head and neck, and dental decay. Neuromuscular disorders are, however, the most common cause of dysphagia in adults and may occur as a result of a cerebrovascular accident, traumatic brain injury, spinal cord injury or a degenerative neurological disease (ASHA, 2005).

Many neurodegenerative disorders are characterised by swallowing problems. Although each disorder has its own pattern of symptoms, dysphagia frequently occurs in disorders such as Parkinson’s disease, motor neuron disease, multiple sclerosis, myasthenia gravis, muscular dystrophy and HIV and AIDS (Sonies, 2000).

In South Africa, hospices provide support and care for people with neurodegenerative disorders and have been offering palliative care to patients and their families facing life-threatening illnesses since 1989. Palliative care may take place in an outpatient clinic, at home or in a chronic care facility (Hospice Palliative Care Association of South Africa, 2005).

Within the hospice setting, a team approach is vital for the provision of effective care to patients and their families. The multidisciplinary team supports the development of care plans, which reflect the needs and desires of both the patients and their families, and assist in solving complex problems related to a terminal illness (Pollens, 2004).

An interdisciplinary team approach is commonly utilised in the management of dysphagia in the hospice setting (Marelli, 1999). This includes discipline-specific assessments followed by team meetings where information is exchanged and recommendations are discussed (Rossetti, 2001). Team members may include family members, doctors, caregivers[1], dieticians, physiotherapists, occupational therapists, speech-language therapists and specialists such as neurologists and ear, nose and throat specialists (Kirker & Oliver, 2003).

---

[1] Caregivers refer to individuals working in the hospice setting who have completed one or more of the following: a nursing degree or diploma, a short course in palliative nursing, an HPCA community caregiving course, a diploma in palliative medicine or an MPhil in palliative medicine.

Nurses and caregivers are fundamental team members as they will continue to implement the treatment programme at the affected individual's home. Dieticians are primarily responsible for maintaining adequate nutrition. Physiotherapists focus on improving the individual's sitting position for feeding, while occupational therapists may provide therapy to improve the individual's ability to self-feed (Logemann, 1998).

Doctors are key members of the hospice team, as they are responsible for developing and monitoring the patient's plan of care. In addition, the physician's responsibilities include providing feedback – from a physician's point of view – to the team and collaborating with hospice team members in problem-solving to meet the needs of the patient and his/her family (Marelli, 1999).

The role of the speech-language therapist in the hospice team is to carefully conduct an assessment of the patient's communication, cognition and swallowing status and to develop strategies that improve the patient's quality of life and assist both the family and caregivers to provide care for the patient. With regard to dysphagia, it is the role of the speech-language therapist to maximise the patient's current swallowing functions, compensate for irreversible loss of function and reassess changes in the swallow. In addition, the speech-language therapist is responsible for improving the patient's comfort and eating satisfaction and promoting positive feeding interactions for family members and hospice caregivers (Pollens, 2004).

The management of dysphagia is of the utmost importance as the presence of dysphagia is a risk factor for airway obstruction, aspiration, malnutrition and dehydration, which can in turn result in weight loss, failure to thrive, pneumonia and death. Dysphagia can thus pose a severe health risk and the prognosis for patients diagnosed with dysphagia is worse than that for similar patients without dysphagia (College of Audiologists and Speech-Language Pathologists of Ontario, 2005).

1.2 STATEMENT OF THE PROBLEM AND RATIONALE

In the preceding discussion, the inclusion of a team approach in palliative care is specified. However, the realities of current practice in the South African context are somewhat different. While information regarding the inclusion of speech-language therapists in hospices in South Africa is unavailable, results of a survey completed in hospices in the United Kingdom show that specialists are seldom included in hospice teams. This is especially true for speech-language therapists. Only a minority of the hospices involved in the survey indicated that they included speech-language therapists in the management of patients with degenerative disorders. Furthermore, the survey indicated that the majority of patients who were referred to speech-language therapists were referred for the consideration of a percutaneous endoscopic gastrostomy (PEG) and not for the management of swallowing problems (Oliver & Webb, 2000).

The apparent lack of inclusion of speech-language therapists in palliative care is disconcerting, as many of the patients receiving palliative care experience speech, language and swallowing difficulties. As a result of the limited involvement of speech-language therapists in the hospice setting, there is often limited knowledge among caregivers of swallowing difficulties and the management of such difficulties (Oliver & Webb, 2000).

Further research completed in the Wisdom Hospice in the United Kingdom (Kirker & Oliver, 2003), revealed that none of the caregivers in the hospice team had received dysphagia training, and as a result these members had limited knowledge of the identification and management of dysphagia. A similar tendency is observed in nursing homes in Australia, where only a limited number of staff members are formally trained in the management of dysphagia and access to other professionals, such as speech-language therapists, is restricted (O’Loughlin & Shanley, 1998).

Research completed in the South African context has shown that nurses working in both hospitals and nursing homes have poor knowledge of the assessment and management of dysphagia, as well as the role of the speech-language therapist in the management of dysphagia (Letsholo, 2000; Moothalugan, 2002). There is, however, limited information available about the hospice caregivers' perceptions and current practices in the assessment and management of dysphagia in patients with neurodegenerative disorders.

In South Africa, a severe shortage of qualified speech-language therapists necessitates a transdisciplinary team approach (Moodley, Louw & Hugo, 2000). This approach is characterised by role expansion and role release and is both community-based and cost effective. It emphasises the pooling and exchanging of information and skills between professionals and the family (Rossetti, 2001). The utilisation of a transdisciplinary team approach allows for palliative care to occur in community-based and in-home hospice services. This is advantageous to patients, as the provision of in-home hospice services reduces the stress and anxiety of travelling and allows patients to stay in the comfort of their own homes (Weindling, 2000). This entails the speech-language therapist releasing her role and hospice caregivers expanding theirs to manage dysphagia in their clients.

A team approach facilitates the provision of support to the patients, the family members and the professionals involved (Oliver, 1996). Nursing personnel and hospice caregivers are used by hospices for the provision of palliative care. However, it appears, from the above studies, that hospices neither employ nor consult with speech-language therapists in the management of dysphagia.

In order to improve dysphagia services, collaborative relationships between hospice team members and other disciplines need to be formed. According to Kirker and Oliver (2003), the provision of training to hospice caregivers in dysphagia management may result in caregivers having increased confidence when assessing and managing dysphagia in patients with degenerative disorders.

To further the interests of patients with dysphagia, it is necessary to investigate the perceptions and practices of hospice caregivers in the management of dysphagia. Detailing their management practices may assist in determining whether there is a need for the services of a speech-language therapist in the transdisciplinary model.

This study will therefore aim to answer the following research question: How do hospice caregivers in South Africa manage dysphagia in individuals with neurodegenerative disorders?

1.3 CLARIFICATION OF TERMINOLOGY

The following terms are defined according to their use in this study.

- § **Dysphagia:** This refers to a difficulty in moving food from the mouth to the stomach (Logemann, 1998). In this study, the term is used to indicate adults affected by neurodegenerative disorders with associated swallowing problems and includes swallowing problems that result from poor cognitive awareness for the upcoming eating situation and inadequate visual recognition of food.

- § **Aspiration:** In this study this term is used to refer to the entry of oral secretions and foreign material into the airway below the level of the true vocal folds as a result of swallowing problems associated with neurodegenerative disorders (Dikeman & Kazandjian, 2003).

- § **Palliative care:** This type of care focuses on improving the quality of life of patients and their families through the prevention and relief of suffering, the early identification and assessment of pain and other problems, including physical, psychosocial and spiritual issues (Hospice Palliative Care Association of South Africa, 2004).

- § **Hospice:** This is a non-profit organisation that provides specialised palliative care to patients facing incurable disease so that they may live as full and comfortable lives as possible (Van der Berg, 2003). Hospice care may take place in an outpatient clinic, at home or in a chronic care facility. The caseload can include people who suffer from a range of illnesses, including – but not limited to – Alzheimer’s disease, amyotrophic lateral sclerosis, Parkinson’s disease, cancer and HIV and AIDS (Marelli, 1999).

- § **Hospice caregiver:** This refers to individuals working in the hospice setting who have completed one or more of the following training courses: a nursing degree or diploma, a short course in palliative nursing, a Hospice Palliative Care Association of South Africa (HPCA) community caregiving course, a diploma in palliative medicine or an MPhil in palliative medicine.

- **Neurodegenerative disorders:** These are incurable disorders caused by the gradual loss of neurons, often leading to death. These disorders include Alzheimer's disease, Parkinson's disease, motor neuron disease and multiple sclerosis (Pedretti, 1996).

- **Assessment:** Within the context of dysphagia, assessment refers to the process of determining the nature and cause of dysphagia, as well as the impact of dysphagia on quality of life, culminating in the development of a treatment programme (Dikeman & Kazandjian, 2003).

- **Collaboration:** This refers to the bringing together of perceptions and skills of individuals from many disciplines. It involves working with other disciplines, as well as the patient and family to reach a common goal (Chapey, 2001).

- **Management:** For the purpose of this study, this term refers to all aspects of treatment, including the use of a team approach and the inclusion and education of family members.

- **Rehabilitation strategies:** In this study, the term rehabilitation strategies refers to procedures that focus on changing the swallow physiology by improving the range of motion and coordination during the swallow. These procedures usually require the patient to follow instructions and to practice exercises independently (Daniels, 2000).

- **Compensatory strategies:** Within the context of dysphagia management, this term refers to the strategies that utilise postural changes, changes to the food consistency or the modification in the volume and speed of the food presentation to reduce the patient's symptoms without changing the physiology of the patient's swallow (Logemann, 1998).

- **Bolus:** The bolus is the soft mass of chewed food, liquid or other material manipulated into a ball within the mouth for ingestion (ASHA, 2002).

1.4 ABBREVIATIONS

The following abbreviations are used throughout this study:

HIV:	Human immunodeficiency virus
AIDS:	Acquired immune-deficiency syndrome
MND:	Motor neuron disease
ALS:	Amyotrophic lateral sclerosis
MS:	Multiple sclerosis
PEG:	Percutaneous endoscopic gastrostomy
NG:	Nasogastric
HPCA:	Hospice Palliative Care Association of South Africa

1.5 DIVISION OF CHAPTERS

Chapter 1: Introduction

Chapter 1 provides an introduction to the study. The problem the research will address, the rationale for the study and outline of the chapters are presented. The terminology and abbreviations used in the text are then clarified.

Chapter 2: The assessment and management of dysphagia associated with neurodegenerative disorders within palliative care

Chapter 2 describes the palliative care of individuals with degenerative disorders, paying specific attention to palliative care in the South African context. In addition, the chapter provides a description of dysphagia in certain neurodegenerative disorders and highlights current practices in the assessment and management of dysphagia in neurodegenerative disorders.

Chapter 3: Method

Chapter 3 provides a description of the method used to plan and execute the research. Information presented in this chapter provides a detailed description of the aims, research design, ethical considerations, apparatus and material, respondents and procedures used for data collection and analysis in the study.

Chapter 4: Results and discussion

In Chapter 4, the results of the study, which investigated hospice caregivers' perceptions and practices in the management of dysphagia in neurodegenerative disorders, are presented and discussed. These results are organised according to the stated aims and sub-aims of the study.

Chapter 5: Conclusions and implications

Chapter 5 provides a final conclusion to the study and discusses the clinical implications of the results. A critical evaluation of the study is provided, as well as recommendations for future research.

Appendices

Essential information regarding the data collection and analysis procedure is included in the appendices.

1.6 SUMMARY

Chapter 1 provides a rationale for the study to take place. It includes an overview of dysphagia in neurodegenerative disorders, existing research regarding hospice caregivers' current practices in caring for patients with dysphagia, and the subsequent need for research in the South African context. Terminology that is specific to this study is clarified, and the chapter concludes with a brief outline of all five chapters to be included in the dissertation.

CHAPTER 2

THE ASSESSMENT AND MANAGEMENT OF DYSPHAGIA ASSOCIATED WITH NEURODEGENERATIVE DISORDERS WITHIN PALLIATIVE CARE

Aim: In this chapter the assessment and management of dysphagia in individuals with neurodegenerative disorders will be discussed and the current management of dysphagia within palliative care is considered. This chapter aims to describe palliative care with specific reference to the hospice and the South African context. This provides the theoretical basis for the empirical part of the study.

2.1 INTRODUCTION

Neurodegenerative disorders are progressive in nature and are not responsive to curative treatment. Patients affected by neurodegenerative disorders require palliative care that focuses on the control of pain and other symptoms to ensure the best quality of life (Pollens, 2004).

The World Health Organization (1990) defines palliative care as the active total care of patients whose disease is not responsive to curative treatment. Management of pain, other symptoms, and psychological, social and spiritual problems are paramount. Palliative care aims to affirm life and regards dying as a normal process. The care provided neither hastens nor postpones death, but instead focuses on providing relief from pain and other distressing symptoms such as dysphagia. Palliative care integrates the psychological and spiritual aspects of patient care and offers a support system to help patients live as actively as possible until death. The goal of palliative care is to achieve the best possible quality of life for patients and their families (WHO, 1990).

Palliative care programmes have been in existence for a number of years. In the USA, palliative care is currently one of the fastest growing segments of the health care industry. Within the space of four years, the number of hospice admissions in the USA increased by 400 000, from 500 000 patients admitted in 1998 to 900 000 admitted in 2002 (Schumacher, 2004).

Initially, the majority of hospice patients were individuals diagnosed with terminal cancer. However, this has changed. According to research completed in the USA, cancer patients now only account for 50% of hospice admissions. Hospices now provide care for all terminally ill patients who have been diagnosed with neurodegenerative disorders including patients with HIV and AIDS (Schumacher, 2004).

The admission of patients who have been diagnosed with HIV and AIDS has had a significant effect on the rapid growth of hospice. In 2001, an estimated 22 million people had died of AIDS and it was reported that globally there is in excess of 60 million individuals infected with HIV (Ippolito, Galati, Serraino & Girardi, 2001). To ensure a better quality of life, the provision of palliative care to individuals already infected with HIV and AIDS is crucial (Foley, Aulino & Stjernsward, 2003).

Other factors that have increased the number of hospice patients includes the shift of service delivery from in-patient care to community-based care and the desire of patients and families to improve the quality of life of the patient and make use of their limited time together (Marelli, 1999). The majority of terminally ill patients have indicated that they prefer to be cared for in the comfort of their homes and the provision of in-home hospice services makes this possible (Fairview Health Services, 1999).

The increase in both the number and diversity of patients admitted to hospice presents a number of challenges for hospice caregivers as they now need to provide care to patients with a broader range of terminal diseases. In addition, palliative care should be provided to patients with neurodegenerative disorders from the time of diagnosis as there are no curative treatments available, which means that caregivers are required to adapt to the constantly changing profile of a terminally ill patient (Schumacher, 2004).

Hospices not only provide palliative care to patients, but offer assistance and support for the patients' family members. In the South African context, an integrated community-based home care model was developed. This model of care aims to enhance community initiatives and train members of the community to provide basic nursing and psychosocial support to patients and families in their homes (Uys, 2001). Palliative care in South Africa is, however, faced with numerous challenges, which will be discussed in the following section.

2.2 PALLIATIVE CARE IN THE SOUTH AFRICAN CONTEXT

South Africa has undergone extensive changes in the last decade. Not only have there been political changes, but also changes in the national health and education system (Kritzinger, 2000). Palliative care in South Africa has also undergone changes in its service delivery to meet the needs of the South African population.

Although palliative care has traditionally been associated with end-of-life care, the HIV/AIDS pandemic has necessitated that palliative care broaden its scope of practice. In South Africa alone, AIDS-related complications are responsible for 90 000 deaths per annum and there is an urgent need for the care and treatment of individuals with HIV and AIDS. Many people do not have access to antiretroviral treatment and rely solely on palliative care for treatment (Foley et al., 2003; Uys, 2003).

The essential role that palliative care plays in the care for individuals with HIV and AIDS was recognised in the *Full report of the Joint Health and Treasury Task Team charged with examining treatment options to supplement comprehensive care for HIV and AIDS in the public health sector* (2003). The findings of the task team indicated that the effective management of individuals infected with HIV and AIDS included both antiretroviral therapy and palliative care.

Palliative care is essential in the period before death to improve quality of life and assist in pain management. The provision of effective palliative care to individuals infected with HIV and AIDS will decrease the demand for acute care in already overcrowded hospitals, provide a low-cost service in currently underserved communities, and provide care and support to individuals and their families (*Full report of the Joint Health and Treasury Task Team charged with examining treatment options to supplement comprehensive care for HIV and AIDS in the public health sector,* 2003*).*

There are, however, a number of challenges to be met in providing effective palliative care in the South African context. The national health system aims to provide universal primary health care, which will provide increased accessibility to rural health care services, ensure that people with terminal illnesses receive effective care and recognise the importance of teamwork in health care delivery. However, palliative care has not been fully incorporated into the national health plan and palliation is not specifically mentioned as part of the role of community health centres (Beck, 1999).

The majority of palliative care in South Africa is, therefore, offered by hospices. However, as the Hospice Palliative Care Association of South Africa is registered as a non-governmental organisation, it does not receive an income from government sources. It, therefore, relies solely on community support for finances and staffing, and professionals such as doctors and social workers often provide their services voluntarily (Gwyther, 2002).

Although there are now more than 50 hospices throughout the country, there are still large areas of South Africa that are not served by any hospice or palliative care service (Gwyther, 2002). In 2004, the Hospice Palliative Care Association of South Africa cared for 29 000 patients and their families. It also cared for children infected or affected by HIV and AIDS. However, there is an estimated five million people who are in need of palliative care. This includes home support and pain relief (Carlisle, 2003).

Traditionally, the role of the hospice caregiver has been to identify and refer individuals who experience swallowing difficulties to a speech-language therapist and, only after the assessment has been completed, to implement the recommendations made and monitor and maintain adequate nutrition and hydration through safe feeding practices (Ramritu, Finlayson, Mitchell & Croft, 2000). This is, however, not possible in South Africa. The limited number of practicing speech-language therapists in South Africa has resulted in the task of identifying and managing dysphagia in neurodegenerative disorders becoming the responsibility of hospice caregivers.

In addition to the inadequate involvement of speech-language therapists within the hospice setting, the number of dysphagia training programs available to caregivers is limited. Furthermore, the majority of the dysphagia training programs currently available focus on providing caregivers with the knowledge and skills needed to identify the signs of dysphagia and referring the patients to trained dysphagia professionals. The limited access to specialists in the hospice setting means that these programs often fail and caregivers are required to manage swallowing difficulties without having received sufficient training (O’Loughlin & Shanley, 1998).

Health services in South Africa are plagued by inequity and inadequate resources (Beck, 1999). However, these resource limitations should not prevent the management of dysphagia. It is essential that an intervention plan that maximises the potential for oral intake, while reducing the risk for health complications, forms part of a palliative care program (Huckabee & Pelletier, 1999).

In order to identify and manage individuals with swallowing difficulties, caregivers will need adequate knowledge and understanding of the anatomy and physiology of the swallowing process and will need to be trained to provide basic assessments and to manage swallowing problems (O'Loughlin & Shanley, 1998). An overview of the dysphagia symptoms associated with neurodegenerative disorders and the assessment and care of these patients is explored in this chapter.

2.3 DYSPHAGIA AS A SYMPTOM OF NEURODEGENERATIVE DISORDERS

Neurodegenerative disorders are progressive in nature. Swallowing problems associated with neurodegenerative disorders usually begin early and gradually worsen as the disorder progresses. There may, however, be variation in the onset, progression and severity of the dysphagia symptoms. As a result, the management of dysphagia in neurodegenerative disorders is complex and requires a team approach (Murry & Carrau, 2001).

In order to provide optimal care for the patient with dysphagia, it is necessary to understand the changes in swallowing associated with each condition (Murry & Carrau, 2001). To demonstrate the variety of symptoms associated with neurodegenerative disorders, a summary of the swallowing difficulties associated with neurodegenerative conditions is presented in Table 2.1.

Table 2.1 Swallowing difficulties associated with common neurodegenerative disorders

Neurodegenerative disorder	Symptoms of dysphagia
Parkinson's disease	§ Pumping action of the tongue § Reduced tongue mobility § Delayed swallow § Reduced pharyngeal muscle contraction § Pooling in the vallecular space (Bird, 1994).
Motor neuron disease/amyotrophic lateral sclerosis	§ Poor lingual control § Nasal regurgitation § Poor coordination between the voluntarily initiated swallow and the reflexive swallow § Reduced laryngeal elevation (Cherney, 1994).
Multiple sclerosis	§ Reduced lingual control § Delayed pharyngeal swallow § Reduced pharyngeal muscle contraction § Excessive laryngeal adduction (Logemann, 1998).
Myasthenia gravis	§ Difficulty chewing § Reduced lingual mobility § Reduced pharyngeal peristalsis § Increased muscle weakness with use (Logemann, 1998).
Muscular dystrophy	§ Weakness of oropharyngeal muscles § Weakness of the smooth muscles of the oesophagus (Bielefeldt, 2004).
HIV and AIDS	§ Opportunistic infections such as oral candidiasis and the herpes simplex virus affect the oral cavity (Halvorsen, Moelleken & Kearney, 2003). § Pain and inflammation in the mouth § Pain during swallow § Loss of muscle strength (Phillips et al., 1998). § Food agnosia § Swallowing apraxia (Logemann, 1998)

From Table 2.1 it is evident that there are different symptoms for each neurodegenerative disorder. The management of these disorders will, therefore, not only have to be multifaceted, but be progressively modified to ensure optimum management for the specific time in the disease process (Logemann, 1998).

Neurodegenerative dysphagia is a common symptom of Parkinson’s disease. Parkinson’s disease affects all areas of functioning and requires a team approach, which includes both the patient and the family. Non-pharmacological therapy can improve mobility, speech, psychological wellbeing and swallowing, and there is both subjective and objective evidence to suggest that intervention for dysphagia in Parkinson’s disease is beneficial and therefore necessary (Gage & Storey, 2004).

Dysphagia is also a common symptom in motor neuron disease with up to 90% of patients developing swallowing problems (Kirker & Oliver, 2003). Motor neuron disease or amyotrophic lateral sclerosis (ALS) is a progressive degenerative disease characterised by the loss of neurons in the cortex, brain stem and spinal cord (Hadjikoutis & Wiles, 2001). Swallowing problems occur as a result of poor coordination between the voluntarily initiated swallow and the reflexive swallow. Reduced tongue movement, pooling of saliva in the valleculae and pyriform sinuses and difficulty chewing further compound the swallowing difficulties. As a result, laryngeal penetration and aspiration can occur, which may cause pneumonia, lung abscesses and death (Hadjikoutis & Wiles, 2001).

The early identification and management of dysphagia in individuals with ALS is imperative as it can improve the patient’s quality of life and maintain safe oral feeding for an extended period of time. The management of dysphagia, however, requires a team approach, which includes the speech-language therapist, hospice caregivers, dieticians and nursing staff (Kirker & Oliver, 2003).

Yet another neurodegenerative disorder in which dysphagia is a prevalent symptom is that of multiple sclerosis (MS). Multiple sclerosis is an idiopathic inflammatory disease of the central nervous system, which typically affects adults between 20 and 45 years of age. Symptoms of multiple sclerosis relate to multiple lesions in the neurological system involving demyelination of the cortex, cerebellum, brain stem and spinal cord. Symptoms include dizziness, fatigue, numbness, weakness, visual impairment and dysphagia (understandingMS.com, 2004). Dysphagia is reported to occur in between 33% and 43% of patients affected by MS. However, the swallowing disorders vary from patient to patient as lesions may affect a combination of neurological sites, including the corticobulbar tracts, brain stem, cerebellum or cranial nerves. During the management of dysphagia, patients with MS respond well to compensatory strategies such as postural changes and modification of the amount and speed of food presentation. Early identification and management of dysphagia in multiple sclerosis is, therefore, vital (Calcagno, Ruoppolo, Grasso, De Vincentiis, & Paolucci, 2002).

Swallowing disorders also affect individuals diagnosed with myasthenia gravis, a chronic autoimmune disease characterised by abnormally rapid weakening of voluntary muscles with use and improvement with rest (Duffy, 1995). Individuals with myasthenia gravis may experience difficulty walking, speaking, swallowing and breathing due to weakness in the muscles of the mouth and throat (Robinson, 1999). There is no curative treatment for myasthenia gravis. However, medication can be used to effectively control the symptoms. Medication for the disease usually results in improved swallowing. However, swallowing disorders associated with myasthenia gravis are best managed through compensatory strategies, as these strategies will immediately improve the swallow without contributing to fatigue (Logemann, 1998).

Dysphagia is also a common symptom of muscular dystrophy, as muscular dystrophy can cause muscle weakness in the oropharyngeal area and oesophagus. This, in turn, affects the oral, pharyngeal and oesophageal phases of the swallow and can result in the patient aspirating (Bielefeldt, 2004). Muscular dystrophy is the name of a group of inherited disorders, which cause the strength and muscle bulk to gradually decline. Muscular dystrophies are incurable and few drugs have any effect. Treatment of muscular dystrophy is mainly directed at preventing the complications of weakness, including decreased mobility and respiratory weaknesses (HealthAtoZ.com, 2005).

Neurological complications and associated dysphagia can occur in individuals infected with HIV and AIDS, with up to 60% of patients with advanced HIV and AIDS experiencing neurological dysfunction during the course of their illness (HIV Insite Perceptions Base, 2004). One of the most common complications of the HIV and AIDS infection is the AIDS dementia complex. According to Folstein (1998), the AIDS dementia complex can be viewed as an acquired neurodegenerative disorder. The management of dysphagia in patients with HIV and AIDS will, therefore, be included in this discussion.

Patients with AIDS dementia are at risk for dysphagia as dementia can cause food agnosia, where patients do not recognise food and as a result will not accept the food into their mouth. Patients with AIDS dementia will keep food in their mouths without swallowing, as they do not know how to initiate the swallow. Swallowing disorders associated with AIDS dementia benefit from thermal-tactile stimulation, as these strategies will heighten the sensory input. However, this technique can only be used if the patient does not have oral thrush, which is a common infection in patients with HIV and AIDS (Logemann, 1998).

Research has shown that both ischemic stroke and intracerebral haemorrhage are strongly associated with HIV and AIDS (Nogueira, 2005). The presence of neurological complications in patients suffering from HIV and AIDS, in turn, increases the frequency of dysphagia, as research has indicated that up to 50% of acute stroke patients are dysphagic (Halberg, Ohlsson & Westergren, 1999).

The presence of dysphagia can result in malnourishment and dehydration. This is particularly hazardous for patients with HIV and AIDS, as the provision of appropriate nutrition is a key component of care in HIV and AIDS. In South Africa, the Department of Health has established the importance of nutritional intervention for boosting the functioning of the immune system and all South African health care facilities are to provide nutritional support for HIV and AIDS patients (Dworzanowski, 2002).

From the above discussion, it is clear that several neurodegenerative disorders are associated with dysphagia. Dysphagia can increase morbidity if it is not treated as patients with dysphagia are at risk of developing aspiration pneumonia, which is the leading cause of death in the neurogenic population (West, 2004). Patients with dysphagia are also at risk for malnutrition and dehydration. Malnourishment further increases a patient’s risk for pneumonia because if a patient’s immune system is weak, they are more susceptible to infection. Furthermore, malnutrition and dehydration result in patients being lethargic and less alert, increasing the probability of aspiration. It is, therefore, imperative that patients with dysphagia are timely identified and managed (Paik, 2005).

The presence of dysphagia, however, not only affects a patient’s nutrition and hydration it also has a profound influence on his/her quality of life, as it interferes with the most cardinal of human functions; the ability to eat and drink. Feeding is a significant aspect of social, medical and emotional wellbeing and the presence of dysphagia may evoke feelings of anxiety, shame, fear and embarrassment as it prevents a person from participating in activities of daily living (McHorney & Rosenbek, 1998). The acknowledgement of this profound effect necessitates care, which considers and manages dysphagia in terminal patients.

2.4 THE ASSESSMENT OF DYSPHAGIA ASSOCIATED WITH NEURODEGENERATIVE DISORDERS

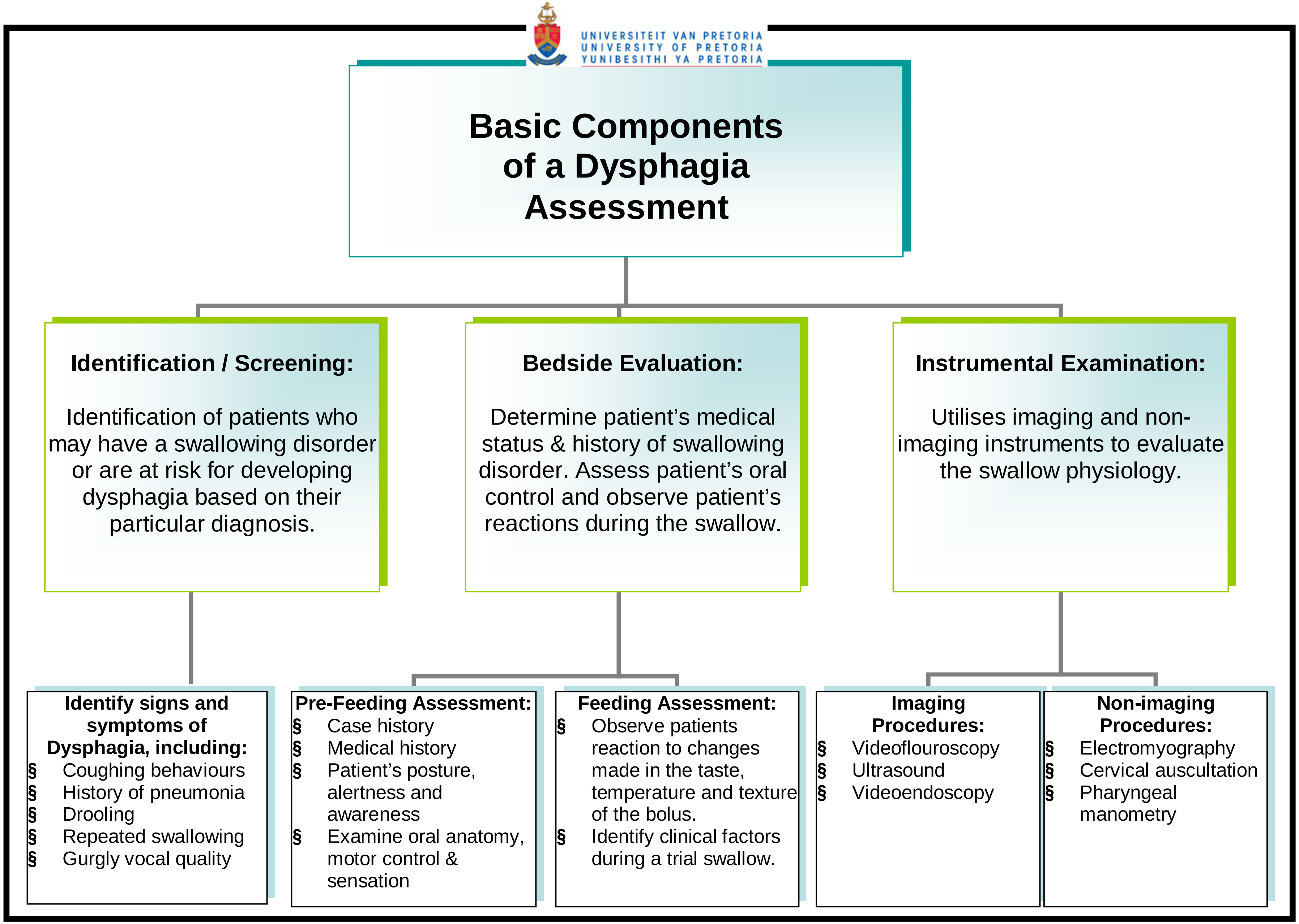
In order to provide optimal care for a patient with neurodegenerative dysphagia, the prognosis and severity of the disorder, as well as the nature of the dysphagia, must first be determined (Sonies, 2000). A comprehensive assessment is necessary to identify and describe the factors that affect swallowing performance, to determine the effects of the swallowing disorder on the individual’s quality of life, and to identify any barriers to successful swallowing. The assessment should not only result in a diagnosis of the swallowing disorder, but should also provide a clinical description of the characteristics of the swallowing disorder and recommendations for intervention and support (ASHA, 2001).

The swallowing assessment should be both static and dynamic in that it describes the patient's current swallowing status and identifies potentially successful intervention strategies and compensations (ASHA, 2001). Swallowing problems associated with neurodegenerative disorders generally deteriorate over the course of the disease and need constant reassessment to determine whether the patient is able to maintain adequate nutrition and hydration (Logemann, 1998).

Dysphagia is traditionally assessed by the speech-language therapist through various instrumental procedures and clinical observations. This includes obtaining a relevant case history, conducting a patient and family interview, and using formal and informal procedures to assess aspects of the swallowing function (Kirker & Oliver, 2003). All of the available swallowing assessments, however, have their limitations and cannot be used in isolation. This necessitates the use of a dysphagia test battery that takes the patient's setting and the available facilities into consideration (Ramsey, Smithard & Kalra, 2003). The basic components of a dysphagia assessment are presented in Figure 2.1 on page 21.

According to Figure 2.1, there are three basic components of a dysphagia assessment: identifying a patient with a possible swallowing disorder, conducting a bedside evaluation and performing an instrumental examination of the swallow. In the hospice setting, however, instrumental procedures are rarely used to assess swallowing disorders for a number of reasons. Patients with neurodegenerative disorders are often reluctant to leave the house to go to the hospital for this instrumental evaluation. In addition, they are often frail and immobile, and transporting them to hospital may be difficult (Weindling, 2000).

The access to instrumental procedures is further limited by logistical and financial problems. Research completed in South Africa indicates that 72% of speech-language therapists working in the hospitals do not have access to diagnostic equipment (Ishwarduth, 2004). Furthermore, instrumental examinations can only be performed by trained professionals. In South Africa, there is a severe shortage of practicing speech-language therapists who are trained in the use of instrumental procedures. In addition, there is a tendency for these professionals to practice at a tertiary level. This, in itself, is problematic, as tertiary service delivery does not reach the disadvantaged communities of South Africa (Fair & Louw, 1999). As a result, the dysphagia assessments in the hospice setting are often limited to clinical bedside examinations (Weindling, 2000).



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Basic Components of a Dysphagia Assessment

Identification / Screening:

Identification of patients who may have a swallowing disorder or are at risk for developing dysphagia based on their particular diagnosis.

Bedside Evaluation:

Determine patient’s medical status & history of swallowing disorder. Assess patient’s oral control and observe patient’s reactions during the swallow.

Instrumental Examination:

Utilises imaging and non-imaging instruments to evaluate the swallow physiology.

Identify signs and symptoms of Dysphagia, including:

§ Coughing behaviours
§ History of pneumonia
§ Drooling
§ Repeated swallowing
§ Gurgly vocal quality

Pre-Feeding Assessment:

§ Case history
§ Medical history
§ Patient’s posture, alertness and awareness
§ Examine oral anatomy, motor control & sensation

Feeding Assessment:

§ Observe patients reaction to changes made in the taste, temperature and texture of the bolus.
§ Identify clinical factors during a trial swallow.

Imaging Procedures:

§ Videoflouroscopy
§ Ultrasound
§ Videoendoscopy

Non-imaging Procedures:

§ Electromyography
§ Cervical auscultation
§ Pharyngeal manometry

Figure 2.1 Basic components of a dysphagia assessment (conceptualised from ASHA 2001; Logemann, 1998; O’Loughlin & Shanley, 1998).

Clinical bedside examinations of the patient’s swallowing status provide vital information about the individual’s specific symptoms and assist the clinician in developing an individualised treatment plan. The bedside examination is not a single test, but rather a collection of tools and techniques. There is, however, no universally accepted protocol for clinical bedside examinations and they vary considerably (McCullough, 1999).

There are a number of clinical indicators that are associated with an increased risk of aspiration, including – but not limited to – a weak voluntary cough, cough on swallow or impairment of the level of consciousness. These indices have been examined to determine which are most associated with dysphagia. The research results, however, vary considerably and, therefore, so do the results for the sensitivity and specificity of using a bedside examination for the detection of aspiration (Ramsey et al., 2003).

When methods for evaluating dysphagia at the bedside are used in isolation, their levels of sensitivity and specificity are insufficient (Tohara, Saitoh, Mays, Kuhlemeier & Palmer, 2003) and Logemann (1998) suggest that the clinical bedside examinations fail to identify the presence of aspiration in 40% of aspirating patients. This is, however, contradictory to results obtained by Lin et al. (2001), where a study comparing the results obtained from the fiberoptic endoscopic examination of swallow to those of the clinical bedside examination indicated that the clinical bedside examination accurately identified aspiration, with a sensitivity of 84.6% and a specificity of 75%. The study by Lin et al. (2001) further found that bedside examinations are capable of detecting most aspiration, even silent aspiration, and provide important information for the development of an individualised treatment programme. Others have found similar accuracy rates (Health Services/Technology Assessment Text, 2004; Linden, Kuhlemeier & Patterson, 1993; Smithard et al., 1998).

Furthermore Tohara et al. (2003) indicated that when bedside assessments are combined, they have a high level of sensitivity and specificity. In settings where instrumental assessment procedures are not available, the bedside evaluation remains a valuable way of identifying patients with dysphagia. Hospice caregivers can therefore be trained to identify the signs and symptoms associated with dysphagia while feeding patients with neurodegenerative disorders.

“A comprehensive bedside examination usually involves taking a case history, which includes a comprehensive review of medical or clinical records and interviews with patients, their families and other health care professionals, assessing oral motor structures and their function, assessing speech and vocal quality and determining the adequacy of airway protection for boluses of various sizes and consistencies” (ASHA, 2001: 181).

It is necessary to obtain as much information as possible about patients and their swallowing disorders in order to make an accurate diagnosis and develop an appropriate treatment plan (Shipley & McAfee, 1998). Obtaining a full medical and swallowing history is particularly important for patients with neurodegenerative disorders as information regarding the prognosis, severity and stage of the disorder will determine the best management plan for the patient (Sonies, 2000).

Information pertaining to the swallowing disorder can be obtained from the patient and his/her family. The case history endeavours to obtain the following information: the localisation of the disorder, whether it occurs in the oral or pharyngeal stages of the swallow, the easiest and most difficult food consistencies to swallow, and the nature of the swallowing disorder. During the interview with the patient, it is important for the caregiver to observe the patient’s ability to follow directions and answer questions as this will influence the management of the dysphagia (Logemann, 1998). A comprehensive case history will enable the caregiver to identify the cause of dysphagia in 80% to 85% of the patients (Spieker, 2000).

The hospice caregiver has regular contact with the patient and will usually gather the patient’s case history (Johnson & Smith-Temple, 2005). However, caregivers need to be trained to include questions that relate to the onset, duration and severity of dysphagia, the perceived level of obstruction, feelings of pain or discomfort, the presence of a gurgly voice and coughing or choking before, during or after the swallow (Alford, 2005).

The results obtained from the bedside assessment are then utilised to determine whether there is an aspiration risk. There is inconsistency in the research regarding the clinical factors that predict a risk for aspiration. Abnormal phonation, abnormal laryngeal elevation, wet spontaneous cough, impaired swallowing of secretions and impaired pharyngeal gag have been suggested to predict laryngeal penetration (Linden et al., 1993).

Although there is no consensus on the accuracy of the dysphagia bedside examination, according to Farrell & O'Neill (1999), the accuracy of the bedside examination has improved considerably and can be used independently to detect dysphagia, predict mortality and the occurrence of chest infection and identify patients at risk for inadequate nutrition (Smithard et al., 1998). In the hospice setting the clinical bedside examination is the most suitable method of dysphagia assessment because of the caregivers' limited access to resources (O'Loughlin & Shanley, 1998).

The care of patients in the hospice setting is mostly administered by hospice caregivers who currently lack the expertise to assess and manage feeding difficulties (Pollens, 2004). The Swallowing on a Plate Program (O'Loughlin & Shanley, 1998), which was developed to train registered nurses in nursing homes in basic dysphagia assessment and management, suggested training caregivers to perform both a pre-feeding assessment and a swallowing assessment. The pre-feeding assessment commences as the caregiver enters the patient's room. The caregiver should observe the patient's posture in bed, alertness, general awareness, tongue movement, cough strength and voice quality. Only once this information has been collected and the risk of aspiration is low, should a trial swallow be considered. During the swallowing assessment, the patient's lip seal, tongue movements, timing of the swallow, coughing, choking and changes in voice quality should be observed (O'Loughlin & Shanley, 1998).

In order to accurately determine whether there is a risk for aspiration, the caregiver needs to be aware of all the possible clinical signs and symptoms of dysphagia. Hospice caregivers may not be aware of all these signs. Research conducted in a nursing home indicated that nursing assistants were not aware that a wet or gurgly voice or throat clearing may be a sign of dysphagia. Additionally, although nursing assistants were aware that choking, coughing or chewing problems may indicate the presence of dysphagia when these symptoms presented during feeding, the nursing assistants did not identify the patients as dysphagic (Pelletier, 2004).

The aim of training the hospice caregivers to complete a pre-feeding assessment and a swallowing assessment is not to perform the role of the speech-language therapist, but rather to assist caregivers in an area where they have received limited training (O'Loughlin & Shanley, 1998). It is imperative that there is still a collaborative partnership between speech-language therapists and other health care professionals (Moodley et al., 2000). However, for this collaborative partnership to be effective, a transdisciplinary team approach needs to be implemented. In this approach, team members share perceptions and skills across disciplines and treatment plans are carried out by a single team member, namely the hospice caregiver. The transdisciplinary approach involves team members from different disciplines working cooperatively. The disciplinary boundaries disappear as team members work to accomplish a common objective (Albrecht, Freeman & Higginbotham, 1998).

2.5 THE MANAGEMENT OF DYSPHAGIA ASSOCIATED WITH NEURODEGENERATIVE DISORDERS

Managing dysphagia in adults with neurodegenerative disorders is difficult, as it involves progressively changing strategies. Poor management can result in aspiration. Aspiration often results in pneumonia, which can cause death (West & Redstone, 2004). There is no single optimal pattern of care for all individuals with dysphagia and the incorrect pattern of care may actually harm patients, rather than help them. Therefore, it is imperative that an individual management plan be drawn up based on the results of the assessment (Sonies, 2000).

According to ASHA (2002) the speech-language therapist should be the primary professional involved in both the assessment and management of swallowing disorders. This includes performing clinical swallowing and feeding assessments, performing instrumental assessments, making decisions about the management of swallowing disorders, developing treatment plans and providing treatment for individuals with swallowing disorders (ASHA, 2002).

As stated previously, in the hospice setting, the involvement of the speech-language therapist is limited. As a result, caregivers often manage swallowing problems without the expertise of a speech-language therapist, which may be detrimental to the patient, as the management of dysphagia requires a multidisciplinary approach (Oliver & Webb, 2000).

Treatment for individuals with neurodegenerative disorders must focus on maximising current function and compensating for the irreversible loss of function (ASHA, 2002). Traditionally, the management of patients with dysphagia can be divided into compensatory and rehabilitative techniques (Daniels, 2000). Rehabilitation focuses on changing the swallow physiology by improving range of motion and coordination during swallow. These procedures usually require patients to follow instructions and to practice exercises independently. Motor, sensory and cognitive impairments in patients with neurodegenerative disorders may, therefore, complicate the use of rehabilitative treatment, shifting the focus of intervention from rehabilitation to compensation (Daniels, 2000).

2.5.1 Compensatory strategies

Compensatory strategies help reduce the patient's symptoms and allow the patient to feed safely without using exertive exercise or having to follow extensive instructions. Compensatory treatments include making postural changes, changing the food consistency or modifying the volume and speed of food presentation. These strategies help to alleviate the patient's symptoms without changing the physiology of the patient's swallow (Logemann, 1998).

Although compensatory strategies are often appropriate for individuals affected by neurodegenerative disorders, the success of these approaches is directly dependent on the caregivers. It is the caregivers who will need to implement these strategies during feeding. Although caregivers may be aware of the strategies, research has shown that they do not implement them consistently and feeding often occurs in the incorrect position (Pelletier, 2004).

Postural changes are recommended for numerous types of dysphagic patients. However, there is no single posture that will improve swallowing in all patients. A speech-language therapist would therefore have to first identify the physiological or anatomical disorder in the swallow and then determine the posture that will facilitate the best swallow (Huckabee & Pelletier, 1999).

Postural changes include the chin-tuck posture, chin-up posture and head rotation. The chin-tuck posture assists patients with a delayed swallow reflex as it narrows the airway entrance and allows the patient to gain oral and pharyngeal control of the bolus (Paik, 2005). The head rotation posture is beneficial for individuals with a unilateral paralysis or paresis. Individuals who experience difficulty propelling food back may use the chin-up position. The chin-up posture is seldom recommended as it requires a neurologically intact swallow response to prevent penetration of the airway (Logemann, 1998).

The limited number of referrals to speech-language therapists implies that caregivers are not always aware of the physiological or anatomical disorder that causes the swallowing difficulties. Thus basic positioning principles should then be employed. These include aligning the patient's body and head before feeding and sitting the patient in an upright position with the chin slightly tucked in (O'Loughlin & Shanley, 1998). Sitting in the upright position with the feet on the floor and the knees at a 90° angle improves the stability of the pelvis and allows the head and shoulders to remain aligned. If this stability is not present the patient will not have jaw stability. This will, in turn, negatively affect the lip and tongue movements. In addition, aligning the head and body, allows the epiglottis to better protect the airway and improves the safety of the swallow (West & Redstone, 2004).

To further compensate for inadequate swallowing function, sensory awareness can be heightened through bolus modification. The bolus texture, taste, density and volume can be adjusted to improve the swallow in neurogenic patients (ASHA, 2002). The process of swallowing is dependent on sensory feedback. Therefore, the presentation of a sour bolus will activate more sensory receptors and will provide a pre-swallow alert to the nervous system. This will, in turn, reduce the time taken from the command to swallow until the onset of oral transit, and improve the triggering of the pharyngeal swallow. A reduction in pharyngeal delay time, oral transit time and pharyngeal transit time will result in a quicker and more efficient swallow and a reduction in aspiration (Logemann & Pauloski, 1995).

The presentation of a cold bolus aims to achieve a similar result of heightened sensory awareness. However, only altering the temperature of the bolus has little effect on the swallow and many patients benefit from small sips of iced lemonade between bites of food (West, 2004). Furthermore, the modification of the food volume can serve to heighten the patient's sensory awareness. The presentation of smaller volumes of food may be seen as a safety precaution and this is a commonly used technique (O’Loughlin & Shanley, 1998). However, this is not always the case. Increasing the bolus volume of a liquid viscosity may impair the efficiency and safety of the swallow. On the other hand, an increase in bolus volume and viscosity can also result in an increase in sensation and help decrease the pharyngeal delay time (Bisch, Logemann, Rademaker, Kahrilas & Clave, 1994). A careful balance needs to be found between presenting the patient with too large a bolus that may cause aspiration and a large enough bolus to stimulate sensation (West, 2004).

“Safe swallowing may be achieved in most patients with neurogenic dysphagia by manipulating the viscosity of ingested fluids” (Goulding & Bakheit, 1999:119). However, the manipulation of food consistencies should be the last strategy to be examined, as the removal of food consistencies will have a negative impact on the patient’s quality of life (Logemann, 1998).

There are a number of concerns regarding the use of thickened liquids. The optimal fluid consistency for a safe swallow has not been established and the caregivers subjectively judge fluid thickness. The use of the correct consistency for feeding is imperative. Aspiration may still occur if the fluid is too thin. However, if the fluid is too thick, it will be unpalatable and rejected by patients. This will, in turn, result in patient dehydration and malnutrition (Goulding & Bakheit, 1999).

The use of a pudding consistency in neurogenic patients may improve airway protection without increasing residue (Bisch et al., 1994). However, thickening liquids will not improve swallowing in all patients. Patients who experience reduced pharyngeal wall contraction, reduced tongue strength or reduced tongue base posterior movement experience increased difficulty in swallowing thick, high viscosity food (Logemann, 1998).

Although diet modification should be the last strategy to be implemented, it is being used more frequently in hospitals and long-term care facilities as thickened liquids are easy for caregivers to implement. The use of thickened liquids has been described as one of the most frequently used approaches for treating swallowing disorders in long-term care facilities (Mertz, 2005). It is, therefore, imperative that caregivers are knowledgeable about diet modification and that they are trained to implement these techniques effectively.

The swallow mechanism is complex and incorrectly modified diets may exacerbate the problem. In order to provide optimal and appropriate treatment for neurogenic dysphagia, an understanding of the temporal sequence associated with each degenerative neurological condition is necessary (Sonies, 2000). The management of swallowing problems associated with degenerative disorders often involves progressively changing strategies and may even result in a shift from oral to non-oral feeding (Logemann, 1998). Hospice caregivers are, however, faced with an ethical dilemma as they need to decide whether the provision of non-oral feeding to a terminally ill patient will benefit or burden the patient (Zerwekh, 2003).

2.5.2 Non-oral feeding

Non-oral feeding is the provision of nutrition, hydration and medication through a route other than the mouth (ASHA, 2002). Feeding tubes can be classified as nasogastric (NG), nasojejunal, gastrostomy or jejunostomy.

The NG tube is placed through the nose, pharynx and oesophagus into the stomach. NG tubes are often utilised as they can be easily inserted at the bedside. However, NG tubes should not be used over extended periods of time as they may cause mucosal injury (Dharmarajan & Unnikrishnan, 2004).

The placement of an NG tube should be carefully considered as there are a number of disadvantages for the patient. The NG tube can be uncomfortable and even painful for the patient and incorrect placement can place the patient at risk for aspiration pneumonia (Hoefler, 2000).

Gastrostomy is the preferred method of non-oral feeding over a long period. Although the percutaneous endoscopic gastrostomy (PEG) can be positioned under local anaesthetic, it is not without complications. Patients may experience diarrhoea, bleeding, tube displacement and infection after the PEG placement (Davis & Conti, 2003). The use of gastrostomy tubes are not always appropriate for patients in the hospice setting as individuals with dementia may pull out the tube or become irritated by the presence of a gastrostomy tube (Hoefler, 2000).

Patients who experience gastroesophageal reflux can receive a jejunostomy. A jejunostomy tube enters the jejunum and requires prepared feedings because it is below the level of the stomach. Patients with a jejunostomy may still have gastroesophageal reflux and it can cause diarrhoea (Dharmarajan & Unnikrishnan, 2004; Logemann, 1998).

There has been much debate on whether or not to provide non-oral feeding to patients with a neurodegenerative disorder. Tube feeding may add to the patient’s distress and discomfort rather than alleviate it (Hoefler, 2000). However, the provision of tube feeding may also prolong the patient’s life and increase alertness of the terminally ill patient (Marelli, 1999).

Patients with dysphagia may become dehydrated and malnourished, which results in the patient becoming weaker. That, in turn, leads to even less consumption. Non-oral feeding may then be appropriate to maintain hydration and nourishment and result in patient experiencing increased energy (National Multiple Sclerosis Society Long Term Care Committee, 2005).

Although the use of non-oral feeding in terminally ill patients is increasing, it must be carefully considered, as the use of non-oral feeding may be ineffective and inappropriate and result in undue suffering (Davis & Conti, 2003). In addition, the provision of tube feeding will not necessarily prevent aspiration pneumonia and may have a negative effect on the patient’s quality of life (Hallenbeck, 2002).

When inevitable death is imminent, a time comes when it is useless or excessively burdensome to continue hydration and nutrition, whether by tube feeding or by other means (Smith, 1991). The potential burdens to providing non-oral feeding to degenerative neurogenic patients (Hoefler, 2000; Marelli, 1999; Zerwekh, 2003) are presented in Table 2.2.

Table 2.2 Potential burdens to providing non-oral feeding to patients with a neurodegenerative disorder

- Tube feeding is irritating and painful for most patients.
- Tube feeding can cause nausea, diarrhoea and dehydration.
- A gastrostomy or jejunostomy tube requires surgery.
- Tube feeding may result in vomiting, aspiration and subsequent pneumonia.
- Artificial feeding may cause distress for the patient rather than alleviate it.
- Feeding tubes can place a barrier between the caregiver and the patient.
- Artificial feeding may give terminally ill patients false hope.
- In a patient with multiple organ failure, artificial hydration can worsen peripheral and pulmonary oedema.
- Tube-fed patients often have to be restrained to prevent them from pulling their feeding tube out. Restraining the patient may result in the patient becoming depressed or angry and can increase their risk for developing bedsores and pneumonia.
- Tube feeding may heighten discomfort by prolonging the dying process.

The potential burdens described in Table 2.2 for providing non-oral feeding to degenerative patients are numerous and the decision to provide non-oral feeding should therefore be made by a multidisciplinary team (Hallenbeck, 2002). The speech-language therapist has an important role to play in the provision of non-oral feeding and he/she should be involved in decisions regarding the safety of oral feeding and the ability to maintain adequate nutrition (Davis & Conti, 2003).

The limited access to speech-language therapists, however, means that hospice caregivers need to make decisions regarding non-oral feeding without the specialist input of a speech-language therapist. Hospice caregivers, therefore, need to be aware of the potential burdens and benefits of non-oral feeding so that they are able to assist the patient and his/her family make an informed decision (Zerwekh, 2003).

Patients with a neurodegenerative disorder will reach a stage where they will stop eating and drinking. This is very upsetting for family members and friends who may be concerned that the patient will die of starvation. The word 'starvation' invokes horrific images of drastic weight loss and body wasting. However, patients will die of dehydration, not starvation. According to Hoefler (2000), dehydration is not painful and is natural and predictable at the end of life.

There is little evidence to suggest that tube feeding can result in improved quality of life (Hallenbeck, 2002). It is the philosophy of the Hospice Palliative Care Association of South Africa to provide physical, emotional and spiritual support to terminally ill patients to make death as painless and meaningful as possible. Tube feeding is contradictory to this philosophy as the provision of tube feeding may be painful and uncomfortable and only prolong the suffering (Brodeur, 1991). Therefore, caregivers in the hospice setting often rely on oral feeding and may be required to feed patients who should not be fed orally.

2.6 CONCLUSION

There are many factors that need to be taken into consideration when determining the best care of neurodegenerative dysphagia. A management plan can only be drawn up once the dysphagia has been assessed. The assessment and care of dysphagic patients with neurogenic disorders is complex and requires a team effort (West & Redstone, 2004). However, the involvement of the speech-language therapist in the hospice setting is not common and there is limited collaboration between hospice caregivers and speech-language therapists. As a result, hospice caregivers are often required to manage swallowing difficulties without sufficient training (O'Loughlin & Shanley, 1998; Oliver & Webb, 2000).

2.7 SUMMARY

This chapter provides an introduction to the management of dysphagia within palliative care and an overview of palliative care in the South African context. It includes a discussion of the assessment and management of dysphagia in patients with neurodegenerative disorders and highlights some of the challenges facing the hospice caregiver.

CHAPTER 3

METHOD

Aim: The aim of this chapter is to provide a description of the method used to plan and execute the research. Information regarding the research aims, design, material, respondents and procedures used for data collection and analysis is presented in this chapter. Issues of reliability, validity and ethics are also discussed.

3.1 INTRODUCTION

Conducting research in the field of dysphagia is vital, as it forms the basis of sound clinical practice (Lewison & Carding, 2003). However, the quality of research findings is reliant on the accountability of the research process followed. The research process focuses on the procedures used and aims to provide a structured inquiry into the exploration of topics, the description of situations or provision of explanations (Babbie & Mouton, 2001).

Although dysphagia management had its origins in the 1930s, it was only in the early 1980s that the focus on research and clinical practice in dysphagia increased drastically (Huckabee & Pelletier, 1999). Within this short period of time, there has been rapid progress in the development of diagnostic and management procedures for dysphagia. However, it is still a relatively new discipline and there remains a considerable need for further research (ASHA, 2002).

In addition to the need for further research, there has also been an increased need for the provision of dysphagia services in hospitals, outpatient facilities and long-term care facilities (ASHA, 2002). Although the diagnosis and treatment of dysphagia forms an integral part of speech-language therapy, the speech-language therapist is not traditionally a member of the interdisciplinary team in the management of dysphagia (Pollens, 2004). Therefore, research is required to determine the current practices in the management of dysphagia in a South African context.

By exploring the hospice caregivers' perceptions and practices in the management of dysphagia, the speech-language therapist can determine whether further training is needed and develop a model to facilitate transdisciplinary teamwork in the hospice setting. This could, in turn, improve the provision of palliative care for patients and their families in South Africa.

3.2 AIMS AND SUB-AIMS

3.2.1 Main aim

The aim of this study was to determine hospice caregivers' perceptions and reported practices in the management of dysphagia in individuals with neurodegenerative disorders.

3.2.2 Sub-aims

- To determine the hospice caregivers' *awareness* of dysphagia in individuals with neurodegenerative disorders.
- To describe the hospice caregivers' reported practices in the *management*[2] of dysphagia in neurodegenerative disorders.
- To determine the hospice caregivers' *attitudes*[3] with regard to the provision of artificial nutrition and hydration to individuals with neurodegenerative disorders.
- To determine whether a *team approach* is followed in the management of dysphagia in neurodegenerative disorders and to ascertain whether the speech-language therapist is a member of the team in the hospice setting.

---

[2] For the purpose of this study, the term 'management' refers to all aspects of treatment, including the use of a team approach and the inclusion and education of family members.

[3] For the purpose of this study, the term 'attitude' will refer to a "psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour" (Eagly & Chaiken, 1993).

3.3 RESEARCH DESIGN

The research design is the plan for conducting the research. It focuses on the research problem and the results the study aims to achieve (Babbie & Mouton, 2001). In order to achieve the aims of this study, a quantitative research design was required, which examined perceptions, attitudes and practices in a particular group of health professionals.

A non-experimental, descriptive survey research design was, therefore, selected for the purpose of this study. Non-experimental methods are regularly used to answer questions regarding the characteristics of a group of individuals. Non-experimental designs do not have direct control over any variable in the study, but instead provide a description of a subject population through structured and objective gathering of information (Cooper & Schindler, 2001). Babbie (1998) indicated that the best method to collect data to describe a population that is too large to observe directly is survey research.

A survey is the collection of information on a wide range of cases (Floyd & Fowler, 2002). The survey in this study included as many hospice caregivers as possible, in order to increase the reliability of the results. The survey aimed to explain and explore the perceptions, management practices and attitudes that the respondents have regarding the management of dysphagia in neurodegenerative disorders.

The use of a descriptive survey allowed the researcher to describe the characteristics of a large number of respondents and made it possible for responses to be easily gathered and counted. Data gathered through descriptive surveys, however, have several disadvantages. Although surveys allow many questions to be asked regarding a specific topic, they are less likely to provide respondents with the opportunity to communicate what is important to them (Robinson & Lai, 2005). In addition, descriptive surveys are inflexible, as the questionnaire cannot be modified during the study to incorporate new variables (Babbie & Mouton, 2001).

3.4 ETHICAL CONSIDERATIONS

The goal of ethics in research is to ensure that no-one is harmed or suffers any adverse consequences as a result of the research activities (Cooper & Schindler, 2001). Survey research requires interaction with other people, which has the potential for a conflict of interests. Therefore, certain ethical considerations must be taken into account. Ethical issues that need to be considered include voluntary participation, protection from harm, anonymity, confidentiality and honesty with respondents and colleagues (Babbie & Mouton, 2001). The following aspects were considered in order to meet the ethical conduct of research.

Consent

§ Consent was obtained from the University of Pretoria's Faculty of Humanities Research Proposal and Ethics Committee prior to commencing with the study (Appendix G).

§ Consent for the study was also obtained from the Chairperson of the Hospice Palliative Care Association of South Africa (HPCA) Ethics Committee (Appendix F).

§ The hospice managers were contacted telephonically to obtain consent. The hospice managers who agreed to participate in the research were then sent letters detailing the goal of the study and the respondents' selection criteria (Appendix A).

§ An introductory letter was presented to the research respondents. This letter provided information regarding the goal of the study and assurance of the anonymity of the respondents (Appendix B).

§ Participants were required to read and sign a letter of informed consent before completing the questionnaire to show their willingness to cooperate in the research project (Appendix D). In line with ethical guidelines, the purpose, procedure, risks and benefits of the study were disclosed. Participation in the study was voluntary and respondents could choose to withdraw at any time throughout the duration of the study (Cooper & Schindler, 2001) (Appendix C).

Confidentiality and anonymity

- To ensure anonymity, all informed consent forms were separated from the questionnaires and no identification numbers were placed on the questionnaires prior to their return.
- Respondents' name and workplace were unknown to the researcher and all completed questionnaires were placed in sealed envelopes to ensure that the information provided remained private (Babbie & Mouton, 2001).
- Each questionnaire was allocated a research number upon return.
- No names were used in the discussion of results to ensure anonymity.

Action and competence of the researcher

- The researcher endeavoured to maintain objectivity and integrity throughout the research process by accurately and honestly presenting both the results and limitations of the research.
- References consulted were accurately recorded and the highest possible technical standards were adhered to (Babbie & Mouton, 2001).

Protection from harm

- The risks associated with participation in the study were minimal and it was ensured that the respondents did not suffer any physical harm, pain, embarrassment or loss of privacy during the research (Cooper & Schindler, 2001).
- There was a risk that participation in the research may have resulted in caregivers considering their past care of individuals with dysphagia as inadequate or increasing their anxiety levels for the care of dysphagia in neurodegenerative disorders. In order to reduce these risks, the participants were ensured of anonymity and informed that, upon completion of the research study, they would have access to the final research report. This would allow the respondents to determine whether they required additional training in the management of dysphagia.

3.5 RESPONDENTS IN THE STUDY

It is vital that the sample be representative of the population as this influences the validity and reliability of the results of the study (Babbie & Mouton, 2001). The target population for this study was hospice caregivers employed in hospices throughout South Africa.

3.5.1 Selection procedures of respondents

There are 58 hospices registered with the Hospice Palliative Care Association of South Africa. Non-probability sampling was utilised as logistical constraints prevented the researcher from guaranteeing that every hospice caregiver would be represented in the sample (Babbie & Mouton, 2001).

The hospice managers were contacted telephonically and the nature and purpose of the study was explained to them. Forty of the 58 hospices agreed to participate in the research. Due to the subject selection criteria imposed on all respondents, a letter detailing the criteria for the selection of caregivers to participate in this study was sent to the hospices to ensure that the questionnaires were appropriately distributed (Appendix A).

An information brochure detailing the nature, purpose and potential benefits of the study (Appendix C), an introductory letter (Appendix B), and a letter of informed consent (Appendix D) were given to the respondents. Only respondents who signed the letter of informed consent were included in the study.

To further ensure that the caregivers who completed the questionnaire met the selection criteria, the researcher double-checked that information provided in the biographical section of the questionnaire met with the subject selection criteria. There were six completed questionnaires where the respondent did not meet the selection criteria and these were discarded.

Although 40 hospices agreed to participate in the study, only 20 hospices returned the questionnaires, thereby representing a 50% response rate. According to Babbie and Mouton (2001), a 50% response rate is considered adequate, indicating that the response rate in this study is adequate for the purpose of analysis and reporting.

3.5.2 Selection criteria of respondents

The following criteria were used in the selection of hospice caregivers as respondents in this study:

§ ***Professional qualification:*** A prerequisite for selection was that the respondents were qualified in palliative care. This included respondents who were in possession of either a degree or diploma in nursing or palliative medicine or individuals who had completed the Hospice Palliative Care course in community caregiving (Hospice Palliative Care Association of South Africa, 2004).

§ ***Experience:*** A further criterion for subject selection was that the caregivers have at least one year's working experience in a hospice setting. The amount of experience may have an impact on the caregivers' perceptions and management of dysphagia in neurodegenerative disorders and, therefore, needs to be taken into consideration (Fey & Johnson, 1998).

§ ***Language:*** The questionnaire was compiled in both English and Afrikaans as this is the language in which the researcher is proficient and the respondents were therefore required to be able to read and understand either Afrikaans or English and be proficient in writing either English or Afrikaans in order to complete the questionnaire.

§ ***Race and ethnicity:*** In order to avoid bias, race and ethnicity were not considered in the participant selection criteria. South Africa is a multi-cultural country. Therefore, the study could not be confined to one cultural group, as this would limit the usefulness of the information obtained.

§ ***Willingness to participate in the study:*** Respondents were required to complete an informed consent form (Appendix D). This ensured that participation in the study was strictly voluntary.

3.5.3 Description of respondents

A total of 64 caregivers completed the questionnaire. The caregivers were selected according to the procedures described in 3.5.1. All respondents' completed an informed consent form to indicate they were voluntarily participating in the study. A summarised description of the respondents is presented in Table 3.1.

Table 3.1 Biographical characteristics of respondents

Biographical information	Category	Percentage (%)
Place of residence	Northern Cape	16%
	Eastern Cape	16%
	KwaZulu-Natal	27%
	Gauteng	17%
	Free State	9%
	Mpumalanga	6%
	Western Cape	9%
Gender	Male	5%
	Female	95%
Age	25 to 40 years old	28%
	41 to 50 years old	22%
	51 to 60 years old	30%
	>60 years old	20%
Highest level of qualification	Nursing diploma	30%
	Nursing diploma and short course in palliative care	31%
	Nursing degree	10%
	HPCA community caregiving course	19%
	Short course in palliative care	4%
	Other	6%
Type of training in dysphagia	No training	41%
	Training as part of professional qualification	45%
	In-service training	9%
	Training as part of palliative care seminars	5%
Hospice setting	In-patient hospice unit	8%
	Community-based hospice	44%
	Home-care organisation	27%
	In-patient hospice unit and home-care organisation	2%
	In-patient hospice unit and community-based hospice	5%
	In-patient hospice unit, community- based hospice and home-care organisation	6%
	Community-based hospice and home- care organisation	8%
Number of years experience	Less than two years	38%
	Two to six years	32%
	More than six years	30%

Section A of the questionnaire gathered biographical information from the respondents. Biographical information is important to the research process as it provides a better understanding of the respondents' background and enables the researcher to interpret the responses more reliably (Neuman, 2005).

According to Table 3.1, the respondents depicted a diverse group of hospice caregivers. They held various qualifications, but only 49% of the respondents indicated that they had received training in dysphagia. The respondents represented a wide range of age groups and were currently employed in various hospice settings, with the majority of respondents working in community-based hospices. These results are indicative of the diversity of the sample.

A general description of the respondents was presented in Table 3.1 on page 40 and will now be discussed in detail. The second question in Section A of the questionnaire obtained information about the gender of the participants. In the literature, certain careers are still traditionally dominated by females. The female-orientated careers include nursing, occupational therapy and physiotherapy (Louw, Louw & Van Ede, 1999). Previous research indicates that only 3.1% of nurses are male (Evans, 1997). This trend was reflected in the results as 95% of the respondents were females.

Data was collected from hospices throughout South Africa. The respondents' place of residence is therefore graphically represented in Figure 3.1. From Figure 3.1, it is apparent that respondents resided in seven of the nine provinces, with the majority residing in the Northern Cape, Eastern Cape, KwaZulu-Natal and Gauteng. There is a high number of member hospices in KwaZulu-Natal, which may account for the large number of respondents from this province (Hospice Palliative Care Association of South Africa, 2005).

There were, however, no respondents who were residents of the North-West or Limpopo. The lack of respondents from Limpopo may be explained by the fact that there are currently no hospices registered with the Hospice Palliative Care Association of South Africa in Limpopo (Hospice Palliative Care Association of South Africa, 2005). One hospice in the North-West was unable to assist in the research project due to restructuring.

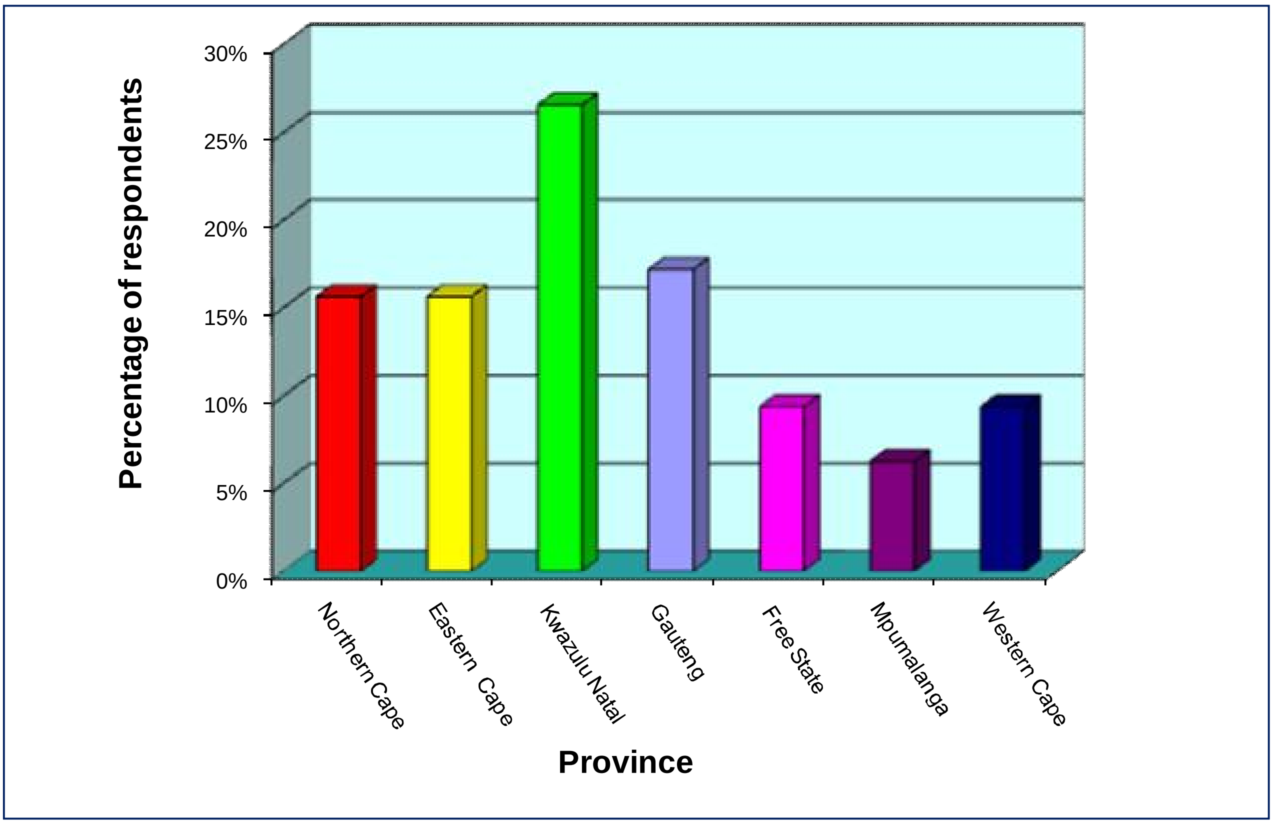


Figure 3.1 Respondents' place of residence (n=64)

Information regarding the respondents' age was gathered in the third question. The data obtained is displayed graphically in Figure 3.2. Respondents' ages ranged from 26 to 73 years, which represents adults in early, middle and late adulthood. The information obtained in the questionnaire is therefore representative of a wide range of ages.

Adults in early adulthood (20 to 39 years of age) and middle adulthood (40 to 59 years of age) are usually the most economically active. In South Africa, the mandatory age of retirement is 65 years (Louw et al., 1999). It was, therefore, surprising that 19% of the respondents indicated that they were older than 60 years. This, however, appears to correspond with an international trend for the employment of older nurses and caregivers. There are fewer younger people entering the nursing profession and, as a result, the nursing workforce is aging rapidly (Letvak, 2002).

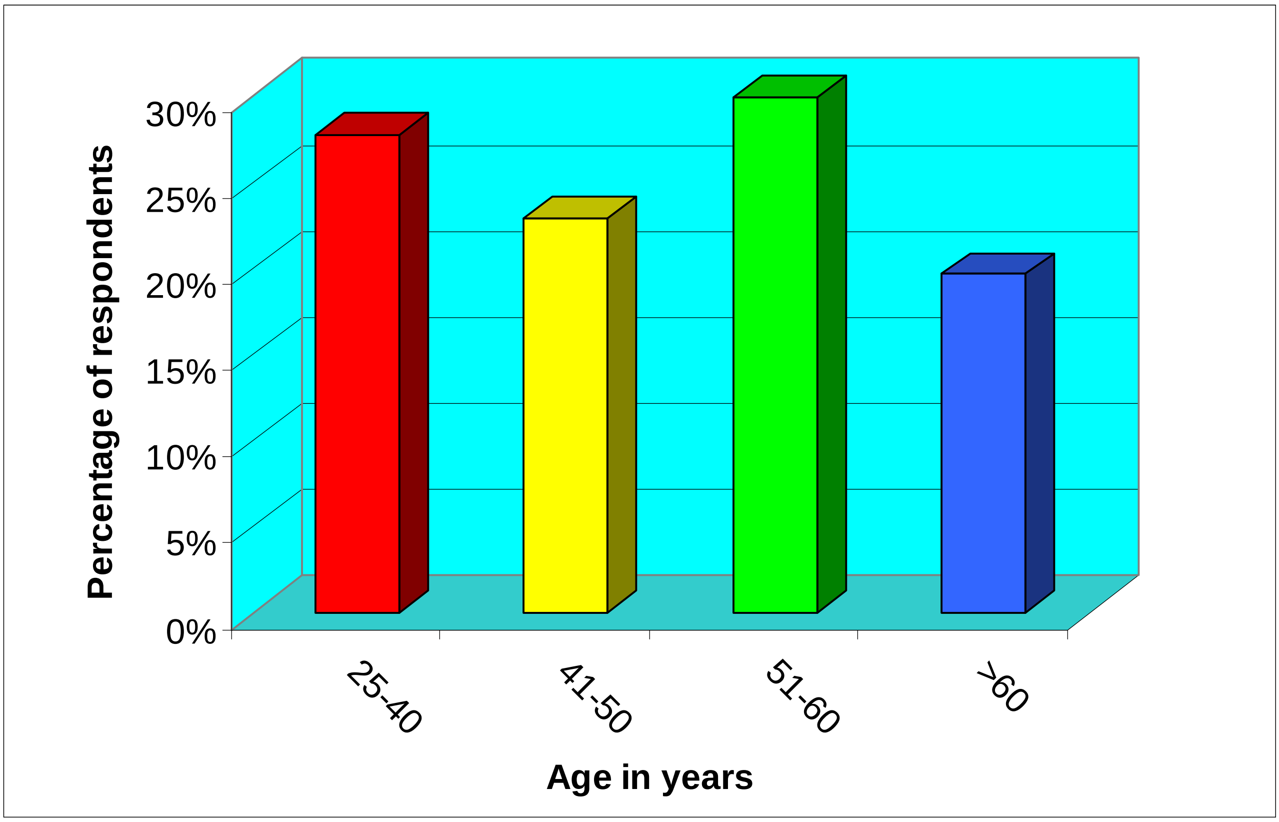


Figure 3.2 Age of respondents (n=61)

In the United Kingdom, 20% of the registered nurses are aged 50 and over. Further research into the older nurses' employment setting has established that the older nurse prefers to work in the home and community setting (Buchan, 1999). This may explain the results obtained in the third question of the questionnaire. According to Figure 3.2, 49% (30% aged between 51 and 60 years and 19% aged over 60 years) of the respondents were aged 50 and over. This may have far-reaching effects in their management of dysphagia in neurodegenerative disorders as research has shown that older nurses and caregivers are less likely to participate in continuing professional development (Wray, Aspland, Gibson, Stimpson & Watson, 2007).

The fourth question in Section A of the questionnaire gathered information regarding the respondents' professional qualifications. This data is presented in Figure 3.3

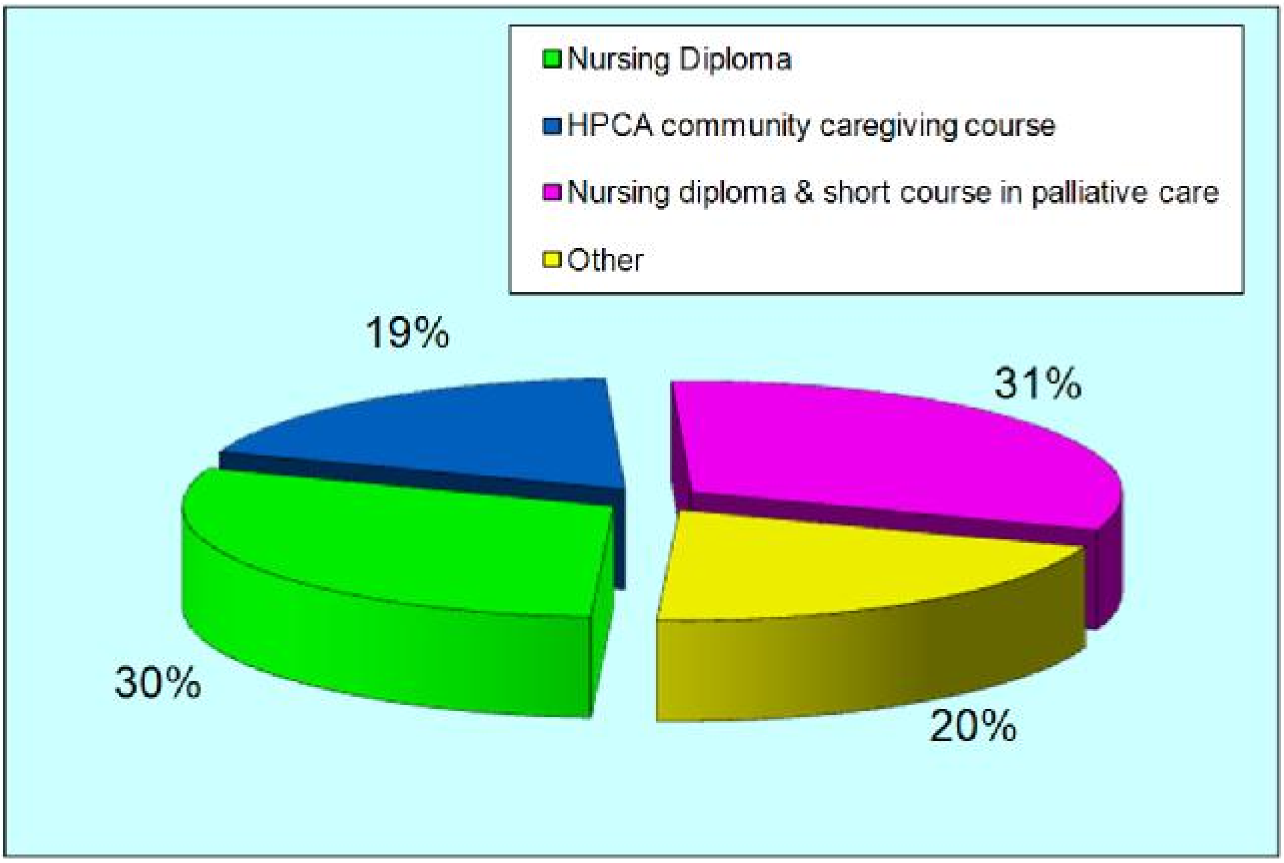


Figure 3.3 Respondents' level of qualification (N=64)

Figure 3.3 indicates that the respondents' levels of qualification were fairly evenly distributed between three qualifications: nursing diploma, Hospice Palliative Care Association of South Africa community caregiving course, and a combination of a nursing diploma and short course in palliative care. At the time of the study, all of the abovementioned categories of professionals were working as caregivers in the hospice setting. It is, therefore, crucial that their perceptions and practices in the management of dysphagia are investigated.

According to Figure 3.3, 20% of the respondents indicated that they held other qualifications. These are presented in Table 3.2.

Table 3.2 Other qualifications held by the respondents (N=13)

Participant’s qualification	No of subjects
Nursing degree	5
Short course in palliative care	1
Doctor	1
BSc Degree	2
Nursing degree and short course in palliative care	3
Diploma in palliative medicine	1

The care of dying patients is an essential part of nursing and, as such, palliative care is included in the training of nurses (Lugton & Kindlen, 1999). There has, however, been a shift in the training of nurses and the focus of the nursing curriculum has moved away from comfort-orientated care to primarily curative-orientated care. It is, therefore, recommended that nurses attend continuing education programs that focus on caring for the dying (Sheehan, Forman, Kitzes & Anderson, 2003). Figure 3.3 indicates that 31% of the respondents had a diploma in nursing and had attended a short course in palliative care and were well qualified for their work as hospice caregivers.

All health professionals should receive training in palliative care. However, this is not always the case, and in South Africa the majority of palliative care training occurs in the hospice setting. The HPCA provides training in community caregiving, palliative nursing and palliative medicine (Foley et al., 2003).

According to Figure 3.3, 19% of the respondents had attended an HPCA community caregiving course. Community caregiver training provided by the HPCA trains caregivers in basic health care (Anatomy and Physiology), AIDS awareness, basic nursing techniques and palliative care principles. The training lasts for approximately three months, after which the caregivers are appointed. The hospice caregiver is then provided employment within hospice community-based home care programs and hospice in-patient palliative care units. Hospice caregivers are required to work under the supervision of professional nurses and social workers (Foley et al., 2003). It is, however, unclear how much training caregivers receive regarding dysphagia and the management thereof.

It is principally the hospice caregivers who support and help the patients and their families with day-to-day tasks, of which eating forms a large component. It is, therefore, imperative that they receive training in the area of dysphagia. Research conducted in the training of nurses in feeding and swallowing problems indicated that nurses receive insufficient training in these areas and as a result are not always competent in the screening and managing of swallowing problems (Magnus, 2001). In addition, training related to feeding and swallowing problems is not always unified and textbooks differ in the amount and type of information provided (Pelletier, 2004). As previously mentioned, access to a speech-language therapist in hospices is limited and hospice caregivers manage dysphagia without specialist input. It was, therefore, crucial to include the opinions of as many different hospice caregivers as possible.

In the fifth question in Section A of the questionnaire, the respondents were asked to indicate whether they had received training in dysphagia management. This data is presented in Figure 3.4 below.

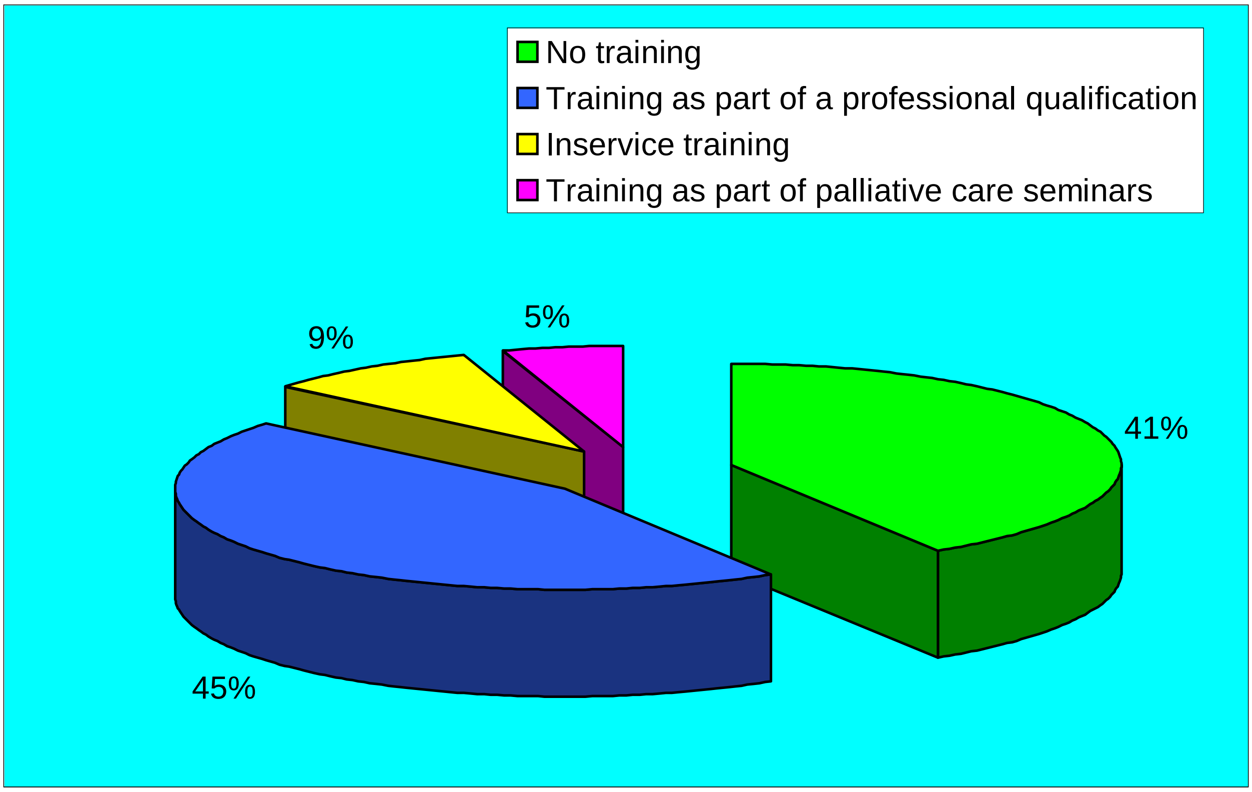


Figure 3.4 Respondents' type of training in dysphagia management (N=64)

According to Figure 3.4, 59% of the respondents indicated that they had received training in dysphagia. However, a large proportion of these respondents indicated that the training they had received was part of their professional qualification. As previously mentioned, it is unclear how much training hospice caregivers receive as part of their professional qualification and there is evidence in the literature to suggest that nurses and nursing assistants have insufficient knowledge regarding dysphagia and feeding (Chang & Lin, 2005; Pelletier, 2004).

The type of training hospice caregivers receive may affect their perceptions and practices and there is extensive literature reporting on the efficacy of dysphagia training programmes. Research findings indicate that the provision of in-service dysphagia training to caregivers has a positive effect on both the caregivers' knowledge and management of dysphagia and is therefore recommended (Chang & Lin, 2005; Kaiser, Williams, Mayberry, Braun & Pozek, 2000; Lin et al., 2001; Lipner, Bosler & Giles, 1990).

According to Figure 3.4, 41% of the respondents had not received any training in dysphagia management. This data was further analysed to determine whether specific age groups did not receive training. The data is presented in Figure 3.5 below.

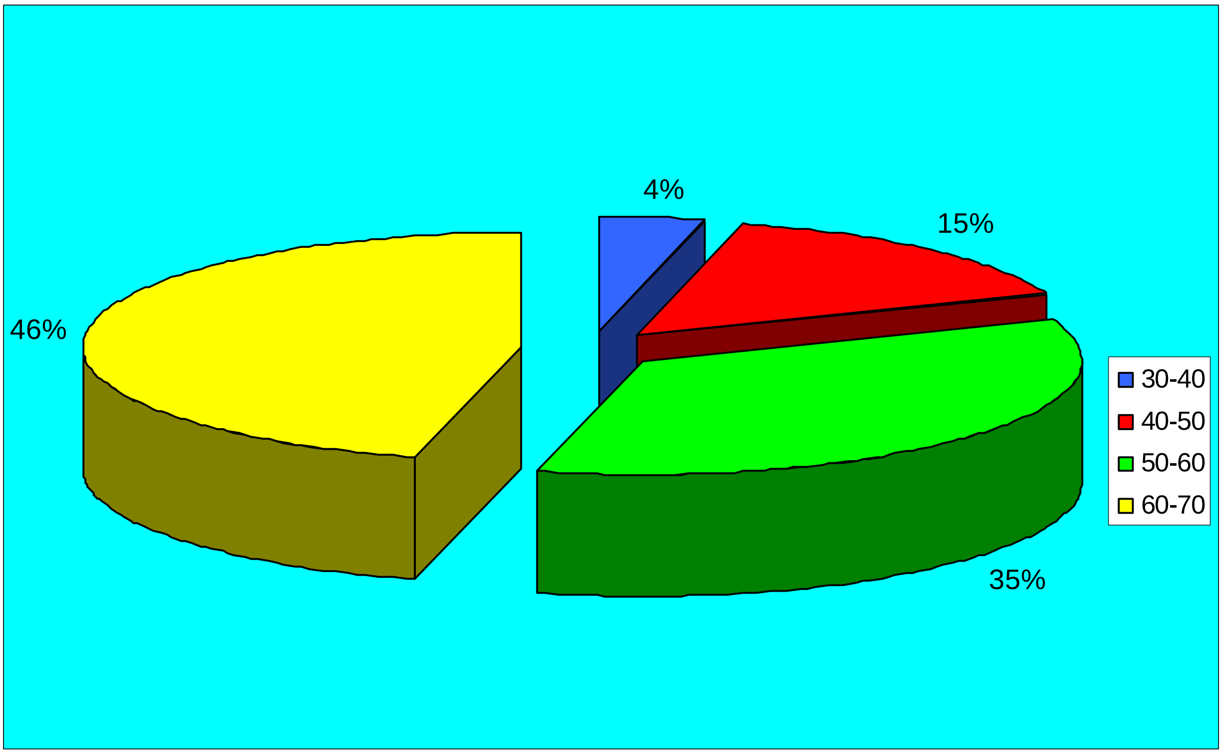


Figure 3.5 Age distribution of hospice caregivers who did not receive training (N=26)

From Figure 3.5, it is clear that the 81% (46% being 50 to 60 years old and 35% being 60 to 70 years old) of respondents who did not receive training were over the age of 50 years. This result is congruent with previous literature, which indicates that older nurses and caregivers are less likely to participate in continuing professional development activities. The reason for this is unclear. It is possible that older caregivers did not have dysphagia management as part of their curriculum; that they have numerous years of experience and feel that the continuing education programs are not relevant or may be unsuitable; or they may have conflicting personal commitments (Wray et al., 2007). The lack of participation in continuing education programs may, in turn, result in older nurses not adapting to the recent advances in dysphagia.

Trends in the assessment and management of dysphagia have changed substantially in the last few years. It is, therefore, imperative that professionals remain up to date and continue their professional development (ASHA, 2002). The participants were, therefore, asked to indicate the date that they received their training in dysphagia management. The results showed that 23% of those who received training had done so before 1995, 27% received training between 1995 and 2000, and 50% of those who received training did so after 2000. Individuals who received training before 1995 may require re-training. Continued professional development is important as it can increase perceptions, confidence, and competence and, as a result, improve the care provided to both patients and their families (Foley et al., 2003).

The sixth question in Section A of the questionnaire determined the hospice setting where the respondents were currently working, as this may have an influence on the hospice caregivers’ perceptions and current practices. The results are displayed in Figure 3.6

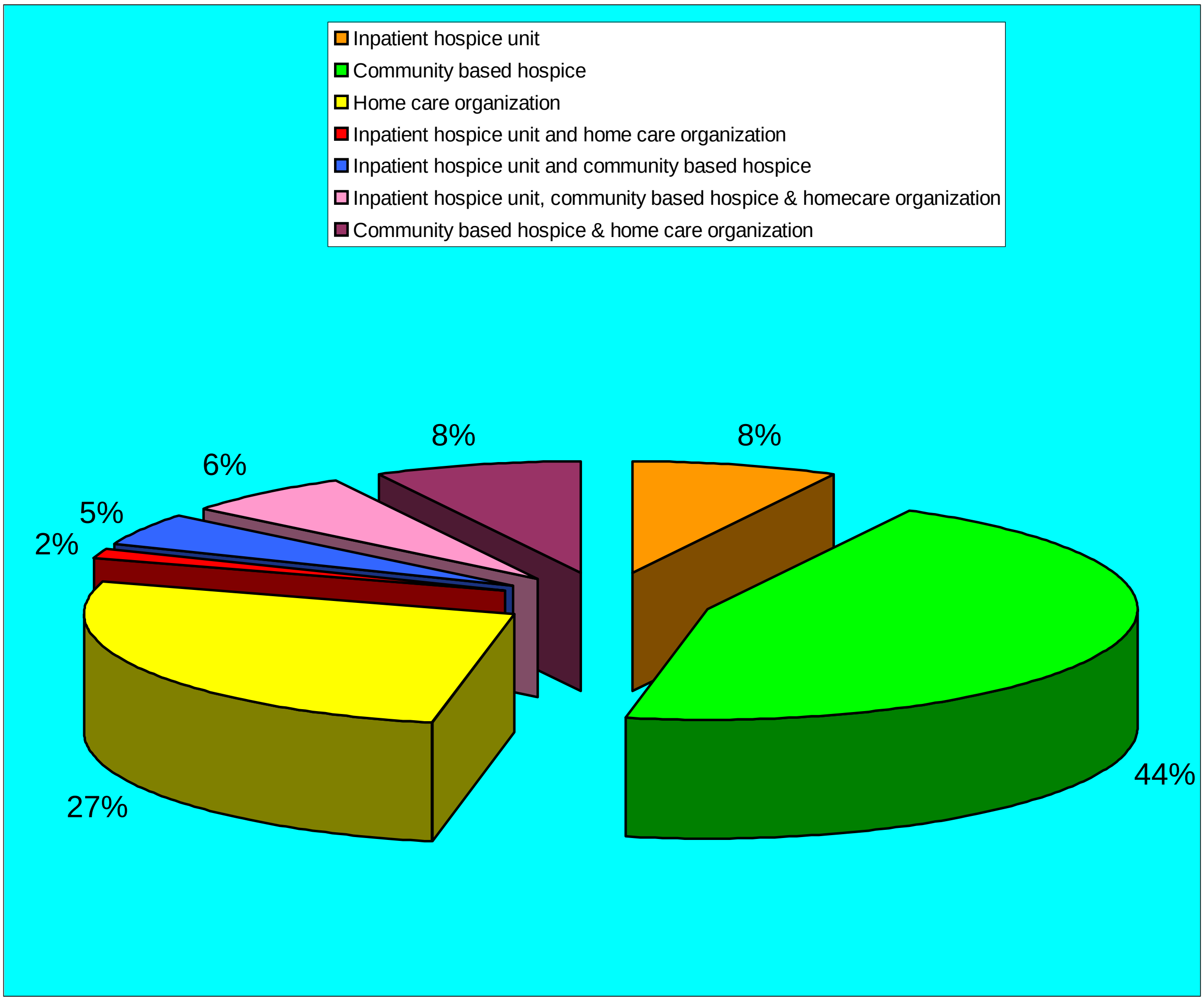


Figure 3.6 Hospice setting that the respondents are currently involved in (N=64)

According to Figure 3.6, the majority of hospice caregivers are involved in a community-based hospice (44%) or a home-care organisation (27%). The HPCA aims to provide palliative care to all who require it, irrespective of whether they are able to pay (Hospice Palliative Care Association of South Africa, 2005). In Africa, a large number of HIV and AIDS patients are found in resource-poor settings with limited access to health care professionals. There is, therefore, a large number of community-based hospices and home-care organisations that provide care for HIV-infected individuals who do not have access to antiretrovirals (Foley et al., 2003). According to Marelli (1999), “a community-based hospice can be defined as a ‘not-for-profit’ volunteer organisation that serves a defined rural geographical area” (Marelli, 1999:5).

Palliative care is, however, crucial in every setting. The prevalence of home-care organisations has increased dramatically over the past few years. In the USA, home health care is the fastest growing segment of health care services (American Federation of Home Health Agencies, 1998 in Weindling, 2000). Home-care organisations provide hospice care with trained hospice caregivers in the comfort of the patient's home (Marelli, 1999).

Home-based care was introduced in Africa in the late 1980s and the HPCA was involved in implementing home care, utilising an integrated community-based home care model. In this model, community caregivers are trained for a period of three months in the theory and practice of home-based HIV care and then appointed to work in teams of two under the supervision of a nurse. There are, however, numerous limitations to the provision of home-based care as the hospice caregivers involved in community-based hospices and home-care organisations do most of their work on foot and have limited access to both specialist input and sophisticated equipment. The community caregivers also focus on providing information and counselling to affected patients, with less time being spent on the provision of physical care. This will, in turn, affect the identification and management of dysphagia in these patients and the hospice caregivers' perceptions and practices in this area (Uys, 2001).

Another factor that has an influence on the caregivers' perceptions and practices in management of dysphagia is the number of years spent working in the hospice setting. Individuals at the early career period with limited experience may lack self-confidence and skills, which will affect the data collected (Louw et al., 1999). The results are displayed in Figure 3.7.

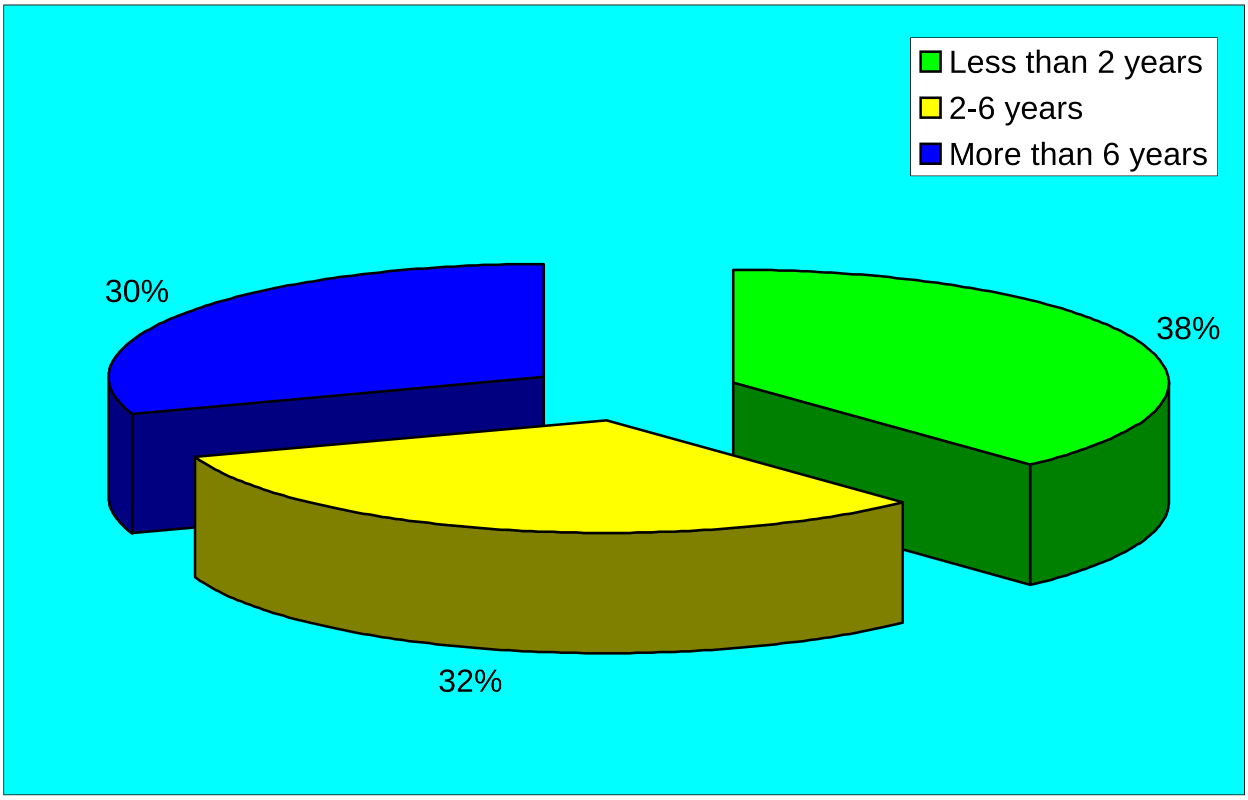


Figure 3.7 Respondents' work experience (N=64)

From Figure 3.7, it is clear that the number of years the respondents have worked in a hospice is fairly evenly distributed. This is positive, as the results of this study reflect the perceptions and practices of both newly qualified professionals and more experienced professionals. Over the last few years there has been a dramatic change in the composition of hospice patients. Hospices have shifted from providing care primarily to individuals diagnosed with terminal cancer, to providing care to individuals with neurodegenerative disorders as well. This change will probably be reflected in the training of these various professionals (Schumacher, 2004).

The biographical information obtained in Section A of the questionnaire indicates that the respondents were of diverse backgrounds from hospices throughout South Africa. This implies that the responses obtained reflect a wide range of hospice caregivers' perceptions and reported practices in the management of dysphagia in individuals with neurodegenerative disorders.

3.6 APPARATUS AND MATERIAL

A mail-distributed, self-administered questionnaire was used in the study to obtain specific information from the hospice caregivers. As an instrument, such a questionnaire is used to collect information from respondents who complete the questionnaire themselves and then return it to the researcher (Bourque & Fielder, 2003).

The advantage of self-administered questionnaires is that they are less expensive and quicker to administer than interviews, and a large geographical area may be included in the research. The self-administered questionnaire ensures that the same questions are presented to all the respondents and interviewer bias is avoided. In addition, self-administered questionnaires offer some anonymity, which is important as it encourages open and honest responses and can be effective if there is a high response rate (Hoyle, Harris & Judd, 2002).

One of the greatest limitations of self-administered questionnaires is their low response rate. However, certain measures were employed during the study to improve the response rate. For example, stamped, addressed return envelopes were sent out with the questionnaire and follow-up contact was made with the respondents (Bourque & Fielder, 2003). A further disadvantage associated with self-administered questionnaires, which is particularly relevant in South Africa, is the wide range of languages spoken and not all of the respondents are proficient in English or Afrikaans. In order to avoid misunderstandings, the questionnaire consisted of clear straightforward questions (Bourque & Fielder, 2003).

Certain guidelines (Neuman, 2005) were followed in the development of the questionnaire to ensure that the results obtained were reliable and valid. The questions avoided the use of jargon, slang and abbreviations. The language used was clear and unambiguous and emotional language was avoided. Furthermore, questions were worded carefully to ensure that they were not leading or biased. A pre-study was conducted to ensure that the questions were clearly formulated (Neuman, 2005).

3.6.1 Types of questions included in the questionnaire

The questionnaire is the form used to facilitate communication between the researcher and the respondent (Brace, 2004). The questionnaire (Appendix E) utilised in this study consisted of a variety of question types, including close-ended, open-ended, partially open, matrix and contingency questions.

Close-ended questions ask the respondent a question and provide the respondent with fixed responses from which to choose, whereas open-ended questions allow for an unstructured, free response (Neuman, 2005). Each form of question has its advantages and disadvantages.

The advantage of utilising closed-ended questions is that they are easier to use by both the respondent and the researcher (Frazer & Lawley, 2000). However, closed-ended questions cannot be utilised in isolation as these questions may allow for respondents with no knowledge to answer anyway and may suggest ideas that respondents would not have thought of. Thus, a total reliance on closed-ended questions might distort the results. Therefore, partially open-ended questions were also included as they allowed the respondent to offer a response the researcher had not included (Neuman, 2005).

While open-ended questions allow respondents to answer questions freely, these questions are time-consuming and difficult to analyse (Hoyle et al., 2002). Therefore, closed questions were mainly utilised. Questions regarding facts, behaviours and perceptions were included in the questionnaire to determine hospice caregivers' perceptions and practices in the management of dysphagia in neurodegenerative disorders.

A description of the type of questions, corresponding questions and justification for including the types of questions in the questionnaire is provided in Table 3.3.

Table 3.3 Types of questions included in the questionnaire

Type of question	**Corresponding questions**	**Justification for including this type of question**
Closed-ended questions	Questions 2, 8, 9, 12,17, 19, 20, 21, 23, 27, 29, 30	§ Easier to use by both the respondent and the researcher than open-ended questions. § Easy and quick for respondents to answer. § Answers to closed-ended questions are constant and can be meaningfully compared (Frazer & Lawley, 2000).
Partially open questions	Questions 4, 6, 13, 20	§ Important information can be overlooked when utilising closed questions alone. § Partially open questions provide the respondent with a fixed set of choices with a final choice of ‘other’ (Babbie & Mouton, 2001).
Open-ended questions	Questions 1, 3, 5, 7, 14, 25, 16, 22, 24, 25	§ Opportunity to answer questions freely and provide additional information (Neuman, 2005).
Matrix questions	Questions 11, 18, 26, 30	§ Provide a set of answer categories for a number of questions. § Useful to obtain information about subjective aspects. § Likert-response categories were utilised to construct the matrix questions as they allow responses to be compared and are fast and easy to complete (Babbie & Mouton, 2001).
Contingency questions	Question 10, 28	§ Serves to gain finer details regarding a response in a prior question’s response. § Facilitate the completion of the questionnaire. § Ensures that respondents do not complete questions that are not relevant to them (Babbie & Mouton, 2001).

3.6.2 <u>Content of the questionnaire</u>

The questionnaire consisted of four sections. The questions were grouped according to topics to minimise confusion and assist respondents in organising their thoughts (Neuman, 2005). The topics are presented in Figure 3.8.

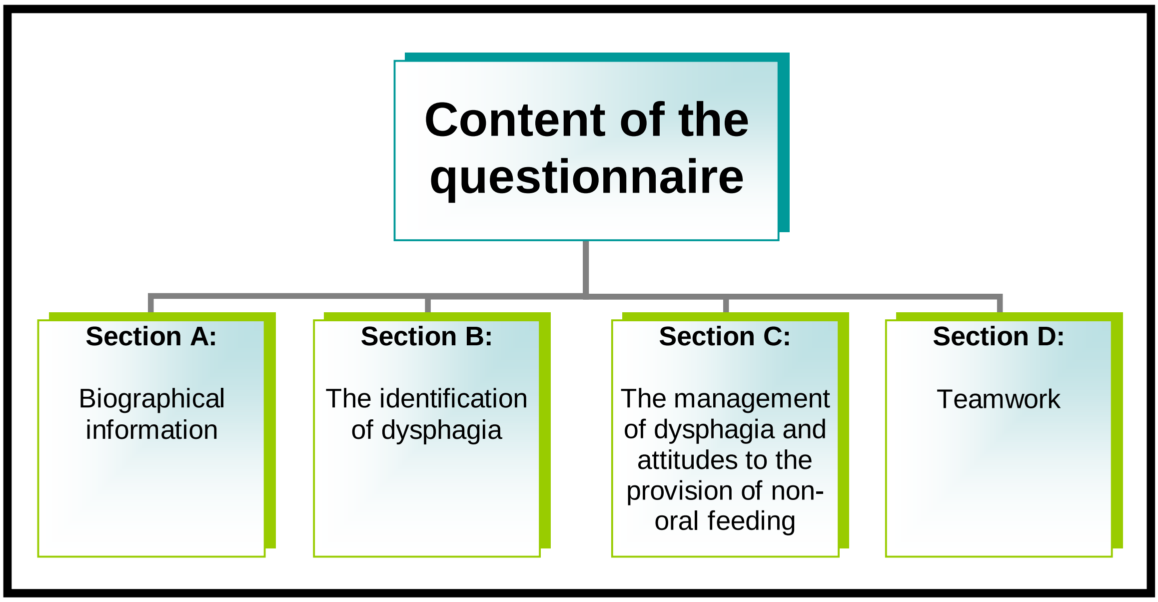


Figure 3.8 Visual representation of the content of the questionnaire

§ ***Section A: Biographical Information***

Researchers hold opposing views on where biographical questions should be placed. Some are of the opinion that biographical questions should be placed at the beginning of the questionnaire, whereas others believe that they should be placed at the end. For the current study, it was decided to place the biographical questions at the beginning, as they are easily answered and are non-threatening (Bourque & Fielder, 2003).

Biographical information includes information pertaining to the respondent’s residential area, gender, age, qualifications, degree of experience and exposure to dysphagia. This information was vital, as it formed part of the selection criteria of the respondents. Biographical information provides a better understanding of the respondents’ background and enables the researcher to interpret the responses more reliably (Neuman, 2005).

§ *Section B: The identification of dysphagia*

Section B aimed to establish hospice caregivers' perceptions and practices in the identification and assessment of dysphagia. Questions in this section addressed the caregivers' perceptions of the signs, symptoms and causes of dysphagia.

Dysphagia commonly occurs in neurodegenerative disorders. It is imperative that it is identified as early as possible, as dysphagia that is not treated can result in severe complications and even death for some patients (Bryant & Sharp, 2002). It is vital that caregivers are aware of the signs of dysphagia so that they are able to identify patients with possible dysphagia. Early identification of dysphagia and initiation of intervention can help sustain oral intake. These signs include unexplained weight loss, complaints of swallowing difficulties, coughing or choking, food remaining in the mouth after swallowing or the presence of a gurgly voice (O'Loughlin & Shanley, 1998).

The patient's alertness, ability to follow instructions, cooperativeness and attention also need to be assessed to determine the focus of intervention. Neurodegenerative disorders are often associated with cognitive deficits, which may result in the focus of intervention shifting from rehabilitation to compensation (Huckabee & Pelletier, 1999).

In addition to the abovementioned signs, it is important to collect information regarding the medical history, neurologic and cognitive status of the patient. The medical diagnosis cannot always reliably predict the nature of the swallowing problem, but it can eliminate specific treatment strategies (Huckabee & Pelletier, 1999). Section B, therefore, also aimed to determine which aspects hospice caregivers' took into consideration during the identification of dysphagia and who was responsible for the identification and assessment of dysphagia.

§ *Section C: The management of dysphagia*

In hospice clinics, there is limited access to speech-language therapists due to financial constraints. As a result, nurses and/or caregivers find themselves having to deal with patients with swallowing difficulties. It is, therefore, crucial that caregivers are knowledgeable about the management of dysphagia in neurodegenerative disorders, as it is their role to maintain safe hydration and nutrition (Ramritu et al., 2000).

The questions included in this section aimed to determine the caregivers' management practices, awareness of basic procedures and compensatory techniques used to manage dysphagia. Basic procedures used to manage dysphagia include seating the person in an upright position, providing verbal prompts, giving the person ample time to swallow, offering small amounts of food per spoon and modifying the food consistency (O'Loughlin & Shanley, 1998).

Compensatory interventions include modifying the patient's diet, food texture and body position. Compensatory techniques have an immediate effect on the swallow and are essential for the maintenance of safe oral feeding (Huckabee & Pelletier, 1999). Caregivers were, therefore, asked to indicate – based on their experience – which position they thought was safest for feeding dysphagic patients and the food consistencies they found to be the easiest for patients with dysphagia to swallow.

Caring for loved ones with dysphagia can be frustrating and upsetting. Therefore, family members need to be provided with information to assist them with the management of feeding difficulties (Fairview Health Services, 1999). For this reason, questions were included in the section to determine what guidelines family members are receiving.

The provision of non-oral feeding to individuals with neurodegenerative disorders is a controversial issue. Some authors are of the opinion that a person's inability to feed him/herself is never an excuse to let the person go hungry, even if it means feeding by artificial means (Williams, 1991). Other authors, on the other hand, are of the opinion that by providing tube feeding, one is prolonging the individual's life, and thereby prolonging their suffering (Brodeur, 1991). For this reason, questions were included in this section to determine the hospice caregivers' attitudes towards non-oral feeding.

§ *Section D: Teamwork*

The complexities of neurodegenerative disorders, which present with dysphagia, are best managed through a team approach. Team members include the patients' family members, speech-language therapists, dieticians, physiotherapists, occupational therapists, nursing staff, doctors, caregivers and specialists, including neurologists and ear, nose and throat specialists (Kirker & Oliver, 2003).

There are three models of teamwork that can be used to manage dysphagia: multidisciplinary teamwork, interdisciplinary teamwork and transdisciplinary teamwork (Rossetti, 2001). In multidisciplinary teamwork, there is limited collaboration between the team members. Each team member completes a separate assessment and continues with treatment in isolation. The individual is, therefore, treated by numerous professionals, but they rarely collaborate. Interdisciplinary teamwork, on the other hand, allows the team members to complete separate assessments, but team meetings are held where their findings are discussed and individualised management is planned (Rossetti, 2001).

A multidisciplinary team approach is optimal in the assessment and management of dysphagia (Logemann, 1998). In the South African context, however, where there is a severe shortage of qualified speech-language therapists, the most effective team approach is that of a transdisciplinary approach. Here the focus is on sharing perceptions and skills with both caregivers and other health professionals. This allows for the team to collaboratively assess and plan the treatment of a patient, but only one team member is chosen to provide all the necessary services (Fair & Louw, 1999).

The questions included in this section aimed to determine whether a team is currently functioning in the hospice context and, if so, what professionals are involved. In addition, this section seeks to determine the caregivers' attitudes towards teamwork.

The content and layout of the questionnaire was developed by consulting with two qualified speech-language therapists who have work experience in acquired neurogenic communication difficulties and dysphagia, statisticians and nurses. Only once these professionals were satisfied with the questionnaire, did the researcher proceed with a pre-study.

3.6.3 Pre-study aimed at developing the questionnaire

3.6.3.1 Aim

A pre-study was completed to increase the reliability and validity of the questionnaire. When designing a questionnaire, there is always the possibility of error and, therefore, a pre-study is crucial to protect against errors (Babbie & Mouton, 2001)

3.6.3.2 Respondents

The same criteria, as outlined for the main study, were applied in the selection of respondents for the pre-study. The respondents of the pre-study were not selected for the main study. The questionnaire was given to six of the hospice caregivers from a hospice in the Witwatersrand area to evaluate, in accordance with literature recommendations (Leedy & Ormond, 2001). This hospice was excluded from the main study to ensure that these respondents did not complete the questionnaire again.

3.6.3.3 Procedure followed during the pre-study

The following procedure was followed:

§ Informed consent was obtained from six hospice caregivers working in the Witwatersrand area. These caregivers were given the questionnaire and requested to complete it in full.

§ The respondents were asked to highlight aspects that were ambiguous or required revision.

§ All comments, questions and suggestions made by the hospice caregivers were recorded by the researcher and used to make alterations to the questionnaire.

§ Once the questionnaire had been completed, the caregivers were thanked and asked to refrain from discussing the content of the questionnaire with any other caregivers.

§ The necessary changes were made to the questionnaire.

3.6.3.4 Results of the pre-study

Several changes were made to the questionnaire based on the recommendations of the pre-study respondents. The recommended changes are presented in Table 3.4.

Table 3.4 Results and recommendations of the pre-study for the questionnaire

<table>
<tr><th>Original question</th><th>Recommendations made</th><th>Revised question</th></tr>
<tr>
<td>Based on your experience, indicate which of the following cause dysphagia
Please use the code:
A = Always
F = Frequently
S = Seldom
V = Very rarely
D = Don’t know
<table>
<tr><td>Factor</td><td>A</td><td>F</td><td>S</td><td>V</td><td>D</td></tr>
<tr><td>Huntington’s disease</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Motor neuron disease</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Mysanthia gravis</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Wilson’s disease</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Guillain-Barré syndrome</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Bell’s palsy</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Pulmonary hypertension</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Parkinson’s disease</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Alzheimer’s disease</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Intractable angina</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Hepatorenal syndrome</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Postpolio syndrome</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Morphanis syndrome</td><td></td><td></td><td></td><td></td><td></td></tr>
</table>
</td>
<td>The respondents recommended that this question be removed as several of the disorders mentioned were rare and they did not have experience with them.</td>
<td>This question was removed from the questionnaire.</td>
</tr>
<tr>
<td>Please indicate the level of confidence that you have in the management of dysphagia.
<table>
<tr><td>Not confident</td><td>1</td></tr>
<tr><td>Moderately confident</td><td>2</td></tr>
<tr><td>Confident</td><td>3</td></tr>
</table>
</td>
<td>Respondents indicated that they would prefer to have a 5-point Likert scale for this question.</td>
<td>Please indicate the level of confidence that you have in the management of dysphagia.
<table>
<tr><td>Not confident</td><td>1</td></tr>
<tr><td>Slightly confident</td><td>2</td></tr>
<tr><td>Moderately confident</td><td>3</td></tr>
<tr><td>Confident</td><td>4</td></tr>
<tr><td>Very confident</td><td>5</td></tr>
</table>
</td>
</tr>
</table>

Please indicate your position on each of the following statements.
Please use the code:
SA = Strongly agree
A = Agree
D = Disagree
SD = Strongly disagree

Statement	SA	A	D	SD
A person's inability to feed him/herself is never an excuse to let the person go hungry.				
In patients who are incompetent, family members should be included in a decision to provide tube feeding.				
Allowing the patient to die of dehydration is a painless death.				
By tube feeding the patient, it unnaturally extends the dying process.				
Assisted nutrition and hydration should not be offered to patients who are in the last stages of dying.				
It is better to let the patient fade away				

The respondents indicated that they would like the opportunity to qualify their positions on these statements.

Please indicate your position on each of the following statements and motivate your response.
Please use the code:
SA = Strongly agree
A = Agree
D = Disagree
SD = Strongly disagree

Statement	SA	A	D	SD
A person's inability to feed him/herself is never an excuse to let the person go hungry.				
Motivation:				
In patients who are incompetent, family members should be included in a decision to provide tube feeding.				
Motivation:				
Allowing the patient to die of dehydration is a painless death.				
Motivation:				
By tube feeding the patient, it unnaturally extends the dying process.				
Motivation:				
Assisted nutrition and hydration should not be offered to patients who are in the last stages of dying.				
Motivation:				
It is better to let the patient fade away.				
Motivation:				

The respondents who participated in the pre-study were similar to those used in the actual study and thus assisted the researcher in increasing the suitability of the questionnaire for hospice caregivers. The questionnaire aimed to comprehensively determine hospice caregivers' perceptions and reported practices in the management of dysphagia in individuals with neurodegenerative disorders. As a result, the questionnaire was lengthy. However, from the pre-study, it was evident that, although the questionnaire was long, the caregivers were able to complete the majority of the questionnaire with ease and the content validity remained high (Cohen, Manion & Morrison, 2000).

Poorly worded questions may threaten the reliability and validity of a questionnaire. Therefore, questions that the respondents were unable to answer were removed. In addition, questions that were ambiguous were highlighted by the respondents and were then modified. Questionnaires, which rely on closed questions alone, may reduce the authenticity of the questionnaire. By providing the respondents with an opportunity to qualify their positions, the validity of the questionnaire was improved. The pre-study assisted in improving the structure and design of the questionnaire, thereby adding to the validity and reliability of the questionnaire (Cohen et al., 2000).

3.7 RESEARCH PROCEDURE

The research was conducted in several steps. Initially, the purpose of the research was determined and a literature review was completed. The meaning of the concepts and variables included in the study were specified and the sample population was selected. A quantitative research design that examined perceptions, attitudes and practices in a particular group of health professionals was chosen and the questionnaire was developed with the assistance of a pre-study (Babbie & Mouton, 2001).

The data was collected from the sample population and processed by a statistician to allow the data to be analysed, with the research procedure culminating in an accurate description of the results and a discussion of the conclusions and their implications. A detailed account of the data collection and analysis procedures utilised in the research will follow.

3.7.1 Procedure for data collection

§ After obtaining permission from the University of Pretoria's Faculty of Humanities Research Proposal and Ethics Committee to proceed with the study, consent to conduct the research was obtained from chairperson of the HPCA Ethics Committee.

§ A pre-study of the questionnaire was also completed to determine whether the questionnaire was valid and reliable.

§ A list of the member hospices was obtained from the HPCA and the hospice managers were contacted telephonically to explain the nature and purpose of the study. The hospice managers who agreed to participate in the research were provided with copies of the HPCA's letter approving the study, letters detailing respondents selection criteria (Appendix A) and copies of the questionnaire (Appendix E) to be utilised in the research. The hospice managers were asked to provide an estimate of the number of caregivers involved in the particular hospice clinic and their language of preference.

§ The introductory letters (Appendix B), questionnaires (Appendix E) and letters of informed consent (Appendix D) were sent to the hospice manager who, in turn, distributed them among the caregivers. Each questionnaire was placed in an envelope to maintain confidentiality.

§ The respondents signed the letters of informed consent and then completed the questionnaire. The letters of informed consent were separated from the questionnaires placed in the envelope provided.

§ Follow-up contact was made with the hospice manager after two weeks in order to improve the response rate.

§ The hospice manager was asked to collect the completed questionnaires and return them in the addressed return envelope provided.

3.7.2 Data analysis procedure

Data analysis is the interpretation of the data collected (Mouton, 2001). For the purpose of this study, descriptive statistics were utilised during the analysis procedure. Descriptive statistics are used in quantitative research to summarise and display the data collected. The benefit of descriptive analysis is that it provides a description of single variables and associations that connect one variable with another. This, in turn improves the understanding of the situation being researched (Babbie & Mouton, 2001). This is important as it addresses the aims of the current study.

In order to allow for the collected data to be descriptively analysed, the raw data collected in the returned questionnaires was first coded. Answers obtained from the closed-ended questions were coded by converting responses into numerical data. Responses to partially open-ended and open-ended questions were analysed and coded into categories. The raw data was subsequently entered into the computer and the Statistical Analysis System (SAS) program used to analyse the data into frequency tables. The frequency, percentage and cumulative percentage were then calculated for each of the variables and these results were presented in an electronic spreadsheet to identify recurring events, themes and explanations (Wilkinson, 2000).

The variables were then combined and compared using SAS PROC FREQ in order to identify the association between the variables. The numerous graphs and figures presented in Chapter 4 of this study aim to display the frequency distribution and find associations within the data (Martin & Pierce, 1994).

3.8 RESEARCH RELIABILITY AND VALIDITY

3.8.1 Reliability

For a questionnaire to be characterised as a good measurement tool, it must be valid and reliable (Cooper & Schindler, 2001). Reliability refers to the accuracy of the questionnaire and the consistency of results obtained from the same measurement preformed on different occasions (May, 2001). De Vos (1998) emphasises that the term reliability refers to how well a subject is being measured rather than what is being measured. The following guidelines were adhered to in order to ensure that the study is reproducible and consistent.

- The questions included in the questionnaire avoided the use of jargon, slang and abbreviations. The language used was clear and unambiguous and emotional language was avoided. Furthermore, questions were worded carefully to ensure that they were not leading or biased (Neuman, 2005).
- The questions were grouped according to topics to minimise confusion and assist respondents in organising their thoughts (Neuman, 2005).
- In order to improve the response rate and thus increase the reliability of the research, certain measures were employed. These included providing respondents with stamped, addressed return envelopes and making follow-up contact to request returns (Bourque & Fielder, 2003).
- A pre-study was completed with a similar but smaller sample to improve the contents, wording and length of the questionnaire, thus increasing the reliability of the questionnaire.
- The research procedure for data collection and data analysis were described in detail.

Reliability is an important contributor to validity and, therefore, a survey should aim to be both reliable and valid (Cooper & Schindler, 2001).

3.8.2 Validity

“The validity refers to the extent to which a questionnaire measures what the researcher intends it to measure” (Cooper & Schindler, 2001:210). The benefit of utilising a mail-distributed, self-administered questionnaire is that it allows the researcher to gather information without influencing the responses of the participants (Cohen et al., 2000).

To further improve the validity of the research, an introductory letter was included that provided the respondent with the assurance of anonymity. The assurance of anonymity should improve the validity of the results as it encourages honesty and reduces the possibility of response distortion due to socially desirable responding (Kimmel, 1998). The two major forms of validity are external and internal validity. The internal validity is the capacity for the questionnaire to determine what it is intended to determine (Cooper & Schindler, 2001).

Content validity is a form of internal validity, which refers to the adequacy with which the questionnaire covers the topic being measured (Cohen et al., 2000; De Vos, 1998). In order to ensure a high degree of content validity, the topic of the questionnaire was defined and an in-depth literature study completed to ensure that the questions included in the questionnaire provided adequate coverage of the topic concerned (Cooper & Schindler, 2001).

The content validity of the questionnaire was determined in the pre-study. The recommendations that were made assisted the researcher to improve the structure and design of the questionnaire, thereby adding to the validity of the questionnaire (Cohen et al., 2000).

The validity of the research was further improved by ensuring that the quantitative data collected during the research was reviewed a number of times, thus avoiding inaccurate reporting of the results. In addition, reference was made to the results of previous qualitative and quantitative studies to demonstrate the appropriateness of the conclusions presented.

With regard to quantitative research, the emphasis is on achieving both validity and reliability, as reliability is a prerequisite for achieving validity. Therefore, in order to increase the credibility and trustworthiness of the study, issues related to validity and reliability were treated with priority (Cormack, 2000).

3.9 SUMMARY

This chapter provided a detailed description of the research process that was followed in this study. The main aim and sub-aims of the research were presented and a description of the selection criteria, materials and apparatus used in the study and procedures followed during data collection and data analysis was provided. In addition, issues pertaining to ethics, as well as the validity and reliability of the research were discussed.

CHAPTER 4

RESULTS AND DISCUSSION

Aim: The aim of this chapter is to present and discuss the results of the study, which investigated hospice caregivers' perceptions and practices in the management of dysphagia in neurodegenerative disorders. Graphs and tables are utilised in this chapter to display the results, which are then interpreted and discussed.

4.1 INTRODUCTION

The research process is a cyclical process, which involves clearly defining the research problem, developing an appropriate research design and collecting, analysing and interpreting the data in an attempt to solve the research problem (Frazer & Lawley, 2000). Since the main aim in the current study is to determine hospice caregivers' perceptions and reported practices in the management of dysphagia in individuals with neurodegenerative disorders, the results described in this chapter are organised according to the stated aims and sub-aims of the study. However, because not all the datasets were complete the number of responses vary.

4.2 THE HOSPICE CAREGIVERS AWARENESS OF DYSPHAGIA IN INDIVIDUALS WITH NEURODEGENERATIVE DISORDERS

Caregivers need to be aware of the signs of dysphagia so that they are able to identify patients with possible dysphagia. Early identification of dysphagia and the initiation of intervention can help sustain oral intake (O'Loughlin & Shanley, 1998). The questions included in Section B of the questionnaire aimed to determine the hospice caregivers' awareness of the signs and symptoms of dysphagia.

In order to determine how frequently the hospice caregivers care for dysphagic patients with neurodegenerative disorders, information was gathered regarding the number of dysphagic patients that the respondents cared for each month. The results are displayed in Figure 4.1 below.

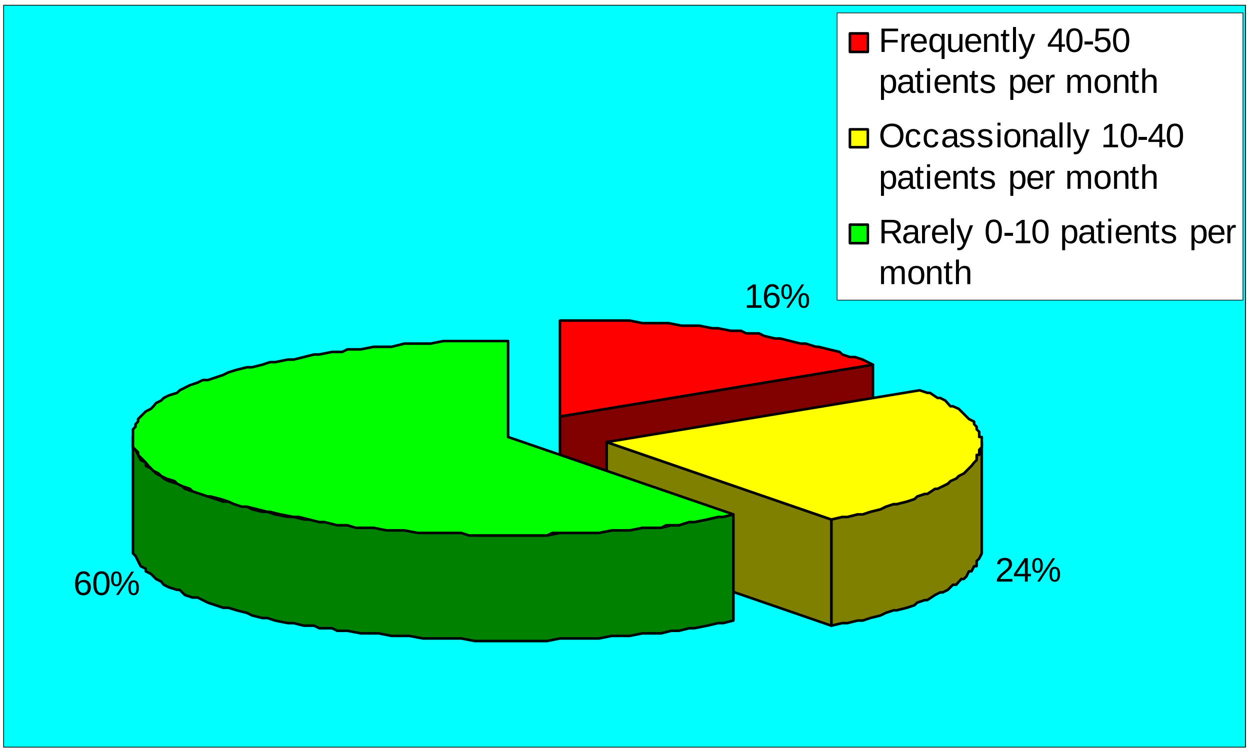


Figure 4.1 Number of patients with dysphagia associated with neurodegenerative disorders cared for by respondents within a month (N=63)

According to Figure 4.1, the majority (60%) of the respondents rarely cared for dysphagic patients diagnosed with neurodegenerative disorders. Although from Figure 4.1 it is apparent that patients with dysphagia formed part of the hospice caregivers' caseload, only 16% of the respondents reported frequently seeing patients with dysphagia, while a further 24% of the respondents indicated that they occasionally see dysphagic patients.

Hospice care has expanded to provide care for all terminally ill patients, including those who have been diagnosed with neurodegenerative disorders. However, cancer is still the foremost cause of death in people under 65 and the second most common cause of death in adults over 65. Therefore, cancer patients still account for a large percentage of hospice admissions (Balducci, Lyman & Ershler, 2004).

The prevalence of neurodegenerative disorders is, however, increasing. Neurodegenerative disorders are projected to surpass cancer as the second most common cause of death among the elderly (Ong, Woo, Seong Ng, Tan & Tang, 2004). Thus, hospice admissions of patients affected by degenerative neurological disorders, including HIV and AIDS, motor neuron disease, Parkinson's disease and Alzheimer's disease will continue to grow. It is clear from Figure 4.1 that patients with swallowing difficulties are seen by hospice caregivers. Therefore, hospice caregivers need to be able to assess and manage swallowing problems.

In order to determine the most suitable approach to the assessment and management of dysphagia in patients with a neurodegenerative disorder, the patients' diagnosis must be identified and taken into consideration (Logemann, 1998). Therefore, the respondents were asked to indicate whether they were aware of the patient's diagnosis. All (n=64) of the respondents indicated that they were aware of their patients' diagnosis. As a contingency question, respondents' were then required to indicate, according to their experience, which condition is most frequently associated with dysphagia. Figure 4.2 graphically displays the results obtained.

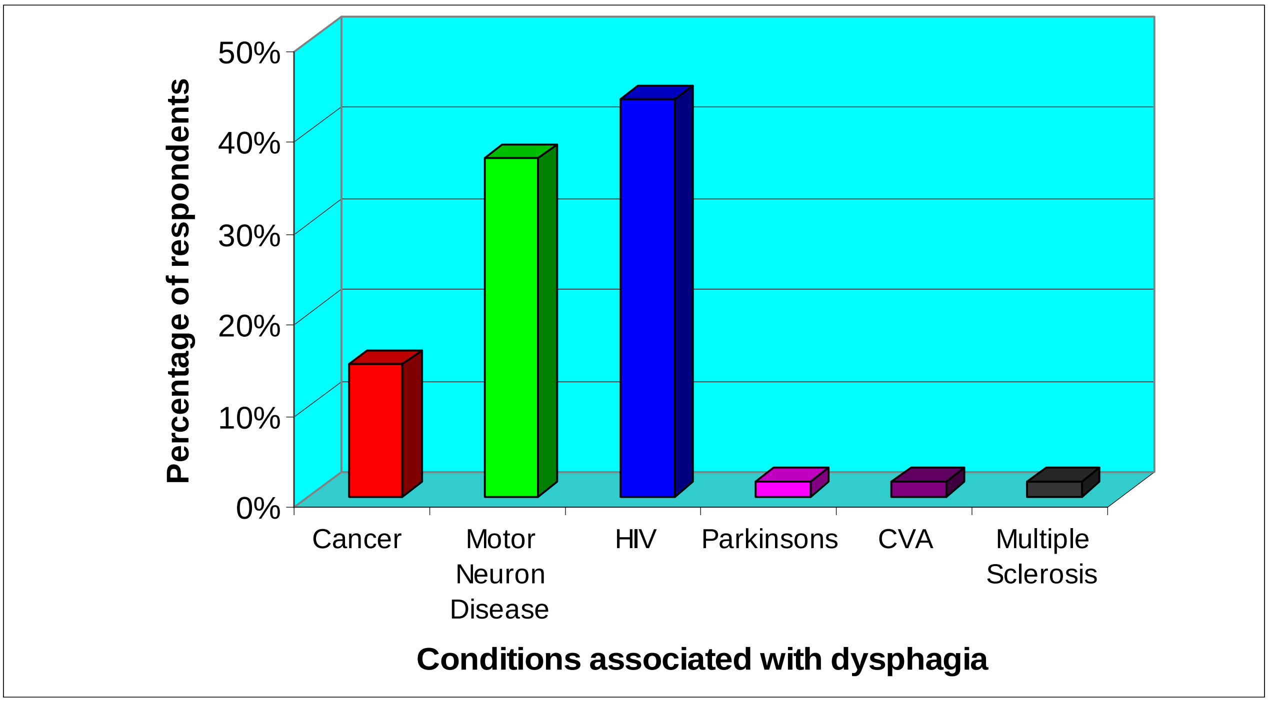


Figure 4.2 Respondents' perceptions of conditions most frequently associated with dysphagia (n=62).

According to Figure 4.2, a large percentage (43%) of the respondents indicated that, based on their experience, HIV and AIDS were most frequently associated with dysphagia. This finding corresponds with evidence in the literature that suggests that there is a high rate of dysphagia present in patients affected by HIV and AIDS (Karus et al., 2005).

Swallowing difficulties in patients with HIV and AIDS have several aetiologies. Severe infections of the mouth and oesophagus can lead to difficulty swallowing due to pain and inflammation. HIV and AIDS dementia can cause motor impairments and negatively affect swallowing. In addition, HIV- and AIDS-related complications include multiple neurological impairments, which may result in weakness and coordination impairments that will, in turn, negatively affect the individual’s ability to swallow (Phillips et al., 1998).

A considerable number (37%) of respondents indicated that, in their experience, motor neuron disease was most frequently associated with dysphagia. This is consistent with literature that indicates that up to 90% of patients with motor neuron disease develop symptoms of dysphagia (Kirker & Oliver, 2003).

According to Figure 4.2, only a limited number (2%) of respondents indicated that Parkinson’s disease and multiple sclerosis were frequently associated with dysphagia. A possible explanation for this finding is that a large portion of the hospice population constitutes patients with HIV and AIDS, and fewer patients with Parkinson’s disease or multiple sclerosis (Hospice Palliative Care Association of South Africa, 2008). In addition, although dysphagia is a common symptom of Parkinson’s disease, patients with Parkinson’s disease seldom complain of swallowing problems and dysphagia in patients with Parkinson’s disease may often go undetected as it can manifest as a silent swallowing disorder (Volonté, Porta & Comi, 2002).

Dysphagia is a common symptom of multiple sclerosis (MS), and it is estimated that between 33 to 43% of patients with MS develop swallowing problems. However, compensatory strategies such as postural changes, modification of the amount and speed of food presentation, and change in food consistency are highly effective. These strategies are often sufficient to eliminate aspiration (Calcagno et al., 2002). Therefore, respondents implementing these compensatory strategies with patients may have succeeded in reducing swallowing disorders in patients with MS and are therefore unaware of the frequency of dysphagia in MS. It is also possible that the patients themselves might be implementing compensatory strategies without realising that they are doing so.

Patients who have dysphagia may present with a number of signs and symptoms, including coughing or choking before, after or during the swallow, difficulty initiating the swallow, drooling, unexplained weight loss, recurrent pneumonia, the presence of a wet or gurgly voice and nasal regurgitation (Palmer, Drennan & Baba, 2000). To determine the hospice caregivers' awareness of dysphagia in individuals with neurodegenerative disorders, the respondents' were asked to rate the possible symptoms of dysphagia. The results are presented in Table 4.1.

Table 4.1 Respondents' perceptions of the possible symptoms of dysphagia

Possible symptom of dysphagia	**Category**	**% of respondents**
Patient vomits	- Always - Frequently - Seldom - Very rarely - Don't know	20% 16% 36% 23% 5%
Patient complains of pain during swallowing	- Always - Frequently - Seldom - Very rarely - Don't know	47% 32% 16% 5% 0%
Constipation	- Always - Frequently - Seldom - Very rarely - Don't know	16% 30% 23% 26% 5%
Coughing before, during or after swallow	- Always - Frequently - Seldom - Very rarely - Don't know	32% 43% 19% 3% 3%
Headaches	- Always - Frequently - Seldom - Very rarely - Don't know	23% 3% 24% 28% 22%

Possible symptom of dysphagia	**Category**	**% of respondents**
Recurrent pneumonia	- Always - Frequently - Seldom - Very rarely - Don't know	13% 17% 26% 32% 12%
Changes in voice	- Always - Frequently - Seldom - Very rarely - Don't know	18% 44% 30% 7% 1%
Dizzy spells	- Always - Frequently - Seldom - Very rarely - Don't know	11% 19% 16% 25% 29%
Unable to recognise food	- Always - Frequently - Seldom - Very rarely - Don't know	15% 5% 13% 44% 23%
Inability to move	- Always - Frequently - Seldom - Very rarely - Don't know	20% 15% 15% 45% 5%
Malnutrition	- Always - Frequently - Seldom - Very rarely - Don't know	39% 32% 13% 11% 5%
Reflux	- Always - Frequently - Seldom - Very rarely - Don't know	16% 45% 21% 8% 10%
Diabetes	- Always - Frequently - Seldom - Very rarely - Don't know	11% 3% 13% 24% 49%
Difficulty starting the swallow	- Always - Frequently - Seldom - Very rarely - Don't know	55% 32% 3% 0% 10%

Possible symptom of dysphagia	**Category**	**% of respondents**
Unable to control food in mouth	- Always - Frequently - Seldom - Very rarely - Don't know	24% 27% 29% 18% 2%
Lengthened mealtime	- Always - Frequently - Seldom - Very rarely - Don't know	67% 25% 3% 3% 2%
Breathing difficulty	- Always - Frequently - Seldom - Very rarely - Don't know	29% 27% 26% 13% 5%
Food remaining in mouth after swallow	- Always - Frequently - Seldom - Very rarely - Don't know	25% 54% 13% 8% 0%
Stomach cramps	- Always - Frequently - Seldom - Very rarely - Don't know	24% 14% 29% 23% 10%
Temperature spiking	- Always - Frequently - Seldom - Very rarely - Don't know	13% 10% 18% 29% 30%
Diarrhoea	- Always - Frequently - Seldom - Very rarely - Don't know	17% 15% 17% 34% 17%
Patient refuses food	- Always - Frequently - Seldom - Very rarely - Don't know	27% 54% 14% 3% 2%
Weight loss	- Always - Frequently - Seldom - Very rarely - Don't know	68% 21% 8% 2% 1%

Possible symptom of dysphagia	**Category**	**% of respondents**
Vomiting blood	- Always - Frequently - Seldom - Very rarely - Don’t know	12% 7% 23% 47% 11%
Drooling	- Always - Frequently - Seldom - Very rarely - Don’t know	26% 36% 13% 20% 5%
Patient complains of swallowing difficulties	- Always - Frequently - Seldom - Very rarely - Don’t know	76% 24% 0% 0% 0%
Swallowing repeatedly	- Always - Frequently - Seldom - Very rarely - Don’t know	46% 29% 16% 3% 6%

According to Table 4.1, the respondents’ awareness of the symptoms of dysphagia was inconsistent. The majority of the respondents were aware of the more visible symptoms of dysphagia such as difficulties starting the swallow, lengthened mealtime and weight loss. It is, however, of concern that not all of the respondents’ were aware that symptoms such as coughing before, after and during the swallow and the presence of pneumonia are possible symptoms of dysphagia. Table 4.1 presented an overview of the respondents’ awareness of the symptoms of dysphagia. A detailed discussion of these results will follow.

Common symptoms of dysphagia include swallowing repeatedly, malnutrition and patient’s complaint of swallowing problems (Mari, Matei, Ceravolo, Pisani, Montesi & Provinciali, 1997). The majority of respondents were aware of these possible symptoms and Figure 4.3 presents the symptoms that the majority of respondents perceived to be frequently associated with dysphagia.

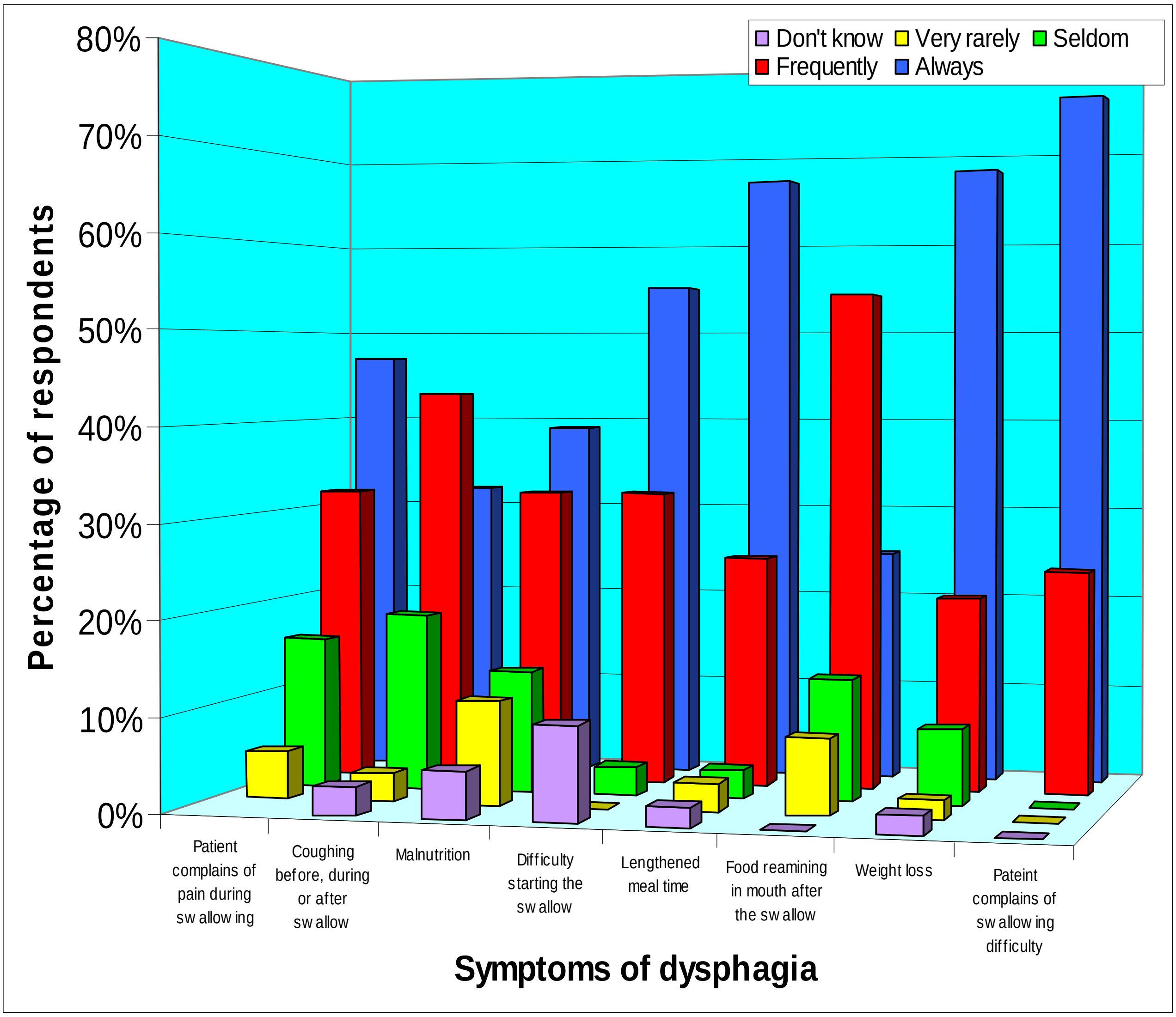


Figure 4.3 Symptoms which the majority of respondents perceived to be frequently associated with dysphagia (N=64)

According to Figure 4.3, the majority of the respondents were aware of the visible symptoms of dysphagia. These symptoms are, however, insufficient for the identification of dysphagia and the more subtle symptoms of dysphagia, such as changes in voice, also need to be taken into consideration (Mari et al., 1997). In addition, 76% of respondents indicated that patients' complaints of swallowing disorders are always a symptom of dysphagia. However, as mentioned previously, patients with Parkinson's disease seldom complain of swallowing problems and, as a result, dysphagia in patients with Parkinson's disease may often go undetected.

Furthermore, many patients with a neurological disorder are unaware of their swallowing disorder and fail to cough when food enters the airway. These patients do not always display the symptoms mentioned in Figure 4.3. When caring for a patient with a neurodegenerative disorder, the caregiver must always be aware of the possibility that the patient is aspirating silently (Logemann, 1998). Approximately 40% of patients with dysphagia who aspirate on their food do so silently and neither cough during the swallow nor complain of swallowing difficulties. The detection of silent aspiration relies on clinical suspicions and the observation of subtle symptoms such as changes in voice quality and breathing difficulties (Bakheit, 2001). A summary of the symptoms of dysphagia, which the respondents were less aware of, is presented in Figure 4.4.

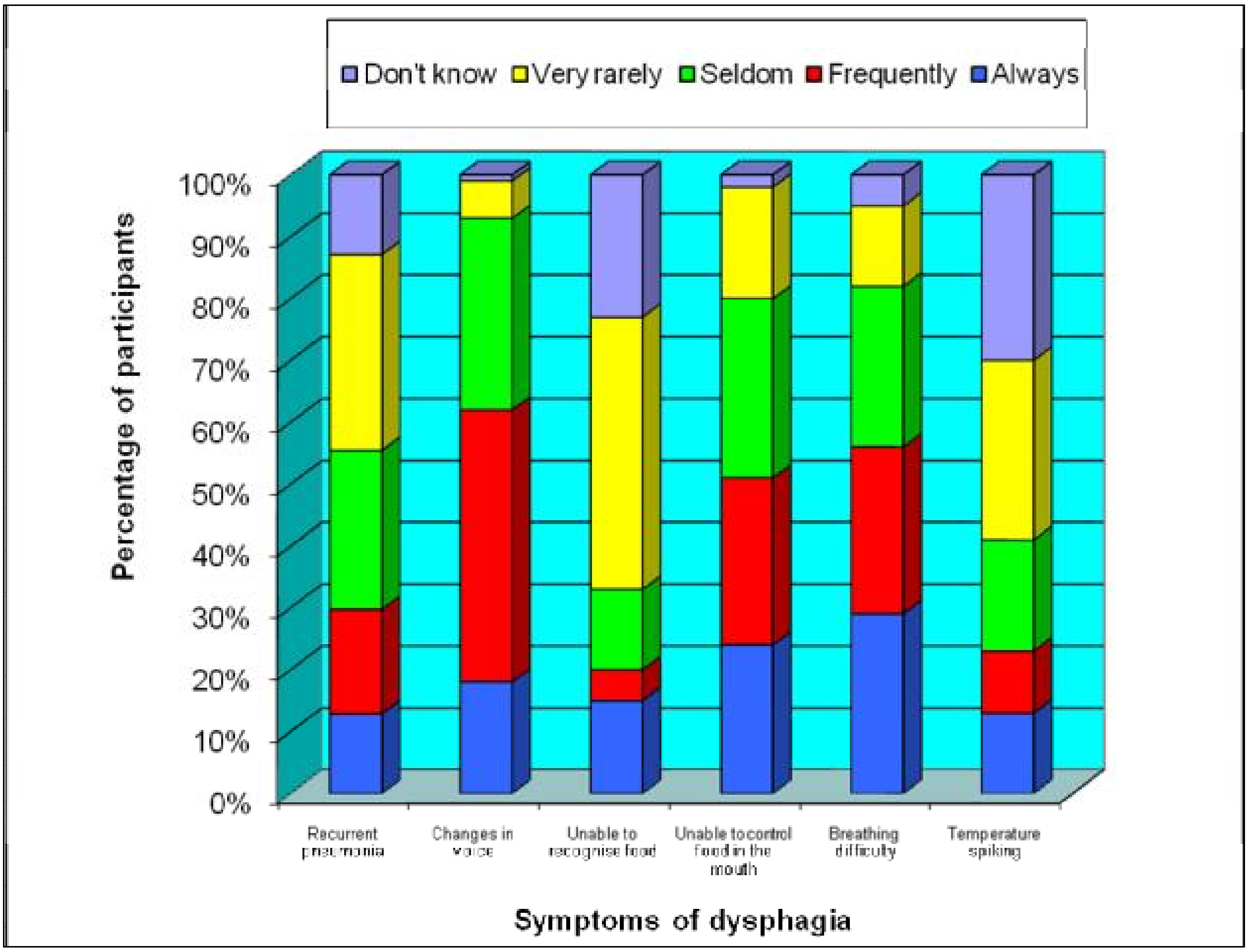


Figure 4.4 Symptoms which the majority of respondents perceived to be rarely associated with dysphagia (N=64)

Silent aspiration is particularly difficult to identify and the videoflouroscopic examination has been documented as the gold standard in the identification of aspiration (Linden et al., 1993). However, as mentioned previously, there is limited access to videofloroscopy in the hospice setting. Therefore, caregivers need to rely on detecting clinical signs in order to identify and predict the presence of aspiration. Signs that may indicate the presence of dysphagia include changes in voice, difficulty controlling food in the mouth and history of pneumonia (McCullough, Wertz & Rosenbek, 2001).

Neurodegenerative disorders not only affect the swallow reflex, but often have a profound influence on other aspects necessary for a normal swallow to occur, such as the ability to recognise food. This is especially evident in patients with dementia who frequently refuse to either swallow or accept food as a result of their inability to recognise food (Thomas & Bishop, 2007). From Figure 4.4, it is apparent that only a minority of the respondents were aware that this may be a possible symptom of dysphagia in patients with neurodegenerative disorders.

Another possible symptom of dysphagia, which the respondents were less aware of, is a history of recurrent pneumonia. If a patient is unable to adequately protect his/her airway during feeding, it may result in material entering the lungs that can, in turn, cause recurrent pneumonia, temperature spiking and breathing difficulties. Aspiration pneumonia frequently occurs in patients affected by amyotrophic lateral sclerosis and polymyositis. It is important to identify patients who are aspirating, as they may become malnourished and unable to maintain functioning (Leonard & Kendall, 2007).

According to Figure 4.4, the minority of respondents were, however, aware that the presence of recurrent pneumonia, temperature spiking or breathing difficulties are symptoms of dysphagia. These findings also reflect those of previous research (Pelletier, 2004), which indicated that certified nursing assistants were aware that the presence of choking or coughing before, during or after the swallow may be a symptom of dysphagia, but had limited perceptions of the subtle signs of dysphagia such as recurrent pneumonia.

To determine whether training affected the respondents’ awareness of the subtle symptoms of dysphagia, the responses of those who had received dysphagia training were compared to those who had not. These results are presented in Figure 4.5.

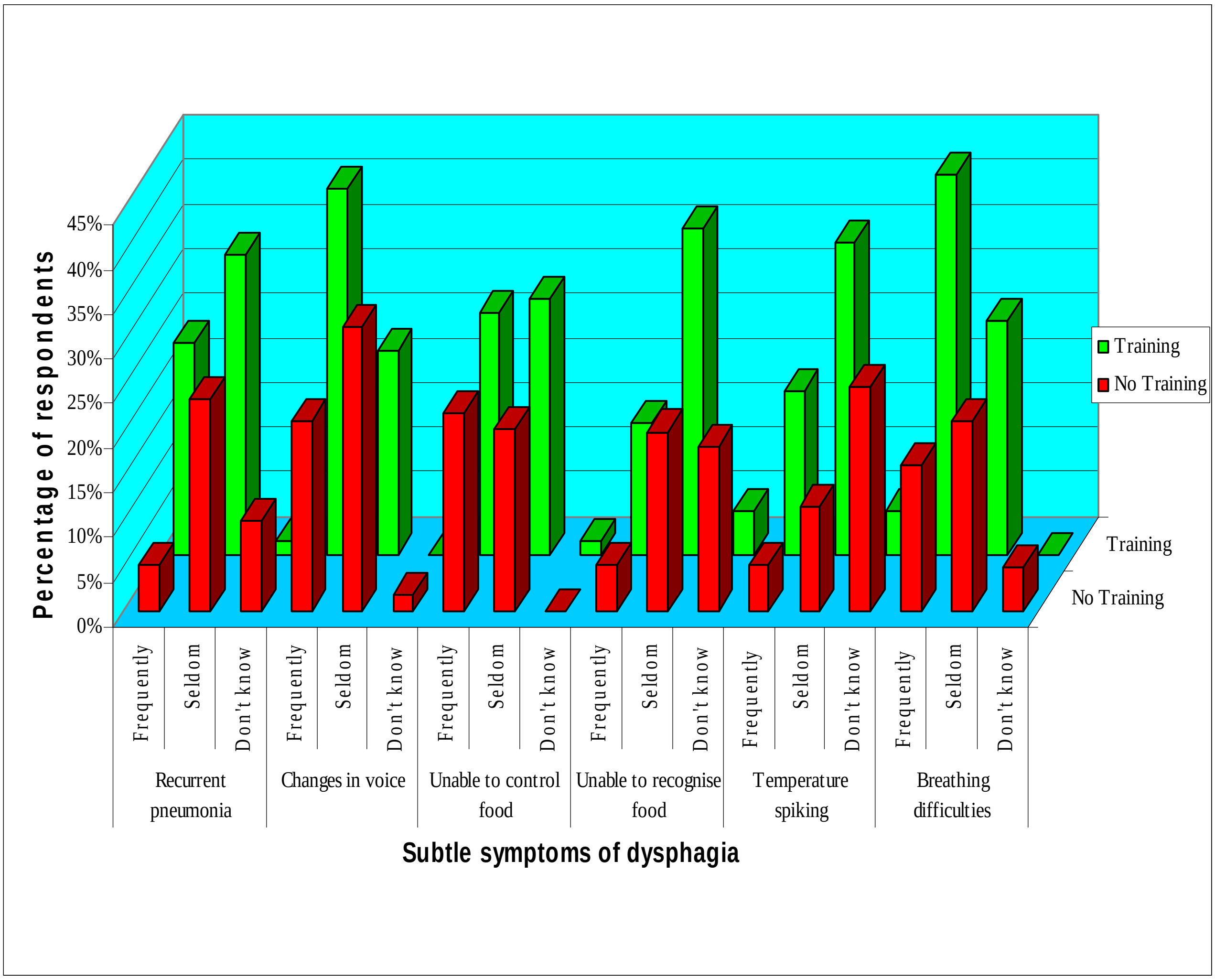


Figure 4.5 Awareness of the subtle symptoms of dysphagia: A comparison between respondents who had received training in dysphagia and those who had no training (N=64)

Respondents in this study indicated that they had received different types of training in dysphagia and that these had occurred at different periods. These variables may cause considerable variation in the responses. From the graph, however, it is apparent that the respondents who had received training in dysphagia were more aware that the presence of recurrent pneumonia, changes in voice quality and breathing difficulties were possible symptoms of dysphagia. This is in agreement with previous research that suggests that training caregivers in dysphagia will improve their awareness of the symptoms of dysphagia (Lin et al., 2001).

Conversely, respondents who had not received training were less aware that the above signs were possible symptoms of dysphagia and were more likely to indicate that they did not know whether the symptoms listed were possible indications of dysphagia. It can, therefore, be concluded that training is important and can facilitate the caregiver's awareness of possible symptoms of dysphagia.

Early identification of patients with dysphagia is essential to ensure that nutrition is maintained and the airway is protected (Leonard & Kendall, 2007). In the hospice setting, caregivers play a major role in identifying dysphagia. Therefore, the respondents' awareness of the aspects that need to be considered when identifying dysphagia was investigated. The results are displayed in Figure 4.6.

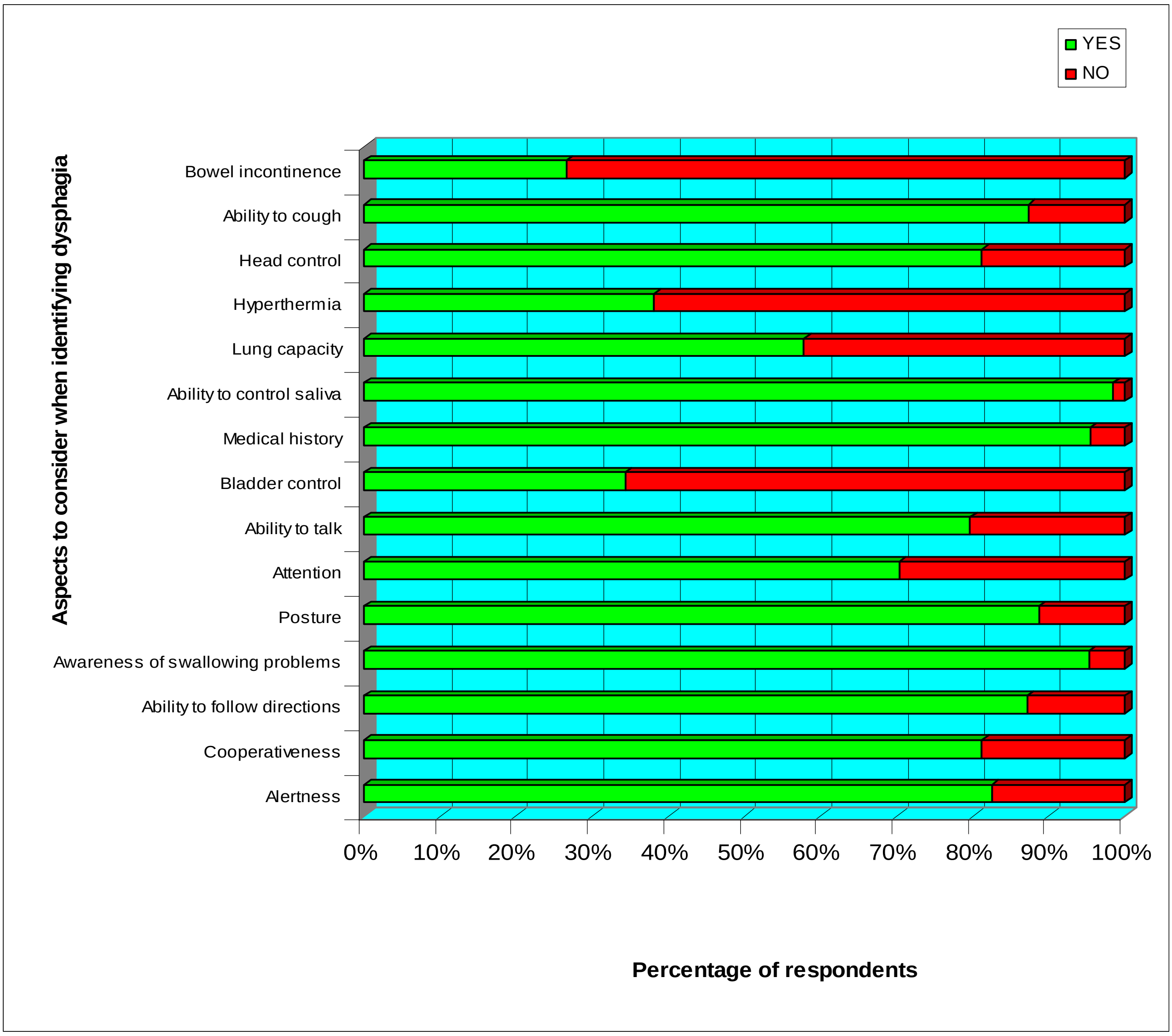


Figure 4.6 Respondents' perceptions of factors to consider when identifying dysphagia (N=64)

In the hospice setting, screening procedures and bedside examinations are predominantly utilised to determine whether the patient is aspirating (Weindling, 2000). Aspects that need to be taken into consideration when identifying dysphagia include the patients' ability to control saliva, their ability to cough, alertness and speech intelligibility (McCullough, 1999).

There is, however, inconsistency in the research regarding the clinical factors that best predict a risk for aspiration. Abnormal phonation, abnormal laryngeal elevation, wet spontaneous cough or weak voluntary cough and impaired swallowing of secretions have all been suggested to predict laryngeal penetration (Linden et al., 1993).

According to research completed by Smithard et al (1998), the most important aspects to consider when identifying dysphagia include a disturbance in conscious level and a weak voluntary cough. When compared with videoflouroscopy, the presence of one or both of these aspects were the best predictors of the occurrence of aspiration (Smithard et al., 1998).

Further studies, however, identify patients' inability to control saliva as one of the most important aspects to consider when identifying dysphagia, as poor management of saliva may be indicative of poor oral control (McCullough, 1999; Sitoh, Lee, Phau, Lieu & Chan, 2000). It is apparent from Figure 4.6 that the majority of respondents were able to indicate the factors that need to be taken into consideration when identifying dysphagia. In addition, respondents were able to identify the aspects that are not indicative of dysphagia, such as the presence of bowel incontinence, hyperthermia and poor bladder control.

The hospice caregivers complete all the direct patient care aspects and are often involved in the feeding of patients. It is, therefore, important that they identify patients with possible dysphagia. The respondents' perceptions of the professional responsible for the identification of dysphagia were therefore investigated. These results are presented in Figure 4.7.

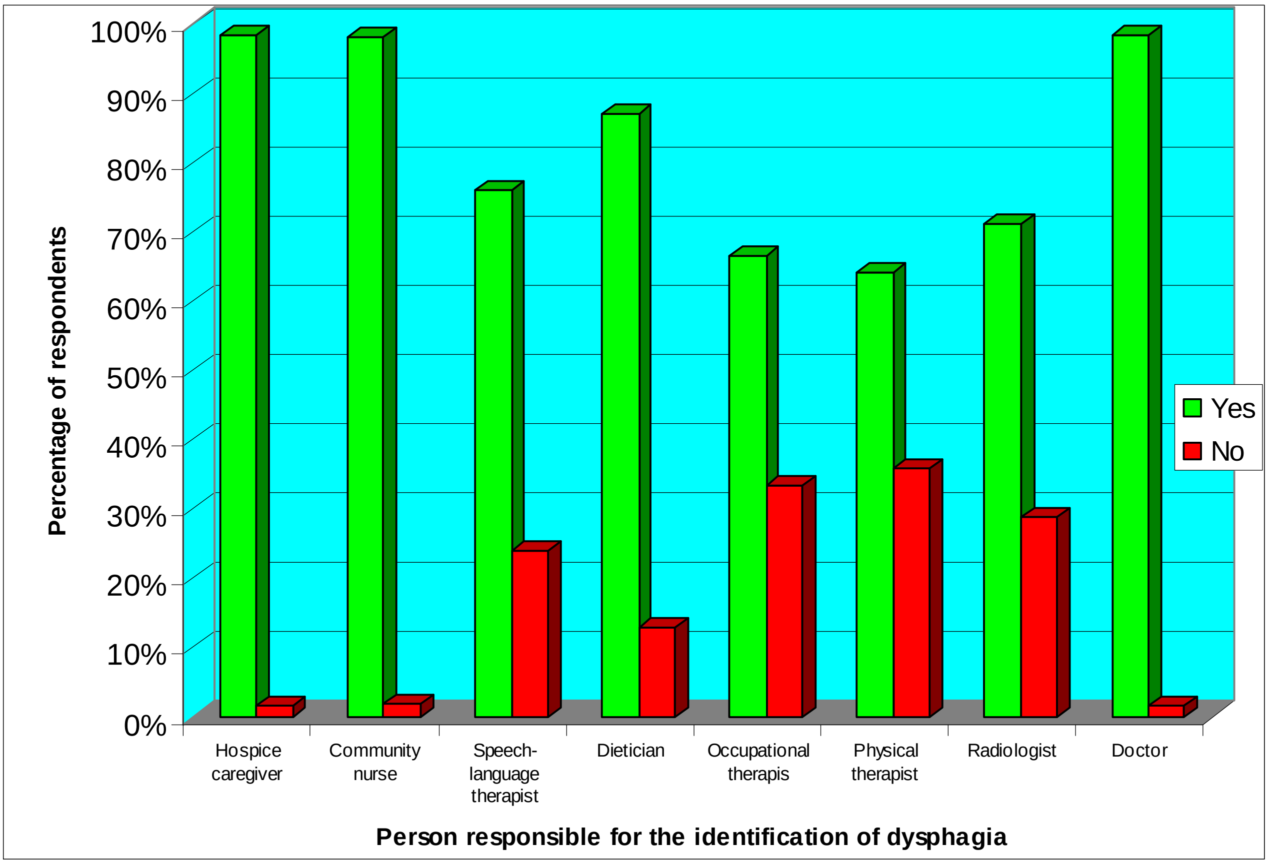


Figure 4.7 Respondents' perceptions of the person responsible for the identification of dysphagia (N=64)

Figure 4.7 shows that the overwhelming majority (98%) of respondents indicated that, in their experience, the hospice caregiver, community nurse and doctor were responsible for the identification of dysphagia. However, 24% of the respondents indicated that the speech-language therapist is not the person responsible for the identification of dysphagia. This result may indicate that the respondents have limited interactions with speech-language therapists and, as a result, are unaware of the role of the speech-language therapist in the management of dysphagia.

Although hospice caregivers may be able to identify patients who are at risk for aspiration, they have insufficient knowledge and skills to complete an in-depth assessment of patients' swallowing status and may need to refer the patient to a specialist (Pollens, 2004). Therefore, the respondents were asked to indicate to whom they refer individuals with swallowing difficulties. The results are displayed in Figure 4.8.

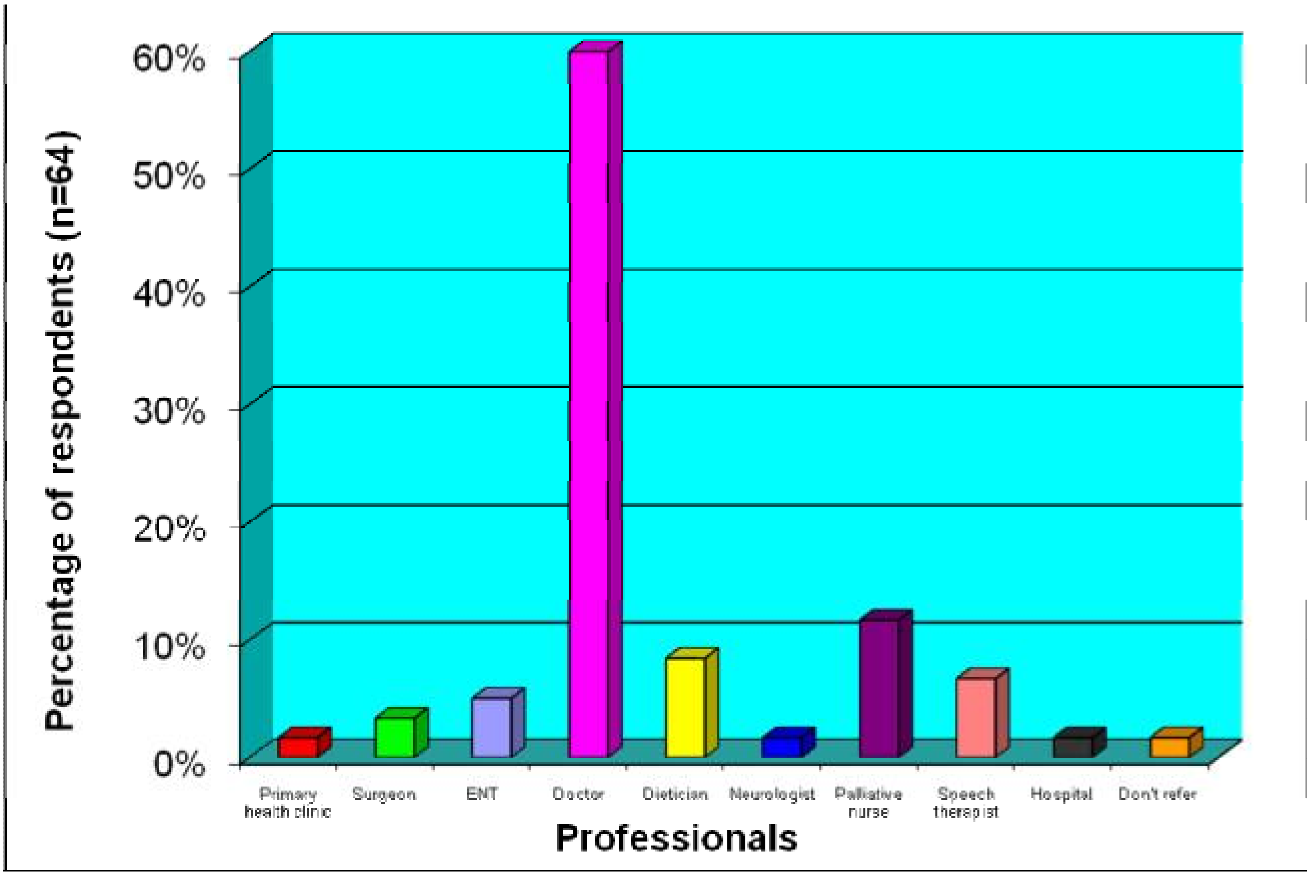


Figure 4.8 Professional to whom respondents refer individuals with swallowing disorders (N=60)

The roles of health care professionals in the assessment and management of dysphagia are not clearly defined and patients with dysphagia are seen by many different specialists, including doctors, ear, nose and throat (ENT) specialists and speech-language therapists (Ekberg, 2000). Upon review of the literature, it was clear that the background of various authors influences whom they think should complete the assessment.

Articles written by speech-language pathologists suggest that they are the primary providers of swallowing services due to their highly specialised knowledge base. On the other hand, articles written by nurses suggest that they should be trained to manage dysphagia (O'Loughlin & Shanley, 1998). Still further literature describes ENT surgeons as the health care professional best suited for the assessment and care of dysphagic patients as ENT surgeons have knowledge of the neurology of the oral cavity and have been trained to use both indirect and direct endoscopy to evaluate the oral cavity (Ekberg, 2000).

In the literature, however, the speech-language therapist is frequently described as the primary professional in the assessment and management of individuals with swallowing disorders because of their specialised knowledge of the anatomy and physiology of the upper digestive tract for swallowing and speech and their extensive knowledge of underlying medical and behavioural aetiologies of swallowing and feeding disorders (ASHA, 2001; Logemann, 1998; Smithard et al., 1996).

It is of concern that the speech-language therapist is not more involved in the identification of patients with dysphagia. According to Figure 4.8, fewer than 10% of the respondents indicated that they referred individuals with swallowing disorders to speech-language therapists. The lack of involvement of the speech-language therapist in the hospice setting is also reflected in previous research (Oliver & Webb, 2000), which indicated that there was a limited specialist involvement in hospices in the UK and Ireland. There appears to be the same shortage of speech-language therapists involved in the hospice setting in South Africa.

Figure 4.8 further shows that respondents seldom refer patients to ENT surgeons, dieticians or neurologists. Instead a large number (58%) of respondents indicated that they most frequently referred patients with swallowing disorders to doctors. These results correlate well with the results presented in Figure 4.7, where the majority of respondents indicated that, in their experience, doctors were responsible for the identification of dysphagia. Doctors, however, do not usually evaluate or manage dysphagia and the conventional diagnostic neurological examination completed by the doctor does not include any formal assessment of the swallowing function, which may negatively affect the early identification of dysphagia (Hind & Wiles, 1998).

The management and early identification of dysphagia is critical, as it can significantly improve the patient’s quality of life in individuals with degenerative disorders (Ekberg, Hamdy, Woisard, Wuttge-Hanning & Ortega, 2000). The progression of swallowing disorders in neurodegenerative disorders, however, varies considerably between patients. The severity of the dysphagia can provide insight into the individual’s prognosis (Leonard & Kendall, 2007). Figure 4.9 is a graphic presentation of the respondents perception of the conditions associated with the most severe forms of dysphagia.

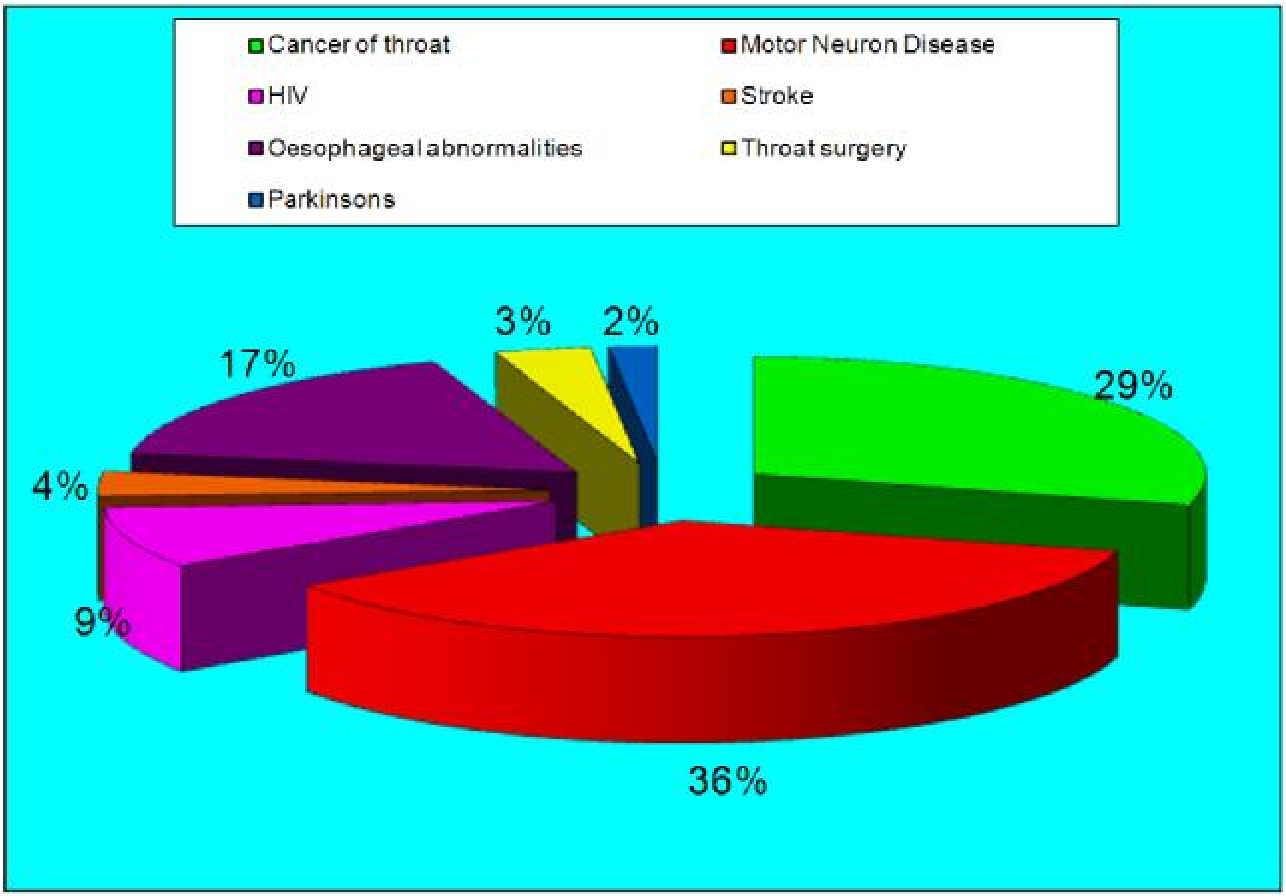


Figure 4.9 Respondents' perceptions of conditions associated with the most severe swallowing disorders (N=60)

According to Figure 4.9, a large portion (36%) of respondents indicated that motor neuron disease was associated with the most severe dysphagia. The respondents' perception of the severity of dysphagia in motor neuron disease is in agreement with literature findings, which describe dysphagia as one of the most distressing symptoms of motor neuron disease, which affects between 70% and 90% of these patients (Kirker & Oliver 2003; Worwood & Leigh, 1998).

The severity of dysphagia in motor neuron disease causes significant distress to patients and their families and has a profound effect on the individual's ability to maintain adequate nutrition. Early identification and management of dysphagia in motor neuron disease is imperative as it will allow the continuance of oral feeding for a longer period of time (Kirker & Oliver, 2003).

A surprisingly low percentage (2%) of respondents indicated that Parkinson’s disease was associated with the most severe dysphagia. Individuals with Parkinson’s disease may have a number of swallowing disorders that affect all three stages of the swallow. The swallowing problems are further complicated by the frequent onset of dementia in the end stages of Parkinson’s disease. There is, however, a large degree of variation in the progression of the disease and some patients do not exhibit severe swallowing disorders, even in the late stages of the disease (Logemann, 1998).

There are numerous conditions associated with HIV and AIDS that can result in dysphagia. These include progressive multifocal leukoencephalopathy, toxoplasmosis, cerebrovascular accidents, central nervous system lymphoma and encephalitis, all of which can affect the patient’s cognition and result in decreased oral control or pharyngeal impairments. These will, in turn, negatively affect the patient's ability to swallow and may result in aspiration (Chan, Ilaria & Jacobs, 1996).

Dysphagia can be detrimental to patients affected by HIV and AIDS as the immunological risk is then heightened because of the lack of adequate nutrition (Leonard & Kendall, 2007). Only 9% of respondents, however, indicated that HIV and AIDS were associated with the most severe dysphagia. This result was unexpected, because in Figure 4.2 on page 70, the majority of respondents indicated that HIV and AIDS are frequently associated with dysphagia. Respondents may view dysphagia associated with HIV and AIDS, although frequent, as less problematic than dysphagia associated with motor neuron disease.

Hospice caregivers often provide care for patients with cancer and, as a result, some of the respondents indicated that cancer of the throat, oesophageal abnormalities and throat surgery were associated with the most severe dysphagia. Although dysphagia is frequently associated with individuals affected by cancer (Marelli, 1999), the inclusion of dysphagia as a consequence of cancer is beyond the scope of the current research as the focus of this research is on dysphagia associated specifically with neurodegenerative disorders.

The first sub-aim was to determine the hospice caregivers' awareness of the signs and symptoms of dysphagia. The results obtained in this section indicate that the hospice caregivers were involved in the management of patients with swallowing disorders and were aware of the visible symptoms of dysphagia. The respondents' awareness of the more subtle symptoms of dysphagia, such as the presence of pneumonia and breathing difficulties, was inconsistent. However, it was evident that training has a positive influence on the hospice caregivers' awareness of the symptoms associated with dysphagia.

Furthermore, the results of the current study suggest the involvement of speech-language therapists and other professionals in the hospice setting was limited. Instead, it was the perception of the respondents that the hospice caregiver, community nurse and doctor were primarily responsible for the identification of dysphagia. Patients with swallowing disorders were most frequently referred to a doctor for an assessment. It can, therefore, be concluded that the identification and management of individuals with dysphagia, in the hospice setting, is frequently performed by the hospice caregiver.

4.3 THE HOSPICE CAREGIVERS' REPORTED PRACTICES IN THE MANAGEMENT OF DYSPHAGIA IN NEURODEGENERATIVE DISORDERS

Feeding an adult with a neurodegenerative disorder can be extremely demanding (West & Redstone, 2004). In the hospice setting, access to a speech-language therapist is limited due to financial constraints and geographical location and, as a result, caregivers frequently manage dysphagic patients without specialised input (Kirker & Oliver, 2003).

In order to feed patients with a neurodegenerative disorder safely and with dignity, caregivers need to be familiar with the appropriate practices in the management of dysphagia (Chang & Lin, 2005). The second sub-aim of the current study, therefore, aimed to determine the respondents' current practices in the management of swallowing disorders.

It is important that the hospice caregiver take certain aspects, such as the patients' diagnosis, their alertness and ability to cooperate and follow instructions, their respiratory function and their age, into consideration when feeding a person with dysphagia (Logemann, 1998). Therefore, information was gathered regarding the caregivers' perceptions of aspects that must be taken into consideration when feeding a person with dysphagia. The results are displayed in Figure 4.10

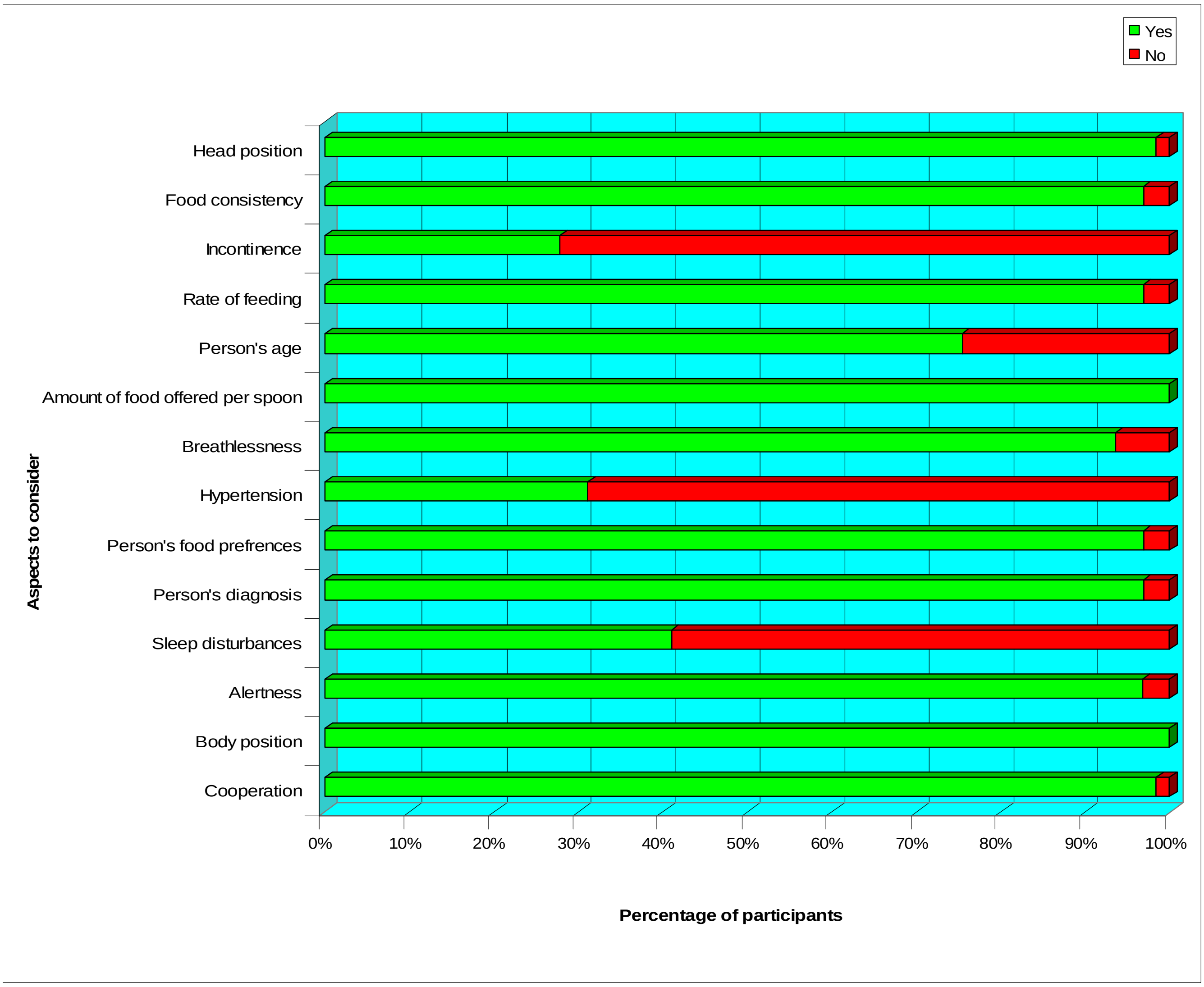


Figure 4.10 Respondents' perceptions of aspects to be taken into consideration when feeding a person with dysphagia (N=64).

It is important for the caregiver first of all to consider the patient's diagnosis, as this will determine the most suitable approach to the management of the dysphagia. Individuals with dementia, for example, will experience difficulties in following directions. A management strategy that contains short, simple instructions and a visual demonstration will then be inappropriate. The management of patients who are unable to follow instructions will predominately rely on compensatory strategies that can be managed by the caregiver (Logemann, 1998).

Another aspect that needs to be taken into consideration when feeding is the patient's head and body position. The correct positioning of the head and body during feeding is imperative as this can help protect the airway and improve the stability of the head and oral structures. Stability will, in turn, improve the independent movements of the oral structures and help reduce the risk for aspiration (West & Redstone, 2004).

The temperature, size and texture of the food also need to be taken into consideration, as individuals with neurodegenerative disorders often have oral sensory impairments. Reduced oral sensation can result in parts of the bolus entering the airway before the swallow has been initiated. Manipulating the amount of food offered per spoon and the taste of the bolus can help provide sensory stimulation and, in turn, improve the swallow and reduce the risk of aspiration (West, 2004).

According to Figure 4.10, the majority of respondents were able to accurately identify the factors that need to be taken into consideration when feeding an individual with a neurodegenerative disorder. This is positive, as taking the abovementioned factors into consideration can help maintain oral feeding.

As stated, modified food consistencies are often recommended to improve feeding in individuals with dysphagia. To determine the hospice caregivers' reported practices in the management of dysphagia in neurodegenerative disorders, the respondents were asked to indicate, based on their experience, whether different food consistencies affected the ease of swallowing, and which consistencies they considered to be the easiest to swallow for a patient with dysphagia.

The majority (89%) of respondents indicated that different consistencies affected the ease of swallow. However, the respondents were not always familiar with the type of consistencies that would be easier for a patient with neurogenic dysphagia to swallow. Figure 4.11 displays the respondents' perceptions of the ease with which people with dysphagia could swallow certain consistencies.

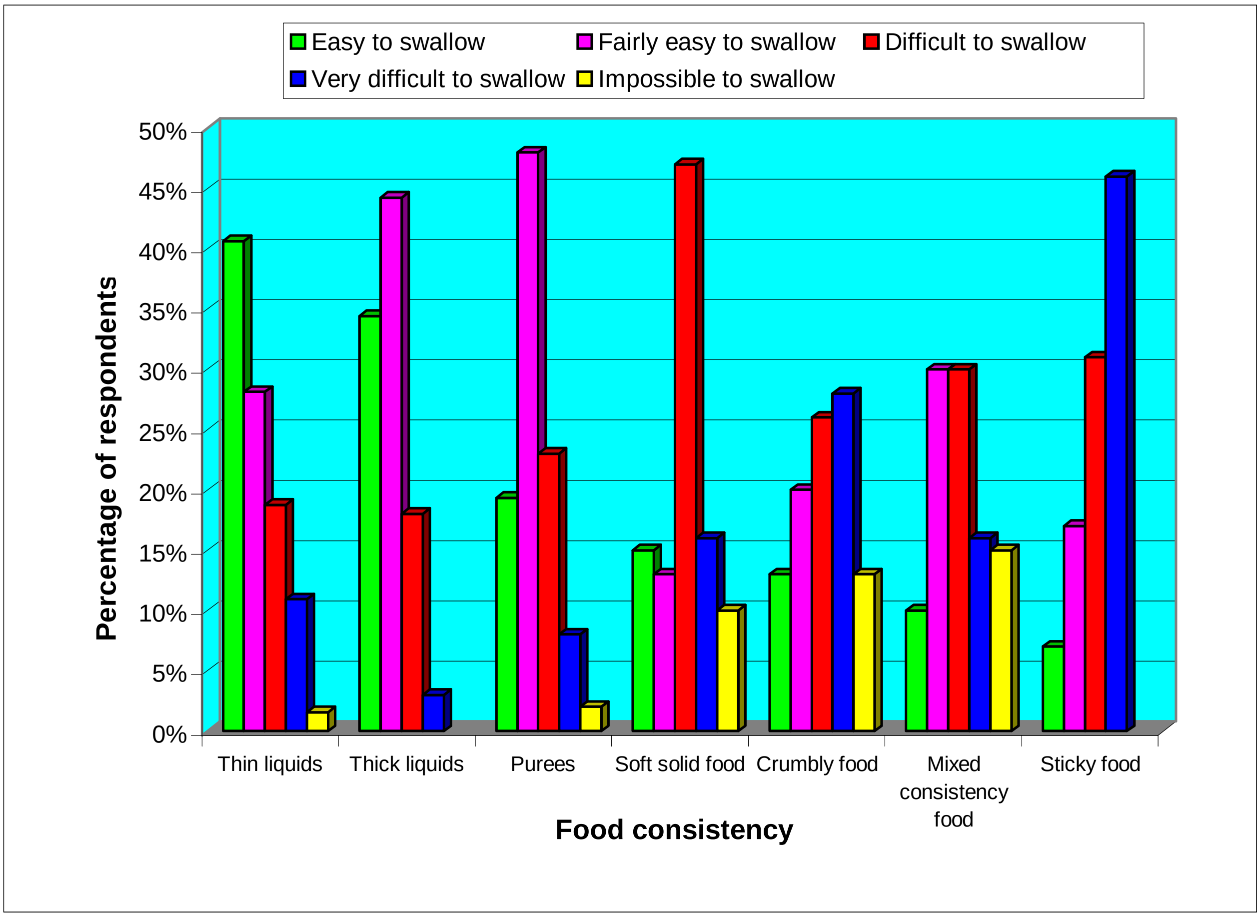


Figure 4.11 Respondents' perceptions of the degree of difficulty with which people with dysphagia swallow various food consistencies (N=64)

Drinking and eating forms an important part of social interactions and is considered to be a pleasurable experience. Thus, it is important to maintain oral feeding for as long as possible (Mertz, 2005). Individuals affected by neurodegenerative disorders may be able to maintain hydration and nutrition with the modification of food consistencies (Bakheit, 2001).

Dysphagia diets are highly individualised and recommendations regarding the most appropriate food consistencies are usually made by a speech-language therapist after conducting a swallowing assessment (Penman & Thomson, 1998). When feeding an individual with neurogenic dysphagia, however, there are some simple yet effective changes that can be made to the diet to improve a patient's ability to swallow (Bakheit, 2001). The hospice caregivers, therefore, need to be aware of the changes they can make to food consistencies in order to promote safe feeding.

Individuals affected by neurodegenerative disorders aspirate more frequently on thin liquids, compared to thick liquids, as they have difficulty maintaining oral control while swallowing thin liquids. There is extensive literature reporting on the difficulty individuals with neurogenic dysphagia have in swallowing thin liquids (Glassburn & Deem, 1998; Martin, 1991; Penman & Thomson, 1998).

Thin liquids are often the most difficult to swallow. Water, for example, has very little taste and texture and does not simulate the swallow reflex adequately in individuals with neurogenic dysphagia (Martin, 1991). Hospice caregivers, however, appear to be unaware of this difficulty and, according to Figure 4.11, the majority of respondents (41% easy to swallow plus 28% fairly easy to swallow) indicated that, in their experience, dysphagic patients were able to swallow thin liquids easily. These results indicate that the respondents may be giving patients with neurodegenerative disorders thin liquids, which places them at risk for aspiration.

Altering the consistency of food can change the rate at which the food passes through the pharynx. This can, in turn, assist the patient in controlling the liquid and reduce the risk of aspiration (Mertz, 2005). According to Figure 4.11, 34% of the respondents indicated that thick liquid was easy to swallow and 44% indicated that it was fairly easy to swallow.

Liquids given to patients with neurogenic dysphagia should be thickened as this allows for a bolus to form in the mouth, which is easier to swallow (Martin, 1991). Unfortunately, when the liquid is thickened, both the taste and texture are affected and patients do not enjoy drinking it. This may be problematic, as patients who are not compliant may drink less and subsequently dehydrate. It is, therefore, recommended that the modification of food consistencies be considered as a last resource once other compensatory techniques, such as changes in body posture, have been attempted (Mertz, 2005).

Pureed food is usually easier for a patient with neurogenic dysphagia to swallow than liquid because it can maintain its shape in the mouth and stimulate the swallow. As seen in Figure 4.11, the majority (19% easy to swallow plus 48% fairly easy to swallow) of the respondents found that, in their experience, individuals with dysphagia were able to swallow pureed food easily.

Patients with neurogenic disorders present with unique dysphagic characteristics. Soft solid food is, however, usually easier to swallow than thin fluids or tough solids as they maintain their shape in the mouth and stimulate the swallow (Martin, 1991). From Figure 4.11, it is apparent that the respondents were unsure which consistencies are overall the easiest consistencies for patients with dysphagia to swallow, as only 14% of the respondents indicated that soft food was easy to swallow. These results are in agreement with previous research, which has found that nurses and caregivers have insufficient knowledge about the appropriate food and liquid consistencies that promote safe swallowing in individuals with dysphagia (Kayser-Jones & Pengilly, 1999).

It is recommended that patients with degenerative neurological disorders avoid foods that are crumbly or fall apart (Martin, 1991). Dysphagia as a result of neural dysfunction can affect the oral phase of the swallow, making the manipulation of food inside the mouth difficult. Crumbly foods are difficult to swallow as a patient who has weak uncoordinated movements will be unable to form a bolus and the food may become trapped between the gum and the cheek (Mitsumoto & Munsat, 2001).

The respondents varied in their responses regarding the ease with which dysphagic patients swallow food of a crumbly texture and, according to Figure 4.11, the responses were evenly distributed across the Likert scale. A similar result was found regarding the respondents’ percepetions of the ease with which patients with dysphagia swallowed food of a mixed consistency. According to Fitzgibbons, (2001), mixed consistencies such as chunky soups or dry cereal with milk are one of the most difficult consistencies to swallow safely. It is recommended that solids and liquids should be presented separately. However, from Figure 4.11, it is apparent that 40% (10% easy to swallow plus 30% fairly easy to swallow) of the respondents found that food with a mixed consistency is easy for a patient with dysphagia to swallow. These results indicate that the respondents may be feeding patients with neurogenic disorders food of mixed consistencies, which places them at risk for aspiration and other dysphagia-related complications.

Although, diet modifications should only be considered as a last resort after other interventions have been unsuccessful, they are being implemented more and more frequently. In resource-poor contexts, diet modification is easier to implement with patients in long-term care than other compensatory interventions, such as postural techniques, because there is limited staff to monitor the implementation of these interventions. As a result, diet modification is currently one of the most regularly used compensatory interventions (Mertz, 2005).

The results presented in Figure 4.11 imply that the respondents are aware that modification of food consistencies can have an effect on a patient's ability to swallow. The respondents' awareness of the consistencies that may be easier for a patient with dysphagia to swallow is, however, largely inadequate. This lack of awareness was further investigated and the responses obtained from respondents who had received training in dysphagia were compared to those who had not. This comparison is presented graphically in Figure 4.12.

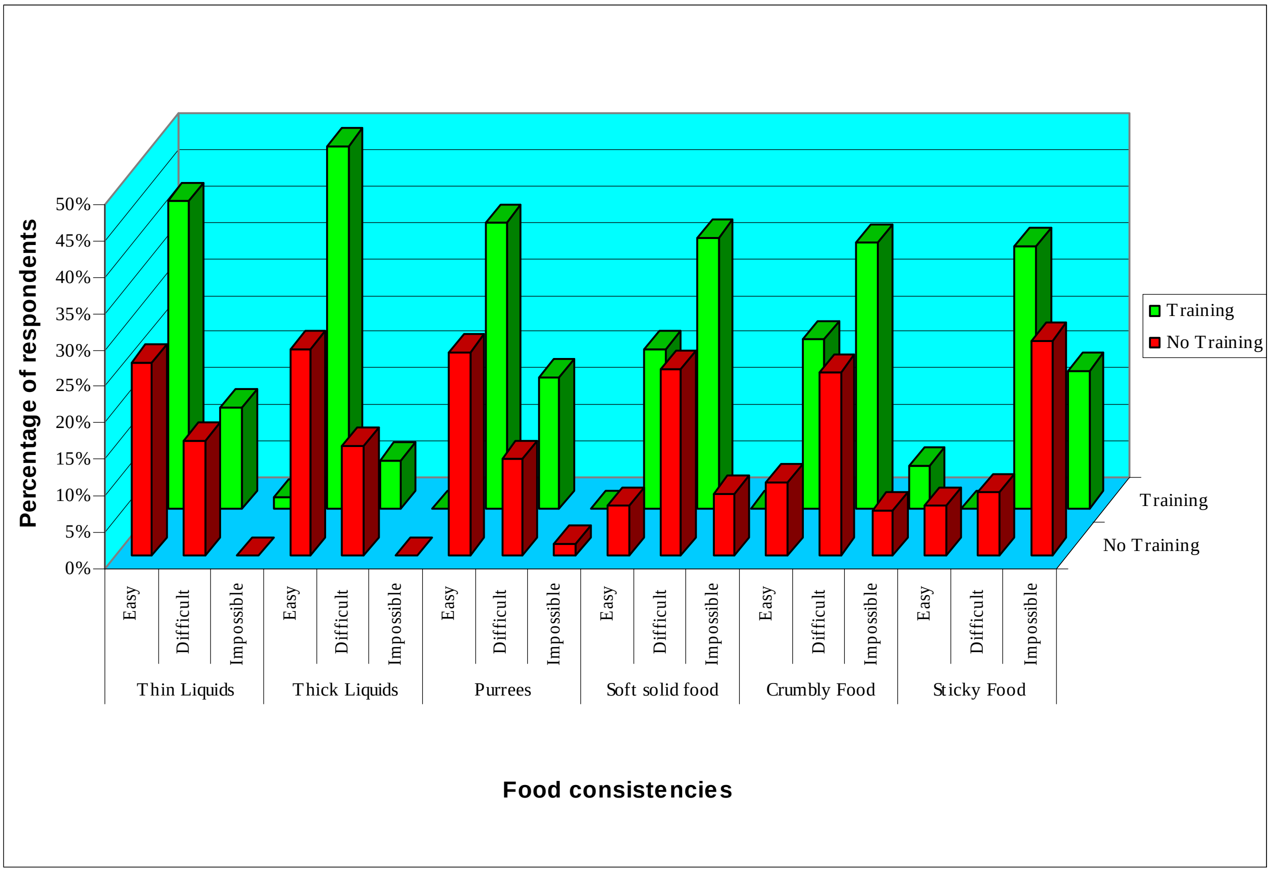


Figure 4.12 Respondents' perceptions of the degree of difficulty with which people with dysphagia swallow various food consistencies: A comparison between respondents who had received training in dysphagia and those who had not (N=64)

It is evident from Figure 4.12 that the discrepancy between the responses of respondents who had received training in dysphagia and those who had not, regarding the ease with which certain textures are swallowed, was minimal. In some instances the trained caregivers were, in fact, less aware of the consistencies that were easy to swallow. Forty-two percent of the trained caregivers indicated that thin liquids were easy to swallow. This data suggests that hospice caregivers have gaps in their awareness of the food consistencies.

The aim of dysphagia management in individuals with degenerative disorders is to maximise current functioning and compensate for irreversible loss of function (ASHA, 2002). Altering food consistencies may be difficult for the patient and may result in a reduced quality of life. As such, other compensatory strategies should first be examined (Logemann, 1998).

Changing the patient's posture is an appropriate management strategy for patients with neurodegenerative disorders as a change in the patient's cognitive functioning may affect his/her comprehension and compliance and exclude the use of direct swallowing therapies. Postural modification can be consistently applied as it is the caregiver's responsibility and does not require the patient to exert effort or follow directions (Chadwick, Joliffe & Goldbart, 2002; Rosenvinge & Starke, 2005).

In the current study, the majority of respondents were aware of the importance of patients' posture during feeding, and 87.10% of respondents indicated that changing the position of a dysphagic patient can improve the patient's ability to swallow. In order to describe the hospice caregivers' practices in the management of dysphagia in neurodegenerative disorders, the respondents' perceptions of the optimal positioning for dysphagic patients during feeding were investigated. These results are displayed in Figure 4.13.

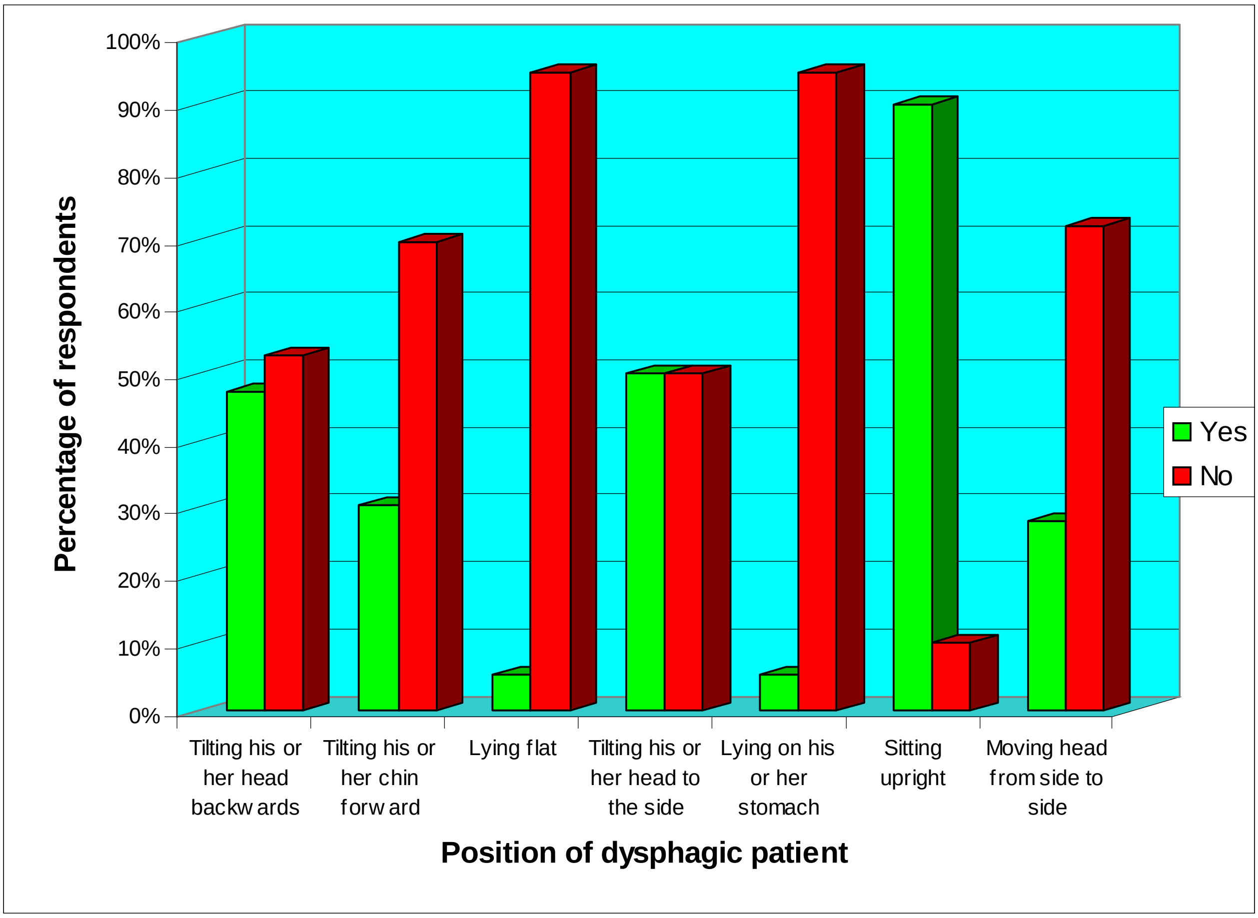


Figure 4.13 Respondents' awareness of the positions which are safe for feeding a dysphagic patient (N=64)

Changing the patient's posture is a compensatory strategy that will assist the individual to swallow safely, but will not change the physiology of the swallow. Optimal positioning of a dysphagic patient affects the direction and flow of liquids that can, in turn, improve the safety of the swallow and sometimes even eliminate aspiration of liquids and other foods (Logemann, 1998).

There are a variety of postural changes that may improve swallowing in specific patients. These include chin-tuck posture, head back, side-lying and head tilt (ASHA, 2002). When feeding a person with neurogenic dysphagia, however, the upright position with the person's head in the midline and tilted forward should result in an improvement in the patient's ability to swallow safely (O'Loughlin & Shanley, 1998; West & Redstone, 2004).

Figure 4.13 shows that the majority (90%) of the respondents indicated that placing a patient in the upright position was a safe position for feeding. These results are consistent with other studies that showed that caregivers were generally aware that positioning a patient in an upright position was important for improving the patient's ability to swallow safely (Pelletier, 2004).

According to West and Redstone (2004), by placing the patient in an upright position with the head and body aligned, the patient's ability to feed him/herself will improve. Self-feeding not only improves the safety of the swallow, but enhances the pleasure of eating for a patient. This is essential, as feeding is socially and psychologically significant to both the patients and their families and should be continued for as long as possible (Bakheit, 2001).

Placing the patient in an upright position improves head stability, which, in turn, allows the oral structures involved in the swallow to function independently and improve the safety of the swallow (West & Redstone, 2004). In addition, by tilting the head forward, the vallecular spaces are widened and food is diverted away from the airway, reducing the risk of aspiration (Squires, 2006).

Although tilting the head forward has been found to be effective in the prevention of aspiration during swallowing (Daniels, 2000), only 30% of the respondents were aware of the safety of this position. According to Figure 4.13, the majority (70%) of respondents indicated that, in their experience, tilting the head forward was not safe for a patient. This is contradictory to literature findings, which show that tilting the head forward allows the epiglottis to form a protective shelf over the vocal folds, which provides protection for the airway (West & Redstone, 2004). Caregivers may experience the head forward position to be unsafe because individuals with neurogenic dysphagia may have weak oral movements, which can result in spillage of food from the mouth and make swallowing with the head forward difficult (Squires, 2006). It can, therefore, be concluded that this position is seldom applied by hospice caregivers when feeding their patients.

Figure 4.13 shows that the respondents are aware that lying down is potentially an unsafe position in which to feed dysphagic patients, as 95% of the respondents indicated that placing a patient in a lying down position on either his/her back or stomach is unsafe.

Although lying down is a position recommended for patients with reduced laryngeal elevation, an in-depth radiographic study of the patients' swallow is required before making this recommendation (Logemann, 1998). It can, therefore, be assumed that the majority of hospice caregivers who participated in the study do not position their patients lying down when feeding them.

Lying down with the head extended is an unsafe position in which to feed many dysphagic patients because, in this position, the vocal folds cannot protect the airway efficiently (West & Redstone, 2004). Similarly, tilting the head back results in a reduction in airway protection. The head back posture is helpful in moving food through the oral cavity by relying on gravity and is, therefore, recommended in certain cases. However, this position should not be used if there is a possibility of aspiration (Logemann, 1998). Figure 4.13 shows that 48% of the respondents indicated that feeding a patient with his/her head back is a safe position. This is of concern as it implies that a large percentage of the hospice caregivers who participated in this study position their patients with their head back for feeding, which may increase the patient's risk for aspiration.

Tilting the head back should not be used as a feeding position prior to an in-depth radiographic assessment (Logemann, 1998). Due to the limited access to videoflouroscopy in the hospice setting, application of the head-back posture during feeding should rarely be utilised. Many patients with neurogenic dysphagia do not cough when aspiration occurs and lifting the chin up during the swallow may further exacerbate the swallowing difficulty (Rasley et al., 1993).

Postural modifications are frequently suggested as a strategy to compensate for dysphagia and reduce the risk of aspiration. Research into the application of postural changes for the feeding of a patient with dysphagia indicates that the majority of patients may benefit from changes in posture (Bakheit, 2001). From the results, it is apparent that, although the caregivers are aware that changing a patient's position could improve the swallow, they are unaware of which positions are safe for the dysphagic patient during swallowing. Further training is required on the optimal position during feeding.

Hospice care is unique in that it views both the patient and the family as the units of care and the provision of family support is a crucial part of palliative care (Meghani, 2004). The respondents were, therefore, asked to list the guidelines they present to the family members. These responses are presented in Table 4.2.

Table 4.2 A summary of the guidelines for feeding a patient with dysphagia, which the respondents present to the family members (N=63)

Guidelines given to family members for feeding a patient with dysphagia	No. of respondents	%
1. Position the patient correctly.	40	63%
2. Give small amounts of food.	29	45%
3. Feed a pudding consistency.	17	27%
4. Feed slowly.	15	23%
5. Be patient while feeding.	13	20%
6. Provide information about how to feed.	11	17%
7. Make allowance for food preferences.	8	13%
8. Try different types of food to see which is easier to swallow.	6	9%
9. Give a liquid diet.	6	9%
10. Food must not be dry.	4	6%
11. Educate about tube feeding.	4	6%
12. Feed at smaller intervals.	4	6%
13. Accept and support the patient.	3	5%
14. Observe alertness of patient.	3	5%
15. Use a syringe to feed.	3	5%
16. Teach how to prepare the food.	2	3%
17. Do not give spicy food.	2	3%
18. Food must look good and taste as good as possible.	2	3%
19. Observe the patient's ability to follow instructions.	2	3%
20. Encourage the patient to drink water.	2	3%
21. No distractions when eating.	2	3%
22. Allow the patient to assume normal eating pattern.	1	2%
23. Give cold food rather than hot food.	1	2%
24. Demonstrate how to clean the oesophageal tube.	1	2%
25. Demonstrate how to treat oral thrush.	1	2%
26. Observe the patient's cooperation.	1	2%
27. Do not force feed.	1	2%
28. Encourage the patient to swallow.	1	2%
29. Provide information on the best nutrition.	1	2%
30. Refer to a dietician.	1	2%
31. Food must not be too hot or too cold.	1	2%

Professional support and advice should be given to families to assist them cope with the anxiety of caring for a person with a progressive illness. As such, there should be clear communication between hospice caregivers and family members (Meghani, 2004). Guidelines for feeding a patient with dysphagia should be given to the family members. This is an essential component of the hospice caregivers' practices in the management of dysphagia in neurodegenerative disorders.

According to Table 4.2, the most commonly reported feeding guidelines given to family members were showing the family members the correct positioning of the patient, feeding dysphagic patients small amounts of food, feeding the patient food that is of a pudding consistency, feeding them slowly, and being patient while feeding. It is, however, apparent that there is a wide selection of guidelines provided to family members. This is of concern as it implies there is no consistency in the guidelines provided to families and certain guidelines may not always improve the patient's swallow. For example, 5% of respondents encouraged family members to use a syringe to feed, which is contradictory to the literature, which recommends that, where possible, family members should be encouraged to use a spoon rather than a syringe as the application of downward pressure on the tongue with the spoon heightens awareness and facilitates swallowing (Stipinovich, 2006).

In addition, only a limited number of respondents included the removal of distractions during mealtimes, the observation of the patient's level of alertness and cooperation, and the use of smaller feeding intervals in the guidelines they provided to the family. These are general suggestions that could improve the safety and efficiency of the swallow and should be communicated to the family members more frequently (Ferrell & Coyle, 2005). To the author's knowledge, there is no research available regarding the guidelines that are provided to family members by hospice caregivers about feeding a patient with dysphagia. This is an area that requires further research.

The second sub-aim of this study was to describe the respondents' practices in the management of dysphagia and thus the respondents' level of confidence in the management of dysphagia was investigated. These results are displayed in Figure 4.14.

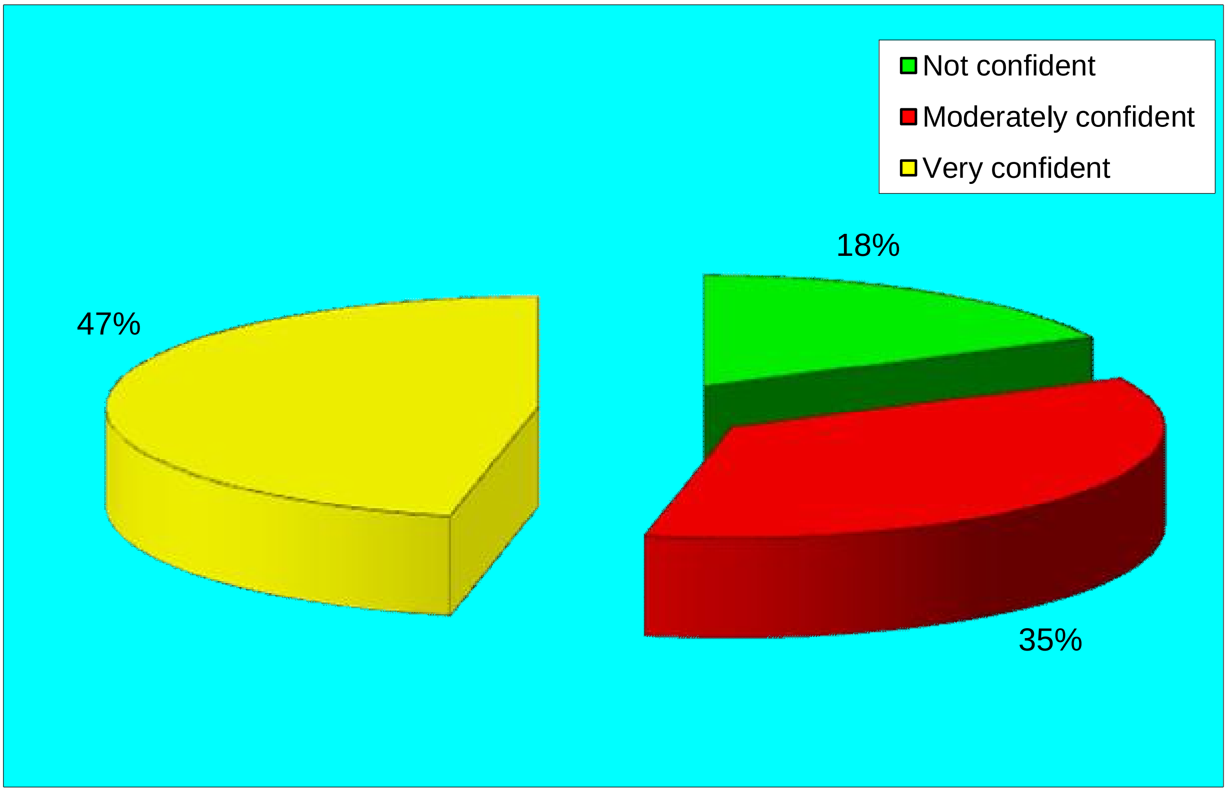


Figure 4.14 Respondents' level of confidence in the management of dysphagia (N=60).

According to Figure 4.14, the majority (47% very confident plus 35% moderately confident) of the respondents were confident in their ability to manage dysphagia. This is a surprising result as it is contradictory to previous research conducted, which found that caregivers involved in the care of dementia patients had difficulty feeding and lacked both the knowledge and confidence to manage dysphagia appropriately (Chang & Lin, 2005).

It has been proposed that work experience can facilitate the development of an individual’s vocational knowledge and confidence (Billet, 2000). It was, therefore, decided to compare the respondents’ professional work experience to their levels of confidence in the management of dysphagia. These results are presented in Figure 4.15

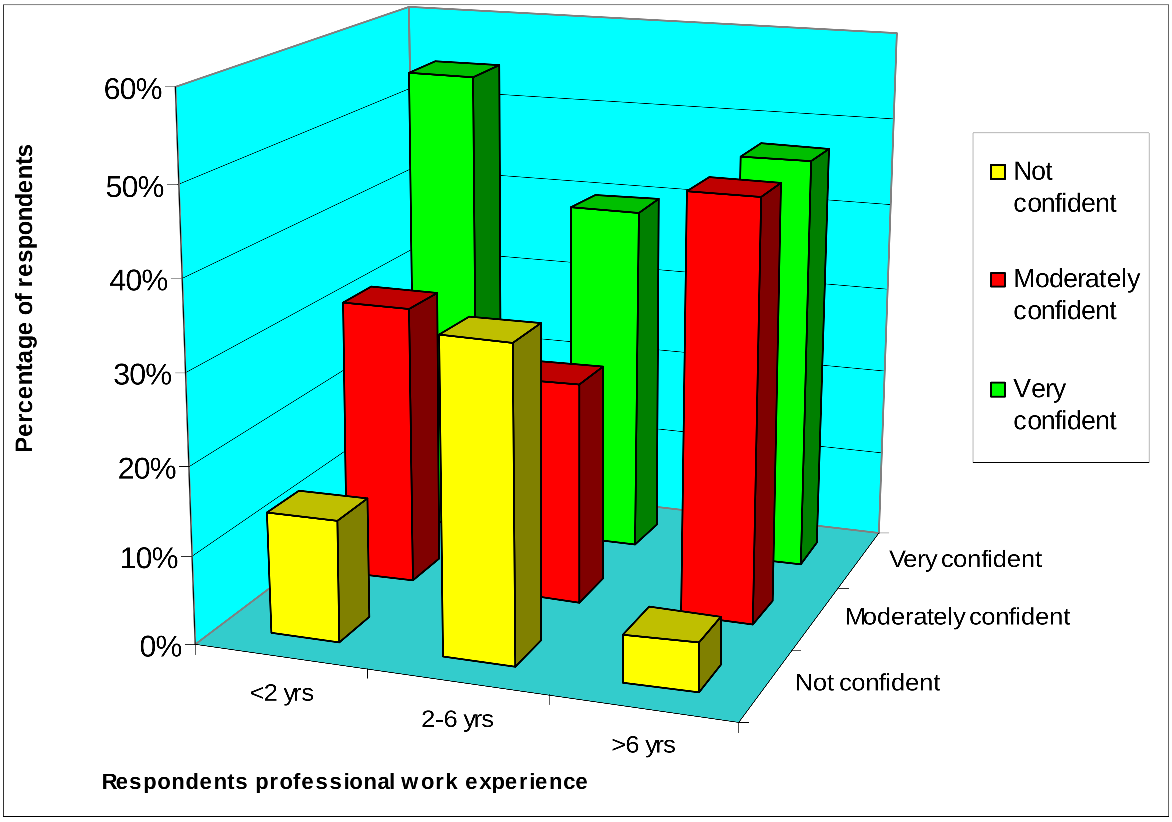


Figure 4.15 A comparison between respondents' levels of confidence in the management of dysphagia and their work experience (N=60).

From Figure 4.15, it is apparent that there was no direct relationship between the number of years' experience that the caregivers had and their level of confidence in the management of dysphagia. The majority (55%) of respondents with less than two years' experience indicated they were very confident in their ability to manage dysphagic patients. However, the largest (35%) percentage of the respondents who were not confident in their management of dysphagia included those who had between two and six years' working experience. This is contradictory to literature reports that indicate that nurses entering the hospice setting experienced feelings of inadequacy and initially lacked confidence in their ability to manage dying patients (Rosser & King, 2003).

Research has found that the training of caregivers in the area of dysphagia can have a positive effect on the caregivers' confidence in the management of patients with swallowing disorders (Lin et al., 2001). A comparison between the respondents' level of confidence and the type of dysphagia training they received was therefore made. These results are presented in Figure 4.16.

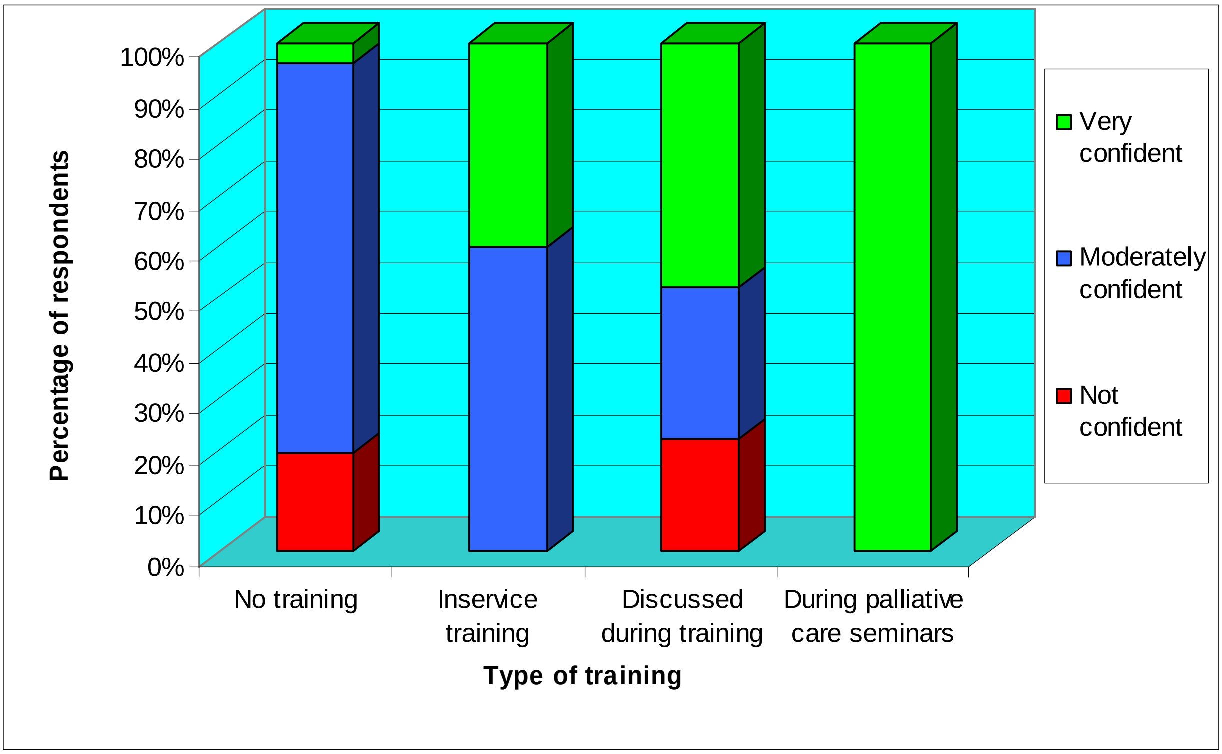


Figure 4.16 A comparison between respondents' level of confidence and the type of dysphagia training they received (N=60).

From Figure 4.16, it is apparent that the provision of training can have a significant effect on the caregivers' level of confidence in their ability to manage dysphagic patients. All of the respondents who had attended palliative care training seminars regarding dysphagia indicated that they were very confident in dealing with swallowing disorders. In addition, none of the respondents who had received in-service training indicated that they were not confident in the management of dysphagia. This is in agreement with research completed in the hospice setting in the United Kingdom, which found that the implementation of a dysphagia training programme in the palliative care setting can significantly improve caregivers' confidence in managing swallowing disorders (Kirker & Oliver, 2003).

The respondents were subsequently required to indicate the disorders they felt less confident managing the associated dysphagia and their reasons for this feeling. Only 47 respondents completed this question and a summary of their responses is presented in Table 4.3.

Table 4.3 Disorders associated with dysphagia respondents felt less confident managing and their reasons for this feeling (N=47)

Disorders associated with dysphagia	No. of respondents	Reason for feeling less confident
Motor neuron disease	34%	Poor prognosis Limited experience Prone to choking Difficult to handle Emotional lability Patient has limited control May have to provide gastric feed Severity of the diagnosis
Advanced cancer of the throat and mouth	26%	Prone to choking
HIV and AIDS	20%	Severity of the diagnosis
Other disorders	20%	Patient in severe pain Anxiety attacks Food comes out through nose Difficult to handle Limited experience Insufficient training

According to Table 4.3, a large (34%) percentage of respondents indicated that they felt less confident in managing dysphagia in patients with motor neuron disease than other diseases. The respondents' reasons for feeling less confident included these patients' poor prognosis, limited control and the possibility of supported nutrition. Dysphagia occurs in about 70% of patients with motor neuron disease and it has been described as one of the most distressing symptoms of the disorder. Patients lose the ability to care for themselves and may not be able to maintain adequate nutrition (Worwood & Leigh, 1998). These characteristics are reflected in the respondents' reasons for feeling less confident.

Hospice caregivers often provide care for patients with cancer and, as a result, 26% of the respondents indicated that they felt less confident managing the dysphagia associated with advanced cancer of the throat and mouth. The inclusion of dysphagia as a consequence of cancer is, however, beyond the scope of the current research as the focus of this research is on dysphagia associated specifically with neurodegenerative disorders.

A large portion (20%) of the respondents specified HIV and AIDS as the disorder associated with dysphagia they felt less confident managing. The reason provided by respondents for this feeling was because of the severity of the diagnosis. The significant effect dysphagia has on the progression of HIV and AIDS is acknowledged in the literature. Dysphagia results in poor nourishment, which further reduces the patient's immunity, thereby increasing his/her susceptibility to infection (Dworzanowski, 2002; Stipinovich, 2006).

Other disorders included by the respondents were Parkinson's disease and all neurodegenerative disorders. Although the effect training has on the caregivers' level of confidence in their ability to manage dysphagic patients has been established in Figure 4.16 on page 102, according to Table 4.3, reduced confidence in managing the associated dysphagia due to insufficient training was only mentioned once. Instead, the reasons most commonly given for the lowered confidence level included the severe pain experienced by patients, the difficulty caregivers experienced in handling patients with these disorders and limited experience.

The second sub-aim was to describe the hospice caregivers' reported practices in the management of dysphagia in neurodegenerative disorders. The results obtained in this section indicate that although the respondents are aware that making postural changes and changing the food consistency can improve the patient's swallow, they are uncertain as to which strategies to utilise to improve the patient's swallow. In addition, there is inconsistency in the guidelines that hospice caregivers' give to family members for the feeding of a patient with dysphagia. It can, therefore, be concluded that hospice caregivers require further training in the management of dysphagia in neurodegenerative disorders.

Patients with neurodegenerative disorders have a poor prognosis and tube feeding may need to be considered. The provision of artificial hydration and nutrition to individuals with a degenerative disorder will, therefore, be discussed in the following section.

4.4 THE HOSPICE CAREGIVERS' ATTITUDES WITH REGARD TO THE PROVISION OF ARTIFICIAL NUTRITION AND HYDRATION TO INDIVIDUALS WITH NEURODEGENERATIVE DISORDERS

In the past, hospices were hesitant to provide tube feeding to any patients in their care since artificial nutrition may reduce the patient's level of comfort and artificially prolong life. However, because of the increase in the range of terminal diseases cared for by hospices, they have been forced to reconsider their position on tube feeding (Wagner, Ersek & Riddell, 2003).

In Question 25 of Section C, the respondents were asked to indicate their feelings regarding the provision of artificial nutrition and hydration to patients with a neurodegenerative disorder. This was an open-ended question and the respondents' answers were analysed and placed into four categories: against tube feeding; it depends on the patient's prognosis; it is the patient and family's decision; and when used appropriately, tube feeding can be beneficial. These results are presented in Figure 4.17.

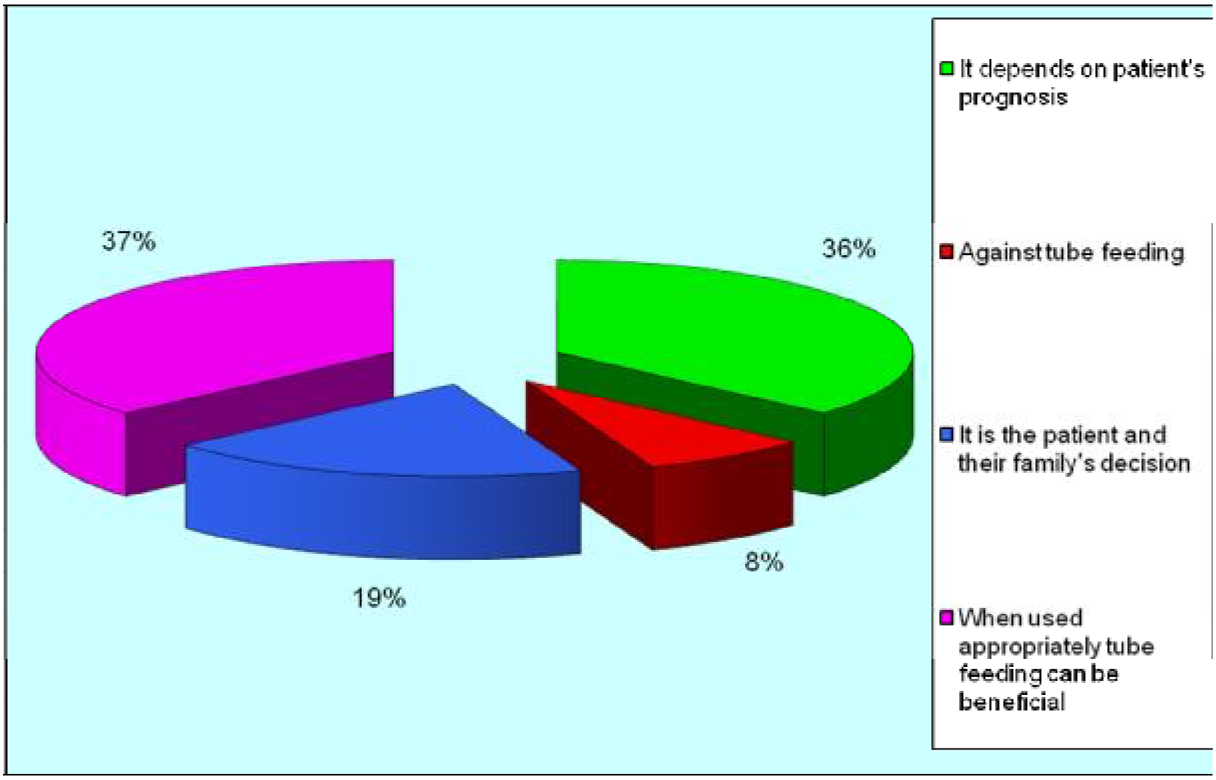


Figure 4.17 Respondents' feelings regarding patients with neurodegenerative disorders receiving tube feeding (N=60)

According to Figure 4.17, a large (36%) portion of the respondents indicated that the provision of tube feeding depends on the patient's prognosis. Many professionals are uncertain about the provision of artificial hydration and nutrition to patients with progressive neurological conditions. Numerous studies regarding the provision of artificial hydration and nutrition to patients with dementia have been performed, the results of which indicate a general inadequacy in the provision of tube feeding in the later stages of dementia (Hoefler, 2000; Post, 2001; Zerwekh, 2003).

Tube feeding in the later stages of a degenerative disorder may be a burden rather than a benefit as it can, in fact, be harmful to the patient. Tube feeding can result in local wound infections and haemorrhaging at the site of insertion, and may increase the risk of patients developing aspiration pneumonia rather than decreasing it. In addition, the patient's quality of life may be diminished as feeding tubes can form a barrier between the patient and his/her family and many patients need to be restrained to prevent them from dislodging their tubes (Hoefler, 2000).

Eating and drinking is an important part of our culture, as it can express both care and compassion. Subsequently, the withdrawal of food can cause family members to become anxious and express concern about patients starving to death. The provision of artificial hydration can often ease this anxiety (Hoefler, 2000). Tube feeding should, therefore, not be automatically withheld from all patients with a degenerative neurological disorder and the decision to initiate tube feeding should be made by the patient and his/her family (Squires, 2006).

According to the Hospice and Palliative Nurses Association, "a decision to initiate, withhold or withdraw tube feeding should be made by the patient and the family with accurate non-judgmental input from the hospice team" (Wagner et al., 2003). The provision of artificial hydration and nutrition needs to take the patient's faith into consideration. Some family members may feel that it is better not to provide tube feeding and that the patient should be allowed to die in peace. Conversely, according to Jewish faith, the utmost care should be taken to ensure that a patient's life is prolonged and a refusal to initiate tube feeding may be considered immoral (Squires, 2006).

The results presented in Figure 4.17, however, indicate that only 19% of the respondents felt that the provision of tube feeding was the patient's and his/her family's decision. This may be as a result of limited access to services and poor involvement of family members. In the rural areas of South Africa there is often more than one family member who is affected by HIV and AIDS and, as such they may be unable to assist with the decision making (Uys, 2001). In addition the availability of physicians, trained nursing staff and feeding tubes may determine whether or not tube feeding is initiated (Gessert & Calkins, 2001).

A significant (37%) percentage of the respondents indicated that, when used appropriately, the provision of tube feeding can be beneficial. This is in accordance with the position statement of the Hospice and Palliative Nurses Association, which indicates that tube feeding is suitable for patients if it can prolong the patient's life, prevent aspiration pneumonia, help maintain the patient's independence or decrease the patient's suffering (Wagner et al., 2003). It is, therefore, recommended that where tube feeding can assist patients, a trial should be done with the feeding tube inserted. Families need to be given sufficient information as tube feeding can sometimes give families a sense of false hope that a terminally ill patient may recover (Wagner et al., 2003).

Only 8% of the respondents indicated that they were against the provision of tube feeding in patients with a degenerative disorder. According to the literature, most dying patients do not experience hunger and death results from dehydration, which is reportedly not painful (Hoefler, 2000). It is, therefore, ethically acceptable and, as seen from the previous discussion, sometimes beneficial to decide not to tube feed patients who are in the last stages of life (Post, 2001; Squires, 2006).

Hospice care aims to minimise the suffering and discomfort of patients with degenerative disorders. There is little evidence to show that the provision of a feeding tube will assist in accomplishing these goals. Research has found the opposite to be true. The provision of tube feeding may not prolong life or increase the patient's strength. Instead, it can result in further complications. The insertion of the tube can be dangerous for a frail patient and it can increase the degree to which a patient aspirates on oral, pharyngeal and nasal secretions. As a result of these findings, tube feeding is discouraged in most degenerative patients (Wagner et al., 2003).

The risks and benefits involved in providing tube feeding to patients with a degenerative disorder are complex and the decision needs to consider more than just the nutritional status of the patient (Squires, 2006). The respondents' type of training or place of residence may affect their feelings about tube feeding patients with a neurodegenerative disorder. The responses presented in Figure 4.17 on page 105 were compared with the respondents' place of residence. The results are displayed in Figure 4.18

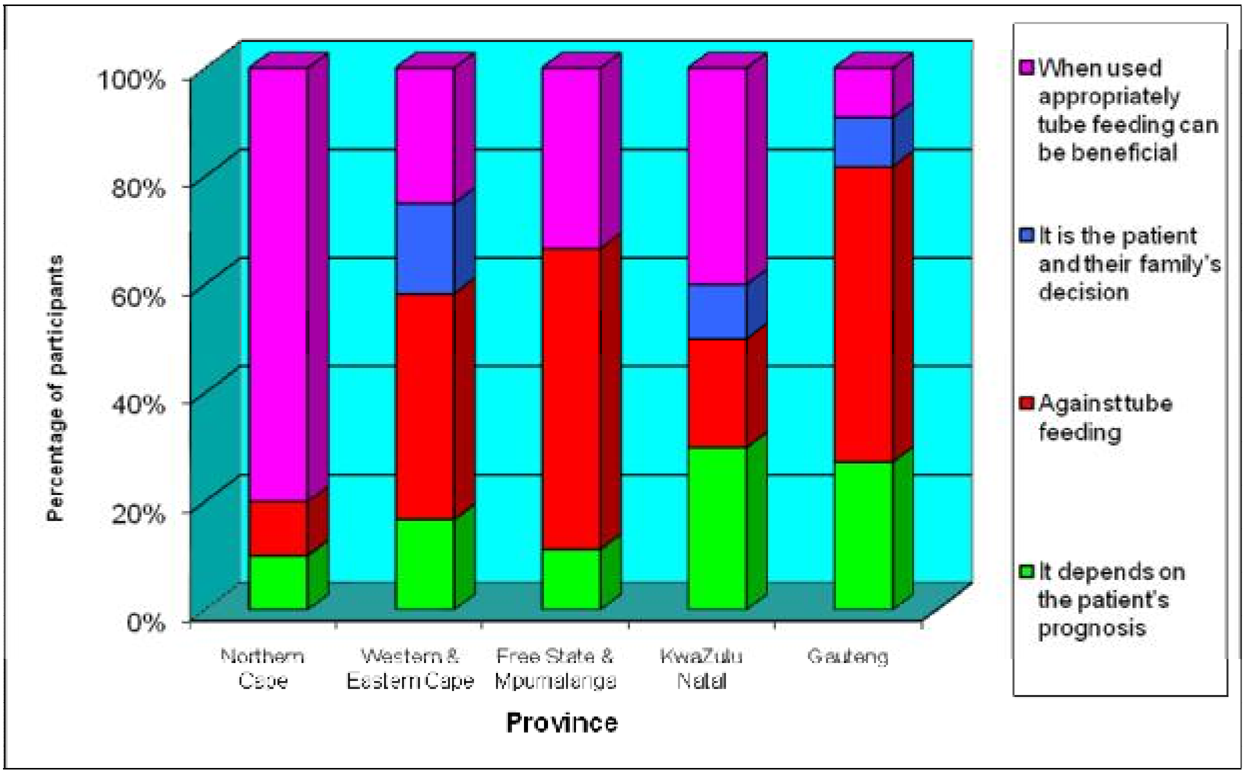


Figure 4.18 Influence of provincial distributions on respondents' feelings regarding patients with neurodegenerative disorders receiving tube feeding (N=60)

From Figure 4.18, it is clear that the respondents' place of residence has a significant impact on the respondents' feelings regarding the provision of tube feeding to patients with a neurodegenerative disorder. The majority of the respondents from the Northern Cape indicated that, when used appropriately, tube feeding can be beneficial. In contrast, 56% of the respondents from the Free State and Mpumalanga and 55% of the respondents from Gauteng indicated that they were against the provision of tube feeding.

The respondents' feelings about the provision of artificial nutrition to patients with a neurodegenerative disorder were further investigated. The responses presented in Figure 4.17 on page 105 were compared with the respondents' qualification. This comparison is presented graphically in Figure 4.19.

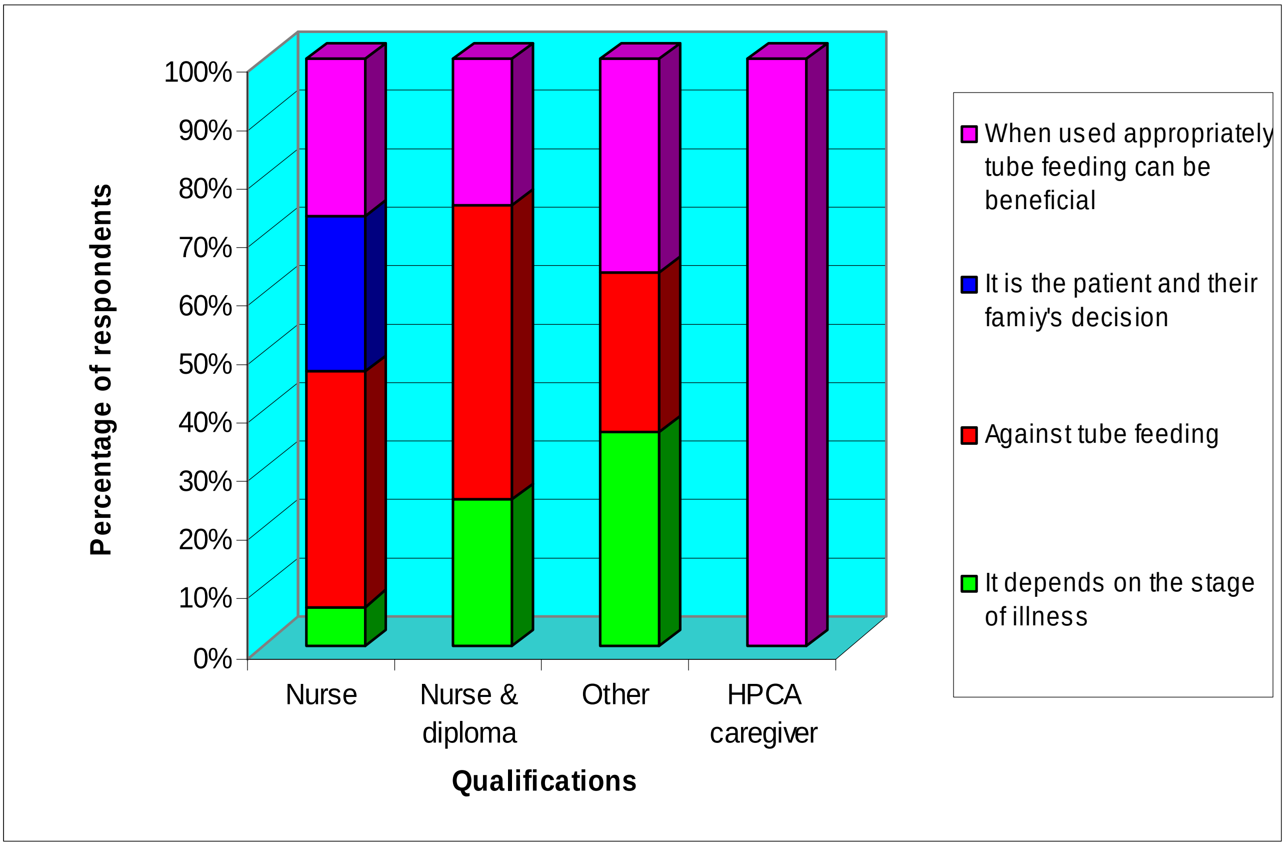


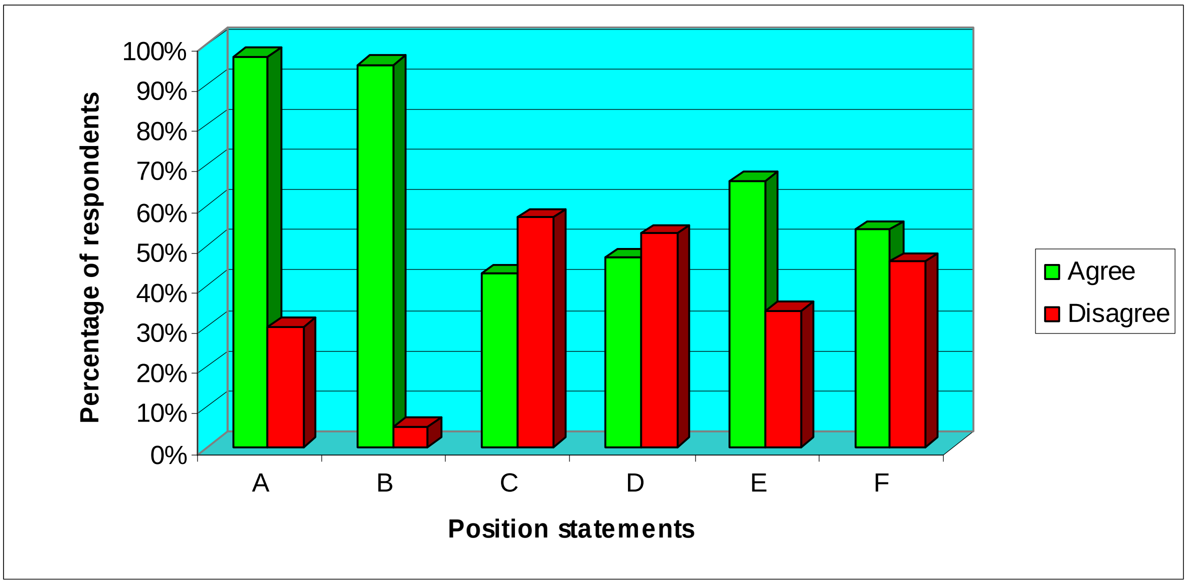
Figure 4.19 Influence of type of training on respondents' feelings regarding patients with neurodegenerative disorders receiving tube feeding (N=60)

From Figure 4.19, it is clear that the type of training has a significant impact on the respondents' feelings about the provision of tube feeding to patients with a neurodegenerative disorder. All of the respondents who had been trained as an HPCA caregiver indicated that, when used appropriately, tube feeding can be beneficial. In addition, only the respondents who had a diploma in nursing felt that the provision of tube feeding should be the decision of the patient and his/her family.

The feelings regarding the provision of tube feeding will have a significant impact on the caregivers of patients with neurodegenerative disorders. As such, the respondents were asked to indicate their position on the following statements:

- A person's inability to feed him/herself is never an excuse to let the person go hungry.
- In patients who are incompetent, family members should be included in a decision to provide tube feeding.
- Allowing the patient to die of dehydration is a painless death.
- Tube feeding the patient unnaturally extends the dying process.
- Assisted nutrition and hydration should not be offered to patients who are in the last stages of dying.
- It is better to let the patient fade away.

These results are presented in Figure 4.20.



A=	A person's inability to feed him/herself is never an excuse to let the person go hungry.
B=	In patients who are incompetent, the family members should be included in a decision to provide tube feeding.
C=	Allowing the patient to die of dehydration is a painless death.
D=	Tube feeding the patient unnaturally extends the dying process.
E=	Assisted nutrition and hydration should not be offered to patients who are in the last stages of dying.
F=	It is better to let the patient fade away.

Figure 4.20 Respondents' position on statements regarding the provision of tube feeding to patients with neurodegenerative disorders (N=64).

Figure 4.20 reveals that the majority of respondents (97%) indicated that patients who are unable to feed themselves should never be allowed to go hungry. In addition, 95% of the respondents indicated that family members should be included in the decision to provide tube feeding. This is contradictory to the results found in Figure 4.20 where only 19% of the respondents indicated that it was the decision of the patient and his/her family whether or not to provide tube feeding.

Families may fear that the patient is hungry and will starve to death and try to ensure that he/she receives adequate nutrition through tube feeding. Nevertheless, the literature reports that death as a result of dehydration is usually pain-free, and patients who refuse to drink fluids or are unable to drink fluids fall into a state of unconsciousness and die peacefully (Wagner et al., 2003). According to Figure 4.20, however, 57% of the respondents disagreed with the statement that allowing the patient to die of dehydration is a painless death. These results are contradictory to previous research, which found that the majority of caregivers felt that dehydration is painless (Hoefler, 2000). The implications of these results are that the hospice caregivers will endeavour to prevent patients from becoming dehydrated.

Although dysphagia is a prominent feature of degenerative disorders, when patients can no longer meet their nutritional requirements through oral feeding, it does not necessarily mean that they will receive artificial hydration and nutrition. According to Figure 4.20, the respondents were divided in their responses about whether patients should be allowed to fade away; whether tube feeding should be offered to patients who are in the end stages of dying; and whether the provision of tube feeding would unnaturally extend the dying process. This division is seen in the literature and some authors are of the opinion that tube feeding will prolong the patient’s life (Post, 2001), whereas other authors are unsure whether the provision of tube feeding will extend a patient’s life and whether it may, instead, cause complications (Bakheit, 2001).

Patients often feel that they are a burden to their families and the provision of a feeding tube may add to the work of the family. A decision, therefore, must be made in a team where all the information is available and the possible benefits and burdens of the feeding tube are carefully considered (Squires, 2006). A description of the team members who manage dysphagia in neurodegenerative disorders in the hospice setting will follow.

4.5 THE TEAM APPROACH FOLLOWED IN THE MANAGEMENT OF DYSPHAGIA IN NEURODEGENERATIVE DISORDERS IN THE HOSPICE SETTING

Swallowing problems as a result of neurodegenerative disorders are complex and require a team of professionals to work together to maintain adequate nutrition and hydration (Logemann, 2007). In Section D of the questionnaire, information was obtained regarding teamwork in the hospice setting.

There is currently little agreement about the composition of the team working in palliative care (Corner, 2003). The first question in Section D, therefore, aimed to determine whether there was a team functioning in the hospice clinic. The majority of the respondents (87%) indicated that a team was present. As a contingency question, the respondents were then asked to indicate professions involved in the team. These results are presented in Figure 4.21.

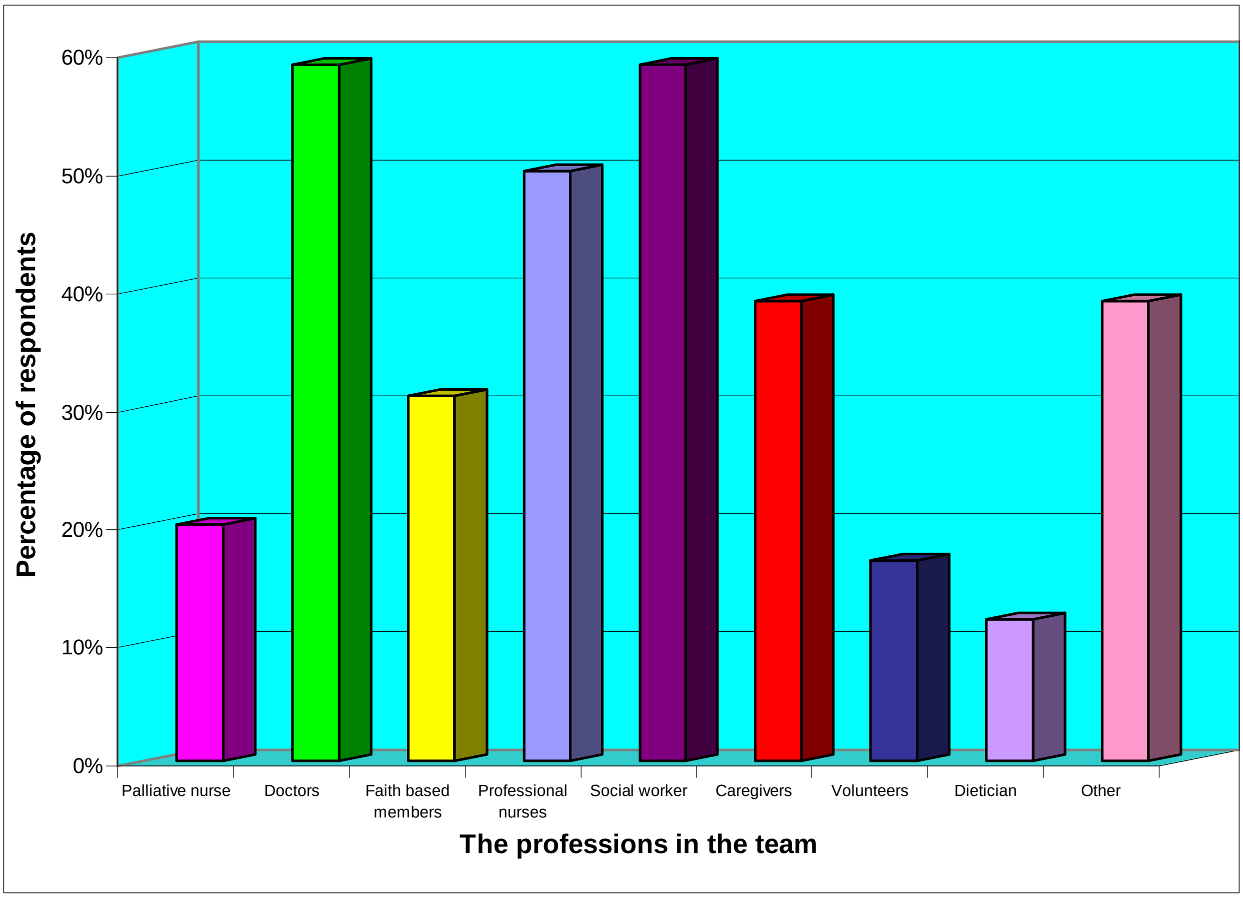


Figure 4.21 Professions in the hospice team (N=63).

According to Bakheit (2001), the basic members of the team caring for a patient with neurogenic dysphagia should include a speech-language therapist, a dietician, a nurse and a doctor. The results in Figure 4.21, however, indicate that there were currently no speech-language therapists involved in the hospices and only 10% of the respondents indicated that a dietician was a member of the team. The majority of the teams functioning in the hospice setting included palliative nurses, social workers, doctors and caregivers.

The results presented in Figure 4.21 indicate that specialist involvement in the hospice setting is limited. Hospices are providing care for patients affected by dysphagia. A multidisciplinary team, which includes the expertise of a speech-language therapist, is crucial in effectively managing patients with dysphagia (Martens, Cameron & Simonsen, 1990).

“The combined effect of individuals with specialist skills working together in a team is greater than the sum of the parts” (Faull, Carter & Woof, 1998: 13). A team approach is advantageous to both the professional and the patient. Teamwork provides professionals with mutual support and facilitates the exchange of knowledge, ideas and skills between the team members, thereby improving the efficacy of the treatment (Atwal & Caldwell, 2006).

Current trends in palliative care reflect the need for a transdisciplinary approach in the management of patients with a neurodegenerative disorder. The use of a transdisciplinary team approach for the management of palliative care patients allows for resources, skills and responsibilities to be shared. In addition, it is advantageous as it allows team members from different disciplines to develop a shared approach and collaborate to establish an optimal treatment plan (Atwal & Caldwell, 2006; Corner, 2003).

The respondents were consequently asked to indicate how valuable they felt the exchange of discipline-specific knowledge and skills between health care professionals was. The results are displayed in Figure 4.22.

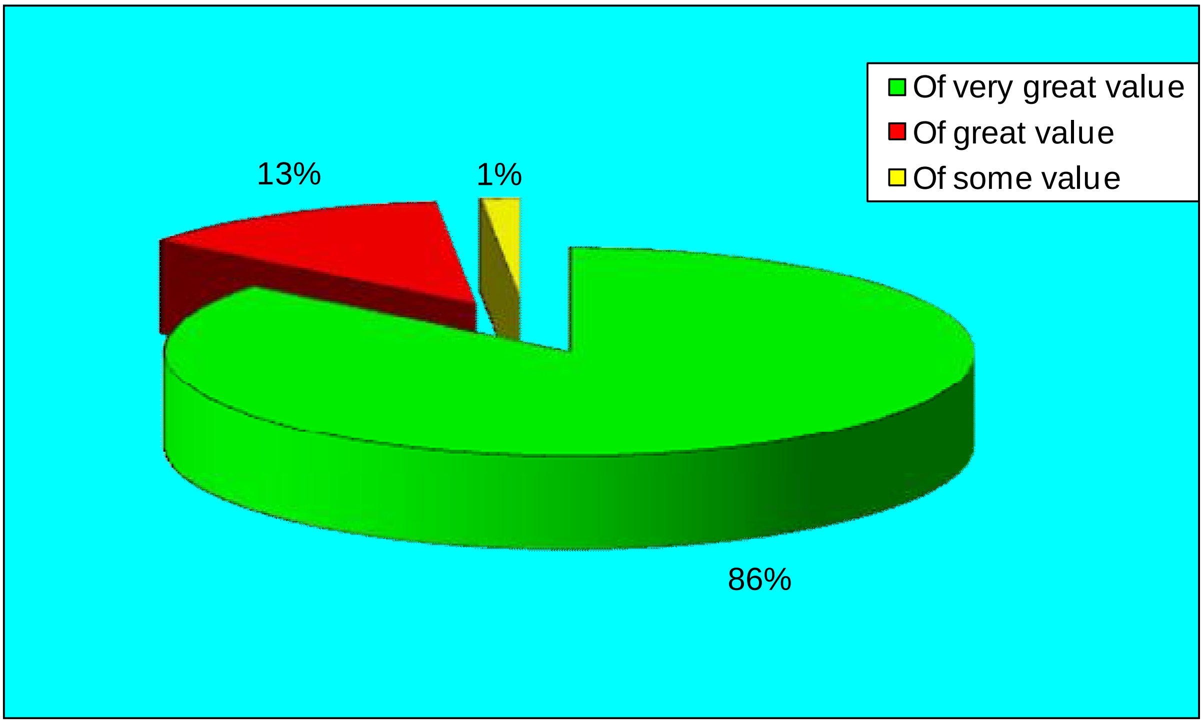
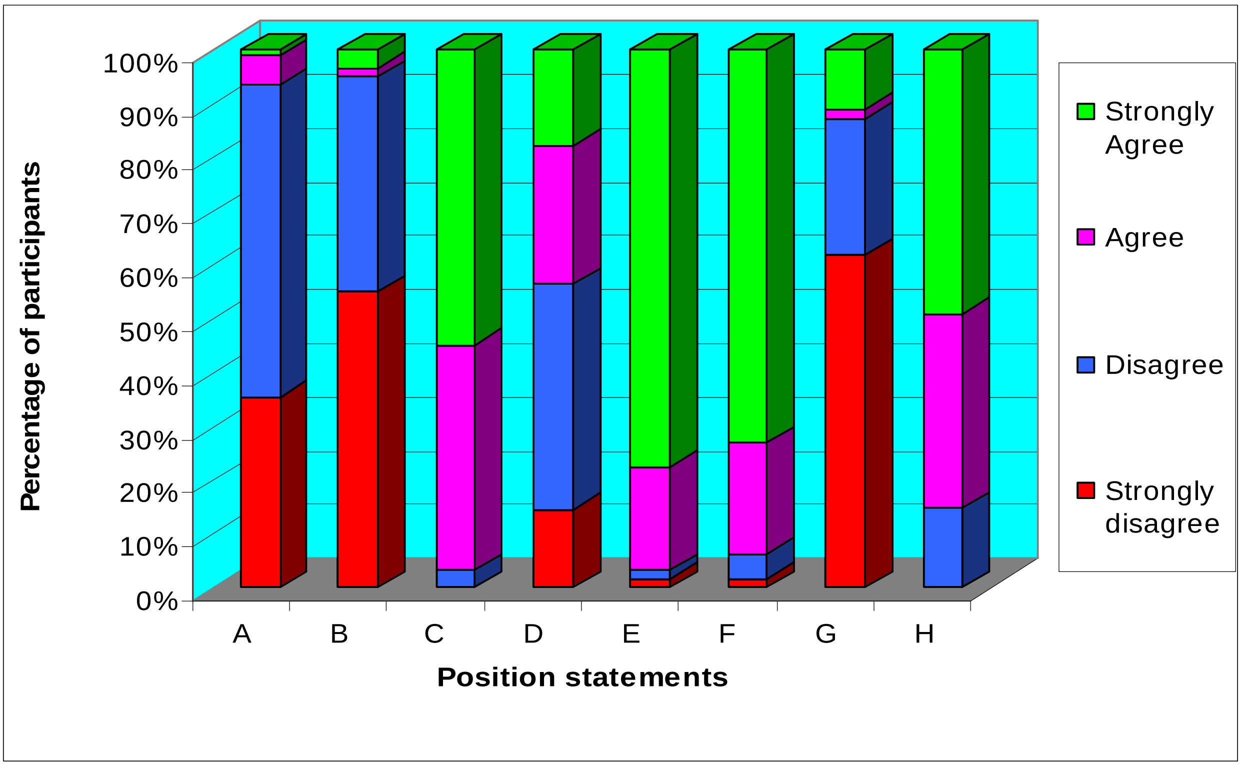


Figure 4.22 Respondents' experience of the value of health care professionals exchanging their discipline-specific knowledge and skills with other health care professionals (N=64).

According to Figure 4.22, the majority (85%) of the respondents felt that the exchanging of information between health care professionals was of very great value. Although the caregivers reported on the great value of teamwork, there is evidence in the literature to suggest that the principles of teamwork are inconsistently applied in health care (Atwal & Caldwell, 2006).

In order for teamwork to be effective, it is important that the members of the team are prepared to work together and value the different contributions made by the various professionals. Teamwork can be problematic when specific disciplines do not understand the contribution of other professionals and when there is a lack of trust between the professionals (Corner, 2003). Therefore, the respondents were asked to indicate their position on statements regarding teamwork. The results are presented in Figure 4.23.



A= Teamwork results in conflict between the team members.
B= Teamwork is impractical because there is no time for all the team members to meet.
C= A team approach should be used to manage dysphagia.
D= One team member should diagnose the patient and then delegate.
E= The patient and family should form part of the hospice team.
F= A team approach should be followed in a hospice setting.
G= Teamwork is irrelevant.
H= The speech-language therapist and hospice caregiver should consult each other about dysphagic patients.

Figure 4.23 Respondents' position on statements regarding teamwork in the hospice setting (N=64)

From Figure 4.23, it is apparent that most of the respondents were positive about the provision of teamwork in the hospice setting. The majority of respondents indicated that they disagreed with statements that suggested that teamwork was impractical and irrelevant and felt that a team approach should be used in the hospice setting to manage patients with dysphagia. In addition, the majority (49% strongly agree plus 36% agree) indicated that the speech-language therapist and hospice caregiver should consult each other about dysphagic patients, although, as previously mentioned, this is currently not being put into practice.

However, in a position statement released by the American Speech-Language Hearing Association, it was recommended that speech-language therapists do not complete training with individuals or groups of individuals from other professions in the evaluation and treatment of swallowing disorders (ASHA, 2004). The implications of this statement are detrimental to the effective provision of transdisciplinary team care to patients with dysphagia.

The results of the respondents' position on the inclusion of the speech-language therapist in the hospice team were compared to whether the respondents felt that the speech-language therapist was the person responsible for the identification of dysphagia. The results are presented in Figure 4.24.

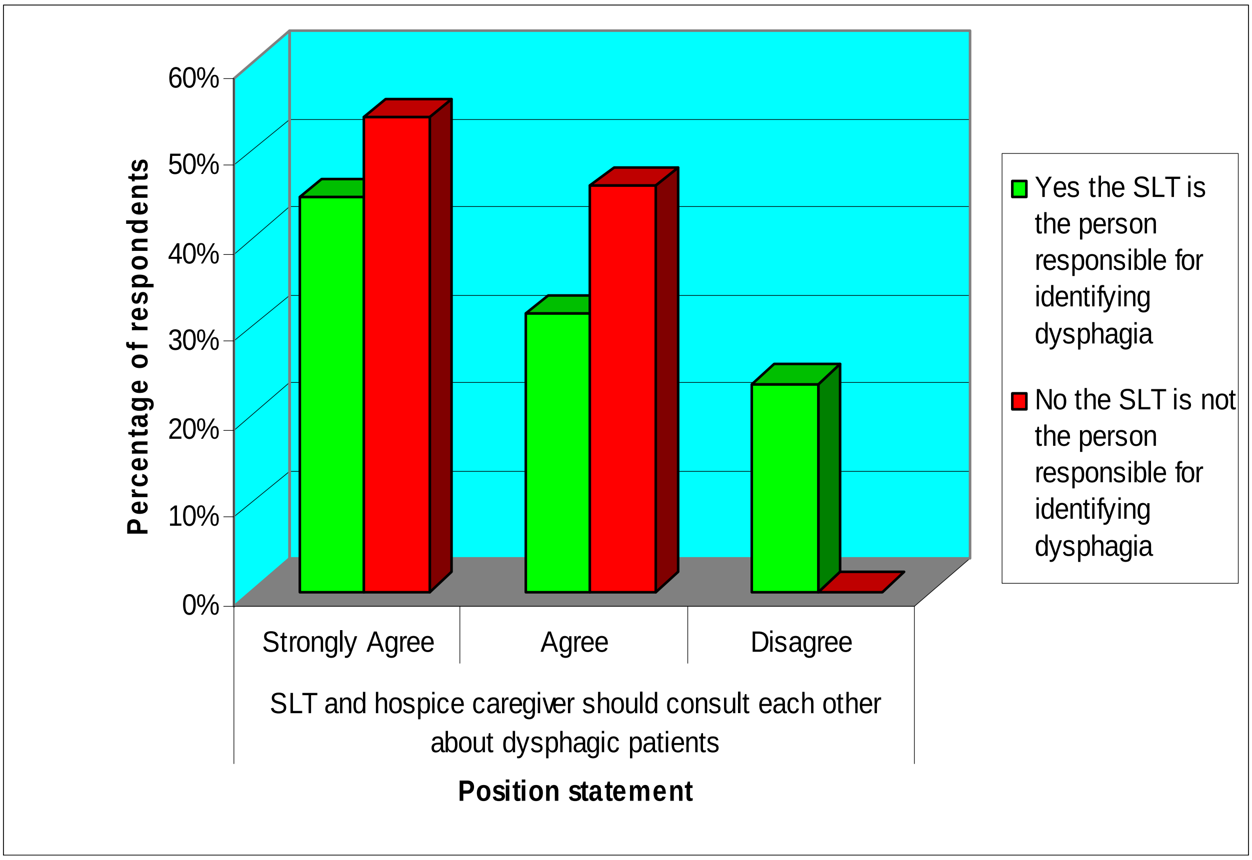


Figure 4.24 Respondents' perceptions on the consultation between speech-language therapists and hospice caregivers regarding dysphagic patients: A comparison between respondents who perceived the speech-language therapist to be responsible for the identification of dysphagia and those who did not (N=64)

According to Figure 4.24, all of the respondents who indicated that the speech-language therapist and hospice caregiver should not consult each other about dysphagic patients felt that the speech-language therapist was, in fact, the person responsible for the identification of dysphagia. Hospice caregivers may have a poor understanding of the speech-language therapist's role in the management of patients with neurodegenerative disorders. A poor understanding of the professionals' roles may cause anxiety (Hall & Weaver, 2001), which may, in turn, result in the caregivers being negative about the inclusion of the speech-language therapist in the hospice team.

Education is an essential component of teamwork (Stewart et al., 2006). Respondents were, therefore, asked to indicate whether they felt the need for further training in the management of dysphagia. The overwhelming majority (93.65%) of respondents indicated that they needed further training. Only the respondents who had attended palliative seminars about dysphagia indicated that they did not require further training. These results imply that training caregivers in the identification and management of dysphagia during palliative care seminars is effective and can improve the caregivers' knowledge and confidence in feeding patients with swallowing disorders.

4.6 CONCLUSION

A questionnaire was distributed to determine hospice caregivers' perceptions and practices in the management of dysphagia in patients with neurodegenerative disorders. The results indicate that dysphagic patients with neurodegenerative disorders form part of the hospice caregivers' caseloads. However, there was limited specialist involvement and caregivers' perceptions of the subtle symptoms of dysphagia, the positions that encouraged safe swallowing and the consistencies that were easily swallowed by people with dysphagia were inadequate. These results indicate that the aim of the research was achieved.

4.7 SUMMARY

This chapter discussed, analysed and displayed the results of the research. The results of the study were divided into four sections according to the sub-aims of the study: to determine the hospice caregivers' awareness of dysphagia in individuals with neurodegenerative disorders; to describe the hospice caregivers' *reported practices* in the management of dysphagia in neurodegenerative disorders; to determine the hospice caregivers' *attitudes* with regard to the provision of artificial nutrition and hydration to individuals with neurodegenerative disorders; and to determine whether a team approach is followed in the management of dysphagia in neurodegenerative disorders and to ascertain whether the speech-language therapist is a member of the team in the hospice setting The implications of these results will be discussed in Chapter 5.

CHAPTER 5

CONCLUSION AND IMPLICATIONS

Aim: The aim of this chapter is to draw conclusions from the results of the study and to discuss their clinical and theoretical implications. The research process and the relevant findings are critically evaluated, and recommendations for future research are presented.

5.1 INTRODUCTION

The ethical practice of speech-language therapy is reliant on a generation of research and the implementation of these findings to better serve individuals with swallowing disorders (Wambaugh & Bain, 2002). In this concluding chapter, an overall evaluation of the present study, as well as recommendations and suggestions for future studies, will be presented and discussed.

5.2 THEORETICAL AND CLINICAL IMPLICATIONS OF THE STUDY

The main aim of this study was to describe hospice caregivers' perceptions and practices in the management of dysphagia in neurodegenerative disorders. Information was obtained from 64 questionnaires, which were completed and returned by hospice caregivers. With objective interpretation of the results, a number of important conclusions can be made from the present study. These conclusions have implications for the management of patients with neurodegenerative disorders in the hospice setting. These conclusions and implications will be discussed under the sub-aims.

- ***Sub-aim 1: To determine the hospice caregivers' awareness of dysphagia in individuals with neurodegenerative disorders.***

The results revealed that patients with dysphagia as a symptom of neurodegenerative disorders formed part of the hospice caregivers' caseload. The caregivers are always informed of the patients' diagnosis. Based on their experience, they found that the conditions most frequently associated with dysphagia included HIV and AIDS, and motor neuron disease.

In South Africa, the prevalence of HIV and AIDS is increasing at an alarming rate. It is estimated that 600 South Africans die each day of AIDS-related complications (Karim & Karim, 2005). It is, therefore, possible that, in the hospice setting, patients with HIV and AIDS and motor neuron disease are most frequently encountered and that caregivers are not necessarily exposed to patients with all the neurodegenerative disorders that are most frequently associated with dysphagia. Nevertheless, hospice caregivers need to be informed of and trained to identify and manage dysphagia associated with these two conditions as they appear to be frequently encountered in the hospice setting and are strongly associated with dysphagia.

The results obtained from the questionnaire indicate that hospice caregivers are able to identify the visible symptoms of dysphagia in patients with neurodegenerative disorders. However, their awareness of the more subtle symptoms of dysphagia, which could assist in the detection of silent aspiration, was insufficient. The implications of these results are that hospice caregivers will be able to identify patients who display obvious symptoms of dysphagia, but patients who are aspirating silently may be missed.

The results of this study further indicate that the respondents regard the hospice caregiver, community nurse and doctor as the persons responsible for identifying dysphagia. Limited referrals are made to specialists such as speech-language therapists, ear, nose and throat specialists and dieticians, which may point to a limited involvement of team members in the hospice setting. The lack of the inclusion of specialists in the hospice setting suggests that hospice caregivers are required to identify dysphagia in patients with neurodegenerative disorders on their own. For this reason, it is essential that they are trained to identify dysphagia.

- ***Sub-aim 2: To describe the hospice caregivers' practices in the management of dysphagia in neurodegenerative disorders.***

The analysis of the results obtained in the questionnaire regarding hospice caregivers' management of dysphagia in neurodegenerative disorders revealed that the respondents were able to accurately identify the factors that needed to be taken into consideration when feeding. Furthermore, the caregivers were aware that the use of compensatory techniques, such as postural changes and changes in food consistency, could improve swallowing.

The respondents were, however, uncertain about which patient positions and food consistencies to utilise to improve the dysphagic patient's swallow. In addition, it was apparent that there was no consistency regarding the guidelines provided to the family members for feeding a patient with dysphagia as a symptom of a neurodegenerative disorder. Suggestions provided to family members ranged from encouraging food preferences to feeding the patient with a syringe.

The implications of the abovementioned results are that caregivers may be feeding patients with dysphagia, as a symptom of a neurodegenerative disorder the incorrect consistencies, which could exacerbate the patient's swallowing problems. Additionally, patients may not be placed in the correct position to allow safe feeding to occur.

Uncertainty regarding optimal positioning and food consistencies for patients with dysphagia may have a detrimental impact on the guidelines provided to family members. Caregivers who indicated that they offer family members information regarding the positioning of patients for feeding may, in fact, be providing incorrect information. Furthermore, the inconsistency of the guidelines provided may mean that some family members are poorly educated about feeding. This will have a significant impact on the patient's family members as an inability to nourish a loved one may be one of the most frustrating and upsetting aspects of caregiving (Fairview Health Services, 1999).

It can be concluded that, because hospice caregivers spend most of their time with the patient and have contact with the family, they need to be trained on the basic principles of safe feeding and how to convey this information to family members.

- **Sub-aim 3: *To determine the hospice caregivers' attitude with regard to the provision of artificial hydration and nutrition to individuals with neurodegenerative disorders*.**

The results obtained in the present study found that there was no consensus among hospice caregivers about the provision of artificial hydration and nutrition. Certain respondents felt that it was the patient's and their family's decision, whereas others were against tube feeding and would not offer it to patients with neurodegenerative disorders. There is a similar lack of consensus in the literature and a decision to initiate, withhold or withdraw tube feeding should be carefully considered (Wagner et al., 2003).

A comparison between the respondents' opinions regarding the provision of artificial hydration and nutrition to patients with neurodegenerative disorders and the respondents' geographical location and type of training revealed that feelings about artificial hydration and nutrition were significantly influenced by the type of training the respondents had received and their place of residence. This implies that some patients will not be offered the choice of receiving artificial hydration and nutrition. Additionally, information provided by caregivers may be biased and may not be provided in an impartial manner. It is recommended that hospice caregivers be informed of the advantages and disadvantages of non-oral feeding and how to assist family members in making this decision.

- ***Sub-aim 4: To determine whether a team approach is followed in the management of dysphagia in neurodegenerative disorders and to ascertain whether the speech-language therapist is a member of the team in the hospice setting.***

Results indicated that a team approach is commonly followed in the management of dysphagia in patients with neurodegenerative disorders. The majority of the respondents reported that the teams functioning in the hospice setting included palliative nurses, social workers, doctors and caregivers. There was, however, limited specialist involvement and the speech-language therapist was not included as a member of the team working in the hospice setting. Although many respondents felt that the hospice caregiver and the speech-language therapist should consult each other on dysphagic patients, this is not being put into practice.

The Hospice Palliative Care Association of South Africa is registered as a non-governmental organisation and, as such, is not part of the public health sector where community service for speech-language therapists has been implemented to improve the provision of health services (Mohamed, 2005). It is, therefore, possible that the hospice management may not be aware of the role of the speech-language therapist in dysphagia management.

It can, therefore, be concluded that hospice caregivers are currently managing individuals with dysphagia without the involvement of speech-language therapists or other professionals with training in dysphagia management. This result highlights the need for the inclusion of speech-language therapists in the hospice setting and the provision of adequate training of hospice caregivers in the management of dysphagia so that an appropriate management plan for patients with dysphagia may be developed.

5.3 CRITICAL EVALUATION OF THE STUDY

The credibility of the conclusions and implications of the results that have been presented above can only be realised when the strengths and weaknesses of the research methodology are considered (Cormack, 2000). The strengths and weaknesses of the current study are presented in Figure 5.1.

Critical Evaluation of the study

Strengths:

- Hospice caregivers' perceptions and practices in the management of dysphagia in individuals with neurodegenerative disorders was established
- Nation wide survey
- Wide range of respondent ages
- Respondents involved in a variety of hospice settings

Limitations:

- Questionnaires limited to English and Afrikaans
- Limited data collection methods
- Disadvantages of a self-administered questionnaire
- Influence of hospice caregiver's perceptions and practices in the management of dysphagia in individuals with cancer

Figure 5.1 Strengths and limitations of the research

As displayed in Figure 5.1, the following strengths and limitations of the current study are acknowledged:

§ The first strength of this study was that hospice caregivers' perceptions and practices in the management of dysphagia in individuals with neurodegenerative disorders were established. There is limited information available on the hospice caregivers' perceptions and practices in the assessment and management of dysphagia in patients with neurodegenerative disorders, making the results of this study valuable to hospice caregivers and speech-language therapists.

§ A second strength of the current study was that data was collected from hospices throughout South Africa and respondents resided in seven of the nine provinces. The results of the study, therefore, reflect the perceptions and practices of a wide range of hospice caregivers.

§ A further strength of the data collected lies in the wide age ranges of respondents. Respondents ranged from 26 to 73 years, which represents adults in early, middle and late adulthood (Louw et al., 1999). This implies that the results of this study reflect the perceptions and practices from a range of ages.

§ The variety of hospice settings in which respondents were involved further added to the strength of this study. Respondents were involved in the in-patient hospice units, community-based hospices and home-care organisations. The results obtained in the current study, therefore, reflect the perceptions and practices of caregivers in the management of dysphagia, with and without access to equipment and specialist input.

§ The first limitation of this study was that the questionnaire was only available in English and Afrikaans. There are eleven official languages in South Africa and neither English nor Afrikaans may be the hospice caregivers' first language, so misunderstandings may have occurred during the completion of the questionnaire. Although the questionnaire avoided the use of jargon, slang and abbreviations and the language used was clear and unambiguous, limiting the questionnaire to English and Afrikaans could still have influenced the results obtained.

- A second limitation of the study may be that no additional data collection methods were used to supplement the information obtained in the questionnaire, for example, observations of hospice caregivers' feeding practices. Self-administered questionnaires are advantageous as they are less expensive and quicker than interviews, and a large geographical area may be included in the research. In addition, self-administered questionnaires offer some anonymity, which is important as it encourages open and honest responses and can be effective if there is a high response rate (Hoyle et al., 2002). However, the data collected from the questionnaires may differ from the caregivers' practices in the feeding of patients with dysphagia.

- A further limitation of utilising a self-administered questionnaire is the possibility that caregivers may confer about the responses to certain questions. A letter containing detailed instructions about the completion of the questionnaire was given to the respondents. However, the researcher could not monitor whether these were followed correctly.

- The fourth limitation of the study was that the focus of the study was limited to the management of dysphagia in neurodegenerative disorders. It was clearly indicated in the letter explaining the purpose and nature of the study that the research was investigating hospice caregivers' practices in the management of dysphagia in patients with neurodegenerative disorders. Hospice caregivers, however, often provide care for patients with oropharyngeal and/or oesophageal cancer and, as a result, the hospice caregivers' perceptions and practices in the management of dysphagia in individuals with cancer may have affected their responses. The inclusion of dysphagia as a consequence of cancer was beyond the scope of the current research.

As is the case in any research methodology followed, there are both strengths and limitations. The above discussion revealed the limitations regarding the utilisation of a self-administered questionnaire as the only method of data collection. There are, however, also strengths to this methodology, which has resulted in determining hospice caregivers' perceptions and practices in the management of dysphagia in individuals with neurodegenerative disorders.

5.4 RECOMMENDATIONS

To further the interests of hospice patients with neurodegenerative disorders and to improve dysphagia services in the hospice setting, the following recommendations are made:

- That further research on the subject of the management of dysphagia in neurodegenerative disorders be completed with the inclusion of structured feeding observations.

- That a training programme for hospice caregivers, which focuses on the management of dysphagia in neurodegenerative disorders, be developed and an evaluation of the effectiveness of such programme be conducted.

- That a speech-language therapist be employed in the hospice setting on a part-time basis and be available to consult with hospice caregivers and provide in-service training.

- That a policy for the management of dysphagia in neurodegenerative disorders be developed and that specific dysphagia management training be incorporated into hospice caregivers' training.

- That research also be undertaken on the guidelines hospice caregivers provide to family members and the implementation of these guidelines.

- That a policy for the application of artificial hydration and nutrition be developed so that caregivers have a guideline regarding the application of tube feeding.

- That a management plan for dysphagic patients be developed and carefully communicated to the staff.

5.5 CONCLUSION

The aim of this study was to determine hospice caregivers' perceptions and reported practices in the management of dysphagia in individuals with neurodegenerative disorders. The results obtained have numerous significant clinical and theoretical implications regarding current dysphagia management in the South African hospice setting. The current study was only the first step and now that the hospice caregivers' perceptions and practices have been described, steps can be taken to improve dysphagia management in the hospice setting.

6 REFERENCES

- Albrecht, G., Freeman, S., & Higginbotham, N. 1998. Complexity and human health: the case for a transdisciplinary paradigm. *Culture, Medicine and Psychiatry* 22, 55–92.
- Alford, B.R. The Bobby, R. Disorders of Speech and Swallowing. *Alford Department of Otohinolaryngology and Communication Sciences, Baylor College of Medicine*. Retrieved August 10, 2005 from http://www.bcm.edu/oto/studs/speech.html.
- American Speech-Language-Hearing Association. 2001. Roles of speech language pathologists in swallowing and feeding disorders: technical report. *ASHA 2002 Desk Reference* 3, 181-199.
- American Speech-Language-Hearing Association. 2002. Roles of speech language pathologists in swallowing and feeding disorders: position statement. *ASHA Supplement* 22, 73*.*
- American Speech-Language Hearing Association. 2004. Speech-language pathologists training and supervising other professionals in the delivery of services to individuals with swallowing and feeding disorders: technical report. *ASHA Supplement* 24, 131-134.
- American Speech-Language Hearing Association. *Swallowing Problems in Adults.* Retrieved March 5, 2005 from www.asha.org/public/speech/swallowing/Swallowing-Disorders-in-Adults.htm.
- Atwal, A., & Caldwell, K. 2006. Nurses' perceptions of multidisciplinary team work in acute health-care. *International Journal of Nursing Practice.* 12: 359-365.
- Babbie, E., & Mouton, J. 2001. *The practice of social research: the South African edition.* Cape Town: Oxford University Press Southern Africa.
- Babbie, E. 1998. *The practice of social research*. London: Wadsworth Publishing Company.
- Bakheit, A.M.O. 2001. Management of neurogenic dysphagia. *Postgraduate Medical Journal,* 77, 694-699.
- Balducci, L., Lyman, G.H., & Ershler, W.B. 2004. *Comprehensive geriatric oncology*. Amsterdam: Taylor & Francis.
- Beck, S. 1999. Health policy, health services, and cancer pain management in the new South Africa. *Journal of Pain and Symptom Management* ,17(1), 16-26.

- Bielefeldt, K. 2004. *Muscular dystrophy and dysphagia*. Retrieved November 20, 2007 from www.vh.org/adult/provider/internalmedicine/GIcases/Esophageal/Dysphagia/Dysphagia.htm
- Billet, S. 2000. Guided learning at work. *Journal of Workplace Learning,* 12(7), 272-285.
- Bird, M.R. 1994. Asymptomatic swallowing disorders in elderly patients with Parkinson's disease: A description of findings on clinical examination and videoflouroscopy in sixteen patients. *Age and Ageing,* 23(3), 251-253.
- Bisch, E.M., Logemann, J.A., Rademaker, A.W., Kahrilas, P.J., & Clave, C.L. 1994. Pharyngeal effects of bolus volume, viscosity and temperature in patients with dysphagia resulting from neurologic impairment and in normal subjects*. Journal of Speech and Hearing Research,* 37, 1041-1049.
- Bourque, L., & Fielder, E. 2003. *How to conduct self-administered and mail surveys. The survey kit (Volume 3).* London: Sage Publications.
- Brace, I. 2004. *Questionnaire design*. London: Kogan Page Limited.
- Brodeur, D. 1991. *Is* a decision to forgo tube feeding for another a decision to kill? *Issues in Law & Medicine*, 6 (4), 395-407.
- Bryant, K.N., & Sharp, H.M. 2002. Ethical issues in dysphagia: when patients refuse assessment or treatment*. Seminars in Speech and Language*, 24(4), 285-299.
- Buchan, J. 1999. The 'greying' of the United Kingdom nursing workforce: implications for employment policy and practice. *Journal of Advanced Nursing,* 30 (4), 818-826.
- Calcagno, P., Ruoppolo, G., Grasso, M.G., De Vincentiis, M., & Paolucci, S. 2002. Dysphagia in multiple sclerosis – prevalence and prognostic factors*. Acta Neurol Scand.*105, 40–43.
- Carlisle, D. 2003. Africans dying of AIDS without pain relief. *British Medical Journal*, 327, 1069.
- Chadwick, D.D., Joliffe, J.J., & Goldbart, J. 2002. Carer knowledge of dysphagia management strategies. *International Journal of Language and Communication Disorders,* 37, 345-357.
- Chan, R., Ilaria, G., & Jacobs, J. 1996. Occupational therapy: bedside evaluation and treatment of dysphagia for people with HIV disease in the hospital. *Int Conf AIDS,* 11(A), 83.

- § Chang, C., & Lin, L. 2005. Effects of a feeding skills training programme on nursing assistants and dementia patients. *Journal of Clinical Nursing,* 14, 1185-1192.
- § Chapey, R. 2001. *Language intervention strategies in aphasia and related neurogenic communication disorders (fourth edition).* Baltimore: Lippincott Williams and Wilkins.
- § Cherney, L.R. 1994. *Clinical management of dysphagia in adults and children*. Gaithersburg: Aspen Publisher, Inc.
- § Cohen, L., Manion, L., & Morrison, K. 2000. *Research methods in education (fifth edition).* London: Routledge Falmer.
- § College of Audiologists and Speech-Language Pathologists of Ontario. *Preferred practice guidelines for dysphagia*. Retrieved July 9, 2005, from www.caslpo.com/english_site/DysphagiaDocument.Pdf.
- § Cooper, D., & Schindler, P. 2001. *Business research methods (seventh edition).* Boston: McGraw-Hill Irwin.
- § Cormack, D. 2000. *The research process in nursing.* Cornwall: Blackwell Publishing.
- § Corner, J. 2003. The multidisciplinary team – fact or fiction. *Journal of Palliative Care,* 10(2), Supplement.
- § Daniels, S.K. 2000. Optimal patterns of care for dysphagic stroke patients. *Seminars in Speech and Language*, 21(4), 323-331.
- § Davis, L.A., & Conti, G.J. 2003. Speech-language pathologists' role and perception levels related to non-oral feeding. *Journal of Medical Speech-Language Pathology,* 11(1), 15-30.
- § Department of Health. 2003. *Full report of the Joint Health and Treasury Task Team Charged with Examining Treatment Options to Supplement Comprehensive Care for HIV/AIDS in the Public Health Sector.* Department of Health.
- § De Vos, A.S. 1998. *Research at grass roots.* Pretoria: Van Schaik.
- § Dharmarajan, T.S., & Unnikrishnan, D. 2004. Tube feeding in the elderly. *Postgraduate Medicine*, 115 (2), 51-61.
- § Dikeman, K.J., & Kazandjian, M.S. 2003. *Communication and swallowing management of tracheostimized and ventilator-dependent adults (second edition).* San Diego: Thomas Delmar Learning.

- Duffy, J.R. 1995. *Motor speech disorders: Substrates, differential diagnosis and management.* St Louis: Mosby.
- Dworzanowski, B. 2002. Caring for people dying of AIDS: lessons learnt from hospices. *Society of Transition,* 33 (3), 420-431.
- Eagly, A.H., & Chaiken, S. 1993. *The psychology of attitudes.* Fort Worth: Harcourt Brace Jovanovich.
- Ekberg, O. 2000. Diagnostic aspects of dysphagia. *Acta Otolaryngal. Supplement*, 543, 225-228.
- Ekberg, O., Hamdy, S., Woisard, V., Wuttge-Hannig, A., & Ortega, P. 2000. Social and psychological burden of dysphagia: its impact on diagnosis and treatment. *Dysphagia,* 17, 139-146.
- Evans, J. 1997. Men in nursing: issues of gender segregation and hidden advantage. *Journal of Advanced Nursing,* 26, 226-231.
- Fair, L., & Louw, B. 1999. Early communication intervention within a community-based intervention model in South Africa. *The South African Journal for Communication Disorders,* 46, 13-16.
- Fairview Health Services. 1999. *The family handbook of hospice care.* Minneapolis: Fairview Press.
- Farrell, Z., & O'Neill, D. 1999. Towards better screening and assessment of oropharyngeal swallow disorders in the general hospital. *Lancet*, (1999), 355-356.
- Faull, C., Carter, Y., & Woof, R. 1998. *Handbook of palliative care*. Oxford: Blackwell Publishing.
- Ferrell, B., & Coyle, N. 2005. *Textbook of palliative nursing*. New York: Oxford University Press Inc.
- Fey, M.E., & Johnson, B.W. 1998. Research to practice (and back again) in speech-language intervention. *Topics in Language Disorders*, 18, 23-34.
- Fitzgibbons, G. 2001. *Simplified diet manual (ninth edition).* Iowa: Blackwell Publishing.
- Floyd, J., & Fowler, J.R. 2002. *Survey research methods (third edition).* London: Sage Publications.
- Foley, K.M., Aulino, F., & Stjernsward. 2003. *Palliative Care in Resource-Poor Settings*. *Clinical Guide to Supportive and Palliative Care for HIV/AIDS*. Washington: Health Resources and Services Administration.

- § Folstein, M. 1998. *Neurobiology of primary dementia*. Washington: American Psychiatric Press.
- § Frazer, L., & Lawley, M. 2000. *Questionnaire design and administration.* Australia: Jon Wiley & Sons.
- § Gage, H., & Storey, L. 2004. Rehabilitation for Parkinson's disease: a systematic review of available evidence. *Clinical Rehabilitation,* 18, 462-482.
- § Gessert, C.E., & Calkins, D.R. 2001. Rural-urban differences in end-of-life care: The use of feeding tubes. *Journal of Rural Health,* 17(1),16-24.
- § Glassburn, D.L., & Deem, J.F. 1998. Thickener viscosity in dysphagia management: Variability among speech-language pathologists. *Dysphagia,* 13, 218-222.
- § Goulding, R., & Bakheit, A.M.O. 1999. Evaluation of the benefits of monitoring fluid thickness in the dietary management of dysphagic stroke patients. *Clinical Rehabilitation,* 14, 119–124.
- § Gwyther, L. 2002. *Palliative care in resource constrained settings: living with HIV/AIDS and other life threatening diseases.* Paper presented at the 14th International Congress on the Care of Terminally Ill, Montreal, Canada.
- § Hadjikoutis, S., & Wiles, C.M. 2001. Venous serum chloride and bicarbonate measurements in the evaluation of respiratory function in motor neuron disease. *QJM,* 94, 491-495.
- § Halberg, I.R., Ohlsson, O., & Westergren, A. 1999. Nursing assessment of dysphagia among patients with stroke. *Scandinavian Journal of Caring Sciences,* 13, 274-282.
- § Hall, P., & Weaver, L. 2001. Interdisciplinary education and teamwork: a long and winding road. *Medical Education,* 35, 867-875.
- § Hallenbeck, J. 2002. Tube feed or not tube feed? *Journal of Palliative Medicine,* 5 (6), 909-910.
- § Halvorsen, R.A., Moelleken, S.M., & Kearney, A.T. 2003. Videofluoroscopic evaluation of HIV/AIDS patients with swallowing dysfunction. *Abdominal Imaging*, 28(2), 244-247.
- § Health Services/Technology Assessment Text. *Diagnosis and treatment of swallowing disorders (dysphagia) in acute-care stroke patients.* Retrieved August 5, 2004 from http://www.ahcpr.gov.

§ HealthAtoZ.com. *Muscular dystrophy.* Retrieved March 5, 2005 from www.healthatoz.com/healthAtoZ/common/standard/transform.jsp?requestURI=/healthatoz/AtoZ/ency/muscular_dystrophy.jsp.

§ Hind, N. P., & Wiles, C. M. 1998. Assessment of swallowing and referral to speech and language therapists in acute stroke. *Q J Med, 98*, 829-835.

§ HIV Insite Perceptions Base. *Neurologic manifestations of HIV.* Retrieved July 30, 2004 from hivinsite.ucsf.edu/InSite?page=kb-04-01-2.

§ Hoefler, J.M. 2000. Making decisions about tube feeding for severely demented patients at the end of life: clinical, legal and ethical. *Death Studies,* 24(3), 233-255.

§ Hospice Palliative Care Association of South Africa. *Palliative care.* Retrieved March 17, 2004 from http://www.hospicepalliativecaresa.co.za.

§ Hospice Palliative Care Association of South Africa. *Hospice nationwide.* Retrieved January 4, 2005 from http://www.hospicepalliativecaresa.co.za.

§ Hospice Palliative Care Association of South Africa. *HPCA member hospices patient load by province.* Retrieved August 9, 2008 from http://www.hospicepalliativecaresa.co.za/MER_stats.htm.

§ Hoyle, R.H., Harris, M.J., & Judd, C.M. 2002. *Research methods in social relations (seventh edition)*. London: Wadsworth.

§ Huckabee, M.L., & Pelletier, C.A. 1999. *Management of adult neurogenic dysphagia.* San Diego: Singular Publishing Group.

§ Ippolito, G., Galati, V., Serraino, D., & Girardi, E. 2001. The changing picture of the HIV/AIDS epidemic. *Annals of the New York Academy of Sciences,* 946, 1-12.

§ Ishwarduth, N. 2004. *An investigation into the nature of hospital-based dysphagia services for adults in South Africa.* Unpublished Masters Thesis, Department of Communication Pathology, University of Kwazulu-Natal: South Africa.

§ Johnson, J.Y., & Smith-Temple, J. 2005. *Nurses' guide to clinical procedures.* Philadelphia: Lippincott.

§ Kaiser, C.M., Williams, K.B., Mayberry, W., Braun, J., & Pozek, K.D. 2000. Effect of an oral health training programme on knowledge and behaviour of state agency long-term-care surveyors. *Special Care in Dentistry,* 20(2), 66-70.

§ Karim, Q., & Karim, S. 2005. *HIV/AIDS in South Africa.* Cape Town: Cambridge University Press.

- § Karus, D., Raveis, V.H., Alexander, C., Hanna, B., Selwyn, P., Marconi, K., & Higginson, I. 2005. Patient reports of symptoms and their treatment at three palliative care projects servicing individuals with HIV/AIDS. *Journal of Pain and Symptom Management,* 30(5), 408-417.
- § Kayser-Jones, J., & Pengilly, K. 1999. Dysphagia among nursing home residents. *Geriatric Nursing,* 20(2), 77-84.
- § Kimmel, A.J. 1998. *Ethics and values in applied social research.* London: Sage.
- § Kirker, F.J., & Oliver, D.J. 2003. The development and implementation of a standardized policy for the management of dysphagia in motor neuron disease. *Palliative Medicine*, 17, 322-326.
- § Kritzinger, A.M. 2000. *Establishing a computer-based data system for early communication intervention in South Africa.* Unpublished doctoral dissertation, University of Pretoria: South Africa.
- § Leedy, P., & Ormond, J. 2001. *Practical research planning and design (seventh edition)*. New Jersey: Prentice Hall.
- § Leonard, R., & Kendall, K. 2007. *Dysphagia assessment and treatment planning a team approach (second edition).* New Jersey: Plural Publishing Inc.
- § Letsholo, P.J. 2000. *Nurses' training regarding the identification and management of dysphagia.* Unpublished undergraduate dissertation, University of Pretoria: South Africa.
- § Letvak, S. 2002. Retaining the older Nurse. *Journal of Nursing Administration,* 32(7/8), 387-392.
- § Lewison, G., & Carding, P. 2003. Evaluating UK research in speech and language therapy. *International Journal of Language & Communication Disorders,* 38, 65-84.
- § Lin, S.H., Lieu, P.K., Phau, S.Y., Seshadri, R., Venketasubramanian, N., Lee, S.H., & Choo, P.W. 2001. Accuracy of bedside clinical methods compared with fiberoptic endoscopic examination of swallowing (FEES) in determining the risk of aspiration in acute stroke patients. *Dysphagia*, 16 (1), 1-6.
- § Linden, P., Kuhlemeier, K.V., & Patterson, C. 1993. The probability of correctly predicting subglottic penetration from clinical observations. *Dysphagia,* 8, 170-179.
- § Lipner, H. S., Bosler, J., & Giles, G. 1990. Volunteer participation in feeding residents: training and supervision in a long-term care facility. *Dysphagia,* 5, 89-95.

- § Logemann, J.A., & Pauloski, B. R. 1995. Effects of a sour bolus on oropharyngeal swallowing measures in patients with neurogenic dysphagia. *Journal of Speech & Hearing Research*, 38 (3), 556-563.
- § Logemann, J.A. 1998. *Evaluation and treatment of swallowing disorders*. Texas: Pro-Ed.
- § Logemann, J.A. 2007*.* Oropharyngeal dysphagia and nutritional management. *Current Opinion in Clinical Nutrition and Metabolic Care*,10 (5), 611-614.
- § Louw, D.A., Louw, A.E., & Van Ede, D.M. 1999. *Human development (second edition).* Pretoria: Kagiso Publishers.
- § Lugton, J., & Kindlen, M. 1999. *Palliative care: the nursing role.* Edinburgh: Churchill Livingstone.
- § Magnus, V. 2001. Dysphagia training for nurses in an acute hospital setting: a pragmatic approach. *International Journal of Language and Communication Disorders,* 36 (Supplement 2001), 375-380.
- § Mari, F., Matei, M., Ceravolo, M.G., Pisani, A., Montessi, A., & Provinciali, L. 1997. Predictive value of clinical indices in detecting aspiration in patients with neurological disorders. *Journal of Neurology,* 63, 456-460.
- § Marelli, T. 1999. *Hospice and palliative care handbook*. Florida: Mosby.
- § Martens, L., Cameron, T., & Simonsen, M. 1990. Effects of a multidisciplinary management program on neurologically impaired patients with dysphagia. *Dysphagia,* 5, 147-151.
- § Martin, A.W. 1991. Dietary management of swallowing disorders. *Dysphagia,* 6,129-134.
- § Martin, P., & Pierce, R. 1994*. Practical statistics for the health sciences*. Melbourne: Thomas Nelson Publishing Company.
- § May, T. 2001. *Social research: issues, methods and process.* Buckingham: Open University Press.
- § McCullough, G.H. 1999. Clinicians' preferences and practices in conducting clinical/bedside and videofluoroscopic swallowing examinations in adult neurogenic population. *American Journal of Speech-Language Pathology,* 8, 149-163.
- § McCullough, G.H., Wertz, R.T., & Rosenbek, J.C. 2001. Sensitivity and specificity of clinical/bedside examination: signs for detecting aspiration in adults subsequent to stroke. *Journal of Communication Disorders*, 34 (1-2), 55-72.

- McHorney, C., & Rosenbek, J. 1998. Functional outcome assessment of adults with oropharyngeal dysphagia. *Seminars in Speech and Language*, 19 (3), 235-247.
- Meghani, S.H. 2004. A concept analysis of palliative care in the United States. *Journal of Advanced Nursing*, 46(2), 152-161.
- Mertz, G.J. 2005. Thickened liquids: practice patterns of speech-language pathologists. *American Journal of Speech-Language Pathology,* 14, 4-13.
- Mitsumoto, H., & Munsat, T.L. 2001. *Amyotrophic lateral sclerosis: a guide for patients and families.* New York: Demos Medical Publishing.
- Mohamed, S.E. 2005. Community service for health professionals to improve services. *Focus*, 1(2), article 4.
- Moodley, L., Louw, B., & Hugo, R. 2000. Early identification of at-risk infants and toddlers: a transdisciplinary model of service delivery. *Die Suid-Afrikaanse Tydskrif vir Kommunikasieafwykings,* 47, 25-39.
- Moothalugan, D. 2002. *Nurses' perceptions regarding the role of the speech-language pathologist in the management of dysphagia*. Unpublished undergraduate dissertation. University of Durban-Westville: South Africa.
- Mouton, J. 2001. *How to succeed in your master's and doctoral studies: A South African guide and resource book.* Pretoria: Van Schaik Publishers.
- Murry, T., & Carrau, R. 2001. *Clinical manual for swallowing disorders.* Pennsylvania: Singular Publishing Group.
- National Multiple Sclerosis Society Long Term Care Committee. *Nursing home care of individuals with multiple sclerosis: guidelines and recommendations for quality care.* Retrieved August 6, 2005 from http://www.nationalmssociety.org/docs/HOM/MS_nursing_guide.pdf
- Neuman, L. 2005. *Social research methods, qualitative and quantitative approaches (sixth edition)*. Boston: Allyn & Bacon.
- Nogueira, P.A. 2005. AIDS/HIV infection and cerebrovascular disease. *Seminars in Cerebrovascular Disease and Stroke,* 5 (1), 40-46.
- O'Loughlin, G., & Shanley, C. 1998. Swallowing problems in the nursing home: a novel training response. *Dysphagia*, 13, 172-183.
- Oliver, D., & Webb, S. 2000. The involvement of specialist palliative care in the care of people with motor neuron disease. *Palliative Medicine*, 14, 427-428.

- § Oliver, D. 1996. The quality of care and symptom control – the facts on the terminal phase of ALS/MND. *Journal of the Neurological Sciences,* 139 (Supplement), 134-136.
- § Ong, Y., Woo, K. T., Seong Ng, H., Tan, P., & Tang, O. 2004. *A clinical approach to medicine.* Singapore: World Scientific Publishing Company.
- § Paik, N. *Dysphagia.* Retrieved July 9, 2005 from http://www.emedicine.com/pmr/topic194.htm
- § Palmer, J.B., Drennan, J.C., & Baba, M. 2000. Evaluation and treatment of swallowing impairments. *American Family Physician*, 61(8), 2453-2471.
- § Pedretti, L. 1996. *Occupational therapy: practice skills for physical dysfunction.* California: Mosby.
- § Pelletier, C.A. 2004. What do certified nurse assistants actually know about dysphagia and feeding nursing home residents*. American Journal of Speech-Language Pathology,* 13, 99-113.
- § Penman, J.P., & Thomson, M. 1998. A review of the textured diets developed for the management of dysphagia. *Journal of Human Nutrition and Dietetics,* 11(1), 51-60.
- § Phillips, A., Bally, G., Craig, A., Flannery, J., Thomas, S., Veldhorst, G., & Garmaise, D. 1998. *AIDS care treatment and support program.* Toronto: The Wesley Central Hospital.
- § Pollens, R. 2004. Role of the speech-language pathologist in palliative hospice care. *Journal of Palliative Medicine,* 7(5), 694-701.
- § Post, S. 2001. Tube feeding and advanced progressive dementia. *Hastings Center Report,* 66(1), 36-42.
- § Ramritu, P., Finlayson, K., Mitchell, A., & Croft, G. 2000. *Identification and nursing management of dysphagia in individual with neurological impairment.* Australia: The Joanna Briggs Institute for Evidence Based Nursing and Midwifery.
- § Ramsey, D., Smithard, D., & Kalra, L. 2003. Early assessment of dysphagia and aspiration risk in acute stroke patients. *Stroke,* 34, 1252-1264.
- § Rasley, A., Logemann, J.A., Kahrilas, P.J., Rademaker, A.W., Pauloski, B.R., & Dodds, W.J. 1993. Prevention of barium aspiration during videoflouroscopic swallowing studies: value of change in posture. *AJR,* 160, 1005-1009.
- § Robinson, R. (Ed.).1999. *Gale Encyclopedia of Medicine*. Detroit: The Gale Group Inc.,

- Robinson, V.M., & Lai, M.K. 2005. *Practitioner research for educators: a guide to improving classrooms and schools*. California: Corwin Press.
- Rosenvinge, S.K., & Starke, I.D. 2005. Improving care for patients with dysphagia. *Age and Ageing,* 34 (6), 587-593.
- Rosser, M., & King, L. 2003. Transition experiences of qualified nurses moving into hospice nursing. *Journal of Advanced Nursing,* 43(2), 206-215.
- Rossetti, L.M. 2001. *Communication intervention, birth to three*. Australia: Thomas Learning.
- Schumacher, J.D. 2004. Hospice care in the United States. Business Briefing: Long Term Health Care. *Business Briefing,* (2004), 14-16.
- Sheehan, D.C., Forman, W.B., Kitzes, J.A., & Anderson, R.P. 2003. *Hospice and palliative care: concepts and practice (second edition).* Canada: Jones & Bartlett Publishers Inc.
- Shipley, K.G., & McAfee, J. 1998. *Assessment in speech-language pathology: a resource (second edition).* Kentucky: Singular Publishing Group, Inc.
- Sitoh, Y.Y., Lee, A., Phau, S.Y., Lieu, P.K., & Chan, S.P. 2000. Bedside assessment of swallowing: a useful screening tool for dysphagia in an acute geriatric ward. *Singapore Medical Journal,* 41 (8), 376-381.
- Smith, W.B. 1991. Is a decision to forgo tube feeding for another a decision to kill? *Issues in Law & Medicine,* 6, 385-394.
- Smithard, D.G., O' Neill, P.A., Park, C., England, R., Renwick, D.S., Wyatt, R., Morris, J., & Martin, D.F. 1998. Can bedside assessment reliably exclude aspiration following acute stroke? *Age and Ageing,* 27, 99-106.
- Smithard, D.G., O'Neill, P.A., Park, C., Morris, J., Wyatt, R., England, R., & Martin, D.F. 1996. Complications and outcome after acute stroke: does dysphagia matter? *Stroke,* 27, 1200-1204.
- Sonies, B.C. 2000. Patterns of care for dysphagic patients with degenerative neurological diseases. *Seminars in Speech and Language,* 21(4), 333-344.
- Spieker, M. 2000. Evaluating dysphagia. *American Family Physician*, 61(12), 3639-3648.
- Squires, N. 2006. Dysphagia management for progressive neurological conditions. *Nursing Standard,* 20 (29), 53-57.

- § Stewart, B., Allan S., Keane, B., Marshall, B., Ayling, J., & Luxford, T. 2006. Palliative care partnership: a successful model of primary/secondary integration. *Journal of the New Zealand Medical Association*, 119 (1242), 2235-2245.
- § Stipinovich, A. 2006. The management of adult dysphagia within the rural South African context. Paper presented at the 2002 North West Conference.
- § Thomas, B., & Bishop, J. 2007. *Manual of dietetic practice (third edition).* Oxford: Blackwell Science.
- § Tohara, H., Saitoh, E., Mays, K.A., Kuhlemeier, K., & Palmer, J.B. 2003. Three tests for predicting aspiration without videoflourography. *Dysphagia*, 18(2), 126-134.
- § UnderstandingMS.com. *Multiple Sclerosis: An Overview.* Retrieved January 16, 2004 from www.understandingms.com/ms/articles/overview.asp.
- § Uys, L.R. 2001. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing,* 11, 99-108.
- § Uys, L.R. 2003. Aspects of the care of people with HIV/AIDS in South Africa. *Public Health Nursing,* 20 (4), 271–280.
- § Van der Berg, R. 2003. *Mission statement*. Goldfields Hospice Association Newsletter 6 (November/December). Welkom: Author.
- § Volonté, M.A., Porta, M., & Comi, G. 2002. Clinical assessment of dysphagia in early Parkinson's disease. *Neurological Sciences,* 23, s121-s122.
- § Wagner, B., Ersek, M., & Riddel, S. 2003. *HPNA position statement artificial nutrition and hydration*. Pittsburgh: HPNA.
- § Wambaugh, J., & Bain, B. 2002. Make research methods an integral part of your clinical practice. *The ASHA Leader, 7*(21), 10-12.
- § Weindling, F. 2000. Speech-language pathology: a home care viewpoint. *American Journal of Speech Language Pathology,* 9, 99-106.
- § West, J.F., & Redstone, F. 2004. Feeding the adult with neurogenic disorders. *Topics in Geriatric Rehabilitation,* 20(2), 131-134.
- § West, J.F. 2004. Oral sensory influences on eating and swallowing in the neurogenic population. *Topics in Geriatric Rehabilitation,* 20(2), 135-138.
- § Wilkinson, D. 2000. *The researcher's toolkit.* London: Routledge Falmer.
- § Williams, B. 1991. Is a decision to forgo tube feeding for another a decision to kill? *Issues in Law & Medicine*, 6 (4), 385-395.

§ World Health Organization. 1990. *Cancer pain relief and palliative care.* Geneva: WHO.

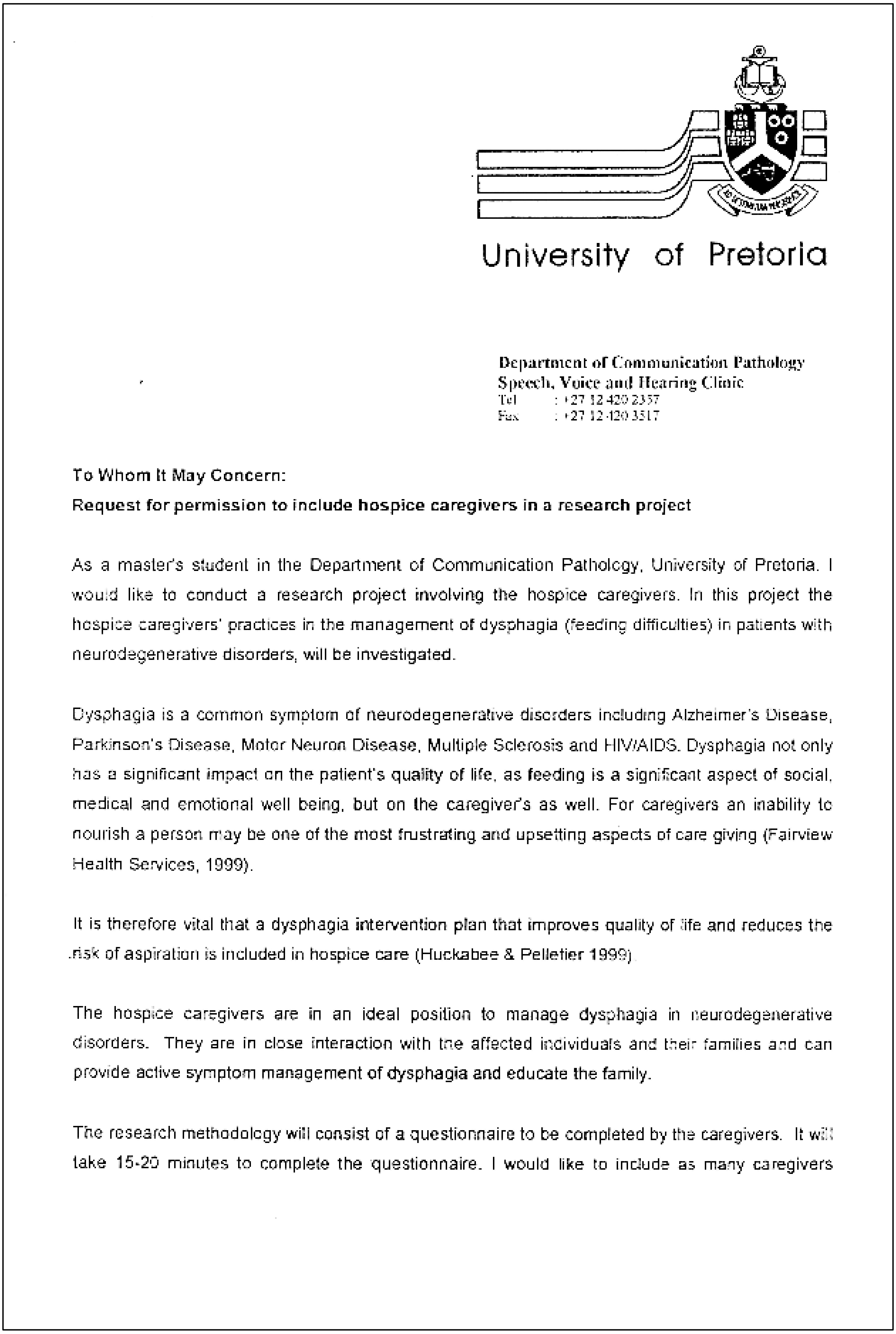
§ Worwood, A.M., & Leigh, P.N. 1998. Indicators and prevalence of malnutrition in motor neuron disease. *European Neurology,* 40, 159-163.

§ Wray, J., Aspland, J., Gibson, H., Stimpson, A., & Watson, R. 2007. The older nurses and midwives in the NHS. *Nursing Management* ,14 (8), 26-30.

§ Zerwekh, J. 2003. End-of-life hydration – benefit or burden? *Nursing*, 33(2), 32hn1-3

APPENDIX A

LETTER TO HOSPICE MANAGERS DETAILING RESPONDENTS SELECTION CRITERIA



University of Pretoria

Department of Communication Pathology
Speech, Voice and Hearing Clinic
Tel : +27 12 420 2357
Fax : +27 12 420 3517

To Whom It May Concern:

Request for permission to include hospice caregivers in a research project

As a master's student in the Department of Communication Pathology, University of Pretoria, I would like to conduct a research project involving the hospice caregivers. In this project the hospice caregivers' practices in the management of dysphagia (feeding difficulties) in patients with neurodegenerative disorders, will be investigated.

Dysphagia is a common symptom of neurodegenerative disorders including Alzheimer's Disease, Parkinson's Disease, Motor Neuron Disease, Multiple Sclerosis and HIV/AIDS. Dysphagia not only has a significant impact on the patient's quality of life, as feeding is a significant aspect of social, medical and emotional well being, but on the caregiver's as well. For caregivers an inability to nourish a person may be one of the most frustrating and upsetting aspects of care giving (Fairview Health Services, 1999).

It is therefore vital that a dysphagia intervention plan that improves quality of life and reduces the risk of aspiration is included in hospice care (Huckabee & Pelletier 1999).

The hospice caregivers are in an ideal position to manage dysphagia in neurodegenerative disorders. They are in close interaction with the affected individuals and their families and can provide active symptom management of dysphagia and educate the family.

The research methodology will consist of a questionnaire to be completed by the caregivers. It will take 15-20 minutes to complete the questionnaire. I would like to include as many caregivers involved in the management of individuals with neurodegenerative disorders as possible in order to obtain a representative sample. Caregivers who act as respondents will remain anonymous.

To meet the requirements of this study the caregivers who participate in the study must have one or more of the following qualifications: nursing degree, nursing diploma, short course in palliative nursing, HPCA community caregiving course, diploma in palliative medicine or an MPhil in palliative medicine.

The results of the research will determine whether the hospice caregivers require additional training in the management of dysphagia and if so what information needs to be included in the training.

Upon completion of the research a copy of the research report will on request be made available to you and caregivers who participate in the study.

I hope that this request to involve the hospice caregivers in my research will meet your approval.

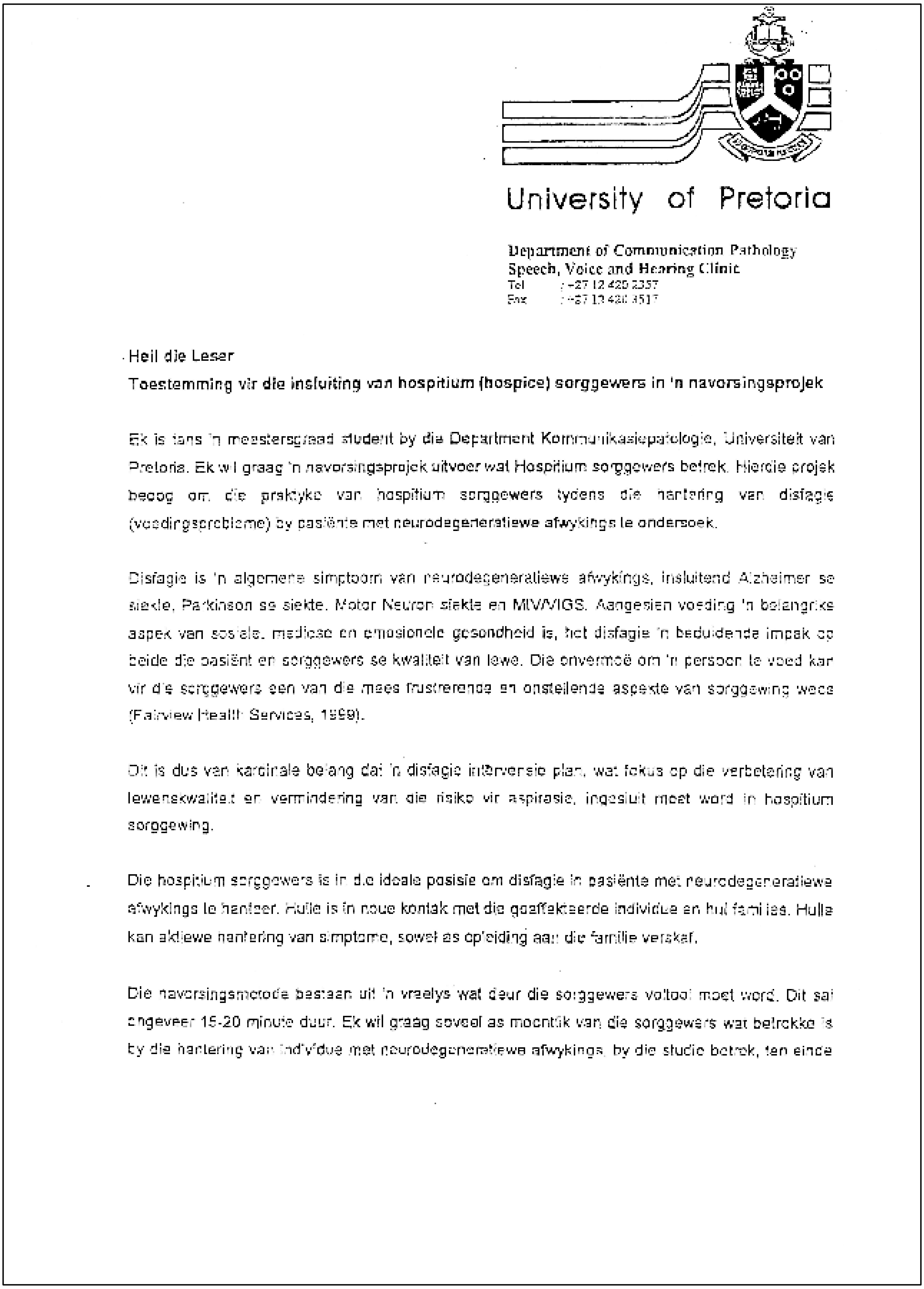
Your co-operation is highly appreciated.

Yours sincerely

Angelique Robertson
M Communication Pathology student
Department of Communication Pathology
University of Pretoria

a. Kritzinger
Dr A Kritzinger
Supervisor

B Louw
Prof B Louw
Head: Department of Communication Pathology
University of Pretoria



University of Pretoria

Department of Communication Pathology
Speech, Voice and Hearing Clinic
Tel : +27 12 420 2357
Fax : +27 12 420 3517

Heil die Leser

Toestemming vir die insluiting van hospitium (hospice) sorggewers in 'n navorsingsprojek

Ek is tans 'n meestersgraad student by die Department Kommunikasiepatologie, Universiteit van Pretoria. Ek wil graag 'n navorsingsprojek uitvoer wat Hospitium sorggewers betrek. Hierdie projek beoog om die praktyke van hospitium sorggewers tydens die hantering van disfagie (voedingsprobleme) by pasiënte met neurodegeneratiewe afwykings te ondersoek.

Disfagie is 'n algemene simptoom van neurodegeneratiewe afwykings, insluitend Alzheimer se siekte, Parkinson se siekte, Motor Neuron siekte en MIV/VIGS. Aangesien voeding 'n belangrike aspek van sosiale, mediese en emosionele gesondheid is, het disfagie 'n beduidende impak op beide die pasiënt en sorggewers se kwaliteit van lewe. Die onvermoë om 'n persoon te voed kan vir die sorggewers een van die mees frustrerende en ontstellende aspekte van sorggewing wees (Fairview Health Services, 1999).

Dit is dus van kardinale belang dat 'n disfagie intervensie plan, wat fokus op die verbetering van lewenskwaliteit en vermindering van die risiko vir aspirasie, ingesluit moet word in hospitium sorggewing.

Die hospitium sorggewers is in die ideale posisie om disfagie in pasiënte met neurodegeneratiewe afwykings te hanteer. Hulle is in noue kontak met die geaffekteerde individue en hul families. Hulle kan aktiewe hantering van simptome, sowel as opleiding aan die familie verskaf.

Die navorsingsmetode bestaan uit 'n vraelys wat deur die sorggewers voltooi moet word. Dit sal ongeveer 15-20 minute duur. Ek wil graag soveel as moontlik van die sorggewers wat betrokke is by die hantering van individue met neurodegeneratiewe afwykings, by die studie betrek, ten einde 'n verteenwoordigende steekproef te verkry. Sorggewers wat aan die studie deelneem sal anoniem bly.

Om aan die vereistes van hierdie studie te voldoen, moet sorggewers wat deelneem aan die studie, oor een of meer van die volgende kwalifikasies beskik: 'n graad in verpleegkunde, diploma in verpleegkunde, kort kursus in palliatiewe verpleging, HPCA gemeenskapsorggewingskursus, diploma in palliatiewe medikasie of MPhil in palliatiewe medikasie.

Die resultate van hierdie navorsing sal bepaal of hospitium sorggewers verdere opleiding in die hantering van disfagie benodig en, indien wel, watter inligting in die opleiding ingesluit moet word.

By voltooiing van die navorsing sal 'n kopie van die navorsingsverslag op versoek aan u en die sorggewers wat aan die studie deelgeneem het, beskikbaar wees.

Ek hoop dat hierdie versoek om die hospitium sorggewers by my navorsingsprojek te betrek u goedkeuring sal wegdra.

U samewerking sal waardeer word

Vriendelike groete

Angelique Robertson
MKommunikasiepatologie student
Departement Kommunikasiepatologie
Universiteit van Pretoria

A. Kritzinger
Dr A Kritzinger
Studieleier

B Louw
Prof B Louw
Hoof: Departement Kommunikasiepatologie
Universiteit van Pretoria

APPENDIX B

INTRODUCTORY LETTER TO RESPONDENTS

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

INTRODUCTORY INFORMATION ABOUT THE GOAL OF THE STUDY

Your time and effort in participating in this study is highly appreciated.

The goal of the study is to investigate hospice caregivers' management practices of dysphagia as a symptom of neurodegenerative disorders, in order to determine whether additional training is required and in what areas this training needs to be given.

The results of the study will on request be made available to the caregivers who participate in the study.

You will remain anonymous throughout the study as your name and workplace will be unknown to the researcher, since the questionnaires are numbered and respondents' names are not filled in. Your letter with informed consent will be kept confidential.

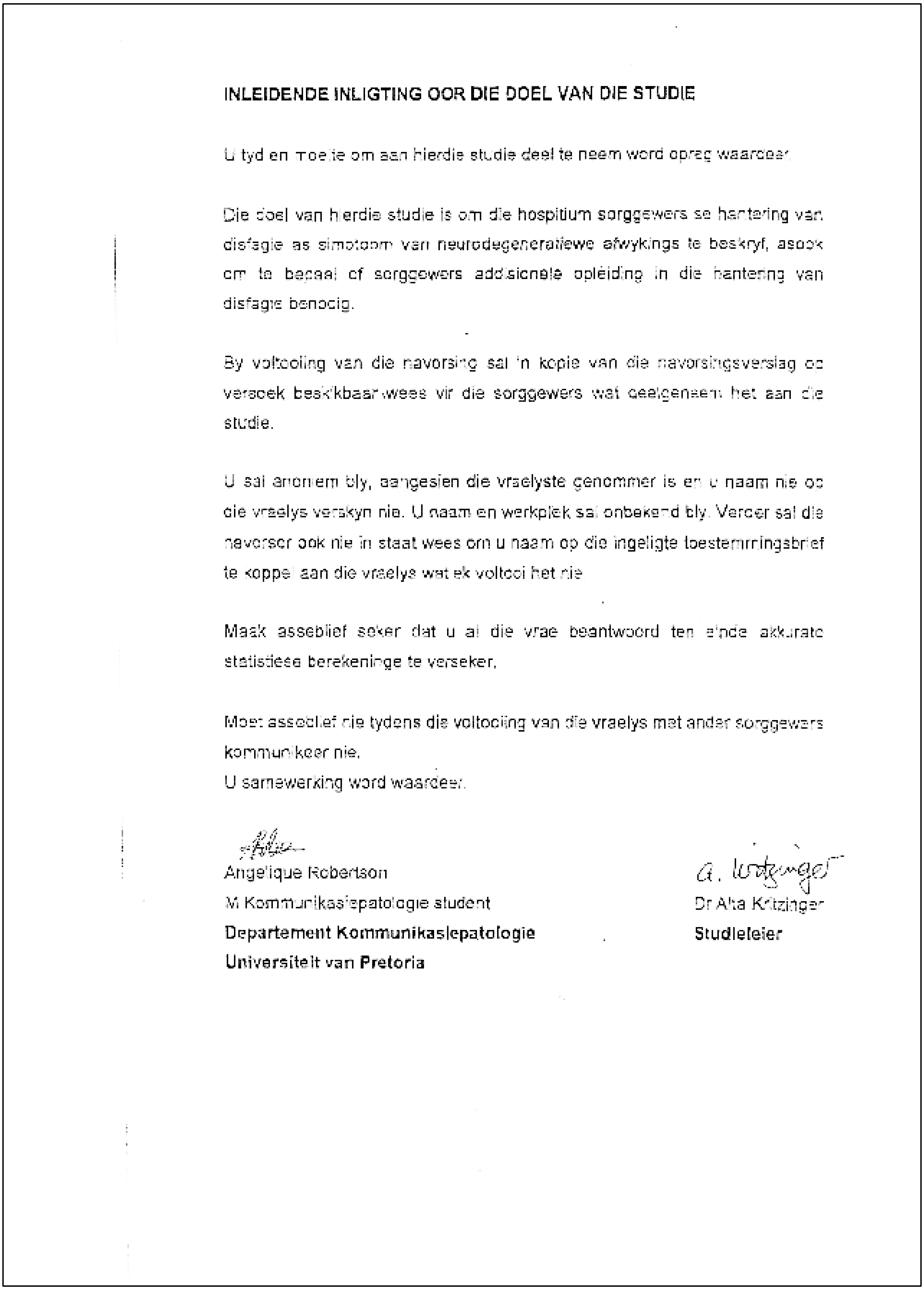
Please make sure that you answer all the questions to ensure accurate statistical calculations.

Please do not communicate with other caregivers during the completion of the questionnaire.

Thank-you for your co-operation

Angelique Robertson
MCommunication Pathology student
Department of Communication Pathology
University of Pretoria

a. Kritzinger
Dr Alta Kritzinger
Supervisor



INLEIDENDE INLIGTING OOR DIE DOEL VAN DIE STUDIE

U tyd en moeite om aan hierdie studie deel te neem word opreg waardeer.

Die doel van hierdie studie is om die hospitium sorggewers se hantering van disfagie as simptoom van neurodegeneratiewe afwykings te beskryf, asook om te bepaal of sorggewers addisionele opleiding in die hantering van disfagie benodig.

By voltooiing van die navorsing sal 'n kopie van die navorsingsverslag op versoek beskikbaar wees vir die sorggewers wat deelgeneem het aan die studie.

U sal anoniem bly, aangesien die vraelyste genommer is en u naam nie op die vraelys verskyn nie. U naam en werkplek sal onbekend bly. Verder sal die navorser ook nie in staat wees om u naam op die ingeligte toestemmingsbrief te koppel aan die vraelys wat ek voltooi het nie.

Maak asseblief seker dat u al die vrae beantwoord ten einde akkurate statistiese berekeninge te verseker.

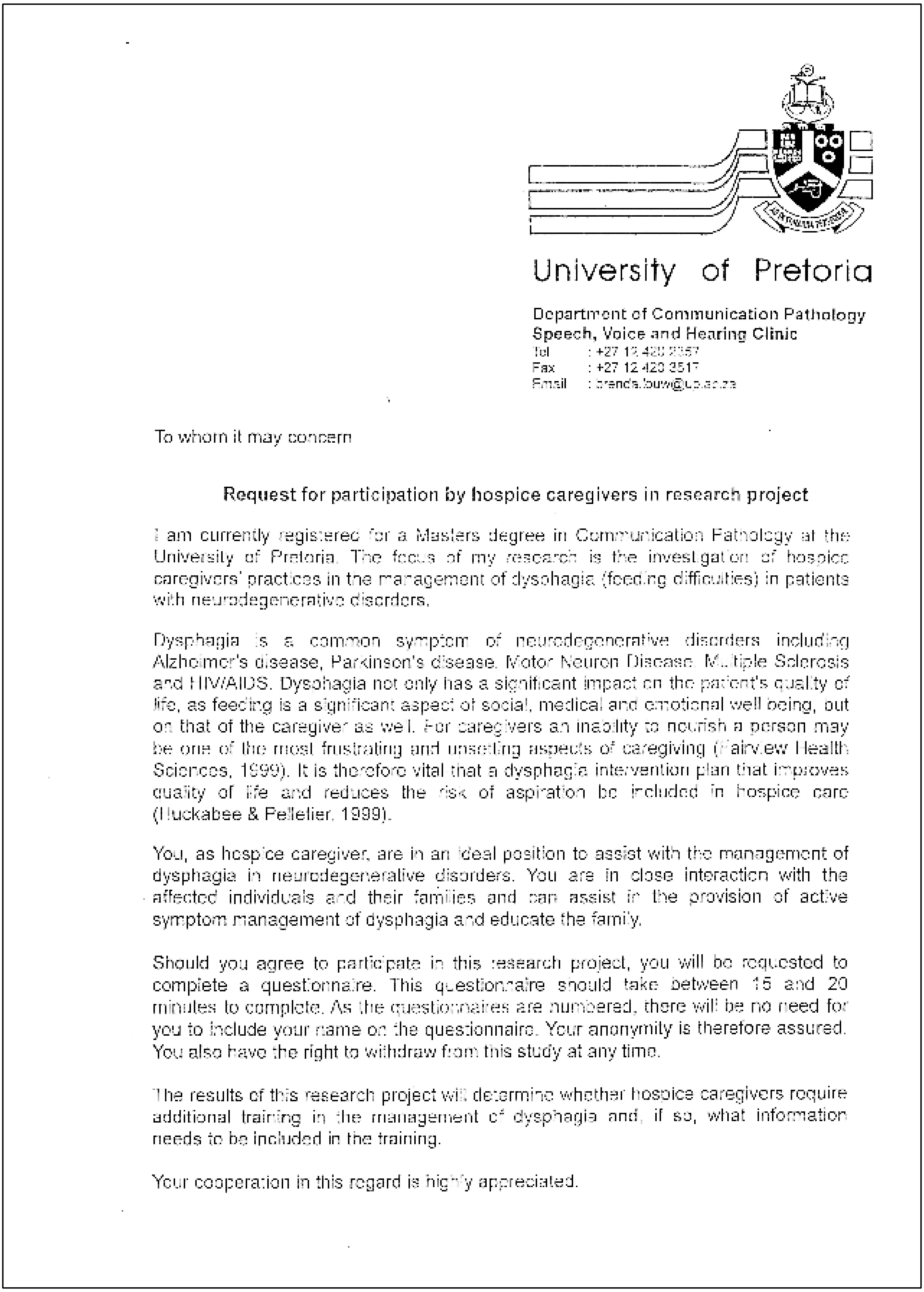
Moet asseblief nie tydens die voltooiing van die vraelys met ander sorggewers kommunikeer nie.
U samewerking word waardeer.

Angelique Robertson
M Kommunikasiepatologie student
Departement Kommunikasiepatologie
Universiteit van Pretoria

a. Kritzinger
Dr Alta Kritzinger
Studieleier

APPENDIX C

LETTER TO RESPONDENTS REQUESTING THEIR PARTICIPATION IN THE STUDY



University of Pretoria

Department of Communication Pathology
Speech, Voice and Hearing Clinic
Tel : +27 12 420 2357
Fax : +27 12 420 3517
Email : brenda.louw@up.ac.za

To whom it may concern

Request for participation by hospice caregivers in research project

I am currently registered for a Masters degree in Communication Pathology at the University of Pretoria. The focus of my research is the investigation of hospice caregivers' practices in the management of dysphagia (feeding difficulties) in patients with neurodegenerative disorders.

Dysphagia is a common symptom of neurodegenerative disorders including Alzheimer's disease, Parkinson's disease, Motor Neuron Disease, Multiple Sclerosis and HIV/AIDS. Dysphagia not only has a significant impact on the patient's quality of life, as feeding is a significant aspect of social, medical and emotional well being, but on that of the caregiver as well. For caregivers an inability to nourish a person may be one of the most frustrating and unsettling aspects of caregiving (Fairview Health Sciences, 1999). It is therefore vital that a dysphagia intervention plan that improves quality of life and reduces the risk of aspiration be included in hospice care (Huckabee & Pelletier, 1999).

You, as hospice caregiver, are in an ideal position to assist with the management of dysphagia in neurodegenerative disorders. You are in close interaction with the affected individuals and their families and can assist in the provision of active symptom management of dysphagia and educate the family.

Should you agree to participate in this research project, you will be requested to complete a questionnaire. This questionnaire should take between 15 and 20 minutes to complete. As the questionnaires are numbered, there will be no need for you to include your name on the questionnaire. Your anonymity is therefore assured. You also have the right to withdraw from this study at any time.

The results of this research project will determine whether hospice caregivers require additional training in the management of dysphagia and, if so, what information needs to be included in the training.

Your cooperation in this regard is highly appreciated.

For further information, please do not hesitate to contact me at 082 907 4468.

Yours sincerely

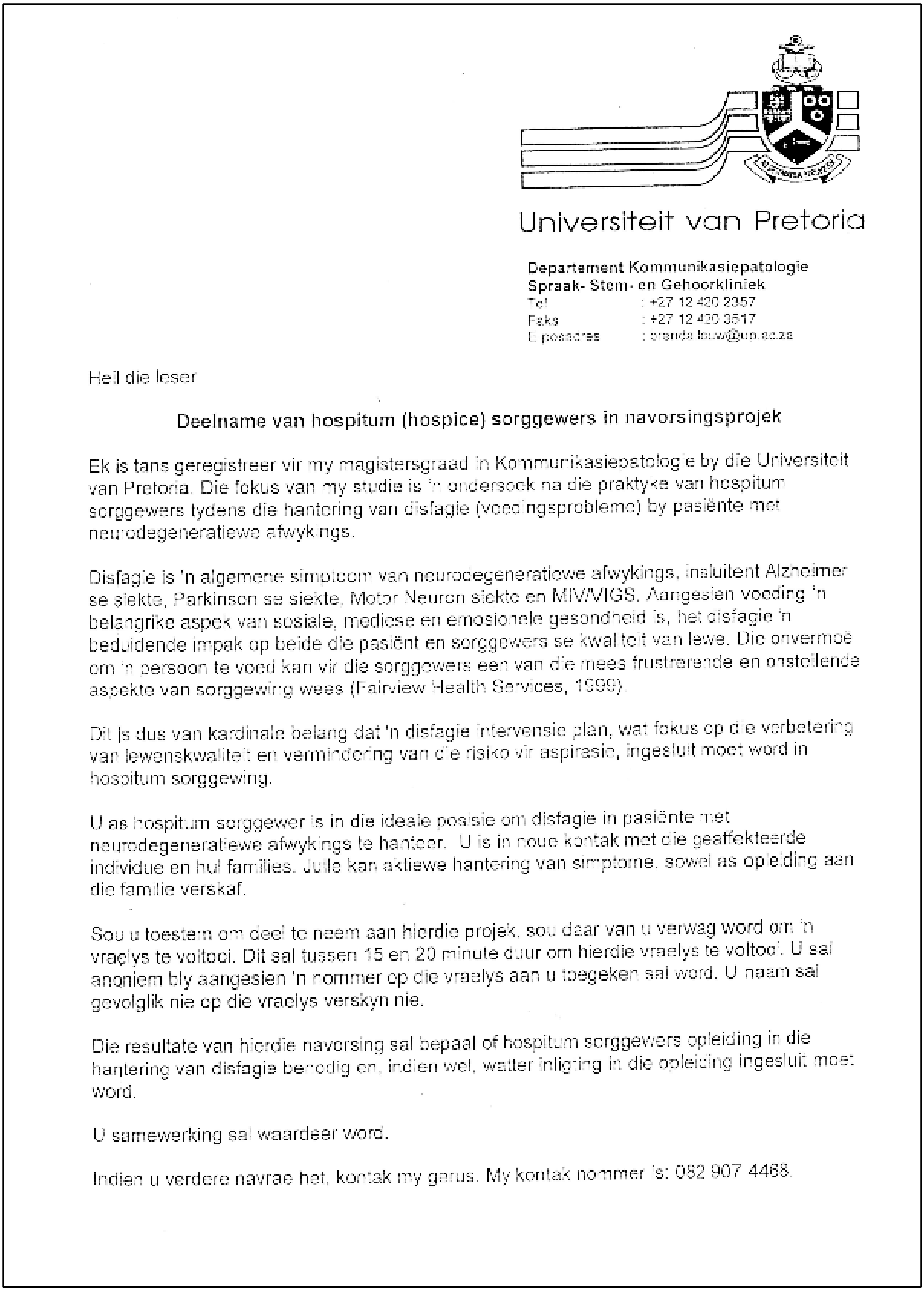
a. m. kritzinger

Angelique Robertson
M Communication pathology Student
Department of Communication Pathology

Dr A Kritzinger
Supervisor

BLouw

Prof B Louw
Head: Department of Communication Pathology
University of Pretoria



Universiteit van Pretoria

Departement Kommunikasiepatologie
Spraak- Stem- en Gehoorkliniek
Tel : +27 12 420 2357
Faks : +27 12 420 3517
E-posadres : brenda.louw@up.ac.za

Heil die leser

Deelname van hospitum (hospice) sorggewers in navorsingsprojek

Ek is tans geregistreer vir my magistersgraad in Kommunikasiepatologie by die Universiteit van Pretoria. Die fokus van my studie is 'n ondersoek na die praktyke van hospitum sorggewers tydens die hantering van disfagie (voedingsprobleme) by pasiënte met neurodegeneratiewe afwykings.

Disfagie is 'n algemene simptoom van neurodegeneratiewe afwykings, insluitent Alzheimer se siekte, Parkinson se siekte, Motor Neuron siekte en MIV/VIGS. Aangesien voeding 'n belangrike aspek van sosiale, mediese en emosionele gesondheid is, het disfagie 'n beduidende impak op beide die pasiënt en sorggewers se kwaliteit van lewe. Die onvermoë om 'n persoon te voed kan vir die sorggewers een van die mees frustrerende en ontstellende aspekte van sorggewing wees (Fairview Health Services, 1999).

Dit is dus van kardinale belang dat 'n disfagie intervensie plan, wat fokus op die verbetering van lewenskwaliteit en vermindering van die risiko vir aspirasie, ingesluit moet word in hospitum sorggewing.

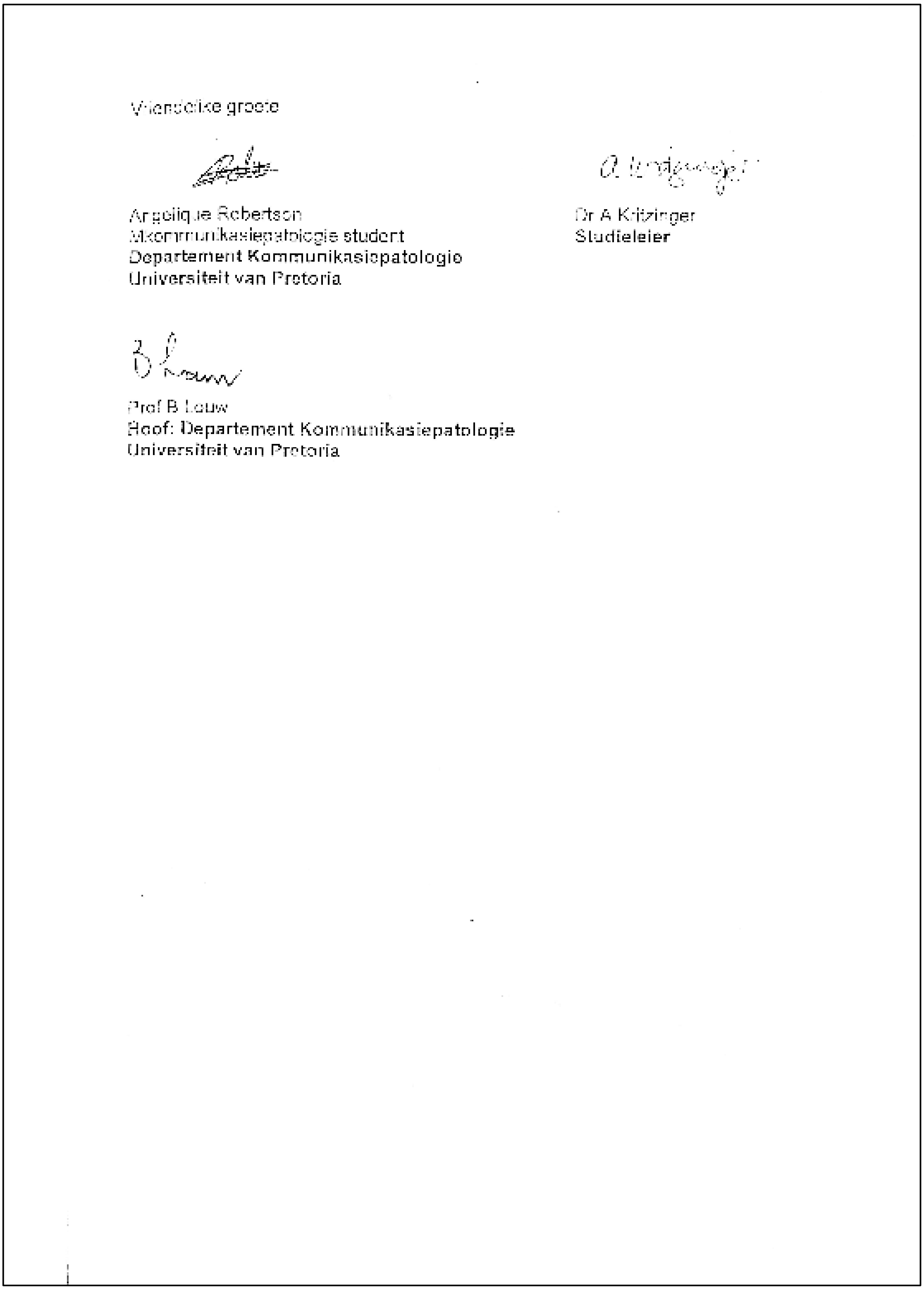
U as hospitum sorggewer is in die ideale posisie om disfagie in pasiënte met neurodegeneratiewe afwykings te hanteer. U is in noue kontak met die geaffekteerde individue en hul families. Julle kan aktiewe hantering van simptome, sowel as opleiding aan die familie verskaf.

Sou u toestem om deel te neem aan hierdie projek, sou daar van u verwag word om 'n vraelys te voltooi. Dit sal tussen 15 en 20 minute duur om hierdie vraelys te voltooi. U sal anoniem bly aangesien 'n nommer op die vraelys aan u toegeken sal word. U naam sal gevolglik nie op die vraelys verskyn nie.

Die resultate van hierdie navorsing sal bepaal of hospitum sorggewers opleiding in die hantering van disfagie benodig en, indien wel, watter inligting in die opleiding ingesluit moet word.

U samewerking sal waardeer word.

Indien u verdere navrae het, kontak my gerus. My kontak nommer is: 082 907 4468.



Vriendelike groete

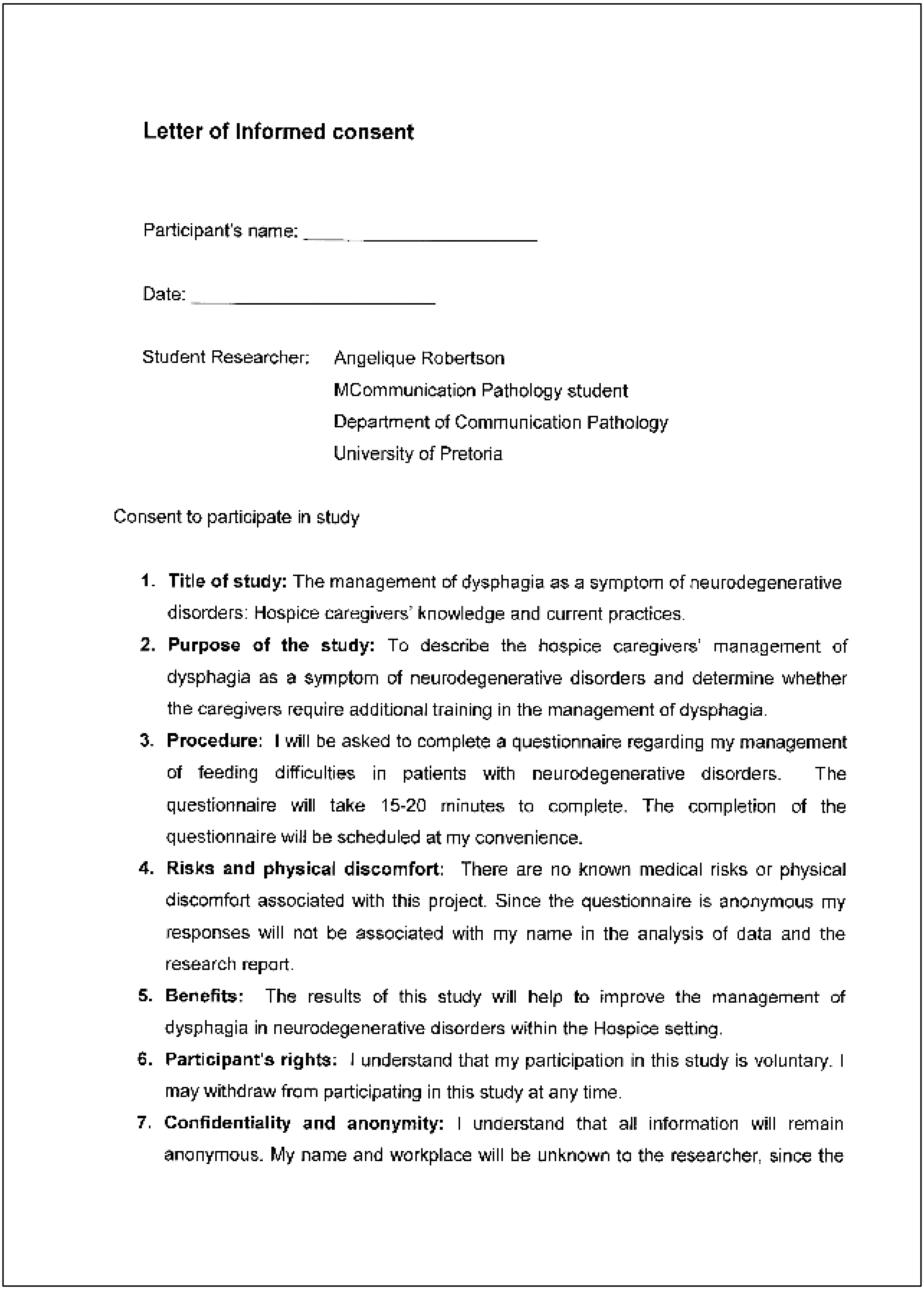
Angelique Robertson
Mkommunikasiepatologie student
Departement Kommunikasiepatologie
Universiteit van Pretoria

a kritzinger
Dr A Kritzinger
Studieleier

B Louw
Prof B Louw
Hoof: Departement Kommunikasiepatologie
Universiteit van Pretoria

APPENDIX D

LETTER OF INFORMED CONSENT



Letter of Informed consent

Participant's name: ______________________

Date: ______________________

Student Researcher: Angelique Robertson
MCommunication Pathology student
Department of Communication Pathology
University of Pretoria

Consent to participate in study

1. **Title of study:** The management of dysphagia as a symptom of neurodegenerative disorders: Hospice caregivers' knowledge and current practices.
2. **Purpose of the study:** To describe the hospice caregivers' management of dysphagia as a symptom of neurodegenerative disorders and determine whether the caregivers require additional training in the management of dysphagia.
3. **Procedure:** I will be asked to complete a questionnaire regarding my management of feeding difficulties in patients with neurodegenerative disorders. The questionnaire will take 15-20 minutes to complete. The completion of the questionnaire will be scheduled at my convenience.
4. **Risks and physical discomfort:** There are no known medical risks or physical discomfort associated with this project. Since the questionnaire is anonymous my responses will not be associated with my name in the analysis of data and the research report.
5. **Benefits:** The results of this study will help to improve the management of dysphagia in neurodegenerative disorders within the Hospice setting.
6. **Participant's rights:** I understand that my participation in this study is voluntary. I may withdraw from participating in this study at any time.
7. **Confidentiality and anonymity:** I understand that all information will remain anonymous. My name and workplace will be unknown to the researcher, since the

questionnaires are numbered and my name is not filled in. Furthermore the researcher will not be able to connect my names on the Informed Consent Letter to the questionnaire that I have completed.

8. The study's Research Protocol has been approved by the Ethics Committee of the Faculty of Humanities, University of Pretoria.
9. If I have any questions or concerns, I may call the researcher, Angelique Robertson, at 082 907 4468 at any time.

I understand my rights as a respondent, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this letter of consent.

____________________________ ____________________________

Participant's signature Date

____

Researcher's signature

Prof B Louw
Head: Department of Communication Pathology
University of Pretoria

Ingeligte Toestemmingsbrief

Naam van deelnemer: ______________________

Datum: ______________________

Navorser:	Angelique Robertson M Kommunikasiepatologie student Departement Kommunikasiepatologie Universiteit van Pretoria

Toestemming om deel te neem aan die studie

1. **Titel van die studie:** Die hantering van disfagie as simptoom van neurodegeneratiewe afwykings: Praktyke en kennis van hospitium (hospice) sorggewers.
2. **Doel van die studie:** Om die hospitium sorggewers se hantering van disfagie as simptoom van neurodegeneratiewe afwykings te beskryf asook om te bepaal of die sorggewers addisionele opleiding in die hantering van disfagie benodig.
3. **Prosedure:** Ek word versoek om 'n vraelys te voltooi rakende my hantering van die voedingsprobleme by pasiënte met neurodegeneratiewe afwykings. Die vraelys sal 15-20 minute duur om te voltooi. Die voltooiing van die vraelys sal op 'n tyd wat vir my geleë is, geskied.
4. **Risiko's en fisiese ongemak:** Daar is geen mediese of fisiese ongemak geassossieer met hierdie projek nie. Aangesien die vraelys anoniem is sal antwoorde tydens die analise van die data nie geassosieer kan word met my naam nie.
5. **Voordele:** Die resultate van hierdie studie sal help om die hantering van disfagie in neurodegeneratiewe afwykings binne die hospitium opset, te verbeter.
6. **Regte van deelnemers:** Ek verstaan dat deelname aan hierdie studie vrywilig is. Ek kan enige tyd as deelnemer aan die studie onttrek.
7. **Vertroulikheid en anonimiteit:** Ek verstaan dat alle inligting anoniem sal bly. Aangesien die vraelyste genommer is en my naam nie daarop verskyn nie, sal my

naam en werkplek vir die navorser onbekend bly. Verder sal die navorser ook nie in staat wees om my naam op die ingeligte toestemmingsbrief aan die vraelys wat ek voltooi het, te koppel nie.

8. Die navorsingsprotokol van hierdie studie is goedgekeur deur die Etiek Komitee van die Fakulteit Geesteswetenskappe, Universiteit van Pretoria.
9. Indien ek enige vrae of bekommernisse het, kan ek die navorser, Angelique Robertson, by tel: 082 907 4468 kontak.

Ek verstaan my regte as respondent, en ek gee vrywillig toestemming deel te neem aan hierdie studie. Ek verstaan waaroor die studie gaan asook hoe en hoekom dit uitgevoer word. Ek sal 'n getekende kopie van hierdie ingeligte toestemings-brief ontvang.

______________________________ ______________________________

Hantekening van deelnemer Datum

____

Hantekening van navorser

B. Louw

Prof B Louw

Hoof: Departement Kommunikasiepatologie

Universiteit van Pretoria

APPENDIX E

QUESTIONNAIRE

For Office Use

QUESTIONNAIRE:

THE MANAGEMENT OF DYSPHAGIA IN NEURODEGENERATIVE DISORDERS: HOSPICE CAREGIVERS' CURRENT PRACTICES

INSTRUCTIONS:

Please answer all the questions by drawing a neat circle (O) around a number in a shaded box or by writing your answer in the shaded space provided.

For the purpose of this questionnaire the term dysphagia refers to difficulty in swallowing.

Respondent number

V1 ☐☐☐ 1

SECTION A

1. What **province** do you reside in?

V2 ☐☐ 4

2. What is you **gender**?

Male	1
Female	2

V3 ☐ 6

3. What is your **age**?

V4 ☐☐ 7

4. What is your **highest** level of qualification?

Nursing Degree	1
Nursing Diploma	2
Short course in palliative nursing	3
HPCA community caregiving course	4
Diploma in palliative medicine	5
Mphil Palliative medicine	6
Other (Specify)	

V5 ☐☐ 9

1

For Office Use

5. Please indicate the **type** of training you have had in dysphagia management and the **date** (use: dd/mm/yyyy) of such training

Type of Training	Date of Training
No training in dysphagia management	1

V6 11 15
V8 19 23
V10 27 31
V12 35 39
V14 43 47
V16 51

6. Please indicate which of the following hospice settings you are **currently** involved with.

An inpatient hospice unit at either a hospital or nursing home	1
A community-based hospice	2
A home care organization that provides hospice care	3
Other (specify):	

V17 52

7. For how many **years** have you been working in a hospice setting?

V18 53

SECTION B

8. How **frequently** do you see patients with swallowing difficulties?

Frequently	(**40-50** patients per month)	1
Occasionally	(**30-40** patients per month)	2
Seldom	(**20-30** patients per month)	3
Rarely	(**10-20** patients per month)	4
Very rarely	(**0-10** patients per month)	5

V19 55

9. Are you **informed** of the **diagnosis** of the patient?

Yes	1
No	2

V20 56

For Office Use

10. If your answer to **Question 9** is **"Yes"**, please indicate, based on your experience, which condition is **most frequently** associated with dysphagia. (For example Parkinson's disease).

V21 ☐ 57

11. Based on your **experience**, which of the following are **symptoms** of dysphagia?

Please use the code:

A = Always (1)
F = Frequently (2)
S = Seldom (3)
V = Very rarely (4)
D = Don't know (5)

Factor	A	F	S	V	D		
Patient vomits	1	2	3	4	5	V22	59
Patient complains of pain during the swallow	1	2	3	4	5	V23	60
Constipation	1	2	3	4	5	V24	61
Coughing before, during or after a swallow	1	2	3	4	5	V25	62
Headaches	1	2	3	4	5	V26	63
Recurrent pneumonia	1	2	3	4	5	V27	64
Changes in voice e.g. Voice sounds gurgly	1	2	3	4	5	V28	65
Dizzy spells	1	2	3	4	5	V29	66
Unable to recognize food	1	2	3	4	5	V30	67
Inability to move	1	2	3	4	5	V31	68
Malnutrition	1	2	3	4	5	V32	69
Reflux	1	2	3	4	5	V33	70
Diabetes	1	2	3	4	5	V34	71
Difficulty starting the swallow	1	2	3	4	5	V35	72
Unable to control the food in the mouth	1	2	3	4	5	V36	73
Lengthened meal time	1	2	3	4	5	V37	74
Breathing difficulty	1	2	3	4	5	V38	75
Food remaining in mouth after swallow	1	2	3	4	5	V39	76
Stomach cramps	1	2	3	4	5	V40	77
Temperature spiking	1	2	3	4	5	V41	78
Diarrhoea	1	2	3	4	5	V42	79
Patient refuses food	1	2	3	4	5	V43	80
Weight loss	1	2	3	4	5	V44	81
Vomiting blood	1	2	3	4	5	V45	82
Drooling	1	2	3	4	5	V46	83
Patient complains of swallowing difficulties	1	2	3	4	5	V47	84
Swallowing repeatedly	1	2	3	4	5	V48	85

For Office Use

12. Based on your **experience** which of the following aspects must be considered when **identifying** dysphagia?

Please use the code: Y = Yes (1)
N = No (2)

Aspect	Y	N	For Office Use
Alertness	1	2	V49 86
Cooperativeness	1	2	V50 87
Ability to follow directions	1	2	V51 88
Awareness of swallowing problem	1	2	V52 89
Posture	1	2	V53 90
Attention	1	2	V54 91
Ability to talk	1	2	V55 92
Bladder control	1	2	V56 93
Medical history	1	2	V57 94
Ability to control saliva	1	2	V58 95
Lung capacity	1	2	V59 96
Hyperthermia	1	2	V60 97
Head control	1	2	V61 98
Ability to cough	1	2	V62 99
Bowel incontinence	1	2	V63 100

13. Based on your experience which **person/s** are **responsible** for the **identification** of dysphagia?

Please use the code: Y = Yes (1)
N = No (2)

Person identifying dysphagia	Y	N	For Office Use
Hospice caregiver	1	2	V64 101
Community Nurse	1	2	V65 102
Speech language therapist	1	2	V66 103
Dietician	1	2	V67 104
Occupational therapist	1	2	V68 105
Physical therapist	1	2	V69 106
Radiologist	1	2	V70 107
Doctor	1	2	V71 108
Other (Specify):			V72 109
Other (Specify):			V73 111

14. To whom do you **refer** individuals with swallowing difficulties?

V74 113

15. If you have been involved in the **management** of patients with **swallowing problems**, please indicate the **aspects** that **alerted** you to the swallowing problem and **how** you **managed** it. (Space is provided for a maximum of four sets of information).

Alerting Aspects	Management

16. Based on your **experience**, which condition is associated with the **most severe** swallowing difficulties?

SECTION C

17. Based on your **experience**, which of the following do you think must be taken into consideration when **feeding** a person?

Please use the code: Y = Yes (1)
N = No (2)

Consideration of ...	Y	N
Cooperation	1	2
Body position	1	2
Alertness	1	2
Sleep disturbances	1	2
Person's diagnosis	1	2
Person's food preferences	1	2
Hypertension	1	2
Breathlessness	1	2
Amount of food offered per spoon	1	2
Person's age	1	2
Rate of feeding	1	2
Incontinence	1	2
Food consistency	1	2
Head position	1	2

For Office Use

V75		115
V76		117
V77		119
V78		121
V79		123
V80		125
V81		127
V82		129
V83		131
V84		133
V85		134
V86		135
V87		136
V88		137
V89		138
V90		139
V91		140
V92		141
V93		142
V94		143
V95		144
V96		145
V97		146

For Office Use

18. In your **experience** how **easily** did the people with dysphagia **swallow** the following **consistencies**

Please use the code:

E	=	Easy to swallow	(1)
F	=	Fairly easy to swallow	(2)
D	=	Difficult to swallow	(3)
V	=	Very difficult to swallow	(4)
I	=	Impossible to swallow	(5)

Consistency	**E**	**F**	**D**	**V**	**I**		
Thin liquids e.g. Water	**1**	**2**	**3**	**4**	**5**	V98	147
Thick liquids e.g. Milkshake	**1**	**2**	**3**	**4**	**5**	V99	148
Purees e.g. Mashed potatoes	**1**	**2**	**3**	**4**	**5**	V100	149
Soft solid food e.g Pasta	**1**	**2**	**3**	**4**	**5**	V101	150
Crumbly food e.g Scrambled eggs	**1**	**2**	**3**	**4**	**5**	V102	151
Mixed-consistency food e.g. Cereal with milk	**1**	**2**	**3**	**4**	**5**	V103	152
Sticky food e.g. Fresh white bread	**1**	**2**	**3**	**4**	**5**	V104	153

19. In your experience do you find that patients **differ** in the **consistencies** they are **able** to swallow **easily**?

Yes	**1**	V105	154
No	**2**		

20. Based on your **experience**, which of the following **positions** are **safe** for the dysphagic patient **during swallowing**?

Please use the code:

Y	=	Yes	(1)
N	=	No	(2)

Position of dysphagic patient	**Y**	**N**		
Tilting his or her head backwards (chin up)	**1**	**2**	V106	155
Tilting his or her head forward (chin down)	**1**	**2**	V107	156
Lying flat	**1**	**2**	V108	157
Tilting his/her head to the side	**1**	**2**	V109	158
Lying on his/her stomach	**1**	**2**	V110	159
Sitting upright	**1**	**2**	V111	160
Moving head from side to side	**1**	**2**	V112	161
Other (specify)			V113	162
Other (specify)			V114	164

21. In your experience do you find that **changing** the position of a dysphagic patient can **improve** the swallow?

Yes	**1**	V115	166
No	**2**		

For Office Use

22. What **guidelines** do you provide the family members with for **feeding** the dysphagic patient?

V116 ☐☐ 167
V117 ☐☐ 169
V118 ☐☐ 171
V119 ☐☐ 173
V120 ☐☐ 175

23. Please indicate the level of **confidence** that you have in the **management** of dysphagia

Not confident	1
Slightly confident	2
Moderately confident	3
Confident	4
Very confident	5

V121 ☐ 177

24. Please indicate in which disorders you **feel less confident** in **managing** the associated dysphagia and give your **reason** for this feeling.

Type of dysphagia	Reason for feeling less confident

V122 ☐ 178
V123 ☐ 180
V124 ☐ 182
V125 ☐ 184
V126 ☐ 186
V127 ☐ 188
V128 ☐ 190
V129 ☐ 192
V130 ☐ 194
V131 ☐ 196

For Office Use

25. How do you feel about patients with a **degenerative neurogenic disorders** receiving **tube feeding**?

	V132 ☐☐ 198
	V133 ☐☐ 200
	V134 ☐☐ 202
	V135 ☐☐ 204
	V136 ☐☐ 206

26. Please indicate your **position** on each of the following statements and **motivate** your response.

Please use the code:
SA = Strongly Agree (1)
A = Agree (2)
D = Disagree (3)
SD = Strongly Disagree (4)

Statement	SA	A	D	SD	For Office Use
A person's ability to feed him/herself is never an excuse to let the person go hungry	1	2	3	4	V137 ☐ 208
Motivation:					V138 ☐☐ 209
In patients who are incompetent, family members should be included in a decision to provide tube feeding	1	2	3	4	V139 ☐ 211
Motivation:					V140 ☐☐ 212
Allowing the patient to die of dehydration is a painless death	1	2	3	4	V141 ☐ 214
Motivation:					V142 ☐☐ 215
By tube feeding the patient it unnaturally extends the dying process	1	2	3	4	V143 ☐ 217
Motivation:					V144 ☐☐ 218
Assisted nutrition and hydration should not be offered to patients who are in the last stages of dying	1	2	3	4	V145 ☐ 220
Motivation:					V146 ☐☐ 221

For Office Use

26. (cont.) Please indicate your **position** on the following statement and **motivate** your response.

Please use the code:
SA = Strongly Agree (1)
A = Agree (2)
D = Disagree (3)
SD = Strongly Disagree (4)

Statement	SA	A	D	SD
It is better to let the patient fade away	1	2	3	4
Motivation:				

V147 ☐ 223
V148 ☐☐ 224

SECTION D

27. Is there **a team** functioning at your Hospice clinic?

Yes	1
No	2

V149 ☐ 226

28. If you answered "**Yes**" to **Question 27**, please state the **professions** in the team:

V150 ☐☐ 227
V151 ☐☐ 229
V152 ☐☐ 231
V153 ☐☐ 233
V154 ☐☐ 235

29. In your **experience** how valuable is it for health care professionals to **exchange** their discipline specific **knowledge** and skills with other health care professionals?

Of very great value	1
Of great value	2
Of some value	3
Of no value	4

V155 ☐ 237

For Office Use

30. Please indicate your position on the following statements

Please use the code:

Please use the code:	**SA**	=	Strongly Agree	(1)
	A	=	Agree	(2)
	D	=	Disagree	(3)
	SD	=	Strongly Disagree	(4)

Statement	**SA**	**A**	**D**	**SD**			
Team work results in conflict between the team members	**1**	**2**	**3**	**4**	V156		238
Team work is impractical because there is no time for all the team members to meet	**1**	**2**	**3**	**4**	V157		239
A team approach should be used to manage dysphagia	**1**	**2**	**3**	**4**	V158		240
One team member should diagnose the patient and then delegate	**1**	**2**	**3**	**4**	V159		241
The patient and family should form part of the hospice team	**1**	**2**	**3**	**4**	V160		242
A team approach should be followed in a hospice setting	**1**	**2**	**3**	**4**	V161		243
Team work is irrelevant	**1**	**2**	**3**	**4**	V162		244
The speech-language pathologist and hospice caregiver should consult consult each other about dysphagic patients	**1**	**2**	**3**	**4**	V163		245

31. Do you feel the need to have **further training** in the management of dysphagia?

Yes	**1**	V164		246
No	**2**			

Thank you for your time and co-operation

VRAELYS:

DIE HANTERING VAN DISFAGIE IN NEURO-DEGENERATIEWE AFWYKINGS: HUIDIGE PRAKTYKE VAN HOSPITUM (HOSPICE) SORGGEWERS.

INSTRUKSIES:

Antwoord asseblief al die vrae deur 'n duidelike sirkel (O) om 'n syfer in 'n ingekleurde blokkie te trek, of deur u antwoord in die ingekleurde spasie te skryf.

Vir die doel van hierdie vraelys verwys die term disfagie na probleme tydens sluk.

Respondentnommer

V1 ☐☐☐ 1

AFDELING A

1. In watter **provinsie** is u woonagtig?

V2 ☐☐ 4

2. Wat is u **geslag**?

Manlik	1
Vroulik	2

V3 ☐ 6

3. Wat is u **ouderdom**?

V4 ☐☐ 7

4. Wat is u **hoogste** vlak van kwalifikasie?

Graad in verpleegkunde	1
Diploma in verpleegkunde	2
Kortkursus in palliatiewe verpleging	3
HPCA gemeenskapsorggewingskursus	4
Diploma in palliatiewe medikasie	5
Mphil in palliatiewe medikasie	6
Ander (spesifiseer):	

V5 ☐☐ 9

1

Vir Kantoor Gebruik

5. Dui asseblief aan watter **tipe** opleiding oor die hantering van disfagie u ontvang het. Verskaf ook die **datum** (gebruik: dd/mm/jjjj) wanneer u die opgelei is.

Tipe opleiding	Datum van opleiding
Geen opleiding in die hantering van disfagie nie	1

V8 11 15
V6 19 23
V10 27 31
V12 35 39
V14 43 47
V15 51

6. Dui asseblief aan in watter van die volgende Hospitum opsette u **huidiglik** betrokke is.

'n Binne-pasiënt Hospitum eenheid by 'n hospitaal of verpleeginrigting	1
'n Gemeenskapgebaseerde Hospitum	2
'n Tuisversorgingsorganisasie wat Hospitum sorg verskaf	3
Ander (spesifiseer):	

V17 52

7. Hoe lank werk u al in 'n Hospitum opset (aantal jare)?

V18 53

AFDELING B

8. Hoe dikwels sien u pasiënte met slukprobleme?

Dikwels	(40-50 pasiënte per maand)	1
Somtyds	(30-40 pasiënte per maand)	2
Selde	(20-30 pasiënte per maand)	3
Min	(10-20 pasiënte per maand)	4
Byna nooit	(0-10 pasiënte per maand)	5

V19 55

9. Word u ingelig oor die pasiënt se diagnose?

Ja	1
Nee	2

V20 56

Vir Kantoor Gebruik

10. Indien u "**Ja**" op **Vraag 9** geantwoord het, dui asseblief aan, gebaseer op u ervaring, watter siektetoestand word die meeste met disfagie geassiosieer. (Byvoorbeeld Parkinsonisme)

V21 ☐ 57

11. Na aanleiding van u **ervaring**, watter van die volgende is **simptome** van disfagie?

Gebruik asseblief die kode:

A = Altyd (1)
G = Gereeld (2)
S = Soms (3)
AN = Amper Nooit (4)
W = Weet nie (5)

Faktor	A	G	S	AN	W			
Pasiënt braak	1	2	3	4	5	V22	☐	59
Pasiënt kla oor pyn tydens sluk	1	2	3	4	5	V23	☐	60
Hardlywigheid	1	2	3	4	5	V24	☐	61
Hoes voor, gedurende of na sluk	1	2	3	4	5	V25	☐	62
Hoofpyne	1	2	3	4	5	V26	☐	63
Herhaaldelike pneumonie	1	2	3	4	5	V27	☐	64
Verandering in stem, bv. Stem klink "nat"	1	2	3	4	5	V28	☐	65
Duiseligheid	1	2	3	4	5	V29	☐	66
Onvermoë om voedsel te herken	1	2	3	4	5	V30	☐	67
Onvermoë om te beweeg	1	2	3	4	5	V31	☐	68
Wanvoeding	1	2	3	4	5	V32	☐	69
Refluks	1	2	3	4	5	V33	☐	70
Diabetes	1	2	3	4	5	V34	☐	71
Sukkel om te begin sluk	1	2	3	4	5	V35	☐	72
Onvermoë om voedsel in die mond te beheer	1	2	3	4	5	V36	☐	73
Verlengde etenstyd	1	2	3	4	5	V37	☐	74
Haal moeilik asem	1	2	3	4	5	V38	☐	75
Kos bly in die mond na sluk	1	2	3	4	5	V39	☐	76
Maagkrampe	1	2	3	4	5	V40	☐	77
Temperatuur pieke	1	2	3	4	5	V41	☐	78
Diarree	1	2	3	4	5	V42	☐	79
Pasiënt weier voedsel	1	2	3	4	5	V43	☐	80
Gewigsverlies	1	2	3	4	5	V44	☐	81
Braak bloed	1	2	3	4	5	V45	☐	82
Kwyl	1	2	3	4	5	V46	☐	83
Pasiënt kla dat hy/sy sukkel om te sluk	1	2	3	4	5	V47	☐	84
Sluk herhaaldelik	1	2	3	4	5	V48	☐	85

Vir Kantoor Gebruik

12. Na aanleiding van u **ervaring**, watter van die volgende aspekte moet in ag geneem word tydens die **identifikasie** van disfagie?

Gebruik asseblief die volgende kode: **J** = Ja (1)
N = Nee (2)

Aspek	J	N		
Wakkerheid	1	2	V49	86
Mate van samewerking verkry	1	2	V50	87
Vermoë om instruksies te volg	1	2	V51	88
Bewustheid van die slukprobleem	1	2	V52	89
Postuur	1	2	V53	90
Aandag	1	2	V54	91
Vermoë om te praat	1	2	V55	92
Blaasbeheer	1	2	V56	93
Mediese geskiedenis	1	2	V57	94
Vermoë om speeksel te beheer	1	2	V58	95
Long kapasiteit	1	2	V59	96
Hipertermie	1	2	V60	97
Kookontrole	1	2	V61	98
Vermoë om te hoes	1	2	V62	99
Inkontinensie	1	2	V63	100

13. Na aanleiding van u ervaring, watter **persoon/e** is **verantwoordelik** vir die **identifikasie** van disfagie?

Gebruik asseblief die volgende kode: J = Ja (1)
N = Nee (2)

Persoon wat disfagie identifiseer	Y	N		
Hospitum sorggewer	1	2	V64	101
Gemeenskapsverpleegkundige	1	2	V65	102
Spraak-taalterapeut	1	2	V66	103
Dieëtkundige	1	2	V67	104
Arbeidsterapeut	1	2	V68	105
Fisioterapeut	1	2	V69	106
Radioloog	1	2	V70	107
Doktor	1	2	V71	108
Ander (spesifiseer):			V72	109
Ander (spesifiseer):			V73	111

14. Na wie **verwys** u individue met slukprobleme?

V74 113

Vir Kantoor Gebruik

15. Indien u betrokke was met die **behandeling** van pasiënte met **slukprobleme**, dui asseblief aan watter **aspekte** u **bewus** gemaak het van die slukprobleem en **hoe** u dit **hanteer** het. (Spasie is verskaf vir 'n maksimum van vier stelle inligting).

Aspekte wat u bewus gemaak het van die problem	Hantering

V75			115
V76			117
V77			119
V78			121
V79			123
V80			125
V81			127
V82			129

16. Met watter **siektetoedstand**, na aanleiding van u **ervaring**, word die **ernstigste** slukprobleme geassosieer?

V83			131

AFDELING C

17. Na aanleiding van u **ervaring**, watter van die volgende moet in ag geneem word tydens die **voeding** van 'n persoon?

Gebruik asseblief die volgende kode:

J = Ja (1)
N = Nee (2)

Inagneming van ...	J	N
Samewerking	1	2
Liggaamsposisie	1	2
Wakkerheid	1	2
Slaapversteurings	1	2
Persoon se diagnose	1	2
Persoon se voedsel voorkeur	1	2
Hipertensie	1	2
Persoon is uitasem	1	2
Hoeveelheid voedsel wat per lepel aangebied word	1	2
Persoon se ouderdom	1	2
Tempo van voeding	1	2
Inkontinensie	1	2
Konsistensie van die voedsel	1	2
Kopposisie	1	2

V84		133
V85		134
V86		135
V87		136
V88		137
V89		138
V90		139
V91		140
V92		141
V93		142
V94		143
V95		144
V96		145
V97		146

Vir Kantoor Gebruik

18. Na aanleiding van u **ervaring**, met hoeveel **gemak** kan persone met disfagie die volgende **konsistensies sluk**

Gebruik asseblief die kode:

M	=	**M**aklik om te sluk	(1)
R	=	**R**edelik maklik om te sluk	(2)
MO	=	**MO**eilik om te sluk	(3)
B	=	**B**aie moeilik om te sluk	(4)
O	=	**O**nmoontlik om te sluk	(5)

Konsistensie	**M**	**R**	**MO**	**B**	**O**		
Dun vloeistowwe, bv. Water	**1**	**2**	**3**	**4**	**5**	V98	147
Dik vloeistowwe, bv. Melkskommel	**1**	**2**	**3**	**4**	**5**	V99	148
Puree, bv. Fyngemaakte aartappels	**1**	**2**	**3**	**4**	**5**	V100	149
Sagte soliede voedsel, bv. Pasta	**1**	**2**	**3**	**4**	**5**	V101	150
Krummelrige voedsel, bv. Roereier	**1**	**2**	**3**	**4**	**5**	V102	151
Gemengde konsistensie voedsel, bv. Ontbytgraan met melk	**1**	**2**	**3**	**4**	**5**	V103	152
Klewerige kos, bv. Vars witbrood	**1**	**2**	**3**	**4**	**5**	V104	153

19. Na aanleiding van u **ervaring**, vind u dat pasiënte verskil in hulle vermoë om konsistensies maklik te sluk?

Ja	**1**	V105	154
Nee	**2**		

20. Na aanleiding van u **ervaring**, watter van die volgende **posisies** is **veilig** vir die disfagie pasiënt **tydens sluk**?

Gebruik asseblief die volgende kode: **J** = Ja (1)
N = Nee (2)

Posisie van die disfagie pasiënt	**J**	**N**		
Kantel sy/haar kop agtertoe (ken op)	**1**	**2**	V106	155
Kantel sy/haar kop vorentoe (ken af)	**1**	**2**	V107	156
Lê plat	**1**	**2**	V108	157
Kantel sy/haar kop na die kant	**1**	**2**	V109	158
Lê op sy/haar maag	**1**	**2**	V110	159
Sit regop	**1**	**2**	V111	160
Beweeg kop van kant-tot-kant	**1**	**2**	V112	161
Ander (spesifiseer):			V113	162
Ander (spesifiseer):			V114	164

Vir Kantoor Gebruik

21. Na aanleiding van u **ervaring**, vind u dat 'n **verandering in** die posisionering van 'n disfagie pasient, die sluk kan **verbeter**?

Ja	**1**
Nee	**2**

V115 ☐ 166

22. Watter **riglyne** verskaf u aan die gesinslede oor die **voeding** van die disfagie pasiënt?

V116 ☐☐ 167
V117 ☐☐ 169
V118 ☐☐ 171
V119 ☐☐ 173
V120 ☐☐ 175

23. Dui asseblief aan wat u vlak van **selfvertroue** in die **hantering** van disfagie is.

Geen selfvertroue	**1**
Geringe selfvertroue	**2**
Matige selvertroue	**3**
Tree op met selfvertroue	**4**
Baie selfvertroue	**5**

V121 ☐ 177

24. Dui asseblief aan met watter afwyking u **minder selfvertroue** ervaar in die hantering van die geassosieerde disfagie en verskaf **redes** vir u gevoelens.

Tipe disfagie	**Rede vir verminderde selfvertroue**

V122 ☐☐ 178
V123 ☐☐ 180
V124 ☐☐ 182
V125 ☐☐ 184
V126 ☐☐ 186
V127 ☐☐ 188
V128 ☐☐ 190
V129 ☐☐ 192
V130 ☐☐ 194
V131 ☐☐ 196

Vir Kantoor Gebruik

25. Wat is u gevoel oor die verskaffing van **buisvoeding** aan pasiënte met 'n **degeneratiewe neurogene afwyking**?

	V132 ☐ 198
	V133 ☐ 200
	V134 ☐ 202
	V135 ☐ 204
	V136 ☐ 206

26. Dui asseblief u **gevoel** oor elk van die volgende stellings aan en motiveer u respons.

Gebruik asseblief die kode:

D = Stem **Definitief** saam (1)
S = **Stem** saam (2)
N = Stem **Nie** saam nie (3)
G = Stem **Glad** nie saam nie (4)

Stelling	**D**	**S**	**N**	**G**	
'n Persoon se vermoë om hom-/haarself te voer is nie 'n verskoning om die persoon te laat honger ly nie	**1**	**2**	**3**	**4**	V137 ☐ 208
Motivering:					V138 ☐ 209
In die geval van 'n pasiënt wat onbevoeg is, moet die gesinslede betrek word in die besluitneming oor die verskaffing van buisvoeding	**1**	**2**	**3**	**4**	V139 ☐ 211
Motivering:					V140 ☐ 212
Om die pasiënt te laat sterf van dehidrasie is 'n pynlose dood	**1**	**2**	**3**	**4**	V141 ☐ 214
Motivering:					V142 ☐ 215
Deur buisvoeding word die pasiënt se sterfproses onnatuurlik verleng	**1**	**2**	**3**	**4**	V143 ☐ 217
Motivering:					V144 ☐ 218
Ondersteunende nutrisie en hidrasie moet nie aan pasiënte wat in die laaste stadium van sterfte is gebied word nie	**1**	**2**	**3**	**4**	V145 ☐ 220
Motivering:					V146 ☐ 221

Vir Kantoor Gebruik

26. (vervolg) Dui asseblief u **gevoel** oor die volgende stelling aan en motiveer u respons.

Gebruik asseblief die kode:

D	=	Stem Definitief saam	(1)
S	=	Stem saam	(2)
N	=	Stem Nie saam nie	(3)
G	=	Stem Glad nie saam nie	(4)

Stelling	**D**	**S**	**N**	**G**
Dit is beter om die pasiënt net te laat wegkwyn	**1**	**2**	**3**	**4**
Motivering:				

V147 223
V148 224

AFDELING D

27. Funksioneer daar 'n **span** by u Hospitum kliniek?

Ja	**1**
Nee	**2**

V149 225

28. Indien u antwoord by **Vraag 27** "Ja" is, noem asseblief die **professies** wat deel vorm van die span:

V150 227
V151 229
V152 231
V153 233
V154 235

29. Na aanleiding van u **ervaring**, hoe belangrik is dit dat gesondheidsorgpersoneel hulle dissipline spesifieke **kennis en vaardighede** met ander gesondheidspersoneel **uitruil**?

Van baie groot waarde	**1**
Van groot waarde	**2**
Geringe waarde	**3**
Geen waarde	**4**

V155 237

Vir Kantoor Gebruik

30. Dui asseblief u gevoel oor elk van die volgende stellings aan:

Gebruik asseblief die kode:

D = Stem Definitief saam (1)
S = Stem saam (2)
N = Stem **N**ie saam nie (3)
G = Stem **G**lad nie saam nie (4)

Stelling	**D**	**S**	**N**	**G**			
Spanwerk veroorsaak konflik tussen die spanlede	**1**	**2**	**3**	**4**	V156		238
Spanwerk is onprakties, want daar is nie tyd vir al die spanlede om byeen te kom nie	**1**	**2**	**3**	**4**	V157		239
'n Spanbenadering moet gebruik word in die hantering van disfagie	**1**	**2**	**3**	**4**	V158		240
Een spanlid moet die pasiënt diagnoseer en dan delegeer	**1**	**2**	**3**	**4**	V159		241
Die pasiënt en die gesin moet deel van die hospitum span vorm	**1**	**2**	**3**	**4**	V160		242
'n Spanbenadering moet in 'n hospitum opset gevolg word	**1**	**2**	**3**	**4**	V161		243
Spanwerk is nie relevant nie	**1**	**2**	**3**	**4**	V162		244
Die spraak-taalterapeut en hospitum sorggewer moet mekaar konsulteer oor disfagie pasiënte	**1**	**2**	**3**	**4**	V163		245

31. Het u 'n behoefte aan **verdure opleiding** in die hantering van disfagie?

Ja	**1**	V164		246
Nee	**2**			

Dankie vir u samewerking en tyd.

APPENDIX F

ETHICAL APPROVAL FROM HOSPICE PALLIATIVE CARE ASSOCIATION OF SOUTH AFRICA

Hospice
Palliative
Care
Association
of South Africa

no end to caring

16th February, 2005

Dear Ms Robertson,

I am pleased to inform you that the Hospice Palliative Care Association Ethics Committee has approved your study:
Researching the hospice caregivers knowledge and practices managing dysphagia in neurodegenerative disorders.

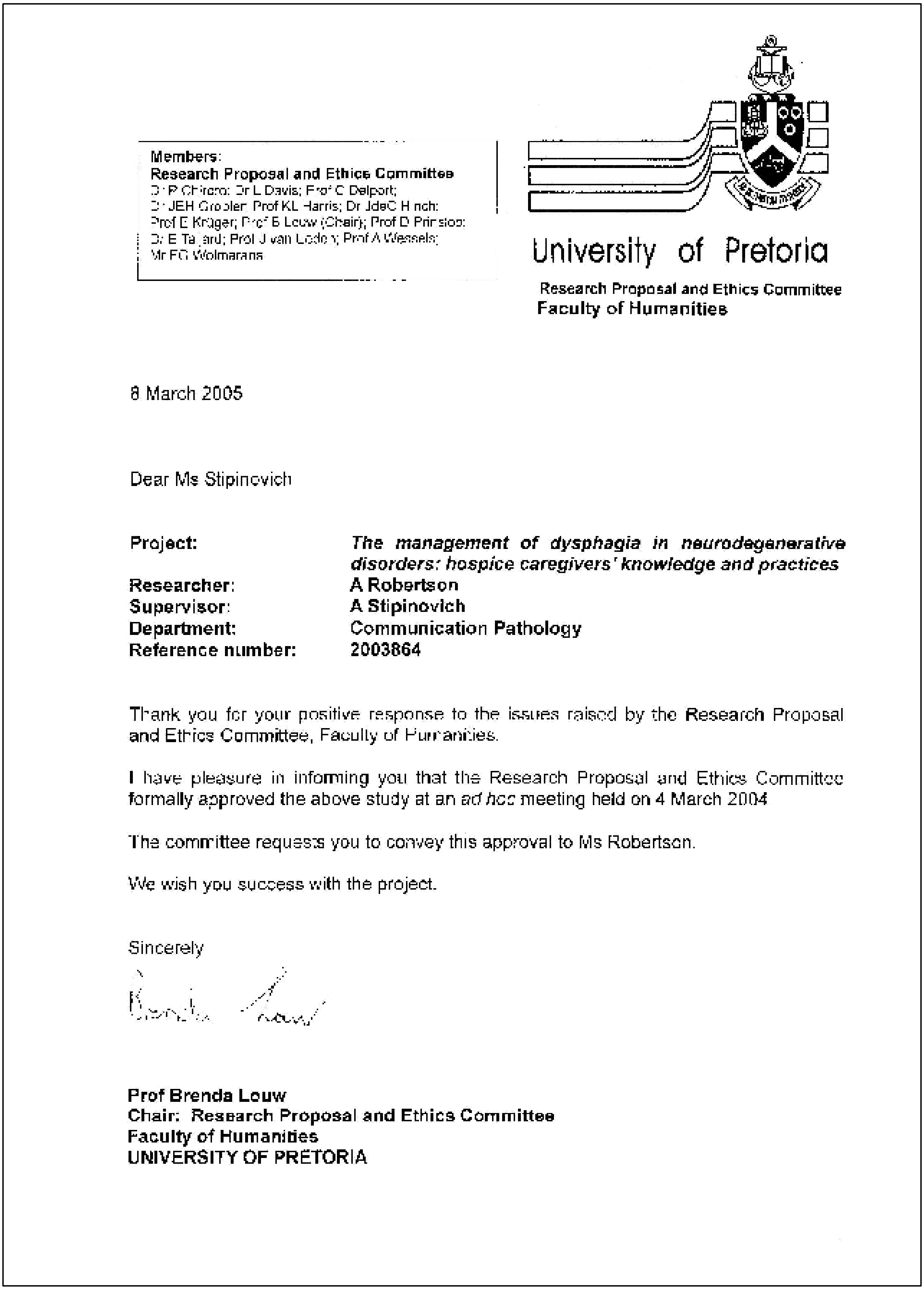
We believe this will be a valuable contribution to our palliative care knowledge and would appreciate it if you would let us have a copy of the completed publication.

Yours sincerely

Dr L Gwyther
Chairperson
HPCA ethics committee

APPENDIX G

ETHICAL APPROVAL FROM RESEARCH PROPOSAL AND ETHICS COMMITTEE, FACULTY OF HUMANITIES, UNIVERSITY OF PRETORIA



Members:
Research Proposal and Ethics Committee
Dr P Chiroro; Dr L Davis; Prof C Delport;
Dr JEH Grobler; Prof KL Harris; Dr JdeC Hinch;
Prof E Krüger; Prof B Louw (Chair); Prof D Prinsloo;
Dr E Taljard; Prof J van Loden; Prof A Wessels;
Mr FG Wolmarans

University of Pretoria
Research Proposal and Ethics Committee
Faculty of Humanities

8 March 2005

Dear Ms Stipinovich

Project:	***The management of dysphagia in neurodegenerative disorders: hospice caregivers' knowledge and practices***
Researcher:	**A Robertson**
Supervisor:	**A Stipinovich**
Department:	**Communication Pathology**
Reference number:	**2003864**

Thank you for your positive response to the issues raised by the Research Proposal and Ethics Committee, Faculty of Humanities.

I have pleasure in informing you that the Research Proposal and Ethics Committee formally approved the above study at an *ad hoc* meeting held on 4 March 2004.

The committee requests you to convey this approval to Ms Robertson.

We wish you success with the project.

Sincerely

Prof Brenda Louw
Chair: Research Proposal and Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA