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Knowledge Translation in Dysphagia: A South African Study

Jaishika Seedat

A dissertation submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg in fulfilment of the requirements for the degree of Doctor of Philosophy.

Johannesburg, 2013

DECLARATION

I hereby declare that this dissertation is my own unaided work. It is submitted to the University of the Witwatersrand for the degree of Doctor of Philosophy in Speech-Language Pathology. It has not been submitted before for any other degree or examination in any other university.

_____

Jaishika Seedat

October, 2013

DEDICATION

This thesis is dedicated to two groups of people: *nurses* employed in public hospitals and *patients* who access public hospitals.

Nurses: You face an incredible daily challenge working within a fragmented and hierarchical system of rules and regulations. You are expected to serve with a smile, be a shoulder to cry on at a moment's notice and hold together the pieces of the institution. Little reward comes your way, with limited respect or regard displayed by fellow health care peers for your efforts and hours. Having embarked on this research, it is easy to see how you get frustrated, tired and apathetic about your work. However, hidden beneath the surface there exists a glimmer of hope and keenness to transform. Only evident if one takes the necessary time to observe and understand nursing rituals, a sense of hope can be identified. As nurses, you have immense power to transform health care delivery positively. Your engagement with patients and professionals alike has the potential to improve efficiency and effectiveness of service delivery and likely dispel the negative perceptions around public health care in South Africa.

Patients: Limited by finance, distance and choice, you are often compelled to receive services at particular institutions. Very often, your sense of urgency is mismatched with that of hospital structures and service providers. Although it may seem that your voice is unimportant, this is untrue. You hold more power than you think you do and you have the ability to influence decisions made and choices taken so that they have meaning for you and add value to your life. Medical illness is in itself a burden and facing the unknown because of not being provided information or not being part of the decision adds to the weight. It is time for you to take greater responsibility for your own health and to start questioning. Only by you initiating this process will health care providers be forced to question and take responsibility for what they do.

ACKNOWLEDGEMENTS

Many say that the PhD journey is a long and lonely one. I have been lucky to have received support and words of encouragement from so many different people on 'my journey'.

Professor Claire Penn: It is difficult to express my gratitude in words. Your support, your words of encouragement, your vision, your enthusiasm and your faith in me have been inspiring and have propelled me through this thesis. Thank you.

Professor Katijah Khoza-Shangase: Thank you for your attention to detail and your questioning. You forced me to confront things in my research that I would have been happier avoiding, but for which I am now glad.

Carnegie Foundation: The funding provided enabled the completion of this study. It allowed the completion of the videofluroscopy procedure for patients in my study as well as allowed me to attend the ASHA conference last year, where a poster presentation of this study was completed.

Professor Peter Fridjohn: Thank you for being patient with my numerous questions and my uncertainties. Your assistance is deeply appreciated.

Mrs Petra Gaylard: Many thanks for your assistance with all the statistical analysis.

Mrs Pamela Ramushu: A very special thank you to you, my research assistant and colleague. Your strict regard for right and wrong and enthusiasm to do right by patients is inspiring. The profession needs more clinicians like you, who share your values, keenness and professionalism.

Nurse Participants: To all the nurses who participated in some way in this study, you have taught me so much. You let down your defences and allowed me to enter your world. You are an inspiring but poorly understood profession. Thank you.

Patients with dysphagia: To all the patients thank you for your participation. Your strength and courage is admired.

Speech-language pathologists at the hospital: A very big and special thank you and note of appreciation for your assistance with logistics, accessing patient files, discussions around patients, allocating me working space and for time invested in my study.

Peers: To everyone at work, thank you for words of encouragement when I needed it most.

To my parents, brother-in-law and sister thank you for always being there, taking care of Divij and Mayal, staying away when things got tough and lending support when I needed it. Thank you for all the patience you showed in these final months.

To Fazel, Divij and Mayal, you have inspired me to take this journey. Your patience, tolerance and unquestioning acceptance of all the missed parties, holidays and week-ends has given me the space and courage to finish. Thank you for your unwavering support and understanding.

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LIST OF ABBREVIATIONS

ASHA: American Speech and Hearing Association

CVA: Cerebrovascular Accident

FEES: Fiberoptic Endoscopic Evaluation of Swallowing

HPCSA: Health Professions Council of South Africa

KT: Knowledge Translation

KTA: Knowledge-to-action

NICE: National Institute for Health and Clinical Excellence

QOL: Quality of Life

SA: South Africa

SANC: South African nursing Council

SASPI: Southern African Stroke Prevention Initiative

SIGN: Scottish-Intercollegiate Guideline Network

SLP: Speech-language pathologist

STATSSA: Statistics South Africa

SWAL-QOL: Swallowing Quality of Life

TBI: Traumatic brain injury

VFS: Videofluroscopy

WHO: World Health Organisation

WHO-ICF: World Health Organisation International Classification of Functioning, Disability and Health

NOTES ON TERMINOLOGY

Academic/teaching hospital: A hospital provides clinical education and training to future and current doctors, nurses, and other health professionals, in addition to delivering medical care to patients. They are generally affiliated with medical schools or universities (hence the alternative term university hospital), and may be owned by a university or may form part of a wider regional or national health system. Some teaching hospitals also have a commitment to research and are centers for experimental, innovative and technically sophisticated services.

Allied health professional: Health care professionals that come from dentistry, optometry, nursing, medicine, and pharmacy. In South Africa, they would include physiotherapists, dieticians, social worker, occupational therapist, speech-language pathologist, audiologist and nurses.

Aspiration: Entry of material (secretions, food, liquid, stomach contents) into the lower respiratory tract.

Auxiliary nurse: The auxiliary nurse carries out basic nursing procedures and takes care of patients on a less specialized level under the supervision of a registered or professional nurse. An auxiliary nurse will have obtained a higher certificate in nursing, and may also be known as an enrolled nurse assistant.

Asian (Racial classification): In South Africa, Asian refers to people of Indian or South Asian origin.

Batho Pele: Putting People First initiative which aims to enhance the quality and accessibility of government services by improving efficiency and accountability to the recipients of public goods and services.

Collaboration: Working together or with each other for a common purpose.

Coloured (Racial classification): During apartheid, the term ‘Coloured’ was used to refer to group of people generally considered to be of mixed race origin. Coloured people, throughout the course of South African history, have been regarded as neither white nor black, and their

ability to exercise their political rights have been dependent on the attitude of government at the time.

Complex intervention study: A study that has to consider multiple interwoven variables, stakeholders and structures and requires an intensive methodology to address the aims.

Developing country: Developing countries are, in general, countries that have not achieved a significant degree of industrialization relative to their populations, and have, in most cases, a medium to low standard of living. There is a strong correlation between low income and high population growth.

Dysphagia: A medical term for a difficulty with swallowing. There may be different underlying causes and consequences.

Empirical evidence: A means of acquiring knowledge either directly or indirectly via experience or observation.

Health system: A combination of resources, organisation, financing, and management that culminate in the delivery of health services to the population.

Interdisciplinary: Involves a group of professionals who work interdependently in the same setting. Consists of practitioners from different professions who share a common patient population and common patient care goals and have responsibility for complementary tasks.

Intra-disciplinary: Teams are composed of professionals from one discipline but include team members from different levels of training and skill within the discipline.

Knowledge-to-action in health: Translating health research, knowledge and evidence into clinical practice to improve health.

Knowledge translation: The exchange, synthesis, and ethically sound application of knowledge within a complex set of interactions among producers of knowledge and relevant stakeholders to accelerate the capture of benefits of research through improved health, more effective services and products, and a strengthened health care system.

Latent theme: An existing theme that is not immediately explicit, obvious or occurring frequently, but which has significant implications.

Multidisciplinary: Involves understanding not only of one's own role but the role of other professionals as well. A collaborative approach to treatment planning of a group of people who come from different health and social care professions but who do not necessarily interact.

Patient's Right Charter: The National Patient's Rights Charter of South Africa, creates a framework for promoting and defending patients' rights.

Prandial aspiration: Aspiration that occurs with a meal, likely as a result of choking.

Primary level services/Primary health care: A first point of entry for South Africans to health services. These facilities treat people who are able to walk and do not need to be confined to bed. Primary health care services cover a comprehensive range of preventive, promotional, curative and rehabilitation services.

Private health sector: The private sector caters to middle- and high-income earners who tend to be members of medical schemes or who are able to afford the cost of private services regardless.

Professional nurse: May also be referred to as a registered nurse. A professional nurse is one who would have received a Bachelor's Degree in Nursing. She is licensed as a professional nurse under the Nursing Act. The professional nurse is responsible for the supervision of the registered Staff Nurse and the Auxiliary Nurse (Enrolled Nursing Assistant). The duties include running a department or ward, keeping records of treatment and progress, advising doctors about a patient's condition and receiving instructions regarding treatment as well as controlling supplies and equipment, materials and medicine. They may also be involved in the training of nursing students.

Public health sector: Health care services that are subsidised by the government with implications for lower cost to the patient.

Quality of life: A state of complete physical, mental and social wellbeing. It includes physical and mental health perceptions and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status.

Registered Staff Nurse: A nurse who would have a Diploma in Nursing. She/he would be a licensed practical nurse, under the Nursing Act.

Secondary level hospital: A facility at which a range of outpatient and inpatient services are offered. It is open 24 hours a day, 7 days a week. The hospital would have between 30 and 200 beds, a 24-hour emergency service and an operating theatre.

Sialorrhea: Also called hyper-salivation or excess production of saliva in the mouth.

Tertiary level hospital: A hospital that provides specialist and sub-specialist care. These hospitals consist of very highly specialised national referral units that together provide an environment for multi-specialty clinical services, innovation and research. The services provided will generally be of high cost and low volume, and ones that require high technology and/or multi-disciplinary teams of people with scarce skills to provide sustained care of high quality.

Traditional dysphagia management protocol: As used in the current study traditional dysphagia management refers to the manner, frequency, protocol and combination of strategies and considerations implemented and recommended by speech-language pathologists in their intervention with patients who present with dysphagia and the subsequent level of patient involvement in their intervention.

Trans-disciplinary: Requires each team member to become sufficiently familiar with the concepts and approaches of his and her colleagues as to blur the disciplinary bounds and enable the team to focus on the problem as part of a broader phenomenon. As this happens, discipline authorization fades in importance and the problem and its context guide an appropriately broader and deeper analysis.

Ubuntu: The philosophy of Ubuntu has its origin in the Southern reaches of Africa and encourages a spirit of cooperation between peoples of all colors and creeds. It is an ‘all for one and one for all’ principle and promotes mutual respect and understanding. Two of the greatest advocates of the Ubuntu philosophy are former South African President Nelson Mandela and former Anglican Archbishop Desmond Tutu.

A NOTE

For this study, the term ‘mouth’ as opposed to ‘oral’ was easier to understand with a multilingual population base. There was need to ensure use of easy and unambiguous terminology given the existence of eleven official languages. For the purposes of the research and data collection process, the term mouth care was used. In the dissertation, mouth care and oral care may be used interchangeably.

The original title of this dissertation was: Feasibility of implementing the Frazier Free Water Protocol in an South African acute medical setting – Addressing the need for Evidence-based practice in Dysphagia. This was subsequently changed to the current title. Hence, the title of the dissertation as reflected in the information letters in the Appendices will contain the original title.

PRESENTATIONS FROM THE STUDY

1. Oral Presentation (International Conference)
   Seedat, J., Penn, C., & Khoza, K. (2010). Implementing the Frazier Free Water Protocol in a South African government hospital: pilot study results. *ENT/SAHNOS/SAAA: 2010 A Laryngeal Odyssey*. Champagne Sports Resort, Drakensburg, South Africa.

2. Poster Presentation (International Conference)
   American Speech-Language and Hearing Association (ASHA) Conference
   Date: 14-17 November 2012
   Venue: Atlanta, Georgia. USA.
   Topic: Implementing a Free Water Protocol... knowledge-to-action transfer implications for dysphagia.

3. Oral Presentation (International Conference)
   International Association of Logopedics and Phoniatrics (IALP)
   Date: 25-29 August 2013
   Venue: Torino, Italy
   Topic: Should poor people, who cannot eat or drink safely, be treated differently? Dysphagia Services in Resource Constrained Contexts.

CHAPTER ONE: INTRODUCTION

Overview

This chapter introduces the reader to the study. It commences with an overview of the study, introduces the researcher and leads into the rationale underpinning the study. The reader will be provided with a brief orientation of the content of each chapter.

1.1 Introduction

This study explored the implementation of a dysphagia protocol in the public health sector of South Africa. Its main aim was to interrogate existing traditional models of dysphagia management and to examine the influence of context on this process. The framework selected was that of knowledge translation using the knowledge-to-action process model by Graham et al. (2006). Knowledge-translation, as per the definition outlined in the notes on terminology (p. xviii) refers to the *application* and *implementation* of information learned and knowledge gained from research into clinical practice. The ease or difficulty with which this process is accomplished in dysphagia for instance, speaks to the effectiveness of knowledge translation.

Traditional dysphagia management for adult patients in South Africa appears to be flawed. There appears to be an incongruence between what we know conceptually and what we practice clinically revealing gaps in knowledge translation for dysphagia. When speaking of traditional dysphagia management, this refers to the manner, frequency, protocol and combination of strategies and considerations implemented and recommended by speech-language pathologists in their intervention with patients who present with dysphagia. For instance, speech-language pathologists may have theoretical understanding of how a strategy such as a head tilt or chin-tuck may assist with the oropharyngeal phase of swallowing, but how this knowledge is imparted to the patient and how effectively it is done because of linguistic differences, may be compromised. Further, the extent to which a patient's social, employment and financial circumstances are reviewed before making recommendations appears to be unknown, with implications for the knowledge-gap referred to above. The positive and negative contextual influences that may be precipitating this knowledge-gap in dysphagia are also unknown.

The above suggests that current dysphagia management protocols and procedures may be without scientific grounding for the South African context or population. This has relevance

for evidence-based practice which is defined as, "…*the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients…[by] integrating individual clinical expertise with the best available external clinical evidence from systematic research*," (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996, p. 71).

Secondly, despite knowledge and awareness by the speech-language pathologist for different professionals to be involved in the management of the patient with dysphagia, studies conducted in South Africa have revealed that this does not always materialise effectively (Modi & Ross, 2000; Seedat, Mupawose & Choonara, 2011). This gap in implementation of a multidisciplinary model of intervention despite awareness of benefits suggests inadequate translation of knowledge into practice. The existing gap, suggested the need to investigate how improved inter-professional collaboration could be initiated and sustained when managing dysphagia in a South African public hospital.

Thirdly, poor mouth care, tooth brushing and mouth hygiene have been documented to be significant contributory factors to aspiration pneumonia for patients with oropharyngeal dysphagia (Millns, Gosney, Jack, Martin, & Wright, 2003). Clinical experience suggests that mouth care is often an area of contention between the speech-language pathologist and nurse. Falling within the job description of the nurse (Kalisch, 2006), clinical experience reveals that the speech-language pathologist may not intervene with a patient for dysphagia because and until mouth care is completed. The repercussions of what happens in the interim with saliva (now laden with gram-negative bacteria as a result of poor oral hygiene) that is swallowed, and the effects of aspiration, appear to be overlooked. Herein lies another gap in dysphagia management. With reasons for this gap not known conclusively, issues around professional boundaries, improved inter-professional working between the speech-language pathologist and nurse and a more feasible mouth care protocol applicable to public hospitals in South Africa, may be able to facilitate improved knowledge translation for this gap. The three identified gaps in dysphagia management were the focus of this study.

As a necessary partner of the speech-language pathologist for successful dysphagia intervention in a hospital context, nurses were intricately involved in each stage of the study. The knowledge-to-action process model (Graham et al., 2006) provided a firm theoretical foundation to explore ways to address the identified gaps so that the end-result may have benefits for both professions, the patient and service provision generally. The study will

reveal the benefit of using a participative bottom-up model of action research to optimise participation and engagement of nurses, who were recognised as a vulnerable, disempowered but vital component of public hospitals in the current study. The study will reveal limitations of working in isolation to manage the patient with dysphagia and the consequent lack of knowledge-to action transfer that may materialise from this. In contrast, the study will provide a glimpse into the benefits of collaboration for dysphagia intervention in a public health context. The process that enabled one to a) *achieve* collaboration, b) *maintain* collaboration and c) *use* collaboration to bridge the knowledge-to-action gap in dysphagia management for the given context will be described.

Despite some identified challenges facing the nursing profession globally and in certain instances, South Africa specifically, I will argue that positive interpersonal interactions and lines of communication may be able to alleviate existing barriers to change and patient care. This study will propose a model of training for nurses that seems able to facilitate improved inter-professional interaction and communication by heeding basic principles of mutual respect, trust, acknowledgement and empowerment. The historical background of South Africa and its status as a developing country make it an interesting, colourful, albeit complex country in which to live and work. The fluctuating political dynamics seem to have left sectors such as health, education, and social welfare vulnerable, under-resourced and inadequately managed (Gilbert & Gilbert, 2004; Thomas & Thiede, 2005). I will argue that it is not possible as a speech-language pathologist to work without a form of awareness of and response to the socio-political aspects that are operating within the country and that there are possible gains to be achieved working collaboratively amidst this overburdened and fragmented hierarchical system of management. Ignorance of the needs of the people, the systems and the structures appears to have inadvertently placed us as health care professionals in a compromising position (South African Speech-Hearing and Language Association [SASLHA], 2008/9). We seem able to identify that particular processes are not optimal, but do not believe ourselves to be capacitated to make the necessary move to modify, if not change the way things are done. In addition to the use of the knowledge-to-action process model (Graham et al., 2006), some guiding considerations to address this need is proposed in figure 27 (p. 233), that may allow speech-language pathologists to move past this feeling of impotence. Organisational and institutional variables will be highlighted and their relevance to an intervention study discussed.

Dysphagia management in South Africa does not appear to be ideal. As probably the most practical and hands-on sub-speciality of speech-language pathology, efficient and effective dysphagia management may be able to show immediate positive effects on a person's swallowing, whereas a generalised implementation of techniques and strategies to manage dysphagia without understanding of contextual and patient variables may result in serious if not fatal consequences for the patient. A traditional dysphagia management protocol was compared against an internationally validated free water protocol subsequent to modifications of the free water protocol, to facilitate knowledge translation for the South African public health care context. The study will reveal the importance of combined quantitative and qualitative data to enhance understanding of the obtained findings from the study. I will propose that a pragmatic paradigm (i.e. qualitative and quantitative methods) may offer many advantages for future dysphagia-based research from developing contexts and based on the results of this study, such research may provide more detailed understanding and explanation.

The lack of intervention based studies and research in South Africa raises questions around the implementation of internationally based techniques and strategies in a developing context like South Africa as it remains unknown how these strategies are practised, how well they are understood and how the use of these strategies are demonstrated to patients with dysphagia by speech-language pathologists. The suitability of these protocols for the South African public health care context is queried. I will contend that this caveat of research is likely to raise questions around standardisation of practice and highlights the issue of variability amongst practising speech-language pathologists, a situation that can no longer be accepted given international inroads into evidence-based practice from all professions. Accountability and practice based on sound reasoning is a minimal expectation of any profession. I will rationalise why the speech-language pathology profession in South Africa needs to engage in evidence-based research and implement evidence-based practice in order to retain its title as a scientific profession and the respect of other allied health and medical professions.

1.2 Introducing the researcher

I am a speech-language pathologist and audiologist. I began my professional career 16 years ago. I worked at a tertiary level teaching hospital (public) in Gauteng, Johannesburg for 11 years before entering academia, where I have been for the last five years. In my capacity as a clinician, a bulk of my workload involved intervention with acute in-patients. Specialisation in the area of adult neurology and dysphagia provided insight into the realities of the hospital

context and staff working within this context. As the 11 years working at the hospital passed, a change in ward culture and passion for work from the staff although subtle and slow was indisputable. Similarly, employment of new speech-language pathology graduates also revealed a work ethos different to what existed previously linking to the generational changes that were happening worldwide.

As I gained clinical experience and via interactions at forums and meetings with fellow speech-language pathologists from other hospitals, it was becoming obvious that what we did and how we practised differed from one institution to the next. Being involved in student training and supervision from my first year of employment at the hospital, the feedback from students and hence universities (training institutions) revealed similar concerns – students were receiving different input of what to do when for different patients depending on the perspective of the supervisor (speech-language pathologist). The lack of standardisation, variation in intervention (assessment and management) and poor monitoring of patient outcome was a growing concern. With an interest in adult dysphagia, I was acutely aware that such variation and lack of evidence to substantiate practice would result in adverse complications and poor outcomes for the patient. I undertook to investigate the reality of the situation.

The training protocol and free water dysphagia intervention protocol developed for the study sought to address several goals including improved outcome from dysphagia management based on implementation of a free water protocol, some uniformity in intervention, improved inter-professional communication and collaboration and overall quicker and earlier access to more patients. Prior to commencing with the research, I was aware of the challenges in undertaking an intervention study within a public hospital in South Africa. The thesis will lead you through the steps taken to prepare the site and participants for the study and show how as the study unfolded the anticipated challenges and barriers were overcome by careful manipulation of variables and keen regard for professional collegiality.

1.3 Rationale for the study

As is the situation with South Africa, social variables, financial and economic dependence, significant rural infrastructure, traditional belief systems, significant illiteracy, and dependency on government support, separate it from a more developed country (Education

Pathways International, 2013) with the underlying causes rooted in social, cultural and economic variables, historical and political elements, international relations, and geographical factors. Despite significant change since South Africa's first democratic election in 1994, it may still be viewed as a developing country South Africa as it still faces issues of illiteracy (18.1% for persons over the age of 20 years), unemployment (24,9% of the total population), disparate levels of service delivery and accessibility, and a growing burden of disease status (Statistics South Africa [STATSSA], 2012). Caution in using only one or a specific variable to gauge level of development or not within a country is necessary, to avoid undermining the importance of each variable when looking at a country holistically, for example economic growth, social development, health status, population dependence on government support, education, unemployment, illiteracy and infrastructure.

With the label of a developing country come many implications for the government and the people of the country, lay and professional alike. Infrastructure, availability of resources and accessibility of resources are unequal for all sectors of the population, with persons belonging to higher income brackets being favoured because of their financial independence (Woolard, 2002). Similarly, sectors such as education, social service, welfare services and health services are also unbalanced either in favour of or against particular population groupings (Woolard, 2002). As a country, the historical effects of apartheid have seen many areas of redress and transformation, since its disbanding in the early 1990's (Luthans, van Wyk & Walumbwa, 2004). Particularly for health care, the vast divide between people of high, middle and low financial groupings have meant a choice between private or public (government subsidised) health care. For a large part of the almost 20 years post-apartheid, the public health care sector has seen an influx of patients that previously were not able to access health services with resultant migration of staff unable to cope with patient demands. Human resources, facilities and standard of care unfortunately were placed under the strain of having to cope with more patients despite not having the necessary staff or infrastructure to support this increased patient load (Benatar, 2004). Implications of improved accessibility to health care albeit still within a developing country saw prevalence of the burden of disease increasing, aligning with changing lifestyles of many previously disadvantaged people. Simultaneously came the HIV/AIDS pandemic and until recently the lack of availability of anti-retroviral medication for those most in need (Benatar, 2004).

For health and medical professionals working within public hospitals, the implications for service delivery seem to have changed quickly and drastically. Implications for the professional speech-language pathologist working in a public hospital appear to also have been profound. Severity of medical pathology such as dysphagia grew, patient numbers (in and outpatient) multiplied, and the demand for speech-language pathology services grew, without similar growth in number of speech-language pathologists qualifying. As a result, it appears that the consistency and sustainability of intervention suffered, with completeness and quality of intervention being inevitably compromised. For dysphagia intervention in public hospitals, these implications were profound in terms of further medical compromise of the patient. Based on personal experience particular aspects of the profession by public employed speech-language pathologists seem to have been afforded less priority balanced against the need for them to manage and keep afloat. Research, and a commitment to practice based on evidence was not enforced and reliance on anecdotal 'evidence' or unproven theories seemed to become more common.

Social circumstances, the environments, lifestyles, cultures and contexts of people are changing i.e. the bio-psychosocial aspects, and these are gaining importance for their influence on management and the medical aspects surrounding dysphagia i.e. the actual pathophysiology. However, in South Africa dysphagia management does not appear to have undergone similar changes with the focus seeming to have remained on pathophysiology alone with the concomitant variables not given due consideration. There seems to be a growing awareness that dysphagia studies for instance, focusing on perceptions and level of knowledge or only on quantitative aspects were insufficient and inadequate to address the transforming needs of clinical practice (Hartley, 1998). Qualitative and quantitative methods of investigation into diagnosis and management of dysphagia need to incorporate more. From a qualitative perspective, a more holistic ethnographic understanding of the socio-cultural, socio-political and socio-financial background of patients seems needed. Knowledge and understanding of the service provision conditions in public hospitals appear necessary to guide the direction of dysphagia research. Insight into patterns of teamwork and collaboration for the dysphagic patient in a public hospital was needed as well as an understanding of why these collaborations did or did not exist, what sustained these partnerships or what was needed to sustain these partnerships if optimal patient management from a dysphagia perspective was the aim. Improved understanding of why particular management

styles/protocols for dysphagia did or did not work and what conditions were necessary for them to work, needed interrogation.

Some agreement that clinical management of the underlying pathophysiology of the swallowing impairment is only one component of dysphagia management by speech-language pathologists seems necessary. Regardless of how efficient and effective management is while the patient is in hospital, these efforts may come to naught if there is poor insight into how these principles and recommendations will be transferred to the home environment or if the speech-language pathologist in unaware of patient compliance because of other priorities other than difficulty swallowing for the patient. In conceptualising this study and its relevance, it was acknowledged that as speech-language pathologists working in South Africa, our theoretical and experiential knowledge of dysphagia is often lost in its translation to clinical practice. This may be because of contextual challenges, institutional constraints, human variables and unfavourable attitudes, perceptions and mind-sets. In line with these challenges, the profession has in recent years, been confronted to verify its stance as a scientific profession by justifying treatment with evidence resulting in speech-language pathologists seeking resources to engage in evidence-based practice (Frymark & Hammond, 2009). There was therefore a need to explore how to effect optimal knowledge translation in dysphagia management for this context for the benefit of the patient as well as the speech-language pathologist. The likelihood of an expanded role of the speech-language pathologist in this context was necessary but needed investigating.

Working from a developing country perspective we are required to a) keep abreast of international practice to ensure holistic management of the patient with dysphagia, b) work within a team approach for the benefit of the patient and c) are professionally 'obligated' to conduct contextually necessary dysphagia research that has meaning for the end-users. There is a need for the outcome of the research to be intervention that is implementable and sustainable (abides by principles of knowledge translation) based on contextual needs and requirements.

Dysphagia irrespective of underlying pathology is a disorder that adversely affects the affected individual's quality of life. The consequences that can arise from dysphagia range from malnutrition, dehydration, poor recovery from medical insult, and aspiration pneumonia to death (Robbins et al., 2007). An increasing burden of disease is predicted for South Africa

and pathologies such as stroke, cancer, HIV/AIDS, traumatic brain injury and cardiovascular conditions all of which are gaining momentum in terms of prevalence (Health Roadmap, 2008; Lawn & Kinney, 2009; STATSSA, 2012). Patients with these conditions are likely to present with dysphagia related symptomatology. There is therefore a need to manage dysphagia more holistically to prevent this vicious cycle of sickness, dysphagia, comorbidity, decreased quality of life and poor recovery as can be seen in figure 1.

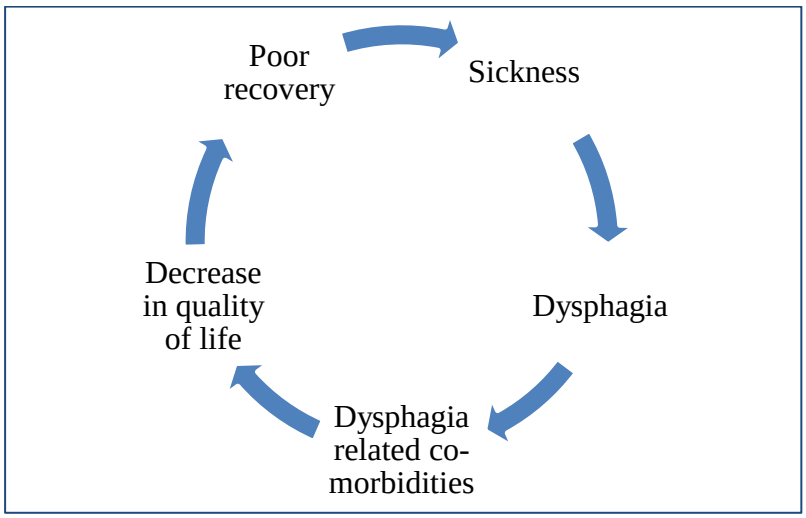

Figure 1: Vicious cycle depicting outcomes of poor or lack of dysphagia management

Dysphagia intervention i.e. assessment and management falls within the job description of the speech-language pathologist (Health Professions Council of South Africa [HPCSA], 2012; Kennedy, 1992). International as well as national guidelines by professional bodies reiterate the need for a prescribed set of clinical and theoretical competencies prior to engaging in dysphagia intervention (ASHA Competencies, 2002; HPCSA, 2010; Scottish Intercollegiate Guidelines Network [SIGN], 2010). Thus, one remains acutely aware that as a disorder dysphagia cannot be practised without caution and experience. Nevertheless, speech-language pathologists in South Africa face an incredible challenge in being required to provide comprehensive services despite having insufficient numbers of qualified therapists (STATSSA, 2012; HPCSA, 2012).

Collaboration within a health care context is an inter-professional phenomenon designed to achieve desired ends that no single professional can achieve unilaterally (Wood & Gray, 1991). The Canadian Medical Association (2007, p. 3) provides the following definition for collaboration that I found appropriate for the current study,

> *"….providers using complementary skills, knowledge and competencies and working together to provide care to a common group of patients based on trust, respect and an understanding of each other's skills and knowledge. This involves a mutually agreed upon division of roles and responsibilities that may vary according to the nature of the practice, personalities and skill sets of the individuals. The relationship must be beneficial to the patient, the physician and other providers."*

Within the management of dysphagia, particular aspects of the disorder lend itself to training and collaborative work with other professionals, in this case the nurse (Batty, 2009). These include dysphagia-screening, implementation of feeding strategies, monitoring of the dysphagic patient for signs of aspiration and mouth care. Unfortunately there remains little knowledge or understanding of how to initiate collaborative partnerships, how to identify which professional to collaborate with for dysphagia management, conditions necessary for the partnership between these professionals to show benefit or what measures need to be considered for these partnerships to be sustained specific to the South African public health care context. The possible insight that could be gained from this knowledge stimulated the undertaking of the current study.

The practice of dysphagia intervention comes with many challenges, not the least of which is patient compliance with recommendations by a speech-language pathologist (Schwartzentruber, 2011). The result of noncompliance is aspiration pneumonia. Many international studies provide compelling evidence of the effects of a clean mouth and water consumption for patients presenting with oropharyngeal dysphagia (Becker, Tews & Lemke, 2008; Logemann et al., 2008; Panther, 2005). The evidence shows that aspiration pneumonia is reduced with good mouth care and there are consequent positive effects on length of hospitalisation, quality of life and patient compliance. Mouth care, a vital component of a free water protocol was identified as the area in which to include nurse involvement for dysphagia management in the current study. A free water protocol refers to the unlimited provision of water to a patient presenting with oropharyngeal dysphagia and aspiration, by a health care professional with an understanding that mouth care for the patient is optimal. Despite theoretical knowledge of the benefits of mouth care, there were identified challenges unique to the South African context, in simply compiling a mouth care protocol and 'asking' nurses to complete it. These included:

- Workloads of nurses in South African public hospitals,

- Staff (nurse and speech-language therapist) morale and disengagement with the notion of teamwork,
- Time constraints,
- Resource limitations,
- Limited inter-professional communication,
- Medical complexity of patients suggesting a greater need for routines that are considered more life-threatening or medically compromising,
- Lack of a shared understanding of the importance of mouth care generally and in relation to dysphagia,
- A top-down model that does not align with collaboration as the goal,
- In addition, historical imbalances of the country that have precipitated the existence of hierarchical and authoritative managerial structures with perceptions of inadequacy amongst the hands-on staff employed within public health care.

It was necessary to determine how some of these challenges could be resolved before introducing the intervention for investigation. The dearth of information on how to facilitate implementation of research findings into daily practice for this context suggested that knowledge-to-action understanding for the free water dysphagia intervention planned for the current study was necessary and this provided further support for the different dimensions of the current study (Ward, House & Hamer, 2009). To address the knowledge-to-action imperative a mixed method of investigation would provide understanding of context and people and based on this understanding enlist their participation in the investigation of the intervention. Dysphagia research in South Africa is sparse, and the limited existing pool of studies provide little new evidence of feasibility of interventions for this context, nor do the studies provide a balance of quantitative data supported by an understanding of the variables that affected implementation of the intervention under investigation. This can be seen in table 6 (p. 53) in chapter two.

The challenges faced by professional dysphagia practising speech-language pathologists working in public health care in South Africa coupled with high levels of emotional and psychological strain because of working conditions, appear to have been at the cost of evidence-based practice in dysphagia. The dearth of scientific South African dysphagia based research, suggests some level of detachment or disengagement with the research aspects of

the profession. Notwithstanding the reason for minimal dysphagia research, the consequences have unfortunately adversely affected the image of the profession in that there is a lack of uniformity in practice because assessment and management decisions are not always based on evidence, unfortunately at the expense of the patient. Adoption of a protocol that is proven effective for the South African context will have multifaceted benefits to the patient, professionals and health care institution. The current undertaking was therefore based on a desire to initiate the creation of an armamentarium of clinical studies (from this context) based on evidence (for this context or similar contexts) that may provide guidance to dysphagia-practising speech-language pathologists.

The current study therefore aimed to investigate how, and under what considerations a free water protocol for dysphagic stroke and traumatic brain injured patients in an acute public hospital in South Africa could be implemented and sustained, thereby addressing the existing knowledge-to-action gap and contributing to evidence-based practice. Collaboration with the nurse as part of an action research imperative was used to address this goal as well as garner optimal support and participation from the nurse not only for purposes of the study but as an attempt to ensure sustainability of the intervention and continued collaboration in dysphagia management thereafter. The benefits that could be gained from such collaboration for the nurse, was also considered. By investigating the potential to foster a collaborative partnership for dysphagia management it was possible to determine the success or not of knowledge translation in dysphagia management. Strives to involve patients more in their own management and to gain an understanding of how or if dysphagia affected their quality of life was also investigated.

1.4 Reader orientation

It is vital to understand the significance of the macro context of a study to grasp full understanding the research process and ensuing findings. Chapter 2 introduces the reader to the South African context. The geographical and population demographics are highlighted and lead into some of the key health challenges facing the country i.e. the burden of disease. Nurses as the key stakeholders within the current study are introduced. Literature describing the transformation of the nursing and the speech-language pathology profession in South Africa is provided. Rationale for why nurses are vital to collaboration in public hospitals and how collaboration for dysphagia may be considered is included in chapter two.

Chapter 3 discusses dysphagia. Definitions, statistics and literature detailing the complications of dysphagia are provided. I introduce the two pathologies significant to the study, namely, stroke and traumatic brain injury and link them to dysphagia with rationale for why these particular pathologies were selected. Dysphagia intervention is described and an appraisal of existing literature on other free water protocol studies undertaken over the years is provided. An overview of the limitations and contributions of these studies to current understanding is provided. The concept of mouth care is also introduced in this chapter. The relevance of mouth care in the general population is described before its relationship to patients with dysphagia is detailed. Medical and quality of life benefits of consistent and effective mouth care are highlighted, and provide support for the significant role for training in mouth care within the current study.

As an intervention study within an acute public hospital that required participation of nurses, careful consideration to prepare the site and stakeholders for the study was necessary. Chapter four describes how this was achieved by providing a discussion of the theoretical foundation of the study. A comparison of evidence-based practice globally and in Africa/South Africa is provided and this is linked to the existing knowledge-to-action gap that is present with dysphagia management in South Africa. A knowledge-to-action process framework by Graham et al. (2006) which aligns with principles of action research is described as the theoretical backdrop for the thesis.

Whilst the overall aim of the study was to determine if a free water protocol was practical to implement in a public hospital in South Africa, mouth care training was a significant component and aim of the study. Chapter five takes the reader through the methodological considerations that were necessary to optimise successful implementation of the free water dysphagia management as well as mouth care implementation to achieve positive and sustained outcomes. A case for use of a mixed method design following a pragmatic framework is built in chapter five.

Chapter six contains the methodology. Rationale is provided for the selection of particular variables, protocols and methods. The reader is made aware of the ethical principles that guided the completion of this study. Details of the specific data collection tools with rationale are provided. This chapter also details how the obtained data was analysed and the validity and trustworthiness of the results is described.

Chapter seven has the details and results of the different pilot studies that were undertaken. This chapter may be considered to be one of the most important chapters in the thesis for the following reasons. As noted above, nurse training was a crucial component of the study. It was imperative to devise a model of training that fulfilled the requirements of the study but that was at the same time beneficial to the nurses receiving the training. Thus the chapter includes a detailed account of the different models of training that were undertaken before the model believed to be most appropriate unfolded. A brief reflection with limitations of each pilot study conducted is provided with a description of how the identified limitations of one pilot study influenced the selection of subsequent pilot study models is detailed. Hence, the principles of action research are given credence. The final training model selected for its suitability was piloted simultaneously with dysphagia intervention provided to dysphagic participants. This allowed me to gain an overall impression of the likelihood of cohesiveness and success of both components of the intervention prior to embarking on the main study.

Chapter eight includes the results of phase one of the main study. These results pertain to the qualitative component of the study and a description of the ethnography. The value in reading the ethnography is the mental image it provides to the reader of the context and people in the study. It offers likely explanations for particular behaviours, actions and events that ensued with nurses and how these influenced the study and findings.

Chapter nine contains the results of phase two of the main study. This information relates to the quantitative aspect of the study, i.e. the dysphagia management. The results of the outcomes for the study group, who received the free water dysphagia management protocol is described and compared against the dysphagia management protocol the comparison group participants received.

Chapter ten contains the discussion. The discussion is presented as an overall integrated chapter that links the results of the qualitative with the quantitative. I attempt to provide substantiated explanations for the findings with existing literature. Where and when necessary, I interrogate contradictory findings from my study with that from current and past studies. The research questions are answered in this chapter.

Chapter eleven contains the conclusions drawn from the study. Included are the implications one may draw from the method and results.

CHAPTER TWO: THE SOUTH AFRICAN CONTEXT

Orientation

This chapter will aim to introduce South Africa and provide some insight into its status as a developing country. A description of health care with a focus on public hospitals will be provided. The role of nurses and speech-language pathologists within this health care structure will be discussed as I aim to highlight the challenges operating within public hospitals and the difficult task both groups of professionals face daily. The challenge in introducing a new intervention in this complex environment will become clearer as I explore ways to foster improved inter-professional working for the benefit of the patient.

2.1 A brief description of South Africa

South Africa is situated at the southern-most tip of the African continent and houses one of the newest wonders of the world, Table Mountain. To the unfamiliar eye, the beauty of the seaside, the fields of fruit and the wine-lands mask the arid dryness and hopelessness of those with limited access to resources and services. Open-air toilets, lack of running water, paraffin lamps and attending school under a tree are a way of life for many South Africans. Almost 20-years post-apartheid, South Africa is still plagued by vast rural-urban and poor-elitist divide (Bryceson, 2000). The Urban Profile of South Africa (2002) estimated that only by 2015 will 56% of the population be living in urban areas. There is little consensus on the definition of 'rural'. It is a multifaceted concept and its definition varies according to the aspects of rurality that are most relevant to the topic at hand (Hart, Larson & Lishner, 2005). However, there is a stereotypical visual image of rural that includes, "*pastoral landscapes, unique demographic structures and settlement patterns, isolation, low population density, extractive economic activities, and distinct sociocultural milieus*," (Hart, Larson and Lishner, 2005, p. 1149).

Parts of South Africa clearly resonate with this image and hence the rural-urban divide (Bryceson, 2000; Leite, McKinley & Osorio, 2006; Tacoli, 1998). There is agreement that the socio-political context of health in South Africa is not ideal (Fassin & Schneider, 2003; Gilbert, 1996; Kalipeni & Oppong, 1998) and with it has come the realisation that redress to counteract the effects of apartheid may not be attained in the very near future. Not only in health, but also in education, human resources and social services alike have the employees

been left in a quandary with many unfavourable perceptions and attitudes related to their work.

South Africa has 11 provinces as seen in figure 2. Gauteng which figure 2 shows as having the smallest land-size capacity (16 548km²) houses the largest percentage of the South African population. Gauteng was the province in which the study was conducted.

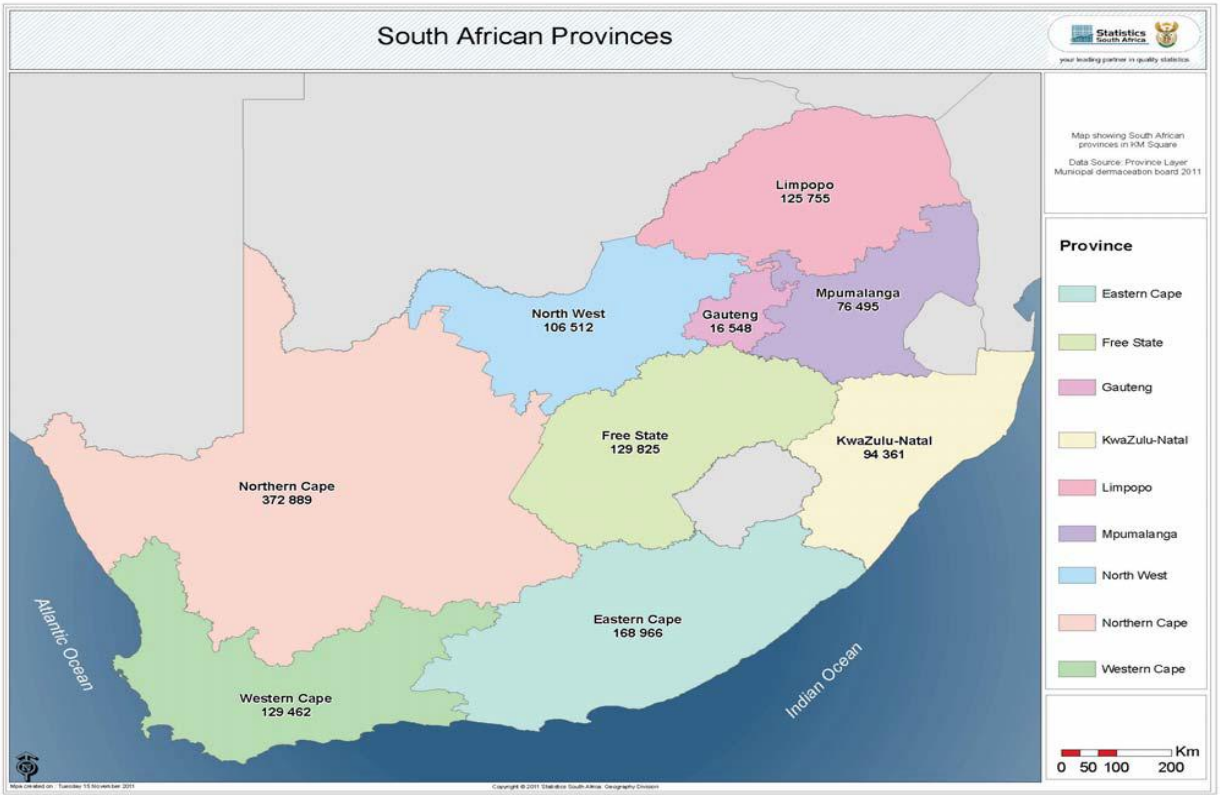

Figure 2: Map of South Africa showing the different provinces from Statistic South Africa, 2012

Figure 2 also shows the Northern Cape as having the largest land-size (372 889 km²) but it accommodates the smallest percentage of the population, 2.17% (STATSSA, 2012). According to the Midyear Population Estimates (2011), Gauteng province is presently the most urbanized province at 96%. Despite the connotation urbanization brings, 1,626 400 urban dwellers lack water supply and 203 300 urban dwellers lack sanitation (Urban Profile: South Africa, 2002). The Urban Profile (2002) further documents that overall crime levels in the metropolitan areas (such as in Gauteng) are higher than in rural areas (like the Northern Cape) due to population density, limited resources, greater stress and increased conflict. This has implications for the incidence of traumatic brain injury and stroke in these areas due to

the combination of factors impinging on persons residing in these areas. These were some of the reasons that Gauteng was considered the ideal province in which to conduct the study.

The 2012 census revealed that the population of South Africa is close to 51 million with 52% (26.07 million) being female (STATSSA, 2012). Its composition of multicultural, multiracial, multi-linguistic and multi-traditional persons verify South Africa's title as a rainbow nation. The racial classification as represented in figure 3 reveals that 79.5% of the population is African, 9% is Coloured[1], 2.5% is Asian and 9.0% are White (STATSSA, 2012). The racial classification is significant for discussion given the history of apartheid in the country when black African people had limited access to services and resources (Woolard, 2002). From 1948, when the right-wing National Party came to power, economic marginalisation, social separation, and racial injustices permeated South Africa (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009). The classification system in existence (racially based) determined "*where a person could live, work, and go to school... resources allocated to their education, health care and pensions*," (Coovadia et al., 2009, p. 819). Packard (1989) noted that low wages, overcrowding, inadequate sanitation, malnutrition and stress caused the health of black people to deteriorate.

The consequent rollover effects of these disparities are contributing reasons for 84% of the South African population accessing public health services, most being non-white and 16% belonging to the private health sector (Coovadia et al., 2009). The current standing confirms the remnants of previous racial segregation.

Coloured[1]: During apartheid, the term 'Coloured' was used to refer to group of people generally considered to be of mixed race origin. Coloured people, throughout the course of South African history, have been regarded as neither white nor black, and their ability to exercise their political rights have been dependent on the attitude of government at the time.

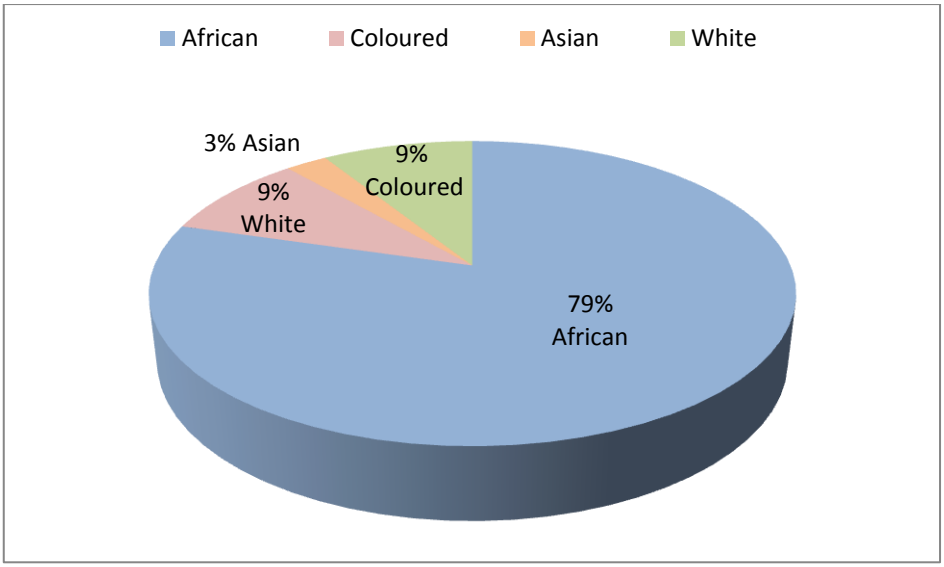

Figure 3: Racial split of South Africa

South Africa has 11 official languages (Kamwangamalu, 2000). Limited and unequal linguistic competency by each South African of all 11 official languages affects one's education, communication, and employment, social positioning, overall literacy levels and opportunities available for growth and future progress. This is significant within a work context such as health care as there may be misunderstanding, poor compliance, limited or ineffective attempts at communication, and life threatening or even fatal consequences for the patient that may be precipitated by language differences between him/her and the medical or health care professional.

Malnutrition is a significant concern amongst many people living in South Africa. A study conducted at Groote Schuur Hospital in Cape Town, South Africa indicated that more than 40% of patients admitted for surgery were nutritionally depleted (Winter, 2007). There is a level of malnutrition on admission, with further nutritional depletion and deterioration whilst hospitalised for various reasons. The first is inadequate recognition by hospital staff of the increased nutritional needs of patients due to illness and injury (Winter, 2007). Secondly, the effect of dysphagia affects eating and compromises nutritional intake (Vandewoude, 2011).

It is impossible to separate the history of South Africa i.e. the inequalities that prevailed during the apartheid era, from the position the country currently finds itself in from a health care perspective. In addressing the many inequalities, the government sought to introduce policies that would improve access to services for the financially disadvantaged. These

included the policy on free maternal and child health care for children less than six years of age and free health care for pensioners (Strategic Plan for Maternal, Newborn, Child and Women's Health, and Nutrition in South Africa, 2012). It is unfortunate that the timing of the introduction of these policies coincided with the sudden increase in HIV/AIDS prevalence in sub-Saharan Africa, as the implications for staff and resources automatically escalated (Benatar, 2004; Coovadia et al., 2009). Medical and nursing staff were the professionals most vulnerable to the influx of patients, and there was a resultant 'escape' of many of these professionals to working contexts that were less stressful or demanding and that offered better salaries, benefits and status (Hull, 2010). Despite the loss to the professions there unfortunately was no subsequent increase in numbers of people entering these professions to make up for the loss (South African Nursing Council, 2010). There have been repeated promises by government to improve working conditions, salaries, and work-related incentives within public health care (Esau & de Waal, 2009). The recent adoption of the Occupation Specific Dispensation has attempted to address this. The Occupation Specific Dispensation provides monetary incentives for nursing and health professionals who improve their theoretical and clinical skills and who show progress within their profession (Fouche, 2007).

2.2 Burden of Disease

Westaway (2010) noted that in 2002 the World Health Organization [WHO] estimated 56 million deaths globally, of which 60% would be due to major chronic disease accounting for 43% of the global burden of disease. The World Bank (2013) has classified South Africa as an upper-middle-income country for use with the World Health Organisation, from an economic perspective. It still however retains its title as a developing country when one heeds the state of unemployment, literacy, government dependency, etc. that were raised earlier. Within the middle-income countries the WHO (2008) reports stroke as being the leading cause of death, accounting for 14.2% of deaths. The WHO (2008) also reports that stroke is the second leading cause of death globally (9.7%), with HIV/AIDS being the sixth (3.5%) globally.

Stroke is among the four leading causes of death in South Africa (Mudzi, Stewart & Musenge, 2012). The prevalence of HIV in South Africa is approximately 10.6%, with 5.38 million people living with HIV in 2011 (STATSSA, 2012). An estimated 16.6% of the South African adult population aged 15-49 years is HIV positive (STATSSA, 2012). In a South African Medical Research Council Report, tuberculosis, pneumonia, diarrhoea and HIV-

related with cardiovascular disease, hypertensive heart disease, interpersonal violence, diabetes and ischaemic heart disease were documented to fall within the top ten causes of years of life lost (Breier, Wildschut & Mgqolozana, 2009). In an attempt to address this existing burden of disease, it was reported that there are approximately 240 000 nurses eligible to practice and 150 509 health professionals registered with the HPCSA (South African Nursing Council [SANC], 2012; Human Resources for Health SA 2030 - Consultation Document V5, 2011). It is easy to surmise that the number of currently practising nurses and health professionals is insufficient to address the health care demands facing the South African health care system given the figures above (Human Resources for Health SA 2030 - Consultation Document V5, 2011). The report notes that the current number of vacant posts in the public health sector would cost R40 billion to fill. The implication for the status of service provision (from the perspective of the patient) and workloads (from the perspective of the health care provider) given this figure is alarming.

According to Westaway (2010) co-morbidity is a common occurrence globally. Gijsen et al. (2001) noted that co-morbidity is associated with risk for disability or mortality as well as higher health care utilization and expenditure. Modi, Modi and Mochan (2006) in an editorial noted that a co-occurrence of stroke and HIV/AIDS is expected for sub-Saharan Africa. The compounded effect of two potentially dangerous and debilitating pathologies each of which more than likely has dysphagia as a complication reduces the positive health outlook for the population but more positively highlights the potential for new research. The WHO (2008) validated this need by stating that measuring how many people and why people die each year together with gauging how various diseases are affecting the living is important in assessing the effectiveness of a country's health care system. It is additionally important to recognise how the manifestation of stroke differs between developing and developed countries for many reasons (Brainin, Teuschl & Kalra, 2007). The differing needs and priorities of stroke manifestation from a dysphagia perspective in tertiary and secondary level hospitals within a developing context needs exploration. The thesis will attempt to describe and address some of these considerations.

2.3 Health care in South Africa

Private and public health care comprises the South African health care structure. Eighty four percent of the population access public health services with only 16% of the population

having the means to access to private health care (Benatar, 2004; Coovadia et al., 2009). This is seen in figure 4 below.

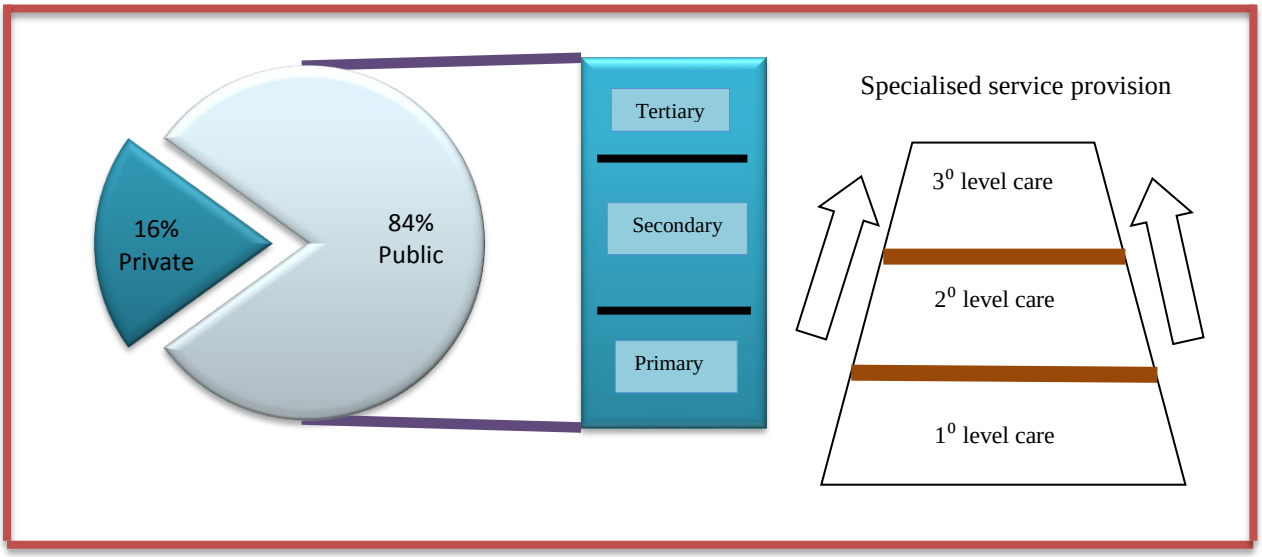

Figure 4: South African health structure showing patient movement from general to specialist service provision

Within the public sector, various levels of health care are available depending on the service required and underlying pathology or disorder (Benatar, 2004). The structure in figure 4 is as follows: community or primary health care (1º), secondary level health care (2º) and tertiary level health care (3º), with primary referring to health care received at the grass-roots levels via clinics. South Africa has 388 public hospitals. Secondary and tertiary level hospitals make up 16% each of the total number (Cullinan, 2006). Tertiary health care is provided at the academic or teaching hospitals, which are linked to a training institution or university. Service provision and care required at a tertiary level hospital requires the expertise of specialists, while secondary level hospitals require intervention of specialists and general practitioners (Cullinan, 2006). Patients are transferred to rehabilitation hospitals once they have recovered sufficiently and are medically stable but still require rehabilitation services. Rehabilitation hospitals would be part of secondary level care. At a rehabilitation hospital, a patient may be hospitalised for anything from weeks to months.

Carlson and El Ansari (2000) note that advocacy, leadership, communication and collaborative partnerships are valuable skills for any person or group of professionals to possess in any context. Literature suggests that this is lacking within the current functioning of the public health sector in South Africa (Hildebrandt, 1996). Disproportionate patient to

health care professional ratios compel one to investigate the possibility of inter-professional training especially when one considers the dire consequences of inefficient management of dysphagia because of time constraints. Within any hospital, nurses and to an extent doctors provide the links in the chain that patients hang on to before their re-entry into the world after a medical instability. The question remains though, whether inter-professional training and additional commitment required for collaboration can be expected or even asked of nurses in South Africa. The thesis will show that this vision is not impossible and may be attained with particular considerations. A critical discussion and review of factors that facilitated and hampered this process for the current study is provided to guide future researchers embarking on similar studies.

Myer, Ehrlich and Susser (2004) note that the South African health care system is still dealing with the colonial and post-colonial affects whilst trying to embrace new public health threats that are linked to a changing global economy. The principles of the Batho Pele ('people first') White Paper were adopted on 1 October 1997 (Darch & Underwood, 2005) to address existing social and racial segregation within the health system in South Africa. The Batho Pele principles are a set of national principles adopted by the National Department of Health to promote accountability and quality control in the delivery of public services at South Africa's juncture from "*racist authoritarianism to constitutional democracy*" (Darch & Underwood, 2005, p. 78). Appendix 20 contains a copy of the Batho Pele Principles.

Batho Pele is a Sesotho word (one of the 11 official languages of South Africa) meaning 'People First'. It was launched in 1997 to transform public (government) service in South Africa at all levels (White Paper on Transforming Public Service Delivery, Batho Pele White Paper, 1997). The new government in place at the time identified that public services were not people friendly and lacked the skills and attitudes to meet the developmental challenges that were facing the country, hence the introduction and launching of the Batho Pele Principles (Russell & Bvuma, 2001). It was developed for the protection of the patient. The translation of this policy into practice remains untested for specific disorders and relates at a conceptual level to knowledge-translation implications in an area such as dysphagia, for example. In considering the White Paper on Transforming Public Service Delivery, Batho Pele White Paper (1997) questions surface if we as dysphagia-practising speech-language pathologists are, in addition to our professional and ethical obligation to the HPCSA, meeting the service delivery needs of South African patient with dysphagia with whom we intervene.

I am unable to confidently answer 'yes' as based on my clinical experience I do not believe that we are. We may be managing the swallowing difficulty within the hospital context, (although evidence to confirm this is still needed) but more importantly the circumstances and day-to-day lifestyle of the patient now hampered by a swallowing impairment is not known in sufficient detail and evidence of this is lacking in the literature.

Unfavourable and undesirable conditions within public hospitals, poor and often unmonitored patient outcome, an increase in preventable secondary infections and co-morbidities and fatalities have had significant media attention over the past decade and has coloured the impression of public health care in South Africa (Roberts in Mail & Guardian, 2011; Holman in Engineering News, 2010). The current thesis is an attempt to address concerns currently challenging health care and service provision in the area of dysphagia by reducing the knowledge-to-action gap (making intervention attainable and sustainable) whilst ensuring that it is based at some level on scientific principles within the speech-language pathology profession. Ensuring that the findings from research are available to and can be implemented by the persons at the grass-roots level and ensuring that it did not just exist at a policy level was investigated.

2.4 The nursing profession in South Africa

Due to the nature of their job, nurses are the professionals who are closest to the patient, who are in daily contact with the patient and who the patient relies on for direction and continuity. The South African Nursing Council Charter of Nursing Practice (2004) states that because nursing takes place in a dynamic social, economic, political and technological environment it needs to be at all times sensitive, relevant and responsive to the individual, community, and societal health care needs and to changing circumstances. The position of the nurse within a medical ward suggests that research that involves patients, interventions, teamwork and inter-professional communication or clinical trials may require the involvement of the nurse at some level. As an authority within the ward, both in terms of administration, routine and patient care, the nurse may be the one professional (either directly or indirectly) pertinent to the success or failure of any research within this context. As an intervention study, nurse acceptance, motivation and knowledge of the study were key to successful knowledge translation.

Hall (2004) comments that there are inherent job stresses in caring for sick people. Over and above the challenges faced in providing care to patients not feeling well, nurses also have to come to terms with human suffering and death of these patients. In addition to emotional responsiveness, which is an intrinsic factor, extrinsic context-dependent factors may influence service delivery by nurses. These include but are not limited to the impact of HIV/AIDS, global migration issues, shortage of nurses and consequent workload of practising nurses, gender bias, cultural and personal values, competence/incompetence, education and training, nursing regulation, social positioning of nursing and nursing resources (Hall, 2004). South Africa is not alone in facing these challenges. Changes to the health care structure, the transition of health policies, changing population and health care demands as well as the HIV/AIDS pandemic and burden of disease make these challenges appear insurmountable and problematic for South Africa when one takes into account the need for research from this context, involving nurses as end-users.

Nursing care within a hospital setting epitomizes the quality of care patients receive and their consequential recovery process. Literature suggests that aspects of recovery for the patient may be aided by increased collaboration and cooperation between the nurse and the allied health or medical professional.(Reeves et al., 2008) Within speech-language pathology, dysphagia is one such area requiring collaboration and cooperation (Reeves et al., 2008). While the speech-language pathologist is responsible for the diagnosis of dysphagia and recommendations for the management thereof, it is ultimately the responsibility of the nurse to follow through with the recommendations relating to aspects of feeding such as positioning, temperature monitoring for aspiration, ordering of modified diets and mouth care (Colodny, 2001; Jackson, Little, Kung, Williams, Siemiatkowska, & Plowman, 2008). The care, comfort and support of the patient fall within the realm of the nurse (South African Nursing Council Nursing Act, 2005).

The SANC defines nursing as a caring profession practised by nurses registered with the council, which supports, cares for and treats a health care user to achieve or maintain health, and where this is not possible, cares for a health user so s/he lives in comfort and with dignity until death (South African Nursing Council Nursing Act, 2005). Several authors have supported the use of teamwork for effective and efficient delivery of health and social care (Long, Kneafsey & Ryan, 2003; Strasser, Falconer & Marino-Saltzmann, 1994).

2.4.1 Historical roots of nursing in South Africa

Nursing as a profession in South Africa began in the last third of the 19th century (Coovadia et al., 2009). At that time, it comprised white English-speaking females set against a religious backdrop. Despite the first black professional nurse qualifying in 1907, it was not until World War II in the face of stark shortages that black females were encouraged to train as nurses. Racial discrimination both in the workplace and in society accompanied these individuals, whilst in contrast they became valued and revered members of the educated domain within their own black communities (Coovadia et al., 2009). Coovadia et al. (2009) noted further that black nurses were not allowed to nurse white patients or have white subordinates. A further consequence of apartheid meant also that black nurses until 1986 had lower salaries than their white counterparts did (Marks, 1994).

The current racial profile of nurses shows a reversal with black nurses occupying a majority of posts (private and public) and white nurses being in the minority (SANC, 2012). Several reasons have contributed to this. Improved access to education for black nurses, older more qualified white nurses seeking greener pastures (higher salaries), and the opportunity to earn a salary whilst still training allow many black nurse to continue financial support of his/her family. Generational differences have added to the transformation of the nursing cohort. Literature across professions have documented changes in work values aligning with characteristics of the different generations (McNeese-Smith & Crook, 2003; Stuenkel, de la Cuesta & Cohen, 2005;). The transformation of characteristics of each generation seen in table 1 is not specific to nursing and is a general worldwide trend across cultures.

Table 1: Characteristics of generation changes (McNeese-Smith & Crook, 2003)

Generation	Period	Characteristics
Silent Generation	1925 – 1942	Hard working, conservative, cautious. Mediators and mentors.
Boom Generation	1943 – 1960	Materialistic focus, long working hours. Traditional work values and ethics.
Generation X	1961 – 1981	Cynical, unmotivated, self-absorbed, questioning authority.
Generation Y	1982 to present	Technologically savvy, needs immediate feedback, requires flexible work schedules, opportunity for professional development and wants supervision.

Despite the generic characteristics of emerging generations clearly migrating toward ego-centrism, Stuenkel et al., (2005) believed that providing opportunities to increase involvement and collaboration among the generations would allow for emergence of positive change in the work environment. I will show how this suggestion was incorporated into the current study by way of action research and knowledge-to-action principles.

Transformation efforts have enabled easier access to colleges for training, access to finance and improved education levels thereby contributing to females entering the profession later in life with younger nurses therefore being more qualified despite their age. With the nursing work force being multigenerational, flexibility in the approach to management of this diverse population is implied (Stuenkel et al., 2005). Distinct characteristics encompass each generation, with views on work ethic, nature of work, work styles, management and managing styles differing (Zemke, Raines & Filipczak, 2000). The South African nursing population is home to diverse cultures, languages and generations. The data collection and later analysis will reveal how implementing a more tailored management style to suit the needs and particular employee mix may initiate positive influence on nurses.

2.4.2 Global migration of nurses

Breier, Wildschut and Mgqolozana (2009) documented that despite young people choosing to study nursing and applications for nursing education programmes being in excess to available places, the profession itself is not growing in proportion. South Africa with both rural and urban communities is under pressure to provide equal levels of care within equally resourced facilities across the rural and urban spectrum which is presently lacking (Breier et al., 2009). Urbanised regions within South Africa house the tertiary and secondary level hospitals that are larger facilities (as discussed earlier in this chapter), have more specialised services and have larger staff compositions. Internal migration of nurses from rural to urban health care settings occurs such that the rural areas are left lacking on various levels, especially human resources. Buchan (2006) in an editorial reported that several countries in Africa have fewer than 10 nurses per 100 000 and in comparison to the United States there is a hundred fold difference in the availability of nurses. Thus, higher income countries have the highest nurse to patient ratios (Buchan, 2006).

Biermann (2006) reported that the more experienced nurses have migrated from countries such as South Africa in the hope of seeking greener pastures, leaving responsibility for the

sick to a smaller pool of nurses who are also inexperienced. Breier et al., (2009) found more recently that because nursing attrition both during and after training is high, almost two thirds of practising nurses are over the age of forty. The compound effect of a multitude of variables has left a larger number of nurses overworked, stressed and frustrated which has a consequent effect on efficacy and efficiency of nursing care that is being provided and this too has implications for research studies that need to be undertaken in health care settings.

Promisingly however, new salaries, a new salary dispensation (Occupation specific Dispensation) and the promise of specialisation are now providing incentives to nurses abroad to return to South Africa (Breier et al., 2009). Tightening of immigration laws in the United Kingdom has also supported the decision for many nurses to return home. This was reflected in a Nursing Council Report in 2010 (SANC, 2010). Despite this, the Joint Learning Initiative Report (2004) revealed that Africa was short of approximately 600 000 nurses to be able to meet the United Nations Health Millennium goal. It is with this backdrop that considerations of how and to what extent nurses could be involved in a collaborative intervention project was addressed.

2.4.3 The concept of 'Caring' in nursing

"*The secret of the care of the patient is in the caring for the patient,"* (Bolderston, Lewis & Chai, 2010, p. 198). Altruism implies active and unselfish care for another person, and herein lies the inherent core expectation of any health profession, in this case nursing. Over and above it being an expectation, altruism historically has been the reason for one's entry into a health profession. This is reflected in the Batho Pele Principles (Appendix 20), referred to earlier in this chapter, and Patient's Rights and Responsibilities Charter (Department of Health, 1999) (Appendix 21), which are displayed throughout public hospitals in South Africa. The Patient's Rights Charter outlines a list of rights and responsibilities of patients accessing public health care enabling the patient to take more responsibility for services received and for level of care, they should expect. It assumes to improve patient literacy around their involvement in their own health. For one to be recognised as a caring professional, the recipient of the 'care' should express a high level of satisfaction, psychological adjustment and compliance with treatment-related recommendations (Bolderston et al., 2010). While caring is not exclusive to the nursing profession, the difference in type of care is circumscribed by the profession and may be shaped by policies, ethical guidelines and scope of practice of that profession. Intrinsically, one's life

experiences, cultural background, gender and personality traits define the 'carer' as an individual and health care professional (Bolderston et al., 2010). Within nursing, Widmark-Petersson, Von Esson and Sjoden (1998) identified an expressive (focusing on the affective dimension and defined as caring *about* a patient) and instrumental (focusing on comfort and defined as caring *for* a patient, or physical care and comfort) dimension in nursing care. Both highlight the expressive nature of caring (Bolderston et al., 2010).

Nurses are thus required to embrace a holistic approach to patient care, which encompasses physical development, emotional, social, intellectual and spiritual dimensions. Many investigators have questioned the existence and depth of such care of nurses working within public hospitals in South Africa today (Jewkes, Abrahams & Mvo, 1998; Van der Colff & Rothman, 2009). A decrease in time available to spend with patients, a reliance on technology, and logistic and human resource issues may result in patients feeling depersonalized (Arthur, Pang & Wong, 2001). However, certain basic aspects of nursing remain intact such as documenting patient's vital signs, administration of medication, making of beds, and suctioning. Given the need for some measure of communication to take place during these interactions, a research imperative to investigate the existence and quality of communication and pragmatic exchanges between patient and nurse during these interactions is necessary. Pastitea (1999, p. 488) noted that nurses felt they were not "*emotionally, socially or economically re-compensated for the time and energy they spend on caring*". Such sentiments raise concerns for nurses in South Africa when one considers institutional and contextual challenges over and above the diverse role and routine of the nurse within the ward. The added implications that research conducted in these settings may have, place an added component to the load of nurses that they may feel uncompensated for as well.

Haegert (2000) in a paper entitled 'An African ethic for nursing' noted that an intrinsic ability like care needed nurturing. She explained that a public care ethic, where the kind of attitudes one chooses to display and the acts that result from these choices cannot be assumed nor taken for granted amongst nurses. Morals are fundamental principles that one believes in and so lives by, they determine one's values. Ethics is the practical outworking of these morals and values with people behaving, acting and changing according to their morals and inner belief (Haegert, 2000). Central to the care provided by nurses is the philosophy of *Ubuntu*. Botha (1996) noted that ethical concepts of compassion, tolerance and fairness are encompassed by *Ubuntu* which appears within the South African Constitution and is realised

as being universally applicable, even more so to the profession of nursing. Ubuntu represents humanity or 'humanness' (Arries, 2009). An ability to consolidate an ethic of community and synthesize different ethical frameworks that exist in nursing practice culminates in a sense of Ubuntu. Arries (2009) believed that an African ethic for nursing is compelling as it provides insight and understanding of the complexity of challenges faced by nurses across Africa. An African ethic has the possibility of creating an ethical environment where nurses can feel respected and valued as human beings and thus can contribute significantly to theories of ethics in nursing practice (Arries, 2009). Haegert (2000) believes that once the patient starts to be seen as being central, nurses will only then start to exercise, develop and fulfil their role as professionals who care ethically.

The evolution of the health care system in South Africa has necessitated a change in thinking and working to attain better outcomes for both patients and staff. It is important that in addition to systems and policies being adopted, facilitating these processes at the grass-roots level must be happen. The importance of ensuring that policies transpire in action and 'doing' is vital. Nurses are the core of the health system and need to be recognised as a core component of any health care team.

2.5 The speech-language pathology profession in South Africa

Speech-language pathology and audiology as a profession began in South Africa in 1936 and was based on principles developed in the United States of America and Europe (Bortz, Jardine & Tshule, 1996). The first programme was established at the University of the Witwatersrand by Professor Pienaar who trained speech-language pathologists over a two-year period (Swanepoel, 2006). These clinicians qualified with a diploma in logopaedics. Over the next ten years, Professor Pienaar realised the need for more intensive and extensive training and the training transitioned from a two to a three to a four year professional degree in 1948 (Swanepoel, 2006).

The second training programme was instituted at the University of Pretoria in 1959 (Swanepoel, 2006). Only in 1962 was audiology formally introduced as a major within the four-year curriculum at each of these universities (Swanepoel, 2006). Coupled with training, there was also a significant drive for creation of employment posts within health, education, the public and private sectors. This consequently increased awareness and recognition of this profession as well as services being offered placing a demand on existing professionals

(Swanepeol, 2006). This led to other universities commencing with training countrywide. In 1996, there were five universities training speech-language pathologists and audiologists, three with English and two with Afrikaans as their language of teaching and learning ((Bortz, Jardine & Tshule, 1996).

As early as 1996, it was acknowledged that speech-language pathology and audiology students came from the "*privileged sectors of the population*" and tended to operate only within these sectors (Bortz, Schoub & McKenzie, 1992, p. 62). This reality made sense given that the profession started and prospered in an apartheid context, hence the demographics of the speech-language pathology and audiology student corps (*from privileged sectors of the population*) seen in the late twentieth and early twenty first century at universities (Pillay, Kathard & Samuel, 1997). As has been the trend of the speech-language pathology and audiology profession almost since its inception, it is necessary to concede that of the 50 million population currently, (STATSSA, 2012) there are only 2500 qualified speech-language pathologists (HPCSA, 2012). Despite strives to address transformation of the speech-language pathology and audiology student corps, recruiting potential students from rural areas and addressing issues of gender balance remain a challenge for university departments (Hartman et al., 2012).

Unlike nursing where transformation has seen a complete reversal along racial lines, speech-language pathology has not yet accomplished such a level of transformation (Seabi, Seedat, Khoza-Shangase & Sullivan, 2013). Some contributing reasons for the slow transformation of the profession can also be dated back to disparities within education, linguistic competency and literacy levels of previously disadvantaged black students (Jansen, 1998). These students find the transition to tertiary education a challenge having received inadequate level of education at primary and/or secondary school level, existing unfamiliarity with English necessary for academic purposes, and the challenge of adjusting to a quicker paced, more independent lifestyle at university often without family structures easily accessible (Jansen, 1998).

Swanepoel (2006) noted however, that for speech-language pathology, university departments are starting to make concerted efforts to align with the broader transformation agenda of Higher Education in South Africa. There is an emphasis on exploring ways to enrol first-year university entrants into speech-language pathology and audiology and concurrently

provide assistance and set-up support structures for second-language English speakers coming from rural backgrounds to make their journey through the degree and university life less challenging and more easily attainable (Seabi et al., 2013). Moving into the 20th century, several training institutions began to offer a choice to qualify in either speech-language pathology or audiology (Swanepeol, 2005). Currently the University of the Witwatersrand is one of two training sites that continues to offer the dual speech-language pathology and audiology degree, and is the only university that does not offer a choice to qualify in either one or both.

In addition to challenges of transformation in terms of race and gender for the profession, current practice has been shaped by the heavy influence of the medical model and its alliance with the scientific method (Pillay, 2003). Given the changing face of the patient population we interface with, the transitioning socio-political climate and the realisation of the need to extend service delivery beyond familiar urban boundaries (described in chapter 2), Kathard (2005) has queried the need for the profession to *"(re)position itself to contribute to the developmental agenda."* Chapter 3 will draw attention to why management beyond the 'medical' is necessary as a means to furthering the position of the profession in terms of service delivery, and will describe how this process has been hampered by the influence of the medical model of service provision.

As it stands there are currently six training institutions that offer the speech-language pathology degree (South African Speech-Language and Hearing Association [SASLHA], 2013). While unavailable in a formal report for public viewing it is likely that each university has documented reasons for offering the single, dual or both degrees. There is no difference in the scope of practice for the single or dually registered clinician (HPCSA, 2012). Upon qualification, the graduate registers with the HPCSA and is required to serve a year of community service at a public health care institution. Thereafter s/he is entitled to work anywhere in any sector of service provision in South Africa.

The speech-language pathology profession nationally is a female dominated profession (HPCSA, 2012). Being the smallest health care profession in South Africa, the profession is often over-shadowed by the size and voice of others (HPCSA, 2012). As with nursing, there appear to be generic traits that can be identified among applicants to the speech-language pathology profession. The definition of speech-language pathology provided by the American

Speech-Language and Hearing Association [ASHA] suggests the need for this professional to be caring, self-motivated with a people-oriented nature as well as persons who are highly skilled and competent, professional, ethical and communicate well (ASHA, Definitions of Professions, accessed January, 2013). They are usually responsive to needs of people, they are accessible, courteous, respectful and credible. The generational changes have not left speech-language pathology students and graduates untouched (Mc-Neese et al., 2003). Formal investigations into how exactly this has influenced work culture, work ethic and professionalism are needed. Financial stability, job security, working conditions, status, systemic rules and regulations, quality of supervision, quality of interpersonal relations with peers and superiors are some extrinsic variables that may influence community service speech-language pathologists to remain in a geographical area or clinical post after their year of internship (Collins et al., 2000).

If it is assumed that speech-language pathologists enter the profession in response to feelings of altruism and desire to help (ASHA, Definitions of Professions, accessed January, 2013) as do nurses entering the nursing profession (discussed earlier in this chapter), it would be interesting to reflect on the responsiveness of these speech-language pathologists to the changing health climate of South Africa and obligations to institutions that employ them to go beyond the 'call of duty' when necessary. Speech-language pathologists working in public health institutions are required to request permission to engage in private work over and above that for which they are employed by the institution (Basic Conditions of Employment Act, accessed October, 2013). Implications for dysphagia intervention are profound with implicit obligations for speech-language pathologists to be available for patients beyond the 8-hour work day given the medical risk patients with dysphagia face. Clarity on whether these obligations are fulfilled and to what extent is unknown.

Tertiary hospitals in South Africa are linked to training institutions with implications for student training, availability of expertise (from the training institution) when necessary and patient accessibility (within ethical limitations) for research purposes. It appears that this avenue is not being exhausted on the part of either academics at training institutions or the speech-language pathologists employed at these hospitals. Stronger collaborations between these two sectors may have significant implications for research, training and clinical practice in speech-language pathology in South Africa. A first step would be to understand what the current situation is and to explore ways to improve this partnership if necessary, as greater

professional collaboration may provide significant benefits for the profession at a national level.

2.6 A collaborative framework

Collaboration is, "*the process of joint decision making among independent parties involving joint ownership of decisions and collective responsibility for outcomes. The essence of collaboration is working across professional boundaries*," (Liedtka & Whitten, 1998, p. 185). This definition succinctly captured the essence of the nurse-speech-language pathologist partnership in the dysphagia intervention under investigation. There is increasingly more evidence confirming that a collaborative patient-centred model for health care intervention has multi-faceted benefits not the least of which relates to the ability of the health care system to address the increasing demands for limited and under-resourced health services, as is the case in South Africa (El Ansari, Phillips & Zwi, 2004 & Grymonpre et al., 2010). There is often much confusion in the use of the terms collaboration and teamwork as well as differing interpretations of each term (i.e. collaboration and teamwork) by the different professionals (Disch in Sherwood & Barnsteiner, 2012). My readings have lead me to the conclusion that for teams to work effectively (irrespective of type of team), collaboration seems necessary. Teamwork I believe would therefore be joint action by two or more people, while collaboration is the process involved. This was supported by Disch (in Sherwood and Barnsteiner, 2012). In understanding the concept of teamwork within a health care setting comes the knowledge that teams would comprise members from different professional groups with two or more members. Teams in hospital settings are often defined according to type, i.e. multidisciplinary teams, interdisciplinary, intra-disciplinary and trans-disciplinary teams. The differences between these teams have been defined on pg. xviii - xx at the beginning of the thesis.

None of these descriptions were relevant or applicable to the nature of the current study. I instead chose to use the term collaboration as opposed to teamwork. The mental image and perceptions around multidisciplinary teams in South Africa by health and medical professionals does not appear to be ideal with findings showing that even for a sub-speciality such as paediatric dysphagia, professionals have little if any knowledge of who the other professionals are that would be involved in the management of the patient or what the specific role of these other professionals would be (Seedat et al., 2011). While this has significance for the process of inter-professional referrals when necessary, the implication for

establishment of teams in an acute hospital context is more concerning and slightly disheartening. Collaboration is able to accommodate different areas of expertise for an existing situation (Disch in Sherwood and Barnsteiner, 2012). Incorporating different perspectives was particularly relevant in this context in view of the diversity of experience, age, education, socio-economic status, professional orientation and gender that participants in the study represented (Disch in Sherwood and Barnsteiner, 2012). The increase in diversity highlights the important role of dialogue amongst the members if the shared goal to improve patient outcomes is to be achieved (Lewin & Reeves, 2011). Statham (2000) asserts that an unavoidable shift in thinking from one of all knowing on the part of professionals to a partnership model is required. Implications of holistic patient care are implicit within a collaborative model.

Daily communication, a good inter-professional relationship with good inter-professional communication, knowledge of the roles of each other, sufficient knowledge and skills to work with dysphagia as well as respect and recognition for colleagues are required for a collaborative partnership (Heritage, 2001). Over and above the speech-language pathologist, the importance of the patient, caregiver and nurse as core members for dysphagia intervention is emphasized (Middleton, 2012). The nurse, speech-language pathologist and doctor are the professionals who remain constant and are involved with the patient from admission to discharge. Clinical experience suggests that pockets of excellence seem to exist within different hospitals in South Africa with teamwork varying on a scale from excellent to none within each of these hospitals. This scenario while concerning reveals a need to investigate why such variability exists. The potential hazards of an independent working ethos may range from lack of accountability, working in pockets, professionals unaware of management or direction of intervention of their colleagues, patients lacking a holistic understanding of the intervention they may be receiving and all round fragmented management of the patient.

Detert, Schroeder and Mauriel (2000) described the notion of institutional culture. Related to the current discussion on collaborative frameworks they maintain that service provision by employees is congruent with the ensuing culture of their institution. One must remain vigilant not to fall into the trap of belonging to a team in ‘name only’ or believing that because a team exists, care is efficient and effective. Collaborative working facilitates comprehensive engagement with the patient and his/her medical condition. In so doing, emergence of diverse treatment options and solutions may surface to the benefit of the patient (El Ansari et al.,

2004). Miller, Ross and Freeman (1999) listed key attributes of collaboration: goal directedness, understanding of each other's roles, recognizing areas of overlap, communication, flexibility and conflict resolution. Long, Kneafsey and Ryan (2003) added degree of integration, extent of collective responsibility, membership and decisions around the client pathway and team management/leadership. The need for a joint belief amongst the members on the process and goal appear to be equally important for effective collaboration (El Ansari et al., 2004).

An abundance of published documentation supports the position of the nurse as being ideal to facilitate and coordinate collaborative partnerships between professionals (Long et al., 2003). There are however articles that describe the less than optimal view other professionals have of nurses, which exposes a dilemma (Swann & Ma, 2005). Interestingly some literature showed that nurses themselves do not view their nurse colleagues with high regard, and instead view the doctor or health care professional as the expert (Long et al., 2003; 'O Connor, 1993). Despite benefit of collaboration for patients and professionals, barriers to attaining collaboration exist, both internationally and nationally. These were outlined by Hagebak (1982):

- Barriers of organisation: structures, systems, personnel and communication,
- Barriers of attitude; political considerations and conflicts and turf guarding,
- Barriers of vision, history, tradition and absence of clear directives or adequate models, and
- Barriers of ignorance, lack of awareness of problems and potential solutions.

As the dissertation unfolds and results of the intervention become clear, it will be seen how and to what extent some of the listed barriers existed and affected the outcomes and participation of nurses within the current study.

A study by Degeling, Maxwell, Kennedy and Coyle (2003) concluded that nurses and nurse managers supported collaboration whereas medical professionals and allied health care professionals questioned working with nurses (Hansson, Friberg, Segeston, Gedda & Mattsson, 2008). Hojat (1999) reported that professionals in 'more powerful' positions at work have the least interest in working collaboratively. Casanova et al. (2007, p. 69) noted that, "*physicians perceive themselves as the dominant authority in patient care while*

perceiving nurse's main function as carrying out orders." It remains unfortunate that such perceptions continue to exist. It seems possible to surmise that like interpersonal relationships amongst health care professionals fluctuating according to the variables and people present at a particular time, the existence and workings of collaborative partnerships may vary similarly.

There are documented qualities and characteristics that are reported to promote collaboration (Disch in Sherwood & Barnsteiner, 2012; Miller et al., 1999). These include understanding of each other's roles and responsibilities, mutual respect, shared goals, clear communication, openness to learning, and ability to change one's viewpoint given new information. The discussion in the thesis will show that these qualities may be reinforced and encouraged even amongst those professionals who may initially appear to be resistant or unwilling, if patient improvement (amongst other things) is reiterated as being a primary objective. For those professionals with different and inflexible worldviews who favour and adhere to professional autonomy and with inequitable power gradients, collaboration may not be successfully attained (Baggs & Schmitt, 1997; Roberts, 1997; Shine, 2002). It was therefore essential to have some understanding of the participants within their daily routines, their worldviews and their interactions with each other, patients and other professionals to inform the choices taken and method chosen for the study.

Chapter summary

This chapter aimed to provide information on South Africa and describe the health care status and structure. In highlighting the increasing prevalence of chronic burden of disease the vulnerable position of health care professionals working in South Africa and specifically in public hospitals to manage the caseloads effectively and efficiently is revealed. The ability of nurses and speech-language pathologists to cope with service delivery demands and health needs of patients was interrogated. It seems that current working protocols are inadequate and unable to meet these demands, hence the need to consider an alternative collaborative partnership model to manage dysphagia.

CHAPTER THREE: DYSPHAGIA

Overview

A holistic description and discussion of dysphagia, symptoms, complications, assessment and treatment is provided. I will focus on stroke and traumatic brain injury as specific causes of dysphagia in relation to the study. Dysphagia intervention and dysphagia research specific to the South African context is evaluated, as I highlight the paucity of evidence-based practice in this context. I will introduce free water protocols as a management protocol for dysphagia and discuss the theoretical underpinning for it. Emergent free water research studies are listed and evaluated against the needs for the South African context and patient population. This will proceed into a literature review on mouth care and quality of life for the patient with dysphagia. I will rationalise why these aspects need to be given greater consideration by speech-language pathologists working in dysphagia in the South African context.

3.1 Dysphagia

Definitions for dysphagia may vary to align with the underlying pathology. This definition was chosen for its relevance to the current study, "*dysphagia refers to any neurological deglutition disorder, which encompasses abnormalities within the oral, pharyngeal and oesophageal phases of swallowing and it may include but is not synonymous with penetration or aspiration*" (Perry & Love, 2001, p. 8). Dysphagia is characterised by difficulty swallowing and because of the involvement of nerve and muscle function, it is considered a highly complicated process (Hamdy, 2007). Central to understanding dysphagia is understanding how swallowing happens and what is involved i.e. the physiology and neurology.

A normal pattern of swallowing is a complex movement requiring coordination of muscles following cranial nerve stimulation arising from the brainstem. This pattern is subsequently monitored and modified by neural regulatory mechanisms in the medulla, sensorimotor and limbic cortical system (Bass & Morrell, 1997). Whilst transporting material from the mouth to the stomach for digestion, swallowing facilitates protection of the airway, rejection of harmful substances, and the preparation of food for digestion (Hamdy, 2007). Traditionally swallowing was believed to involve three distinct phases. However with improved understanding of function came the realisation that it was impossible to look at the different

phases in isolation, swallowing is a process. Triadafilopoulo et al. (1992, p. 556) noted that "*the mouth, pharynx, and [o]esophagus operate as an integrated system and that dysfunction in any of these anatomic and functional components leads to adaptive or compensatory changes in the other.*" For the purpose of the current study, I have chosen to describe each phase separately.

The oral phase is responsible for the preparation of the bolus and transfer of the bolus from the mouth to the oropharynx. The pharyngeal phase involves the coordinated transportation of the bolus from the oropharynx into the upper oesophagus and the oesophageal phase transports the bolus into the gastric cardia (Bass & Morrell, 1997; Logemann, 2003). Neural supply for swallowing involves afferent and efferent supply of different nerves. This is seen in table 2.

Table 2: Afferent and efferent neural supply for swallowing (Dodds, 1989)

Motor nerves for swallowing	**Sensory nerves of mouth and pharynx**
Muscles of face → VII	Soft palate, mouth, anterior 2/3 tongue, nasopharynx→
Muscles of mastication → V^3	V→touch
Intrinsic muscles of tongue → XII	Anterior 2/3 tongue → VII → taste
Palate & Pharynx → X	Posterior 1/3 tongue → IX → touch/taste
Larynx and Oesophagus → XII	Oropharynx → IX → touch
Extrinsic muscles of tongue → XII	Tongue base, larynx → X → touch
Muscles of hyoid → V^3, VII, XII	

Key: V – Trigeminal Nerve, V^3 - Trigeminal Mandibular branch, VII – Facial Nerve, IX – Glossopharyngeal Nerve, X – Vagus Nerve, XII – Hypoglossal Nerve.

Various pathologies, impairments and types of damage may affect the innervation of the nerves directly or indirectly affecting swallowing ability and pattern. The overtness of symptomatology of any impairment plays a significant role in the attention and status it receives. The symptoms of dysphagia depend on the phase of swallow affected and the underlying pathology. The generic and inconspicuous nature of the symptoms, for example coughing, multiple swallows and pooling of residue in the mouth often result in one overlooking the symptom or not associating it with being problematic. In a sense the 'covertness' of the symptomatology by not bringing attention to itself may not alert one to the

need for intervention. This sentiment has significance for quality of life perceptions. Notwithstanding its sometimes less than obvious symptomatology, the severity of complications that can result from late intervention or mismanagement of dysphagia may be dire. The responsibility of informing the patient and/or caregivers about the presence of dysphagia because of the primary insult lies with the medical and allied health team attending to the patient while in hospital at the time of admission. Table 3 below provides a list of oral, pharyngeal (Paik, 2008) and oesophageal symptoms of dysphagia (Palmer, Drennan & Baba, 2000). As table 3 shows, the symptoms are a combination of both overt and covert symptoms.

Table 3: Oral, pharyngeal and oesophageal symptoms of dysphagia

Oral and pharyngeal symptoms (Paik, 2008)	**Oesophageal symptoms (Palmer, Drennan & Baba, 2000)**
Coughing or choking with swallowing	Difficulty initiating swallowing
Food sticking in throat	Sialorrhea
Unexplained weight loss	Change in dietary habits
Recurrent pneumonia	Change in voice (wet)
Nasal regurgitation	Sensation of food sticking in chest
Oral or pharyngeal regurgitation	Food sticking in throat
Drooling	Unexplained weight loss
Change in dietary habits	Recurrent pneumonia

Dysphagia and related symptoms may be due to any number of precipitating variables such as surgery, anaesthesia, pregnancy, compromised lung status, asthenia, decreased cognitive status or level of alertness, memory impairment, structural changes/abnormalities, obstructions, compromised muscle tone or propulsive difficulties to name a few (Logemann, 1998). While objective studies (radiological and laboratory) and/or subjective assessments (bedside) are used to diagnose oropharyngeal dysphagia, oesophageal dysphagia is more easily identified based on case history information and confirmed with diagnostic studies (Palmer et al., 2000). Case history questions specific to oesophageal dysphagia include probing symptoms such as heartburn, burping and sour regurgitation suggesting gastro-oesophageal reflux or psychotropic medications which exacerbate dysphagia (Palmer et al., 2000). Regardless of my distinction between the phases, the significant finding in the study by Triadafilopoulos et al. (1992, p. 556) that altered oropharyngeal function occurred in

patients with dysphagia presenting with oesophageal motility difficulty, and altered oesophageal peristaltic function was found in patients with oropharyngeal dysphagia, link to my initial statement that swallowing is a process.

Neurogenic dysphagia refers to difficulty swallowing caused by a neurologic disorder (Bakheit, 2001). Bakheit (2001) further noted that although neurological swallowing disorders predominantly affect the oral and pharyngeal phases of swallowing, disorders of innervation of the oesophagus might occasionally contribute to neurogenic dysphagia.

Table 4: Causes of neurogenic dysphagia (Bakheit, 2001)

Stroke	Traumatic Brain Injury
Dementia	Cerebral Palsy
Myasthenia Gravis	Parkinson's Disease
Progressive Supranuclear Palsy	Huntington's Disease
Wilson's Disease	Torticolis
Motor Neuron Disease	Multiple Sclerosis
Infectious Diseases	Polyneuropathies
Myopathies	

Table 4 provides a list of causes of neurogenic dysphagia. This thesis will focus on oropharyngeal symptoms of dysphagia consequent to neurologic insult with stroke and traumatic brain injury as specific causes of the dysphagia.

3.2 Complications of dysphagia

Complications of dysphagia include malnutrition and compromised nutritional state, a higher risk of chest infection and aspiration which may lead to aspiration pneumonia, poor functional ability and associated problems of being unable to eat, increased length of institutionalisation and hospitalisation, an increased risk of disability and an increased risk of mortality by more than 5-fold (Hamdy, 2007; Heckert, Komaroff, Adler & Barrett, 2009; Smithard et al., 1996; Smithard, Smeeton & Wolfe, 2007). These studies document the severity of the complications that could arise from dysphagia and alerts one to the fact that swallowing difficulty i.e. dysphagia, constitutes a significant health care problem. Increasing evidence has been presented in the literature of the direct relationship between dysphagia and

morbidity and mortality (Perry & McLaren, 2003; Robbins et al., 2008). Perry (2004) noted in a study conducted on in-patients that presence of dysphagia resulted in an overall deterioration in nutritional status and net loss of body cell mass. Malnutrition, often the result of dysphagia is associated with "*muscle weakness and wasting, impaired respiratory and cardiac function, decreased mobility, depression and lethargy*" (Perry, 2004 p. 1334). Quick and efficient management of the patient with dysphagia has implications for costs to the state or medical aid, length of hospitalisation for the patient, consumable costs, occurrence of secondary infections, mortality figures and quality of life of the patient and family (Perry & McLaren, 2003; Winter, 2007; Perry, 2004; Robbins et.al., 2008).

After a careful review of several studies, aspiration pneumonia, dehydration and malnutrition were listed as the top three complications and concerns associated with dysphagia (Feinberg, Knebl & Tully, 1996; O'Neill, 2000; Schindler, Ginocchio & Ruoppolo, 2008; Teasell et al., 2002). These three co-morbidities were amongst the main reasons for investigating knowledge-to-action translation of the free water intervention in the current study. Dehydration and malnutrition have particular significance for patients with dysphagia receiving public health services in South Africa. Case and Deaton (2005) have documented that health and wealth are important determiners of well-being. They add that due to the strong bi-directional causal links between income and health, it is difficult to conceptualise either without an understanding of both (Case & Deaton, 2005 p. 228). Statistics from the 2011 census conducted in South Africa revealed that black African headed households had an average annual income of R60 613 as opposed to white households whose average annual income was R365 134 in 2011 (STATSSA, 2012). The report also reveals that unemployment amongst the black African group is highest and lowest among the white population group (STATSSA, 2012). It is unfortunate that despite the huge political reform that took place in South Africa in the 1990's the current picture remains remarkably unbalanced.

The enormity of these findings are accentuated as one understands that the patients accessing public health care are South African's from the middle and lower socio-economic bracket and likely not on medical aid. Limited financial access has implications for where and what type of dwelling one lives in, access to education, access to regular and sufficient nutrition, transportation and employment opportunities (Coovadia et al., 2009). If one considers the ratio of South African's accessing public health services (Coovadia et al., 2009) that was highlighted in chapter 2, it is likely that a significant portion of this percentage are living

under less than optimal circumstances and are likely chronically malnourished (Vorster, 2010). An input paper for the Health Roadmap, "C*ombating Malnutrition in South Africa"* (2008, p. 15) documented exactly this. Malnutrition was associated to household monthly income, weekly expenditure on food and employment showing the clear link between poverty, poor health and poor nutrition. Thus it is not far-fetched that many patients who are admitted to public hospitals in South Africa are already malnourished and possibly dehydrated (Winter, 2007). When admitted for reasons relating to dysphagia, the implications for early and appropriate intervention are accentuated due to the presence of the premorbid 'chronic condition' and this often leaves the speech-language pathologist in a compromising and uncertain position when it comes to recommendations at the time of discharge as there may be implications for diet modification which implies cost. Herein lies one of many additional challenges faced by the speech-language pathologist managing dysphagia in a developing context.

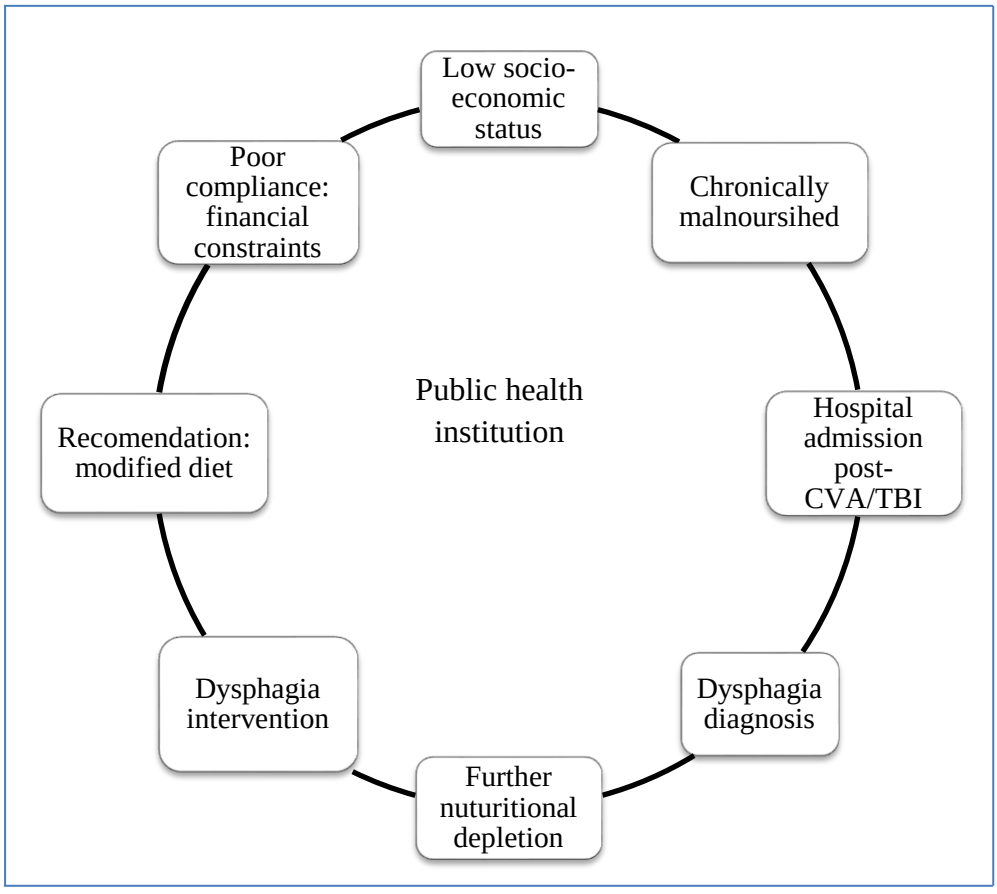

Figure 5: A representation of a typical patient with dysphagia seen in public hospitals in South Africa and the challenge of making appropriate recommendations for dysphagia

Figure 5 highlights the compromising position speech-language pathologists often find themselves in when making recommendations at the time of hospital discharge of the patient with dysphagia. The figure highlights chronic malnourishment as a premorbid condition that when exacerbated by stroke or traumatic brain injury [TBI] with co-occurring dysphagia, a further decrease of oral intake results. This coupled with inconsistent provision of food whilst an in-patient may further reduce the patient's immune system with implications for longer recovery time and hence increased hospitalisation (Winter, 2007). In addition to poor understanding of consequences of dysphagia, financial constraints to obtain foods of specified consistency or the lack of means to prepare these foods may result in poor compliance after discharge. This is a concern with management of both adult and paediatric patients who present with dysphagia.

3.2.1 Aspiration

The entry of material into the larynx below the level of the true vocal folds, into the lower respiratory tract defines aspiration of food (Logemann, 1986; Martin et al., 1994). Aspiration of food, reflux, oropharyngeal dysphagia and oral bacteria may be contributory factors to aspiration pneumonia (Langmore, 1991). In their study to determine the occurrence of swallowing impairment in patients presenting with aspiration pneumonia Martin et al. (1994) found a strong association between dysphagia and aspiration pneumonia. Robbins et al. (2008) supported that patients with dysphagia have an increased incidence of aspiration pneumonia as the aspirated material is typically heavily colonized with bacteria. Logemann et al. (2008) concurred with the description by Daniels, Ballo, Mahoney and Foundas (2000) that aspiration pneumonia is inflammation of the lungs and bronchial tubes caused by inhaling foreign material.

The effects of aspiration are variable with even non-dysphagic persons aspirating microscopic amounts of food and liquid when eating (Palmer et al., 2000). Palmer et al., (2000) proposed four factors that influence the effects of aspiration:

1. Quantity: Aspiration of larger quantities is riskier.
2. Depth: Aspirate entering the trachea is less dangerous than aspirate entering the distal airways.
3. Physical properties of the aspirate: Material laden with infectious organisms or mouth flora can result in bacterial infection and consequently pneumonia (aspiration).

4. Pulmonary clearance mechanisms: Aspiration normally provokes a cough reflex, and if sensation is impaired 'silent aspiration' and resultant respiratory sequelae develop.

These four factors proposed by Palmer et al., (2000) are of particular importance to the proposed study because the Frazier Free Water Protocol which underlies all subsequent free water-based protocols that were developed, is based on the premise that water has a neutral pH and thus provides a safe means of assessing patients with thin liquids (Panther, 2005). The underlying premise of this and other free water protocols is that a small amount of water that may be taken into the lungs (aspirated) is quickly absorbed into the body pool. Consequently, this protocol asserts that water consumed by patients with good mouth care present with no risk for the development of aspiration pneumonia (Panther, 2005). A more in-depth discussion of free water protocols is presented below. Table 5 provides a list of the complications of aspiration which in particular cases can be considered life threatening.

Table 5: Complications of aspiration due to dysphagia (Hamdy, 2007)

Sudden or acute	Chronic (silent aspiration)
Choking or coughing	Respiratory distress
Gasping	Loss of voice quality
Rapid heart rate (tachycardia)	Weight loss
Hunger	Excessive secretions
Refusal to eat	

Bakheit (2001) reported that of the 40% of patients who aspirate food or liquid, the aspiration is silent. There is no triggering of coughing or signs of distress (Bakheit, 2001). A likely aetiology of silent aspiration is reduced functioning of the laryngo-pharyngeal airway protective reflexes commonly seen after stroke. Pneumonia accounts for a significant percentage of all stroke-related deaths and represents the third highest cause of death during the first month after a stroke (Paik, 2008). For this reason early detection and efficient treatment of dysphagia in patients who have sustained a stroke is crucial (Paik, 2008).

Conversely, Feinberg, Knebl and Tully (1996) undertook a study to evaluate the frequency of pneumonia and relate it to prandial liquid aspiration and feeding status (oral vs. artificial). Prandial aspiration of foods or liquids results in choking (Eckberg & Feinberg, 1992).

Feinberg et al., (1996) believed that there was little clinical data to support that oropharyngeal dysphagia results in food and liquid entering the airway, affecting the lungs causing pneumonia. Results of their study revealed no significant difference in the frequency of pneumonia during months of major, minor and no prandial aspiration (choking). It was instead found that frequency of pneumonia was significantly higher during periods of artificial feeding (Feinberg et al., 1996). This finding was supported by several other researchers (Kidd, Lawson, Nesbitt & MacMahon, 1995; Sitzmann, 1990). However the true relationship between pneumonia and prandial aspiration was still unresolved at the completion of their study (Croghan, Burke & Caplan, 1994; Feinberg et al., 1996; Gordon, Langton-Hewer & Wade, 1987). A further complication of the relationship between pneumonia with aspiration and oropharyngeal dysphagia is that not all patients shown via imaging studies to have a swallowing impairment with or without aspiration, develop pneumonia (Martin et al., 1994). This finding opens up the possibility of the influence of oral pathogens and gram-negative bacteria, which if absent in the presence of aspiration of water may not result in pneumonia. Further, and especially significant for the current study, Feinberg et al., (1996) found that most cases of pneumonia were secondary to micro-aspiration of oropharyngeal secretions that were pathologically colonised. This has implications for mouth care, gingival disease and denture use – factors that are given significant consideration in the current study.

3.3 Neurogenic dysphagia

3.3.1 Stroke and dysphagia

According to Hamdy (2007) and Paik (2008) stroke is arguably the most important cause of adult neurogenic dysphagia and the commonest form of neurologic disorder seen in medical wards. Stroke by definition is a clinical syndrome, characterised by rapidly developing clinical symptoms and/or signs of focal and at times global loss of cerebral function, lasting more than 24 hours with no apparent cause other than that of vascular origin (Bhidayasiri, Waters & Giza, 2009). Symptoms of stroke include numbness, weakness/paralysis, slurred/no speech, blurred vision, disorientation and confusion and severe headache (National Institute for Health and Clinical Excellence [NICE], 2008). The documented incidence of new or recurrent stroke in the United States is approximately 795 000 per year (Miller et al., 2010). Lloyd-Jones et al. (2009) reported the prevalence of stroke in the United States to be over 6.5

million. Robbins et al. (2008) had estimated that 18 million adults would require care for dysphagia-related malnutrition, dehydration, pneumonia and reduction in quality of life in the United States by 2010. It remains unclear whether this figure has been reached or exceeded, however, Marik and Kaplan (2003) and Terrado, Russell and Bowman (2001) reported that between 300,000 and 600,000 individuals in the United States are affected by neurogenic dysphagia each year. Hamdy and Rothwell (1998) noted that as many as one in three patients might be affected by swallowing difficulties in the period immediately after a stroke. Statistics from New Zealand reveal that dysphagia following stroke can affect up to 80% of individuals with prevalence being greatest at the time of injury, and subsequently decreasing with time (Wilkinson et al., 2002).

Exact prevalence figures for dysphagia in sub-Saharan Africa or South Africa are not readily available. The South Africa Stroke Prevention Initiative [SASPI] Project Team (2004) concluded at the end of a study on the prevalence of stroke survivors in rural South Africa, that in addition to the country suffering from a huge burden of HIV/AIDS together with diseases related to poverty and violence, it is also exposed to the inevitable epidemic of vascular disease, of which stroke is a consequence. It is further suggested that this figure is increasing in sub-Saharan Africa and amongst the lower-economic sub-groups (Connor et al., 2008; Vorster, 2002). It can be surmised that if incidence of stroke in rural South Africa is increasing and if dysphagia exists in a proportion of these patients, then there is a consequent assumption that the incidence of dysphagia is also on the increase among the general South African population who have suffered a stroke (SASPI Project Team, 2004). This was later confirmed by Tipping (2008) who found stroke to be the fourth most common cause of death in the general population and the most common cause of death in people older than 65 years in South Africa.

There is a vast amount of literature documenting the relationship of stroke to dysphagia and aspiration (Brainin, Teuschl & Kalra, 2007; Martino et al., 2005). Aspiration pneumonia resulting in death is a significant occurrence in patients within their first year of having a stroke (Teasell, McRae, Marchuk & Finestone, 1996). Teasell et al. (1996) reported that patients with brainstem and right hemisphere stroke were 10.2% and three percent more likely respectively, to develop pneumonia following stroke. Teasell et al. (1996) and Teasell, Foley, Fisher and Finestone (2002) showed that there was a greater incidence of aspiration

amongst patients with brainstem as opposed to hemispheric strokes, with medullary strokes specifically (within the brainstem) showing the greatest risk for aspiration.

Various government and non-government based organizations have over the years, conducted health surveys and researched chronic conditions in South Africa. The South African Demographic and Health Survey, (Department of Health, 2003); Initial Burden of Diseases Estimates for South Africa (Bradshaw et al., 2000); The South African Stroke Risk in General Practice Study (Connor et al., 2008) and Chronic Diseases of Lifestyle in South Africa 1995-2005 are some of the studies that were conducted. These investigations have covered a wide range of nutritional aspects within the different ethnic, cultural and urban vs. rural dwellers in South Africa and have investigated prevalence of various health conditions and chronic illnesses. It is concerning that these reports contain very little if any information on dysphagia or even note that dysphagia may be a consequence of the chronic disease or what the consequences of dysphagia may be. While it is difficult to know with certainty what the reasons for exclusion were, it may pertain to limited knowledge of dysphagia and the impact of dysphagia medically, socially and financially on both the patient and government services. Another reason may be the low priority of role of the speech-language pathologist and of multidisciplinary management generally within public health care. Lack of assertiveness or confidence on the part of the dysphagia practising speech-language pathologist to be an active participant within these teams in the hospital or in a research context may also be likely.

A conclusion of a study in a hospital in Cape Town, South Africa was that "*...multidisciplinary stroke care could be successfully implemented in a limited resource setting in a developing country like South Africa*," (de Villiers, Kalula & Burch, 2009, p. 91). While providing support for multidisciplinary management of stroke, it was concerning that in this study there was also no mention of a speech-language pathologist. Only the geriatrician, medical officer, nurse, physiotherapist, social worker, patient and family comprise what the authors refer to as a 'multidisciplinary team'. Despite acknowledging that aspiration and dehydration are likely causes for early mortality within this population, the responsibility for swallow assessments (p. 92) was attributed to the nurse (de Villiers et al., 2009). It is again a point of contention that the role or involvement of the speech-language pathologist (from a dysphagia and communication perspective) is disregarded or possibly unknown by professionals for this very common chronic disease. This lack of insight by

fellow health care professionals in South Africa provides evidence of the less than ideal circumstances that we as speech-language pathologists find ourselves working in. In comparison to the numbers of physiotherapists, occupational therapists and social workers qualified and practising, speech-language pathologists are minimal (HPCSA, 2012). This was touched on briefly in chapter 2. In addition to having to defend our position within a hospital context (e.g. our role with patients in the intensive care unit [ICU] environments) we are also faced with the challenge of having to assert ourselves amongst professional colleagues (who we very often study alongside as undergraduates). This is a cause of dismay. This does however reveal an area that requires further investigation for clearer understanding of reasons behind this lack of inter-professional insight.

In view of the international figures on prevalence, research into the area of dysphagia within this population in South Africa may offer useful insights. In the 2012 Budget Speech by the then Finance Minister of South Africa, Mr Pravin Gordhan, health remained one of the three largest categories of expenditure (National Treasury Budget Speech, 2012). Given the statistics of the population accessing public services the minimisation of unnecessary costs is an important goal for hospital managers and chief executive officers [CEO]. The occurrence and management of dysphagia and sometimes consequence of dysphagia have been shown to contribute, sometimes significantly to these expenses and hence efforts to reduce expenses while maximising patient quality of life is warranted (Coyle, 2012; Enderby et al., 2009).

The management of a patient with stroke is not limited to dysphagia. Communication, movement, environmental and work adjustments, social aspects and activities of daily living all of which relate to quality of life considerations warrant similar levels of intervention. The World Health Organisation's International Classification of Functioning, Disability and Health [WHO-ICF] provide a guiding framework for this. It acknowledges that recovery after stroke is a complex process that involves the interplay of:

- The pathophysiological processes directly related to the stroke and its associated comorbidities;
- The impact this condition has on the individual;
- The contextual variables such as each patient's personal and environmental resources (Miller et al., 2010, p. 2403).

Miller et al. (2010) go on to say that the outcome for the patient (irrespective of the pathology) is compounded not only by the complexity and number of extraneous variables related to the pathology itself, but also by the patient's contextual circumstances. The study by Miller et al. (2010) was significant in that it confirmed that dysphagia management did not end with resolution of the medical aspect. A holistic inclusion of all aspects related to dysphagia, which is discussed later in this chapter, was something the current study also promoted and attempted to achieve.

3.3.2 Traumatic brain injury and dysphagia

Traumatic brain injury is defined as "*an insult to the brain, not of the degenerative or congenital nature, but caused by an external force, that may produce a diminished or altered state of consciousness*," (National Head Injury Foundation, 1985 as cited in Murdoch & Theodoros, 2001, p. 3). Traumatic Brain Injury [TBI] can be classified either as penetrating or non-penetrating or according to the level of severity, based on the level of consciousness experienced by the patient following the trauma. It can be classified as mild, moderate or severe according to the patient's level of consciousness. ASHA (2008) notes that reporting prevalence of TBI depends on the particular population under investigation i.e. severe TBI, consecutive brain injury admissions, acute TBI patients or patients in the rehabilitation phase. Winstein (1983) and Halper, Cherney, Cichowski and Zhang (1999) documented dysphagia as a frequent complication of TBI. Halper et al. (1999) found that the reported dysphagia incidence in the United States for TBI was 26-30% in the mid-eighties, with recent figures being as high as 61% for those admitted to an acute trauma centre. An overall increase in dysphagia incidence within the TBI population has been observed, something that Morgan, Ward, Murdoch, Kennedy and Murison (2003) contribute to either an increased awareness of dysphagia following TBI or increased incidence of TBI patients generally. This is uplifting given the literature presented above on stroke and the oversight of dysphagia with this pathology in South Africa.

In the study by Winstein (1983) it was reported that the average time for non-oral TBI patients to progress to their first full oral meal is 13 weeks. The study concluded that "*the prognosis for functional recovery was very good*" (Winstein, 1983, p. 1995), highlighting the importance of holistic patient management by a multidisciplinary team. The study showed that 50% of participants had motor control difficulties, 12% had sensory problems and 42%

had multiple problems (Winstein, 1983). Not surprisingly, cognition was found to be the biggest factor impacting swallowing within this group (96%), (Winstein, 1983).

Mackay, Morgan and Bernstein (1999) maintain that despite the cognitive component to brain injury, there is a pressing need to ensure adequate nutrition intake within this cohort of patients as they may be at risk for malnutrition and dysphagia, similar concerns as with the stroke population. A concern that was also highlighted with the stroke patients and of relevance to TBI patients, pertains to malnourishment prior to hospital admission and further exacerbation thereof while in-patients. Brooke et al. (1989) found that 60% of TBI patients admitted to rehabilitation facilities after discharge from acute care were 90% below their ideal weight, suggesting malnourishment and inadequate nutrition intake. This may either be due to insufficient nutrition during the acute phase of hospitalisation or similar to stroke patients, chronic malnourishment. Malnutrition during acute phase hospitalisation is concerning as one is aware of the need for patience and time when assisting with feeding routines in TBI patients. The implications for TBI patients in public hospitals in South Africa are accentuated given the time limitations and patient numbers nurses are responsible for within one shift, and the levels of stress and frustration that are consequently exhibited by nurses that may influence displays of patience and empathy (Walker & Gilson, 2004). With chronic malnourishment the relevance of Figure 7 is highlighted as the responsibility of the speech-language pathologist to manage dysphagia while the patient is in hospital almost becomes ‘less’ challenging than ensuring adequate management after discharge because of financial and social circumstances that patients attending public health services find themselves in.

Despite many studies being undertaken on the TBI population with reference to dysphagia, findings are varied. Ward, Green and Morton (2007) believe that this is testament to the complexity of this population of patients, which presents as a confounding obstacle to determining true incidence and prevalence rates. Based on Interpol figures, South Africa has a high level of violent crime, which sets it apart from other crime-ridden societies (Institute for Security Studies, 2009). Within South Africa the eight categories of serious crime that are grouped together as violent crime include: murder, attempted murder, rape, assault with the intent to inflict grievous bodily harm, common assault, indecent assault, aggravated robbery and other robbery. These account for 33% of South Africa’s recorded crime (Institute for Security Studies, 2009). These figures exclude other types of crime such as car-jacking, etc.

that may also result in head injuries and trauma. Aligning with the increasing international prevalence of TBI and hence dysphagia, a similar profile can be expected for South Africa given the statistics above. In a study done by Mackay, Morgan and Bernstein (1999) in Spain, out of 54 severely brain injured patients, 61% showed abnormal swallowing due to loss of bolus control and reduced lingual control. Forty one percent of participants presented with aspiration. Significant figures were also noted in the recent study by Hansen, Engberg and Larsen (2008), where 93% of participants had difficulty with functional oral intake at admission. Of this 64% returned to a normal diet after 126 days of rehabilitation.

The statistics confirm that dysphagia is a problem that exists for TBI patients. Ignorance and ambivalence to the demands dysphagia places on an already overburdened health system (financial) and the patient (quality of life) may be seen as an ethical dilemma, yet another reason why the study was believed to be clinically relevant to government employed speech-language pathologists in South Africa.

3.4 Dysphagia research and practice in South Africa

There is dearth of published information on dysphagia, cost implications around dysphagia intervention and evidence-based practice in relation to dysphagia, in South Africa. Waters et al. (2004, p. 109) noted that "*conducting economic analyses alongside clinical trials provides valuable information on health care utilization … in intervention versus control group populations… quantify the expenditure differences associated with the intervention.*" The South African government contributes approximately 40% of its health budget to public health, which delivers services to 80% of the population (National Treasury, 2012). This is a significant contribution. It is therefore imperative from an economic and financial perspective that every health care worker in South Africa plays a role in ensuring that the intervention they are providing has a positive impact (efficacy) and that the intervention produces the desired effect (effective), thus it must be based on evidence.

Table 6 below contains a list based on searches via Google Scholar, Highwire and the University of the Witwatersrand research portal website, of existing *published* dysphagia studies that have emerged from South Africa since 1999.

Table 6: Publications of some studies that have emerged from South Africa with a dysphagia perspective

Author/s	**Year**	**Title**	**Type/Design**
Huggins, P. S., Tuomi, S. K., & Young, C.	1999	Effects of nasogastric tubes on the young, normal swallowing mechanism	Experimental
Modi, N. & Ross, E.	2000	The current practices, training and concerns of a group of hospital-based speech-language pathologists working in the area of dysphagia.	Survey using questionnaires.
Klugman, T. M. & Ross, E.	2002	Perceptions of the impact of speech, language, swallowing and hearing difficulties on quality of life of a group of South African Persons with Multiple Sclerosis	Survey using questionnaires on perception.
Engelbrecht, L., van der Merwe, A., & Pretorius, J. P.	2006	The surgical management and speech and swallowing rehabilitation of patients with advanced tongue cancer in South Africa	Survey using questionnaires
Bladon, K. & Ross, E.	2006	Swallowing difficulties reported by adults infected with HIV/AIDS attending a hospital outpatient clinic in Gauteng, South Africa.	Semi-structured interviews and record review
Norman, V., Louw, B. & Kritzinger, A.	2007	Incidence and description of dysphagia in infants and toddlers with tracheostomies: A retrospective review.	Retrospective record review
Tipping, B.	2008	Issues in the long-term management of stroke.	Review article – not a study.
Pretorius, S., Van Zyl, L., & Dolloway, K. A.	2008	Nutritional therapy in stroke management: prevention and rehabilitation.	Review article – not a study.

Hewetson, R. & Singh, S.	2009	The lived experience of mothers of children with chronic feeding and/or swallowing difficulties	Semi-structured interviews with mothers
McCulloch, A.	2009	Stages of swallow.	Review article – not a study.
Barratt, J. & Ogle, V.	2010	Recorded incidence and management of dysphagia in an outpatient paediatric neurodevelopmental clinic	Retrospective record review
Mudawi, H. M. Y., Mahmoud, A. O. A., El Tahir, M. A., Suliman, S. H. & Ibrahim, S. Z.	2010	Use of endoscopy in diagnosis and management of patients with dysphagia in an African setting	Prospective, cross-sectional, descriptive study using experimental means
Blackwell, Z. & Littlejohns, P.	2010	A review of the management of dysphagia: A South African perspective	Retrospective record review of prevalence and assessment and management strategies in dysphagia, used in private health care settings
Norman, V., Singh, S. A., Hitler, T., Jones, N., Kenny, N., Mann, R., McFarlane, S. & Moeng, S.	2011	Indications, medical conditions and services related to gastrostomy placement in infants and children at a tertiary hospital in South Africa	Retrospective descriptive study
Seedat, J., Mupawose, A. & Choonara, T.	2011	Multidisciplinary management of paediatric dysphagia in government hospitals in Gauteng, South Africa: A pilot study	Survey of perceptions of health professionals
Fourie, A. & Barratt, J.	2011	Decreasing the prevalence of paediatric dysphagia:	Retrospective record review

		Thoughts from a developing country	
Nel, E. D. & Ellis, A.	2012	Swallowing abnormalities in HIV infected children: an important cause of morbidity.	Descriptive based on patients referred for swallowing disorders

The study conducted by Modi and Ross (2000) revealed that a majority (90%) of speech-language pathologists employed within South African government hospitals are involved in the assessment and management of dysphagia. The study confirmed that ethical and quality assurance measures were major limitations of the profession in public practice, and participants believed that this was affecting the professional image of the speech-language pathologist. Swanepoel (2007) supported the need to maintain the scientific basis of the profession by engaging in evidence-based practice. Whilst providing valuable information, the study by Modi and Ross (2000) was a descriptive account of knowledge and beliefs about dysphagia practice.

The study by Blackwell and Littlejohn (2010) was a survey of dysphagia management practices within private rehabilitation clinics in South Africa conducted via a retrospective record review. While the study provided some useful information regarding bedside evaluations, implementation of diet modification, sensorimotor exercises and counselling strategies, the information on non-oral feeding techniques was limited. There were however suggestions as with the findings of Modi and Ross (2000) that newly qualified graduates are placed in an awkward position. They are inexperienced to assess and manage dysphagia and often lack mentorship and supervision which is essential for dysphagia (Davis & Conti, 2003). This inadvertently leads one to question, how and what assessment and management techniques are used, and highlights the importance of evidence-based practice to address efficient dysphagia management.

Paediatric dysphagia and studies describing knowledge and perception of dysphagia seem to have dominated dysphagia research in South Africa (Norman et al., 2011; Seedat et al., 2011). An added limitation to research conducted is that many of them remain unpublished and so have limited value in their current format (e.g. Alborough, 2012; Fourie, 2010; Hoosen, 2012).

The South African Speech Language Hearing Association [SASLHA] has in a draft document on guidelines for speech-language pathology and audiology service provision in the public health sector, identified as its aim "*to render the highest quality services based on evidence-based practice as far as possible, that produce positive functional outcomes for clients and their families*…" (SASLHA, 2008/9). The draft explains that while evidence-based practice is applicable to different communication disorders, application to the diversity of South African communities, which is emerging, should continue. There is an absence of empirical evidence or limited evidence of clinical procedures and guidelines for the South African context within the

draft document. Validation, recognition and access to speech-language pathology as a profession relies on the recognition of the research we conduct (Swanepoel, 2007) and the study by Modi & Ross (2000) confirmed that. Practice within the public sector seems to be based on experience, information received during undergraduate training and/or anecdotal evidence from colleagues, hence not evidence-based. In undertaking evidence-based research it allows one to make informed decisions about patient management. With intervention based on empirical evidence, length of rehabilitation may be reduced and this may decrease the length of hospitalisation for the patient and may decrease overall patient and institutional costs (Robbins et al., 2008). As noted by Perlman and Schulze-Delrieu (1997) dysphagia warrants substantial research effort into investigations that provide empirical evidence to improve outcomes.

In addition to the draft document by SASLHA (2008/9) discussed above, the HPCSA (2010) has also included various aspects of evidence-based practice [EBP] under several headings, namely: framework for practice, clinical services, prevention and advocacy, education and training and practice settings.

Table 7: Scope of Profession Speech-Language Pathology Document adapted from the HPCSA (2010)

Role Categories	**How and Where? – Role defined from the document**
Framework for practice	Clinical practice in speech language therapy strives to have a firm evidence base.
Clinical services	… using data to guide clinical decision making and determine the effectiveness of services.
Prevention and Advocacy	Active participation in professional organisations to contribute to the best practices in the profession.
Education and Training	Conduct research
Practice Settings	Research facilities

The table above reveals that there are several avenues via which EBP is encouraged and included within the speech-language pathology scope of practice, despite the actual term EBP not being used within the document. Most recent statistics from the HPCSA reveals that there are 2011 qualified speech-language pathologists and audiologists + speech-language pathologists currently practising in South Africa (HPCSA, 2012). When one considers that there are currently in excess of 50 million people living in South Africa (STATSSA, 2012) it

becomes clear that human resources are inadequate to address the needs of those requiring any kind of speech-language intervention. In the context of the current study, the question that immediately comes to mind is, 'How does one even start to consider EBP if as it stands there are not enough of us to go around?' and 'Does it not seem more reasonable to engage in direct service provision as opposed to engaging in research to test efficacy of interventions?' My stance on the subject is that EBP does need to be emphasised. The results of my study reminds me to be cautious within a developing context, to balance statistical and clinical significance to address a country's contextual needs and resources. In 2003, the governments of the United Kingdom and South Africa signed a memorandum of understanding aiming to enhance clinical/technical skills and to explore best practice in health care delivery (NICE, 2009). While the current focus of this initiative does not extend to the allied health disciplines such as speech-language pathology, recognition of the need to develop clinical guidelines in South Africa and establish best practice standards is a step in the right direction.

3.5 Dysphagia intervention (assessment and management)

As discussed in the previous chapter, the complexity of dysphagia in terms of its nature and subsequent management as well as the seriousness of the complications that can arise from poor management suggests that working within a collaborative framework is beneficial for the dysphagic patient (Farneti & Consolmagno, 2007; Logemann, 1994; Singh, Brockbank, Frost & Tyler, 1995). Assessment of dysphagia can be accomplished via subjective and/or objective means, and ideally involves both processes to gain a holistic understanding of the patient. At this stage of intervention the collaboration between the speech-language pathologist and nurse are important in establishing a baseline of severity from which progress can be measured. Results of the assessment should be conveyed to nurses who should be part of the multidisciplinary team, as they play a key role in ensuring that the recommendations made for feeding are adhered to ('O Gara, 1990). With a high proportion of patients with dysphagia being *dependent* in-patients (based on the nature of their pathology), nurses are directly involved in the actual feeding and monitoring process with guidance and support from the speech-language pathologist (Layne, 1990). Prior to conducting subjective and objective evaluations, screening for dysphagia may be undertaken.

There is documented evidence of the benefits of conducting screening such as capitalising on early intervention and the associated financial benefits (Perry, 2001). The aim of dysphagia screening is to determine if a swallowing disorder is present or not. Many international

screening tools have been developed by researchers who have subsequently established the reliability and validity of these tools (Martino et al., 2009; Massey & Jedlicka, 2002; Shepard, 2007). The feasibility of applying and using internationally compiled dysphagia screeners in South Africa has yet to be determined. An ideal protocol for assessment is depicted in the flowchart below.

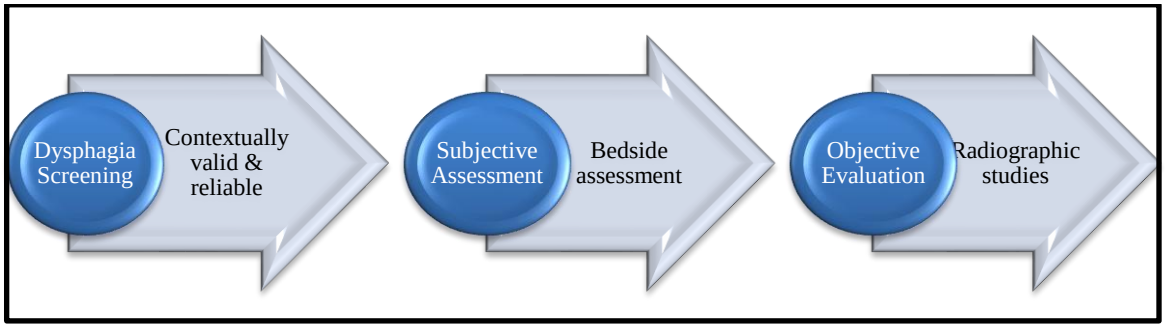

Figure 6: Flowchart of process for dysphagia assessment

Several factors hinder the successful implementation of the above protocol in public hospitals in South Africa. These include but are not limited to the number of qualified speech-language pathologists, high patient loads, time constraints, and insufficient human resources, lack of medical resources, linguistic barriers and influence of traditional medicine. Dysphagia screening which should ideally be the first step in the assessment process is in some first world countries such as the United Kingdom, not reliant on the speech-language pathologist (Lees, Sharpe & Edwards, 2006). Qualified nurses are able to accurately conduct a validated screening tool at the bedside (Weinhardt et al., 2008). The operation and conditions within wards in public hospitals in developing contexts such as South Africa does not make this a feasible option currently. The introductory chapter as well as chapter 2 described some of these conditions in public hospitals in South Africa. A recent study by Jaffe (2012) revealed shortcomings in application and implementation of internationally validated screening tools for the South African context. She subsequently developed a screening tool, the South African Dysphagia Screener with consideration of factors such as time constraints, resource limitations, patient loads, linguistic differences, cultural and traditional beliefs and diet preferences and in her study proved the tool to be valid and reliable, feasible for use in acute public hospital settings in South Africa (Jaffe, 2012).

The second step of dysphagia assessment would be the bedside evaluation which provides insight into the 'why' questions of symptomatology such as aspiration. The bedside assessment is a procedure that a majority of dysphagia-practising speech-language pathologists working in public hospitals in South Africa rely on regularly to identify dysphagia, presence of aspiration, implications of different diets and textures and patients coping mechanisms (Blackwell & Littlejohns, 2010). A bedside assessment is subjective and is guided by theoretical knowledge and clinical experience. Despite its value, bedside assessment cannot confirm the presence or absence of aspiration as a significant number of patients who aspirate do so silently (Leder & Espinosa, 2002; Ramsey, Smithard & Kalra, 2005; Smith, Logemann, Colangelo, Rademaker, Pauloski, 1999). Ideally a combination of bedside assessment with information from objective evaluation will provide the speech-language pathologist with comprehensive information about a patient's swallowing. The value of bedside assessments lie in the ability to provide the speech-language pathologist with the best information on patient history, best measurement of oral and jaw strength and stability and allows the best evaluation of voice (McCullough, 2000). Bedside assessment was a component of the dysphagia assessment process for the current study.

Objective instrumental assessment follows the subjective evaluations. There is an abundance of literature supporting the use of fiberoptic endoscopic evaluation of swallowing [FEES] and videofluroscopy [VFS] for patients with dysphagia (Kelly, Drinnan & Leslie, 2007; Langmore, Schatz & Olson, 1991). Both are instrumental methods of evaluation, each with their own advantages and limitations. Videofluroscopy was used in the current study. Unlike FEES that can be conducted at the patient's bedside, VFS studies are conducted in a Radiology Department and are similar to an x-ray. Videofluroscopy allows the speech-language pathologist to identify any anatomical abnormalities, allows tracking of discrete structural movements and temporal coordination of oral transit and trajectory of the bolus through the aero-digestive pathway (Perlman, Booth & Grayhack, 1994; Rofes et al., 2011). It also allows for identification of aspiration, allows the speech-language pathologist to view what or why the patient is aspirating and enables the speech-language pathologist to view if specific techniques alleviate aspiration (Riquelme et al., 2008). Knowledge and experience with interpretation of the VFS is necessary to ensure correct understanding and interpretation of all variables influencing a patient's swallow. The flexibility of the procedure allows the speech-language pathologist to adjust volume, consistency, and rate of delivery, feeding position and implementation of maneuvers to determine the effects on swallowing (Rofes et al., 2011).

During the assessment process based on the findings, it may sometimes be necessary to consider the need for a feeding tube, either as an interim measure or as a permanent means for delivery of nutrients for a patient (Crary & Groher, 2006). Groher (1994) cautions that it is difficult to determine whether oral or non-oral feeding is the safer of the two options for the patient susceptible to tracheal penetration. Two primary reasons for non-oral feeding include poor airway protection and poor nutritional intake (Crary & Groher, 2006). Despite a belief that non-oral feeding prevents aspiration pneumonia, improves function and physical comfort of a patient and prolongs life, Groher (1994) and Mamum and Lim (2005) found that there was no evidence to support these claims. They therefore undertook to investigate and compare the incidence of aspiration pneumonia and death in patients with dysphagia who were fed orally or via a nasogastric tube. The findings indicated that patients on the nasogastric tube had a higher incidence of aspiration pneumonia and lack of survival benefit (Mamum & Lim, 2005). Their findings were contradictory to findings by Nakajoh et al. (2000). Leibovitz, Plotnikov, Habot, Rosenberg & Segal (2003) and Vollman et al. (2000) agreed that nasogastric tube [NGT] and percutaneous endoscopic gastrostomy [PEG] fed patients show an incidence of aspiration pneumonia, either as a result of lack of oral clearance mechanisms in tube fed patients (hence no protection with subsequent buildup of gram-negative bacteria that is aspirated) or, placement of the PEG reducing lower oesophageal sphincter pressure (hence reflux which is then aspirated). Vollman et al. (2000) however found a higher incidence of pneumonia in post-stroke patients that were on oral feeding as opposed to NGT feeds in a one-year follow-up study. This contradiction in findings is concerning with remaining ambiguity.

Finestone, Foley, Woodbury and Greene-Finestone (2001) found that patients on enteral feeds met or exceeded their daily fluid intake levels as opposed to patients being fed orally on thickened feeds. This contradiction in findings suggests the need for further research into this controversial aspect of dysphagia (Ciocon, Silverstone, Graver, & Foley, 1988; Cogen & Weinryb, 1989; Croghan et al. 1994; Hassett, Sunby & Flint, 1988). There is however agreement that it is likely that while some patients are better able to tolerate small amounts of aspiration, patient level of alertness, pharyngo-laryngeal sensory function, host defenses, and pre-existing respiratory status and function play a role in determining aspiration risk (Cook & Kahrilas, 1999; Groher, 1994). For this reason Groher (1994, p. 235) recommends considering the following variables when taking this decision:

- The patient's swallowing and eating history

- Physical presentation
- Mobility
- Information from objective swallowing studies
- Status of airway protective mechanisms

The management of dysphagia is largely dependent on the underlying pathophysiology, hence the need for management to be patient specific aligning with the patient's needs and requirements (Martens, Cameron & Simonsen, 1990). Traditionally the goals of any management plan would be to reduce morbidity and mortality associated with chest infections, improve nutritional status, and return patients to a normal diet (Singh & Hamdy, 2006, p. 387).

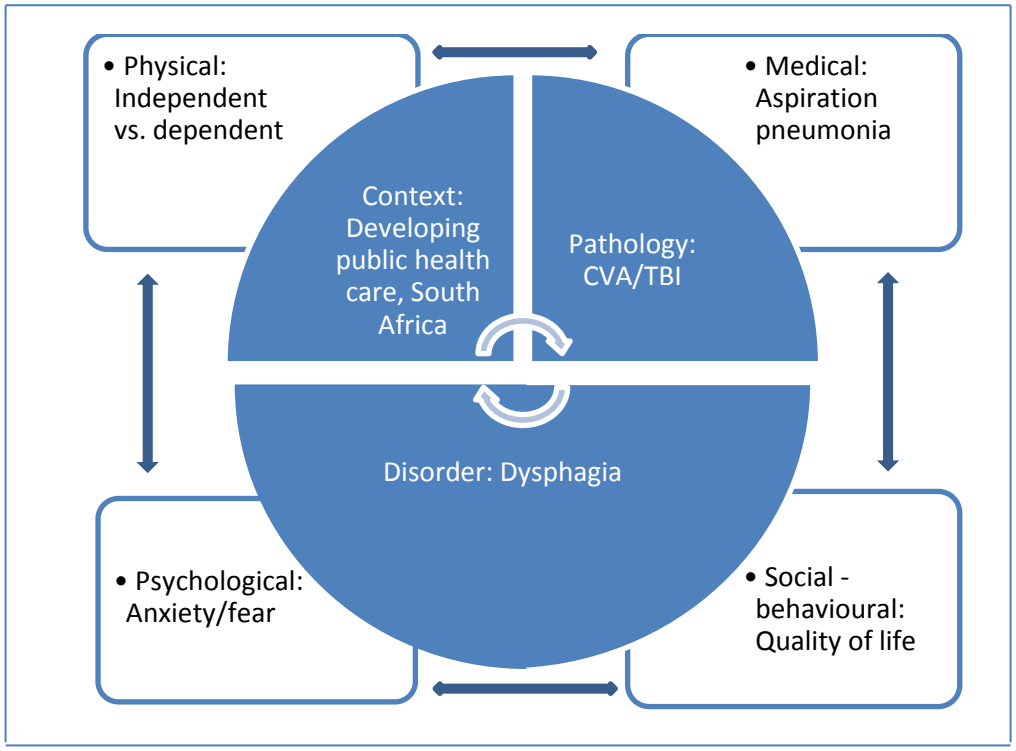

Figure 7: Cycle depicting the complexity of dysphagia with implications for management

In addition to the medical component, the social-behavioural, physical and psychological aspects of the disorder are as important to assess and manage as part of a holistic framework. This is seen in figure 7. It is probable that the framework in the figure above is more applicable and relevant to a developing context such as South Africa when all components may share importance in the average South African patient's life. Literature supports the necessity of medical management of dysphagia to reduce chances of mortality (Singh & Hamdy, 2006). My

stance on this, with reference to figure 7 is that while management of pathophysiology needs to take priority I believe that this should not be to the exclusion of the other components that also require consideration.

In proposing this multifaceted holistic framework for dysphagia assessment and management, the ability of dysphagia-practising speech-language pathologists to accommodate these different needs within their available resources must be explored.

Not unlike other sub-specialities in speech-language pathology, dysphagia-practising speech-language pathologists have a professional and ethical responsibility to be accountable for service provision (Sonies, 2005). The vicious cycle of poor dysphagia management that was depicted in figure 1 pg. 9 may be seen if the physical, psychological, social-behavioural or medical aspects of the disorder (seen in figure 7) are inefficiently or ineffectively managed. There was a need to understand how intervention restricted to only pathophysiological aspects of dysphagia, may leave speech-language pathologists unacquainted and unfamiliar with the fears and anxieties of our patients relating to their experience of eating post-dysphagia diagnosis. The impact of diet modifications on their ability to cope in work contexts, eating in the presence of other people, ability to eat without any assistance are vital areas that should be considered in management plans, but can easily be ignored or not given due consideration because of institutional rules and regulations but which nevertheless remain important.

3.6 A Free Water protocol

The Frazier Free Water Protocol was an original free water protocol proposed by Kathy Panther in the early 1980's. With the Frazier Free Water protocol, the previously prohibited oral intake of water became a defining feature in the treatment of dysphagia and daily hydration of patients (Garon, Engle & Ormiston, 1997). The protocol originated out of concern that both patients as well as caregivers were not being compliant when patients were placed on liquid restricted diets. Thickened liquid is the most frequently used technique for patients with dysphagia within acute and chronic rehabilitation care facilities (Logemann, 1991, 1993; Logemann et al., 2008; Robbins, Langmore, Hind & Erlichman, 2002). The limitations around the use of thickened textures include: a lack of standardised thickened viscosity and poor quality control thereof, limited thickening agents, starch-based thickeners not being suitable for diabetic patients and a lack of empirical evidence to support the clinical perception that a thicker viscosity reduces the occurrence of aspiration (Ramsberger & Frey, 2011; Steele & Swigert, 2006). In addition,

patient dissatisfaction or aversion to thickened liquids and patient non-compliance with thickened liquids also limits the use of thickeners (Ramsberger & Frey, 2011; Robbins et al., 2002; Steele & Swigert, 2006). Patients have also reported a feeling of fullness combined with a constant thirst sensation with consumption of thickened liquids (Schwartzentruber, 2011).

Consequently, three reasons provided the basis for the original Frazier Free Water protocol: safety of water, patient hydration and patient compliance.

1. Safety of water*:* The human body is roughly 60% water. The aquaporin channels in the lungs allow for absorption of small amounts of water – it is quickly absorbed into the body pool (Effros. Jacobs, Schapira & Biller, 2000). According to Panther (2005), the aquaporin channels in the lungs act like a sieve. As water enters the lungs (via the alveoli), it is taken up into the blood vessels and carried out to the bloodstream very rapidly (Panther, 2005). Thus, water provides a safe means of assessing patients with a thin liquid and provides an avenue for recognition of patient readiness for diet advancement.
2. Hydration: The encouragement of free water consumption (except during mealtimes and half an hour after a meal) addresses the issue of hydration. There is a resultant decrease in the risk and cost associated with intravenous fluids.
3. Patient compliance: Patients find thickened liquids unpalatable and when asked to have six to eight cups a day, they expectedly refuse or else do not disclose the truth (Panther, 2005). Patients are quite vocal that a thickened liquid does not quench thirst and thus would rather not have anything to drink (Purdy, 2006). Robbins, Hind and Logemann (2004) noted that mechanically altered diets mainly in the form of thickened liquids, is the treatment of choice for individuals suspected of thin liquid aspiration. They further note that the thickened liquids prescribed is done so broadly, without clinical evidence confirming that the person is aspirating on thin liquids.

Subsequent to the introduction of the Frazier Free Water protocol, many other free water studies emerged. A majority of these studies have retained a generic title of ‘free water protocol’ studies (Bronson-Lowe et al., 2008; Frey & Ramsberger, 2011) aside from the GF Strong Water Protocol (Carlaw et al., 2012). A review of free water protocol studies conducted show that many were based on the theoretical understanding of the physiology of the human body in terms of water absorption by the lungs and the importance of mouth care in preventing build-up of gram-negative oral bacteria. The table below provides a list of some of the different studies that have been conducted since the Frazier Free Water Protocol and a brief overall discussion of these studies follow thereafter.

Table 8: Overview of water protocol studies that have been conducted

Year	Investigator/s	Study	Design	Participants	Results	Critique
1997	Garon, Engle and Ormiston	A randomized control study to determine the effects of unlimited oral intake of water in patients identified with aspiration.	Randomized-control prospective design	• Control group- 10 patients • Study group - 10 patients	• No patients in either group developed pneumonia, dehydration or complications. • Study group: 33 days in study. o Mean of 463cc water intake o 855cc thickened liquid o 1318cc total daily. • Control: 39 days averaged in study. o Mean of 1210 cc/day thickened liquid.	• Small sample. • Poor generalization. • Strict inclusion criteria, which excluded co-morbidities common in the stroke population. • No blinding. • No inter-rater reliability measures reported. • Poor reproducibility.
2005	Panther	The Frazier Free Water Protocol	Retrospective single group study	• 234 charts reviewed over an 18-month period.	• Visual inspection identified two patients who developed aspiration pneumonia.	• Large sample size. • Participant characteristics not discussed. • Patient specific inclusion criteria not discussed. • Significant selection bias. • Limited reproducibility. • Limited clinical application. • Limited generalizability.
2008	Robbins, Gensler, Hind, Logemann, et al.	Comparison of 2 interventions for liquid aspiration on pneumonia incidence.	Randomized, controlled trial	• Drink all liquids in chin-down posture (n = 259) • Drink nectar thick in head-neutral position (n = 133) • Drink honey-thick in head-neutral position	• 52 participants had pneumonia. • More in the thickened group than all liquid group had dehydration (6% vs. 2%). • More in thickened group than all liquid group had urinary tract infection (6% vs. 3%). • More in thickened group than all liquid group had fever (4% vs. 2%). • Dehydration was more common in participants having thickened liquids than thin liquids.	• No control group. • Care providers were not blinded. • Relevance of clinical significance versus statistical significance is queried.

				(n = 123)		
2008	Bronson-Lowe, Leisling, Bronson-Lowe, Hayes et al.	Effects of a free water protocol for patients with dysphagia.	Retrospective design.	• Water protocol experimental (n = 30) • Historical control – eligible but untreated (n = 46) • Concurrent untreated but eligible (n = 25)	• Average fluid intake/daily -significant difference was found favouring the treatment group compared to historical control. • Pneumonia - no significant difference between experimental and historical control groups. • Dehydration - no significant between experimental and historical control groups. • Incidence of pneumonia - significant difference between experiment group and concurrent untreated group, favouring experiment group. • Fluid intake - significant difference between experiment group and concurrent untreated group, favouring experiment group.	• What influenced the results: o increased oral hygiene in the treatment group, o increased oral hydration in the treatment group or o better compliance with aspiration precautions in the treatment group.
2008	Becker, Tews & Lemke	An oral water protocol in rehabilitation patients with dysphagia for liquids.	Randomized trial	• Randomly assigned to either o water protocol o prescribed fluid diet. • All participants received oral care four times a day.	• Treatment group: significantly decreased duration of hospitalisation. • Independent feeders: consumed significantly less fluid than assisted feeders regardless of group.	• Improved generalizability. • Clinical application to be done with caution. • Unpublished format.
2010	Scott and Benjamin	Evaluate the effects of a free fluid protocol for dysphagic residents in a	Prospective single group study.	• 16 males, 10 females – given free fluid over a 10-month period.	• Visual inspection: no patient developed aspiration pneumonia. • No patient suffered from any acute illness. • Three patients died from pre-existing medical conditions.	• Limited information on participant selection. • Limited information on experimental procedures. • No patient characteristics

		long-term care facility.				discussed. • Statistical procedures not described. • Methodological limitations.
2010	Nevitt	Effects of the Frazier Free Water Protocol with thin liquid dysphagia	Unable to discern.	• 15 patients	• No cases of pneumonia. • Increased patient satisfaction.	• Unpublished data. • Limited procedural detail. • Participant selection criteria not discussed. • Statistical procedures not discussed. • Limited clinical application.
2011	Karagiannis, Chivers and Karagiannis	Effects of oral intake in patients with oropharyngeal dysphagia	Randomised controlled prospective study. Two stages: education stage and implementation stage	• Random assignment of 76 patients from a sub-acute unit to a control or intervention group. • Blinding of staff doing chest exams.	• Intervention group: 6 patients developed lung complications (2 Alzheimer's, 2 Parkinson's, 1 intellectual disability, 1 Cancer). Of these six, 3 were immobile and bedridden, 3 were minimally mobile. • Causal relationship between aspiration of water and development of lung complication dependent of level of patient's mobility.	• No mention of influence of mouth care and how this affected development of lung complications, even in patients immobile or with low mobility. • As opposed to only having stroke patients, there was a mixture of neurological pathology.
2011	Frey and Ramsberger	Comparison of outcomes before and after implementation of a water protocol for patients with cerebrovascular accident and dysphagia	Retrospective chart review. Cohort matching of patients with dysphagia before and after the implementation of a water protocol.	• Stroke patients were assigned to treatment paths based on results of assessment and the outcomes of the different paths was evaluated. • Water group n = 30.		• Good description of the water protocol instituted. • Initial screening assessment was thoroughly described. • Statistical procedures were well described. • Restricted to stroke patients only. • Unable to compare the satisfaction of the two groups to thickened

				• No water group n = 28.		liquids. • Retrospective chart review.
2012	Carlaw et al.	Outcomes of the GF Strong water protocol on fluid intake, patient satisfaction, quality of life and adverse events for patients with thin liquid dysphagia rehabilitation setting.	Randomised controlled trial.	• Treatment group n = 6, treatment group n = 8. • Thereafter 5 participants of control group crossed-over to treatment group. • SWAL-QOL administered.	• Treatment group (water intake group) had a 5% increase in fluid intake compared to the control group. • Treatment group had improved SWAL-QOL scores and significant improvement on the fear and symptom sub-scales. • No adverse events such as pneumonia or hospitalisation occurred.	• Outcome measures were assessed prior to initiation of study improving the validity. • No description of statistical methods used was reported. • It is unclear why patients crossed-over from the control group crossed-over to the treatment group. • It was reproducible. • Thorough outline of methods of patient selection. • Thorough descript ion of water and oral care protocol. • Outcome measures were used. • Excellent design. • Data is incomplete.

It is apparent from table 8 that many free water protocol studies have been undertaken since 1997. The following criteria were used to evaluate and compare the studies:

- Sample size
- Participant detail
- Generalizability
- Reproducibility
- Clinical application

Where available, additional criteria such as reliability, outcome measures and completeness of data was commented on.

The studies range from random controlled trials with blinding, to retrospective record reviews. Reviews of the studies reveal that each comprises limitations and positive aspects that influence generalizability, empirical data, clinical significance or reproducibility. Notwithstanding numerous international studies, in different contexts and with different participants, such investigation was warranted in South Africa given its unique people (patients and health care professionals) and context. The methodology designed for the present study was therefore based on a critical review of previous studies. The methodology was specifically chosen to encompass the South African context in an attempt to not only investigate feasibility of applying a free water protocol in an acute health care setting but if necessary adapt the protocol so that it could be used and its implementation sustained.

In addition to incorporating the principles of a free water protocol, the management chosen for the study also included recommendations of Cichero & Murdoch, 2006; Cook & Kahrilas, 1999; Langmore & Miller, 1994; Logemann, 1983; Logemann, 1997 with a combination of direct (involving food) and indirect (involving exercise) strategies, thermal-tactile stimulation, postural changes and behavioural techniques were used:

- Dietary modifications – thin liquid (water), pureed foods, soft solids and solids.
- Viscosity and texture modifications excluding thickened liquid texture
- Exercise and facilitation techniques: strengthening exercises, thermal stimulation, gustatory stimulation
- Postural adjustments: head tilt, chin tuck, head rotation, elevation
- Compensatory: pace of feed, amount of bolus, presentation mode

- Manoeuvres: supraglottic swallow, super-supraglottic swallow, effortful swallow, Mendelsohn manoeuvre
- Other: Tube feeding

The techniques and manoeuvres were used as and when necessary for the patients based on their presenting diagnosis and the outcomes measures that were defined for them.

3.7 Mouth care and dysphagia

3.7.1 Mouth care defined

Numerous studies have documented the importance of mouth care, which is considered an essential component in the daily hygiene routine for hospitalised patients (Rubinstein, 1987 and Yoon & Steele, 2007). For patients with teeth, a toothbrush is essential to remove the plaque that can house pathogens (Pearson & Hutton, 2002). Oral hygiene is defined as,

> *"The condition or practice of maintaining the tissues and structures of the mouth. Mouth hygiene includes brushing the tongue and teeth to remove food particles and residue, bacteria, and plaque; massaging the gums with a toothbrush, dental floss, or water irrigator to stimulate circulation and remove foreign matter; and cleansing dentures and ensuring their proper fit to prevent irritation. Dependent or unconscious patients are assisted in maintaining a healthy mouth condition. Such care includes lubricating the lips and cleaning inside of the cheeks, the roof of the mouth, and the tongue*" (Anderson, 2002 in Mosby's Medical, Nursing and Allied Health Dictionary).

The above definition provides insight into the need to be thorough whilst being careful not to cause irritation or pain during mouth care procedures. In as much as the lack of dentures or teeth in a patient does not preclude the need for mouth care to be done, neither does the fact that a patient is not eating orally preclude the need for mouth care. One must be cautious to not assume good mouth hygiene and care because of lack of complaints by a person as Preston, Punekar & Gosney (2000) caution that unless there is pain, oral pathology can remain undiagnosed and untreated.

3.7.2 The need for mouth care

The status of oral health determines susceptibility of risk for other conditions (Jablonski et al., 2008). Associations between good oral health promoting general health and preventing systemic diseases as people get older has been established (Jablonski et al., 2010; Loesche & Lopatin, 1998; Shay, 2002). Risk of poor nutrition, ischemic stroke, carotid artherosclerosis, and poor glycemic control in diabetics was associated with poor oral health and dental plaque (Berry & Davidson, 2006; Desvarieux et al., 2005; Joshipura et al., 2003; Soares, Moreira, Calvo, & Lobo, 2006; Stewart, Wager, Friedlander & Zader, 2001). Sub-optimal oral hygiene has been linked with an elevated occurrence of respiratory pathogen in oropharyngeal secretions (Mojon, Budtz-Jørgensen, Miche & Limeback, 1997). A pathogen or infectious agent is a biological agent that causes diseases or illness to its host (Science Daily accessed December 2012). For patients who are at risk for aspiration secondary to dysphagia, mouth care is a priority as respiratory pathogens that are aspirated as part of the oropharyngeal secretions may overburden the host defence mechanism leading to bacterial aspiration pneumonia (Yoon & Steele, 2007). This is particularly concerning in critically ill patients as ventilator-associated pneumonia is the second most common nosocomial infection after urinary tract infections, but remains the leading cause of death (Berry & Davidson, 2006).

Patients presenting with dysphagia because of stroke or traumatic brain injury, are likely to be dependent on the nurse for feeding and/or oral care during the very acute stages post-insult. Functional dependency has been documented to have a high correlation with risk for developing pneumonia (Yoneyama et al., 2002). Yoon and Steele (2007) describe two mechanisms via which poor mouth care and hygiene can lead to the colonisation of oropharyngeal secretions by respiratory pathogens. In the first instance, a build-up of plaque which grows more complex as it matures is fuelled by poor oral hygiene, and promotes the growth of periodontal pathogens. These pathogens may be found in periodontal pockets and the saliva of patients with periodontal disease. In healthy individuals, a protective coating prevents adherence of bacteria to the oral cell surfaces. The periodontal pathogen however when present degrades this protective coating, thus altering the surface of the oral mucosa, consequently enabling adherence of the bacteria to the oral surface and into the saliva. Hence, during episodes of aspiration the saliva now laden with pathogens is released into the lung ready to cause infection (Yoon & Steele, 2007).

In the second mechanism, there is a disruption in the protective buffering and antimicrobial properties of saliva, because of poor oral hygiene (Yoon & Steele, 2007). With a disruption in the homeostasis of dental plaque, there is a resultant build-up of bacteria (Marsh, 1999). The saliva now infected with the bacteria leads to aspiration pneumonia when aspirated into the lungs of the dysphagic patient (Yoon & Steele, 2007).

The administration of medication to patients is a common protocol within a hospital context. However, the hidden adverse effects of medically beneficial antibiotics, anti-cholinergics, anti-hypertensives, antidepressants, diuretics, and antihistamines include pathogen colonisation because of diminished saliva production (Jablonski et al., 2008 and Scannapieco, 2006). Scannapieco (2006) therefore recommended implementation of mouth care to reduce dental plaque and ensuing development of pathogens amongst these patients susceptible to aspiration. Thus as opposed to increasing risk of mortality, intervention via a simple and cost-effective manner can ensure a more promising outcome for the patient (Scannapieco, 2006).

3.7.3 Performing mouth care

Amidst the many, often unpleasant duties a nurse must fulfil, it is surprising that studies have documented mouth care as being the most unpleasant by nurses (Wardh, Andersson & Sörensen, 1997). Miller and Rubinstein (1987) found that nurses were often ignorant of how or why mouth care procedures were necessary for hospitalised patients. This is alarming given the level of dependency of patients on nurses to complete activities of daily living, such as tooth brushing. As noted by Berry and Davidson (2006, p. 319), "*Almost without exception, the experience of a fresh, clean mouth following cleaning of one's teeth, is universal*." They subsequently raise a valid and important question, "…*why then, should we as nurses, do any less for our patients*?" (Berry & Davidson, 2006, p. 319). This query prompted the involvement of the nurse in the study.

In response to the poor translation of knowledge-to-action for mouth care, which Wardh et al. (1997) referred to as a knowledge-gap, Yoon and Steele (2007) called for an interdisciplinary approach to enhance mouth care intervention. This suggestion warrants consideration in a developing context given the health care challenges such a context faces. However, the study by Preston, Punekar and Gosney (2000) revealed that there is insufficient knowledge of mouth care procedures amongst health care professionals. They note that this is due to amongst other reasons, health professionals own anxiety in visiting dentists. Using a

collaborative framework, there were implications for the speech-language pathologist and the nurse to share similar levels of knowledge about mouth care, procedures, and protocols. Information to facilitate this was incorporated into the training protocol developed for the study. Within the process of knowledge-to-action transfer of a free water protocol for dysphagia management, knowledge translation of mouth care was a vital aspect.

3.7.4 A mouth care protocol

After a review of existing protocols for mouth care (Panther, 2005; Schleder, Stott & Lloyd, 2002), a protocol believed to be thorough, time efficient and contextually appropriate was developed. Appendix 12 contains a mouth care booklet that details a systematic protocol, the personnel required, equipment necessary and the procedure to be followed when performing mouth care. The rationale for various procedures and steps were included in an easy to read format. Visually appealing diagrams with short and simple instructions were included. The protocol incorporates the need for suctioning when necessary as well as the use of dentures in patients. For the purpose of this study, the protocol was targeted for nurses. However, its use by speech-language pathologists as well, prior to initiation of bedside assessments in institutions where mouth care is irregularly completed after meals, will be advocated after the completion of this study.

The table below contains the mouth care protocol that was used in this study.

Table 9: Mouth care and water provision schedule followed for the study

MORNING		MIDDAY		AFTERNOON		EVENING
☐ Weight ☐ Mouth Care ☐ Breakfast – **NO WATER** ☐ Mouth Care ☐ Recording	**Water given on request or offered periodically**	☐ Lunch – **NO WATER** ☐ Mouth Care ☐ Recordings	**Water given on request or offered periodically**	☐ Snack – **NO WATER** ☐ Mouth Care ☐cordings	**Water given on request or offered periodically**	☐ Supper – **NO WATER** ☐ Mouth Care ☐ Recordings

PLEASE NOTE:

1. **NO WATER** must be given to the patient for half an hour after he or she has eaten. Thereafter patient can be given water.
2. **NO WATER** must be given to the patient with anything he or she eats.

BEFORE the patient has any Water, he or she MUST rinse out their mouth and you MUST clean their tongue.

The protocol provides details of when mouth care should be performed as part of the free water protocol for dysphagia intervention. Specific guidelines in terms of time frames and meals are provided. In addition, table 9 specifies when water should and should not be offered to the patient.

3.8 Dysphagia and quality of life (QOL)

Quality of life [QOL] is described as well-being across a variety of health and non-health related domains (Bjornson & McLaughlin, 2001). The WHO in 1993 described QOL as individual's perceptions of themselves, in terms of their position in life, their culture, their value systems, including their personal goals and expectations, health status, socio-economic security and psychosocial well-being (WHO, 1993; Wayman, 2003). Within many cultures eating is a pleasurable activity. It is an important social event, which can be adversely affected when diet modifications are necessary due to dysphagia. Feelings of embarrassment and fear may result (McHorney & Rosenbek, 1998) and may lead to social isolation and a resultant decrease in life satisfaction and QOL. A challenging aim for a speech-language pathologist is achieving adequate oral intake to meet hydration and nutrition needs, whilst maintaining safety of feeding and patient QOL. Amidst the primary concern of 'safe' oral feeding, is the speech-language pathologist's ethical obligation to respect the patient's rights and quality of life.

As discussed earlier in this chapter, the implementation of diet modifications such as thickened liquids negatively affects QOL (Panther, 2005). Whether a modification is big or small, the impact can be significant for the patient and/or caregiver, and consequently may affect their quality of life negatively. Thus, noncompliance with recommended feeding regimes and diets may occur. Meyer, Levanthal and Gutman, (1985) report that compliance is less likely to occur if it is preventative in nature, if it does not offer immediate relief from pain or other complications. Similarly, if a patient is asked to be compliant over a long period, compliance will decrease (Marlatt & Gordon, 1984). In a study conducted by Panther (2005), she estimated that patients would have a 71.9% rate of compliance with safe-swallowing instruction, with 35.6% being the actual compliance rate. Thus, it becomes necessary to implement quality of life measures to ensure that oral intake is safe whilst quality of life is maximized.

Communication is crucial in situations where potential compromises are being considered. There needs to be detailed information provision to the patient and caregivers with a clear understanding of the risks and consequences. The study by Rosenvinge and Starke (2005) supported this by finding that a simple and low cost measure such as an educational programme was effective in improving compliance in patients with dysphagia. This is especially important for those who want to compromise and who are noncompliant with medically recommended diets. From the writings of Panther (2005) and Davis and Conti (2003) it can be surmised that patients need to get a clear message regarding the potential for aspiration, pneumonia, respiratory failure and even death. Simultaneously however, the speech-language pathologist cannot ignore the patient's very basic drive for fresh water (as opposed to thickened liquids). Considerations of the patient holistically must be the focus which was a key fundamental underlying the current study. This holistic approach to dysphagia intervention was proposed in chapter one and earlier in this chapter. In figure 7, quality of life is inextricably linked to, psychological, social-behavioural, physical and medical aspects of care and comfort. The relevance of the WHO-ICF model described earlier in this chapter as well as the framework depicted in figure 7, talks of the need for context to be central to determining how assessment and management of the dysphagic patient should proceed. True adherence to a quality of life framework implies consideration of the patient's home and work circumstances, social routines and activities, fears and anxieties as well as insight into dependency or not for eating, mobility, food preparation, etc. Figure 7 captures these components.

Extensive literature searches for dysphagia-related quality of life studies in South Africa were disappointing. The dearth of literature surrounding neurologically acquired dysphagia generally which was interrogated early in this chapter, as well as QOL amongst patients with dysphagia as a consequence of neurological insult suggests that this may not be given the necessary attention in clinical situations. It is difficult to say conclusively why this area is not explored in research investigations. Poor and inadequate direct management of dysphagia also contributes to poor quality of life for the affected individual. The manner and frequency with which dysphagia management techniques or strategies are applied and recommended to patients in South Africa has unfortunately not been documented. It remains clear that patient compliance resultantly starts to decrease when outcomes are poor (Meyer et al., 1985). In addition to considering the adverse effects of the inability to swallow 'normally' and the need to either use techniques when swallowing specially modified food, the additional impact for

hospitalised patients, of having a smelly mouth and bad taste in the mouth contribute to reduced QOL for the individual. Tooth brushing considered a basic activity of daily living is a routine that nurses are obliged to conduct for in-patients (Kite & Pearson, 1995). Perrie and Scribante (2011) concurred that even with intensive-care unit [ICU] patients in South Africa, there were no studies documenting what protocol was being followed for oral care, which motivated them to investigate this. Their findings revealed that nurses despite knowledge of aspiration and contaminated secretions, believed that their efforts did not materialise into much because patients got worse regardless (Perrie & Scribante, 2011). Kite and Pearson (1995) earlier recognised that mouth care is one of the basic care routines of nursing that require interrogation. While many reasons may be precipitating poor completion of mouth care for South African hospitalised patients (discussed in chapter 2), formal investigation into this is necessary.

It remains necessary to contextualise QOL for the medically, socially and financially compromised patient living in South Africa. As in any country, QOL means different things to different people, even people living within the same country. This suggests the need for further research to firstly survey what patients with dysphagia understand by quality of life, and based on their understanding and with contribution from the speech-language pathologist, compile a quality of life scale relevant for patients with neurologically acquired dysphagia. In the absence of such a scale and a realisation of the importance to document dysphagic patient's quality of life in the current study, it was necessary to use an internationally validated scale for this purpose, the Swallowing Quality of Life Scale [SWAL-QOL].

The SWAL-QOL is a standardised quality of life scale that was developed for use for patients with dysphagia for purposes of understanding how and what patient's perceived about their swallowing difficulty. While it is acknowledged that not all aspects of the scale may be relevant to patients accessing public health care in South Africa, reasons for its use in this study have been substantiated.

Chapter summary

This chapter provided information on dysphagia. I contextualised dysphagia practice and dysphagia research in South Africa. The concept of a free water protocol was introduced with theoretical underpinning for how it prevents aspiration pneumonia while addressing holistic dysphagia management of the patient. Mouth care and its relation to aspiration pneumonia

was explained and how inadequate mouth care combined with inefficient dysphagia management may lead to reduced quality of life for the patient with dysphagia was explained.

CHAPTER FOUR: THEORETICAL FRAMEWORK

Overview

This chapter will provide a theoretical basis that will reveal ways to address the gap present between knowing and doing in dysphagia and will provide guidelines based on the knowledge-to-action process model (Graham et al., 2006) to facilitate sustainability of an intervention shown to be feasible for a public hospital in South Africa. Theory underlying any kind of implementation research facilitates replication, generalisation, navigation and sustainability of the implementation. This chapter will provide the reader with a theoretical foundation for the study, that being knowledge translation based on the framework proposed by Graham et al. (2006).

4.1 Evidence-based practice

Evidence-based practice [EBP] defined in the introduction has become a fundamental tenet of speech-language pathology in the new millennium and is quickly garnering support within various medical and health care disciplines (Sackett et. al, 1996). Evidence-based practice advocates the provision of observed evidence based on the success of a treatment with harmful or useless therapies in the same vein revealed as such, and kept from widespread use (Sonies, 2005; Moser, 1985). Practise based on evidence grounded in research and scientific development and not on tradition and beliefs holds more value (DeBourgh, 2001) and is the premise of EBP.

The profession of speech-language pathology is believed to be scientific as it employs logical reasoning processes to describe, understand and explore phenomena and relationships (Maxwell & Satake, 2006). Central to its place within a scientific realm is the requirement that each clinician is a researcher facilitating the stimulation of growth and development of the profession (Walley et al., 2007). The move toward engaging in EBP as touched on in the introductory chapter was prompted by several valid but concerning factors. Research from Australia revealed that there is variation in clinical practice, persistent use of therapies and technologies proven not to be effective and conversely poor uptake of therapies and technologies proven effective (Vallino-Napoli & Reilly, 2004). These variables inevitably have led to sub-optimal care of patients resulting in occurrence of co-morbidities and patients enduring serious, avoidable harm to their health (Ketley & Woods, 1993). Especially relevant

to the South African context and based on my clinical experience is the poor documentation of patient outcome measures that would enable patient tracking and follow-up when necessary either from a clinical or research perspective.

While Horn and Gassaway (2007) acknowledge a) the importance of randomised controlled trials to confirm efficacy of an intervention as well as b) the disregard shown by researchers for anything other than experimental studies, they draw attention to the 'unfeasibility' of often implementing these interventions in everyday practice. Moser (1985, p. 173) firmly believed that it is regrettable that some researchers discount interventions not studied by randomised trial and believed this to be poor medicine and poor science. It is unlikely that research conducted under true experimental conditions or the participants involved in these studies reflect a) the real-world clinical environment or b) the patients that access these clinical contexts (Horn & Gassaway, 2007). Thus, they document that whilst it is essential to exercise extensive quality control to reduce errors in treatment delivery, the very same control and hence 'treatment purity' is difficult if not impossible to maintain over time, across contexts and clinicians. Restrictive participant inclusion and exclusion criteria further reduce the external validity of research. For example, patients with co-morbidities are almost never included in studies, but in reality, patients without co-morbidities are few-and-far between. The design characteristics of randomised controlled trials therefore limit the comparative effectiveness of treatments for all types of patients in routine practice (Horn & Gassaway, 2007).

Further, in a typical clinical context the interaction of multiple interventions from various professionals provided concurrently may significantly influence treatment outcomes. Greenhalgh, Robert, Macfarlane, Bate & Kyriakidou (2004, p. 615) comment,

> "*the shifting baseline of context and the multiplicity of confounding variables must be stripped away (controlled for) to make the research objective. However herein lies a paradox. Content and 'confounders' lie at the heart of diffusion, dissemination and implementation of complex innovations. They are not extraneous to the object of the study; they are an integral part of it.*"

This quotation had direct relevance to the current study, as it was in essence the interaction of context, people (stakeholders and participants) and existing variables that contributed to the outcome. While limiting the possibility of generalisation, the findings highlighted the influence of these variables on outcome and revealed that adhering to basic principles of

inter-professional collaboration, discourse and action research, these principles can instead be generalised to other contexts and studies.

In view of the inherent and inevitable limitations of randomised controlled trials, Montgomery and Turkstra (2003) recommend applying experience, reasoning and judgement to facilitate translation of the statistical significance of randomised controlled trials into clinical significance. As summarised by Horn and Gassaway (2007) an intervention that may appear to be effective in isolation may be antagonistic when paired with another intervention with the effectiveness varying for different patients. In any multifaceted context, feasibility of implementing intervention and measuring success of said intervention is a complicated and daunting task (Kitson, Harvey & McCormack, 1998). In applying experience, reason and judgement for knowledge translation one still needs to be cautious to retain the 'evidence' and not lose it in the process.

Having briefly described some controversies around randomised controlled trials specifically, there is evidence of advantages to EBP, whether obtained via randomised controlled trials or quasi-experimental means. Issues of safety, quality and cost-effectiveness have fuelled promotion and engagement with EBP (Sharts-Hopko, 2010). The benefits of EBP within health care are especially pronounced as implications for length of hospitalisation, related financial costs (health related costs and ability to return to employment hence salary implications), occurrence of co-morbidities, patient quality of life and institution costs are influenced positively (Robbins et al., 2008). Davies and Nutley (1999, p. 429) aptly noted that historically the diffusion and adoption of ideas associated with EBP within health during the 1990's provide testament to their power and their relevance to the current health problems and challenges of health care systems in many countries.

No idea or form of practise is free of criticism and some researchers are vocal in their opposition to EBP. There are fears that EBP has the potential to stifle innovation and hamper progress in the given field by reducing the scope for variation in clinical practice. It has also been suggested that EBP devalues professional expertise and fails to acknowledge patient variability (Walshe & Rundall, 2001), something described above. In keeping with some of the listed criticisms, several researchers have conducted general and profession specific studies investigating barriers to EBP, both in terms of conducting EBP studies and implementing the findings from these studies (knowledge translation gap) (Ashford et. al.,

2009; Burton et. al., 2006; Ratner, 2006; Sonies, 2005; Summerhill, 2005; Zipoli & Kennedy, 2005). Barriers identified include a) access to information, b) lack of time, c) a perceived lack of relevance, d) a perceived threat to traditional practice patterns, e) lack of proficiency in seeking information and f) inconvenience of access as opposed to obtaining peer input. The study conducted by Zipoli and Kennedy (2005) revealed that a clinician's own clinical experience (99,6%) and the opinions of colleagues (78.7%) were the most frequently used sources of information in clinical decision making. Nail-Chiwatelu and Ratner (2007) documented studies showing that physicians, nurses, physiotherapists and occupational therapists place high value on consulting colleagues in clinical decision making as opposed to accessing scholarly sources. This supported and confirmed the findings of Zipoli and Kennedy (2005) and reinforced that speech-language pathologists did not behave any differently to other medical and health professionals with regard to evidence-based practice and also highlighted the value of balancing clinical expertise and evidence in clinical decision making.

Internationally changes to the requirements for the ASHA Certificate of Clinical Competence added a mandate that speech-language pathologists engage in EBP (Ratner, 2006). The Academy of Neurologic Communication Disorders and Sciences (in the United States of America) and National Clinical Guidelines for Stroke, and SIGN, Part 3 (in the United Kingdom) show international inroads into the area of EBP (Burton et al., 2006; Zipoli & Kennedy, 2005). Such efforts are only now emerging in particular areas within the speech-language pathology profession in South Africa but is still lacking in others (e.g. dysphagia), (SASLHA, 2008/9). Ashford et al. (2009) highlight however that despite EBP receiving much attention over the last decade, practical application for speech-language pathologists in the area of dysphagia has not been as easy (i.e. knowledge-to-action transfer). The nature of dysphagia attests to this and was confirmed by Sonies (2005) who reported that it is difficult if not impossible, to limit or withhold treatment to an individual who may be at risk for aspiration or aspiration pneumonia just for the sake of research. While it is acknowledged that a significant number of speech-language pathologists are involved in the assessment and management of swallowing disorders from infancy to adulthood, it is questioned if there is sufficient empirical evidence to support our practise, or is much of what is done anecdotal or quasi experimental (Sonies, 2005).

Due to the complexity of dysphagia and potential detrimental consequences of mismanagement, ASHA (2002) stresses that it is essential that speech-language pathologists possess a minimum set of criteria (knowledge and skills) to be adept in their management of dysphagia. Evidence-based practice should not be viewed as an end in itself but as a means to supporting clinical reasoning (Sonies, 2005). According to Logemann (2004), for a profession to become evidence-based two conditions need to be present. Firstly, an adequate number of efficacy studies need to be present, secondly clinicians must be willing to use this evidence in their practice. As condition one appears to be lacking for dysphagia management in South Africa, how or to what extent condition two may be fulfilled cannot be predicted. Literature searches have revealed no published data on therapeutic protocols or assessment procedures for dysphagia that have been conducted on the South African population. Evidence of this is seen in table 6 in the previous chapter. Under the present circumstances, if one had to draw conclusions about the speech-language pathology profession in South Africa being evidence-based as per the requirements of Logemann (2004), it becomes apparent that we are not an evidence-based profession from a contextual perspective. In addition to improving diagnosis and treatment, EBP also facilitates a reduction in variation of clinical practice thereby improving the quality of patient care (Oxman & Flottorp, 2001). The lack of evidence-based dysphagia research for South Africa was one of the reasons that prompted this study.

As shown in chapter two, the state of health care in South Africa at this time is not ideal. The socio-political climate has necessitated numerous policies, regulations and changes that for us as speech-language pathologists have limited the type and severity of patients we can see, when we see patients, and the period over which we can intervene depending on the level of hospital at which we are employed. It is however within these confines that we still need to abide by our professional obligations of service delivery standards by engaging in research and quality clinical practice.

Furthermore, our capacity to see a limited number of patients irrespective of demand because of the transitioning patient climate poses an additional challenge. Conducting intervention studies within a hospital context inevitably relies on some level of participation from more than the one professional as well as the patient. As has been touched on in the introductory chapter and chapter two, in South Africa the diversity and complexity of medical pathologies seen in public hospitals makes this an ideal site for research while it is exactly this scenario

that has adverse effects on staffing, resources, and engagement with research. This juxtaposition is a challenge for promising research and researchers alike from South Africa. Regardless, quality as opposed to quantity as well as an undertaking to provide ethical and professional services confirm the need to provide effective and efficient services which can realistically only be achieved by basing service provision on proven outcomes that are culturally and contextually relevant and scientifically and theoretically proven. This for me would constitute evidence-based practice for dysphagia in South Africa.

In answer to the concerns raised of conducting dysphagia research (interventions) in public hospitals in South Africa there needs to be consensus: why can we not try to do both – conduct empirically based studies while ensuring that we address population needs effectively and efficiently? Berlinger (2002) suggests that it is important to not only question if something works or not as in drug therapies for instance; it is also necessary to determine who it works for, in what setting and how. Thus the need to be sensitive to the practical demands that accompany implementation and that may impede action must be considered for the South African context.

4.2 Addressing the knowledge-to-action gap in dysphagia intervention

The goal of EBP is to improve the health of the public through equitable and efficient application of empirically proven information (Rubenstein & Pugh, 2006). The need therefore to translate the evidence into usable information that can be easily implemented and accessed builds the case for knowledge translation, which subsequently circumvents a knowledge-to-action gap. Rubenstein and Pugh (2006) caution that methods to achieve implementation of an intervention differ from the methods employed in establishing the empirical basis for the said intervention, something often not given sufficient consideration by researchers, and which I attempted to do in the current thesis.

Davis et al. (2003) stated that a large gulf exists between what we know and what we practice. In the introduction chapter, the knowledge-to-action gap present for dysphagia management was described. The information in table 6 confirms the paucity of studies on neurogenic dysphagia both from an intervention (i.e. assessment and/or management) perspective and quality of life perspective in South Africa. Internationally there have been attempts to reduce this gap with the introduction of knowledge translation, which offers a holistic construct likely to improve understanding and overcome the barriers to implementing

EBP (Robbins et al., 2008; Susawad, 2007; Zwarenstein & Reeves, 2006). Ideally situated within health practice, knowledge translation focuses on using evidence-based clinical knowledge to change health outcomes positively (Davis et al., 2003). Knowledge acquisition does not imply an automatic change in clinical practice hence the emergence of a knowledge-to-action framework (Molfenter, Ammoury, Yeates, & Steele, 2009). Knowledge transfer or translation is considered essential for patients to benefit from new interventions (Molfenter et al., 2009). When a clinician is equipped with knowledge but fails to implement it in practise, it creates the knowledge-to-action gap referred to by Davis et al. (2003). Amongst other consequences of the knowledge-to-action gap and relevant to a complex context such as public health care in South Africa, is the inefficient use of limited resources (health care) (Graham et al., 2006).

Different models to facilitate implementation of research have been described, such as Pathman's, Green's and Graham's frameworks (Davis et al., 2003; Graham et al., 2006). Glasziou and Haynes (2005) reported on Pathman's four stages from evidence to action; awareness → agreement → adoption and adherence. Pathman's model was developed as a means to improve patient adherence with vaccinations. This initial model had several shortcomings, such as failing to include the patient, implication that each of the four listed stages are equally significant and that progression from one stage is necessary to proceed to the next (Freed, Pathman, Konrad, Freeman & Clark, 1998). Thus while there is evidence of high rates of transfer between the stages, the shortcoming of this model was the minimal effect on patient outcomes, which is the underlying principle of KTA and EBP (Glasziou & Haynes, 2005) and which was a goal of my study.

Green's model of research implementation underwent several modifications (phase 1 to phase 4), since its initial introduction in the 1960's. It initially suggested that use of health services is a function of people's predisposition to access services, and their need for care (Andersen, 1995). It was criticised for not giving due recognition to social networks, social interactions and culture (Andersen, 1995). Criticisms levelled against the phase 2 and 3 model included the need for health services to maintain and improve the health status of the population as evaluated by professionals and the importance of external environmental variables such as the physical, political and economic components being valid contributors to understanding health use (Andersen, 1995). The fourth phase considered the variables that affect the use and status

of health services and health status. Overall, while more holistic and inclusive, only some components had evidence of validity, with many components remaining untested.

Another model that merges different theories, the The Promoting Action on Research Implementation in Health Services (PARiHS) Framework notes that successful implementation of research into clinical practice is possible based on the interaction of 3 core elements; a) the level and nature of the evidence, b) the context of implementation and c) the method utilised to facilitate the process (Kitson, Harvey & McCormack, 1998). Acknowledging that randomised controlled trials (RCT's) are recognised as providing the best (level 1) empirical evidence (described in the preceding chapter), Kitson, Harvey & McCormack, (1998) caution that irrespective of the scientific status an intervention is given if it is not accepted and taken up by clinicians or patients (for whatever reason), it remains 'worthless'. Hence there is always an imperative to ensure that there is a combination of *research, clinical experience* and *patient preferences* when evaluating the strength of an intervention (Kitson, Harvey & McCormack, 1998). The PARiHS framework is unique in that it is three-dimensional allowing one to interpret successful implementation of an intervention located on a continuum of 'high' to 'low' evidence. However, it remains unclear which of the core elements holds most value in creating the optimal conditions for successful implementation i.e. is evidence vs. context vs. facilitation most influential? Kitson, Harvey & McCormack (1998) have suggested that facilitation was the one element that made a difference in many situations, but this suggestion lacks evidence to support it. The framework does allow one to explore complex theoretical positions around research implementation and can be valuable in identifying elements that were overlooked and exploring the relations between these elements. Thus the framework remains incompletely proven. While not yet at a point where it can conclusively be used as a theoretical underpinning for the study, the framework does hold potential for future mixed method studies in the South African context.

Graham's model (Graham et al., 2006) makes sense of KTA by dividing the KTA process into two concepts: knowledge creation and action. Graham et al. (2006) note that the boundaries between these two concepts and their phases are fluid and permeable, making the entire process dynamic albeit complicated. This feature made the model most suitable to understanding and explaining the method and action undertaken in my study.

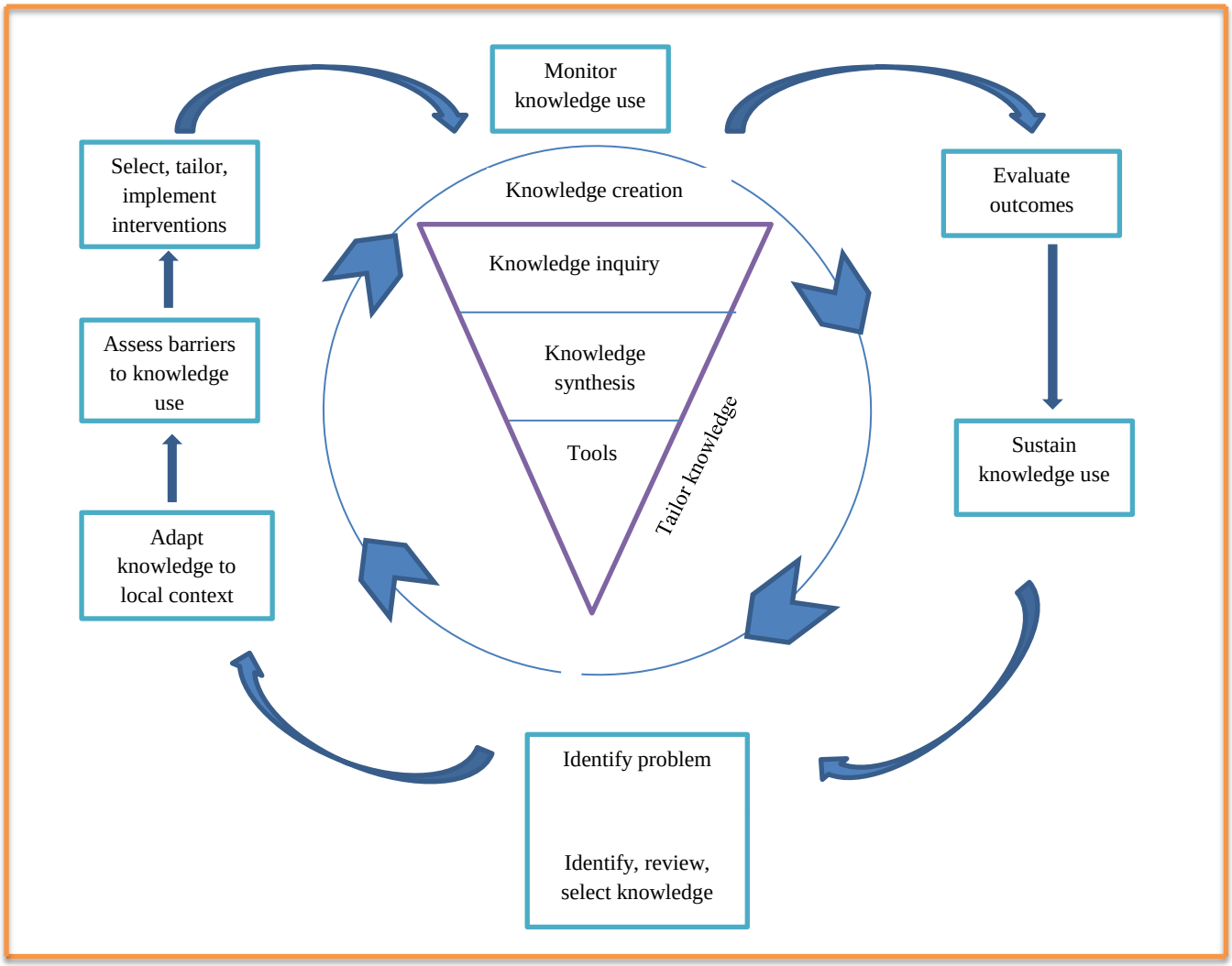

Figure 8: Knowledge-to-Action Process Model (Graham et al., 2006)

4.3 Knowledge-to-Action Process Model (with reference to figure 8 above)

Graham et al. (2006) suggest that knowledge is derived from an empirical and experiential basis. As there is movement of knowledge through the funnel, it becomes more distilled and refined (Graham et al., 2006, p. 18). For my study, the first phase of the funnel, knowledge inquiry, represents all published literature on dysphagia, mouth care, quality of life and dysphagia, dysphagia and evidence-based practice, nursing, relevant history of South Africa and South African health care, teamwork and collaboration. This information was accessed via electronic means (journals, books, and media sources), inter-library loans and library searches, and experiential knowledge. Graham et al. (2006) comment that this is first generation knowledge that is in its natural state and largely unrefined.

Knowledge synthesis (the second tier of the funnel), represents the aggregation of existing knowledge. This process involved, application of unambiguous and replicable methods to

identify, appraise and synthesize relevant studies and information to address the research question and aims of my study. Thus, reading and sorting information into categories with themes and in terms of priority was accomplished. This process was conducted at the initial stages of the study and was revisited at the end after analysis of the results. The third tier represents knowledge tools or products. The purpose of the tools is to present knowledge in a clear, concise and user-friendly way with explicit meanings to facilitate uptake and application of knowledge (Graham et al., 2006). The compilation of the mouth care booklet, posters, record-keeping forms and the mouth care protocol that was developed comprised this tier. A data recording form on an Excel spread sheet for information retrieved from the retrospective record review was also compiled.

The action cycle framed the knowledge creation funnel, and represented the activities that were necessary to apply the knowledge. For my study this cycle was considered vital as it encompassed the ethnography of the context and nurses, the information pertaining to the training provided to nurses, the interactions between the nurse participants and myself as the researcher as well as the collaboration with nurse participants in aspects of dysphagia management (feeding, water provision, temperature monitoring). The importance of context and contextual variables were essential to understand as this enabled identification of barriers to each aspect of the research process and implementation of the intervention. Graham et al. (2006) recommended the identification of facilitators or supports that may prove beneficial to the study at this stage as well. Several supports were identified in the current study:

- A desire by hospital management structures to improve mouth care for patients via the nurses,
- A desire by the nurses themselves to improve their image with their professional colleagues,
- Cooperation of the resident speech-language pathologist to improve the outcome for dysphagic stroke and brain-injured patients and
- Support from management structures to consider modification of nurse routines based on the outcomes from the study; were significant supports for my study going in.

The next phase of the model represents the dissemination, planning and execution of the intervention to facilitate and promote awareness and implementation of knowledge. The preceding step involving the identification of barriers and facilitators was crucial for this

phase to proceed effectively. Once the implementation initiatives commenced i.e. the mouth care training, mouth care implementation and dysphagia intervention; monitoring the use of knowledge begins and proceeds into the next phase. For this Graham et al. (2006) notes the importance of defining what constitutes knowledge use to allow measurement.

There are three types of knowledge proposed by Graham et al. (2006) namely, conceptual, instrumental and strategic knowledge. It became paramount to monitor knowledge use to assess the extent to which it was translated into action. The role of the intervention in bringing about the desired change was also evaluated at this phase. Figure 9 elucidates this process from implementation to change to final-outcome. It was imperative to compile outcome measures against which to measure change post-implementation of the intervention for purposes of the research.

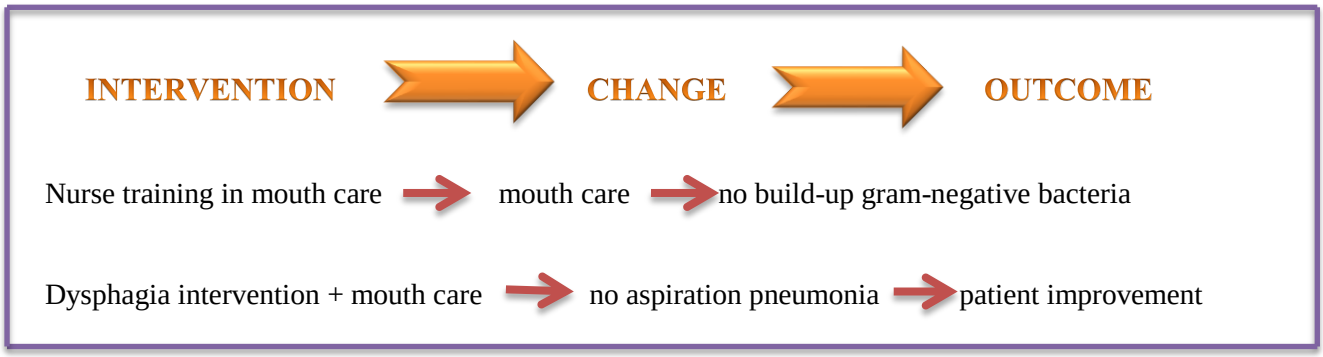

Figure 9: Intervention goals with outcome measures

It was thereafter necessary to define the impact of using the knowledge in the next phase i.e. were the efforts to improve the uptake of knowledge successful or not and how was this evaluated? For the study, this comprised a mixture of objective and subjective evaluations. It was necessary to evaluate if the training was successful. Figure 9 shows that change was expected dependent on frequency and content of mouth care resulting in no build-up of gram-negative bacteria hence no aspiration pneumonia in aspirating patients with dysphagia. Videofluroscopy was used to evaluate aspiration pneumonia, the absence of which implied that a combination of good mouth care, appropriate dysphagia management and patient compliance were successfully attained. The last phase considered sustainability, which is particularly important in a developing context to ensure continuity of intervention that has been shown to be effective. Detail on this is provided in the discussion (chapter 10).

The model proposed by Graham et al. (2006) is user-friendly and logical. Its aptness to my study, method and aims was notable and the theory underpinning the model provided a sound theoretical basis for my study.

Eraut (1985) in his article on knowledge use in professional contexts documented that knowledge is created and used in three contexts; the academic context (action has no role), the policy context and the action context (entails a pragmatic orientation when action is the aim). While the aim was not to change policy, the findings of my study do have implications for policy change or review at an institutional level, if not national health level. This will be discussed in the conclusion chapter of this thesis. Generally, my study adopted a pragmatic orientation given the need to understand the context and its variables to plan the action necessary for implementation appropriately and with insight. The patients comprised the quantitative aspect of the study. Greenhalgh et al. (2004) after careful review of various intervention studies noted that despite empirical studies having been undertaken from a pragmatic rather than academic perspective, it was often presented as 'gray literature', which is unfortunate. They went on to advise that in evaluating interventions, researchers should rather frame their questions probing the process e.g. "*what feature accounts for the success of Program X in this context and the failure of a comparable program in a different context?*" as opposed to focusing on causal inferences, for example, "*Does program X work ...*" (Greenhalgh et al., 2004, p. 615).

The above considerations and theories contributed significantly to the thinking around the present study and in evaluating the results obtained. Whilst there was a need to establish some kind of standardised empirically proven management for dysphagia within the South African public health care context, there was also a compelling need to focus on clinical significance by describing the feasibility and sustainability of this management. The knowledge-to-action process model provided further substantiation of the need for dysphagia management to be more holistic and inclusive for the benefit of the patient, the health care professionals and the institution. The next chapter will provide information on the methodological considerations that were necessary to achieve these imperatives.

CHAPTER FIVE: METHODOLOGICAL CONSIDERATIONS

> "…*most powerful evidence in speech pathology will come from matching the question to the appropriate research design and recognition that the utilization of a combination of methodologies…will best meet the needs of a profession working with populations of people in whom cures will often not be possible*" Reilly (2004, p. 32).

Overview

The theoretical underpinning provided by the knowledge-to-action process model facilitated the choice of methodology necessary for this study and was described in the previous chapter. This chapter will provide a description of the methodology that was necessary for knowledge-to-action translation for dysphagia management in an acute public hospital context. The chapter will outline the need for a participatory role of end-users of the intervention in the research process, and will explain how ethnography enabled participation.

5.1 The need for a pragmatic paradigm

The study followed a mixed method pragmatic paradigm, based on the need to understand the context prior to introducing and implementing nurse training and dysphagia management. Mixed method studies provide insights not possible when only quantitative *or* qualitative data are collected. Greene (2007, p. 13) noted it as an "*opportunity to compensate for inherent method weaknesses, capitalize on inherent method strengths, and offset inevitable method biases.*" Protheroe, Bower and Chew-Graham (2007) support the view of mixed methods in the evaluation of any complex intervention. They agreed with the advantage of one method being able to complement the other and the combination of methods providing better insight than either method alone (Protheroe et al., 2007). Pragmatism accepts that there are varying aspects of reality that lend themselves to different methods of inquiry (Wolfer, 1993). The pragmatic paradigm was particularly suited to the area under investigation within the particular context given the complexity of systemic rules and the varying pockets of professionals within the South African health care environment who shared some commonalities. To focus on the problem to be researched and the consequences of the research, pragmatism was most suitable (Feilzer, 2010).

Historically, dysphagia research adopted an either or approach, i.e. either qualitative, focusing on knowledge, perceptions and attitudes (Davis & Conti, 2003; Hamdy, 2007; Modi & Ross, 2000) or quantitative, providing statistically significant evidence for the success or failure of an intervention (Bronson-Lowe et al., 2008; Garon, Engle & Ormiston, 1997). The documentation of these findings while contributing to existing research and being valid theoretically falls short on relevancy and clinical application for different contexts, cultures and people/patients residing in different parts of the world from the actual study site. The clinical and empirical testing of this perception is in part what the current study aimed to do – was a free water protocol applicable and feasible in its current form in South Africa, or was there a need for modification to ensure optimal knowledge translation?

Implementation of interventions and assessments based on 'ideal' populations was and still is complicated for patients with dysphagia given the varied underlying medical pathophysiology of dysphagia and resultant co-morbidities, leading to adverse consequences from interventions then not suitable or proven effective for particular population groups (Sonies, 2003). Hancock (2007) clearly articulates that mixed methods are necessary to depict the individual experiences of the people and the systemic realities within a context, both of which were objectives of my study.

The historical lack of mixed method research in dysphagia is probably due to a number of factors. Financial implications, logistics, methodological variables, the state of inter-professional collaboration, knowledge-to-action discrepancy and ethical considerations are some extraneous variables that seem to have hampered progress in this regard (Bryman, 2007; Stewart et al., 2008). While Tashakkori and Teddlie (1998) prefer the term 'mixed model' as opposed to 'mixed method' implying that mixing often extends beyond just the methods used in the research or study, Barbour (1998) cautions that there are pitfalls to mixing methodologies within a broad quantitative or qualitative approach. For this reason Caracelli and Greene (1997) stress that it is essential to detail *what* is being mixed, and *how*. The following fields shown in the table (10) below were used to rationalise my use of a mixed design.

Table 10: Supporting information for use of a mixed design – pragmatic paradigm

Field	Qualitative Phase: How?	Quantitative Phase: How?
Data used	Text: Nurses	Numbers: Dysphagia patients.
Data collection	Interviews, ethnography, semi-structured interviews, and questionnaires.	• Amount of water consumed. • Length of hospitalisation. • Presence of aspiration pneumonia measured via videofluroscopy.
Sampling	Random Purposive Sampling: Nurses.	Consecutive Sampling: Patients with dysphagia.
Logic employed	Inductive: No existing framework for nurse training, influencing variables unknown, responsiveness and cooperativeness of nurses unknown, unable to assume nurse response to training.	Deductive: A free water protocol cannot be implemented with adult patients presenting with dysphagia within a South African acute public medical setting due to a variety of internal and external confounding variables.
Type of investigation	Exploratory: No existing framework for training in this context and variables largely unknown.	Confirmatory: Free water + mouth care + appropriate dysphagia intervention will reduce length of hospitalisation, improve QOL, and improve dysphagia outcome when compared against patients who received traditional dysphagia management.
Analyses	Interpretive: Thematic content analysis	Statistical: Non-parametric and descriptive statistics. Whole-group comparisons.
Underlying paradigm	PRAGMATIC	

Table 10 contains information that supports the use of qualitative and quantitative methods for the respective phases of the study. It was necessary to have a combined understanding of the two phases of the study to answer the research question. The inter-relatedness of one phase on the other could not be negotiated nor disputed, substantiating the use of a pragmatic paradigm. Each field is defined in greater detail in Chapter 6, such as purposive sampling vs. consecutive sampling.

5.2 The sequential exploratory design (with reference to figure 12)

The current study followed a sequential exploratory design. The sequential exploratory design is one of four design types proposed by Creswell (2006). Quantitative data from phase 2 of the study were used to explore, enhance and complement the qualitative data obtained from phase 1. Furthermore, data collection for each type was relatively close together in time without any interference of one on the other (Creswell, 2006). Thus information obtained

from observing, training and working with the nurses informed the dysphagia intervention and hence dysphagia outcome and quality of life of the patient. I considered the method to be exploratory in that:

- There was no existing model for mouth care training for the nurses or for provision of free water for patients with dysphagia,
- Extraneous variables that could impact the training and dysphagia intervention were unknown (but possibly assumed), and
- There was no guiding framework from which to work – either for nurse training or the provision of free water to patients with dysphagia in a public health care facility in South Africa (Creswell, Plano Clark, Gutmann, & Hanson in Tashakkori & Teddlie, 2003).

The sequential exploratory design is particularly suited to the exploration of new phenomena (Cabrera, 2011). The paucity of research and published information on quantifiable evidence of dysphagia management in South Africa with an understanding of contextual variables made the selected design ideally suited for this inquiry. I considered the following variables prior to selecting the specific type of mixed design classification:

- Timing of the methods
- Weighting of the methods
- How will the methods be mixed?

(Creswell et al. in Tashakkori & Teddlie, 2003; Hanson in Tashakkori & Tedlie, 2003; Plano Clark, 2005).

Morgan (1998) emphasizes that *timing* relates to when data is analysed and interpreted more than collection i.e. the order in which the data is used. Very often data collection, analysis and interpretation times may be interrelated (Creswell, 2006). My ethnographic (qualitative) phase was necessary at the outset to gain full understanding of the health context, nurse, patient and team culture, and get an impression of nurse routine. This insight guided development of the training protocol. Implementation of the received training by the nurse together with the dysphagia management I provided comprised phase 2 of the study.

The *weighting* according to Morgan (1998), relates to the relative importance or priority of one method over the other to address the aims of the study. The qualitative and quantitative

components were equally weighted in the study and were equally important to address the main aim.

The ethnographic data and quantitative data from the dysphagia management were not collected concurrently. However, there were particular points along data collection, where other qualitative data (such as the information from the interviews) was collected concurrently with quantitative data. Thus, there was some mixing of data at this level. There was independent interpretation of each data set, however it was necessary to integrate and reveal how the findings of each data set influenced the outcome of the other. This integrative discussion is done in the discussion chapter of the thesis.

5.3 A complex intervention study?

This study was classified as a complex intervention study based on the diversity and number of variables that required consideration. This is depicted in figure 10 below. A complex intervention as defined by the United Kingdom Medical Research Council comprises, "*a number of separate elements which seem essential to the proper functioning of the interventions although the 'active ingredient' of the intervention that is effective is difficult to specify*," (Shepperd et al., 2009, p.1). The accuracy of this definition was realised in the data collection process and outcomes from my study. It was challenging to place a higher value on one phase over the other or to single out the one 'active ingredient' that led to the positive outcome of the study. Patient compliance, engagement of managerial structures, nurse commitment, effective dysphagia management and monitoring, support from doctors and professional work ethic were all contributory factors.

The stance of Geoff Wong in the Viewpoint presented by Shepperd et al. (2009) provided support for my classification of this study being a complex intervention. Geoff Wong believed that a complex health intervention is more than a mere grouping together of variables that when grouped together interact in a deterministic manner to produce health outcomes (Shepperd et al., 2009). The very significant impact of human behaviour on the outcome of an intervention implies the influence of the context on the intervention. This then shapes the action taken by that person. "*The 'components' in complex health interventions are invariably made up of people (e.g. researchers) trying to get other people (participants) to 'do' or 'not do' something*," (Shepperd et al., 2009, p. 4). For my study, the action taken by the participants i.e. the nurses, was influenced by their work, personal, environmental,

political and social circumstances, and the action of the researcher i.e. me, was guided by the needs and requirements of the study. The contextual variables and influences shape the actions and choices made by participants and for this very reason, outcomes of an intervention may vary upon repetition. This builds a case for my proposal of the existence of different cohorts of employees within one institution and varying cohorts of employees from one institution to the next.

In the last decade there has been much literature on complex interventions leading to questions on the criteria for evaluating outcomes in public health institutions, measuring outcomes of research in developing countries, questions of whether research in developing countries can be considered ethical and on the responsiveness of research to the needs of the people in that country (Campbell et al., 2007; Rychetnik, Frommer, Howe & Shiell, 2002; Shepperd et al., 2009; Wendler, Emanuel & Lie, 2004). These queries, concerns and novel thinking about the value of research and the method employed in undertaking research, were especially significant for the present study with the country being a developing one, the site being public health care and the on-going debate to address the health and population needs that were being raised within South Africa (Benatar, 2004).

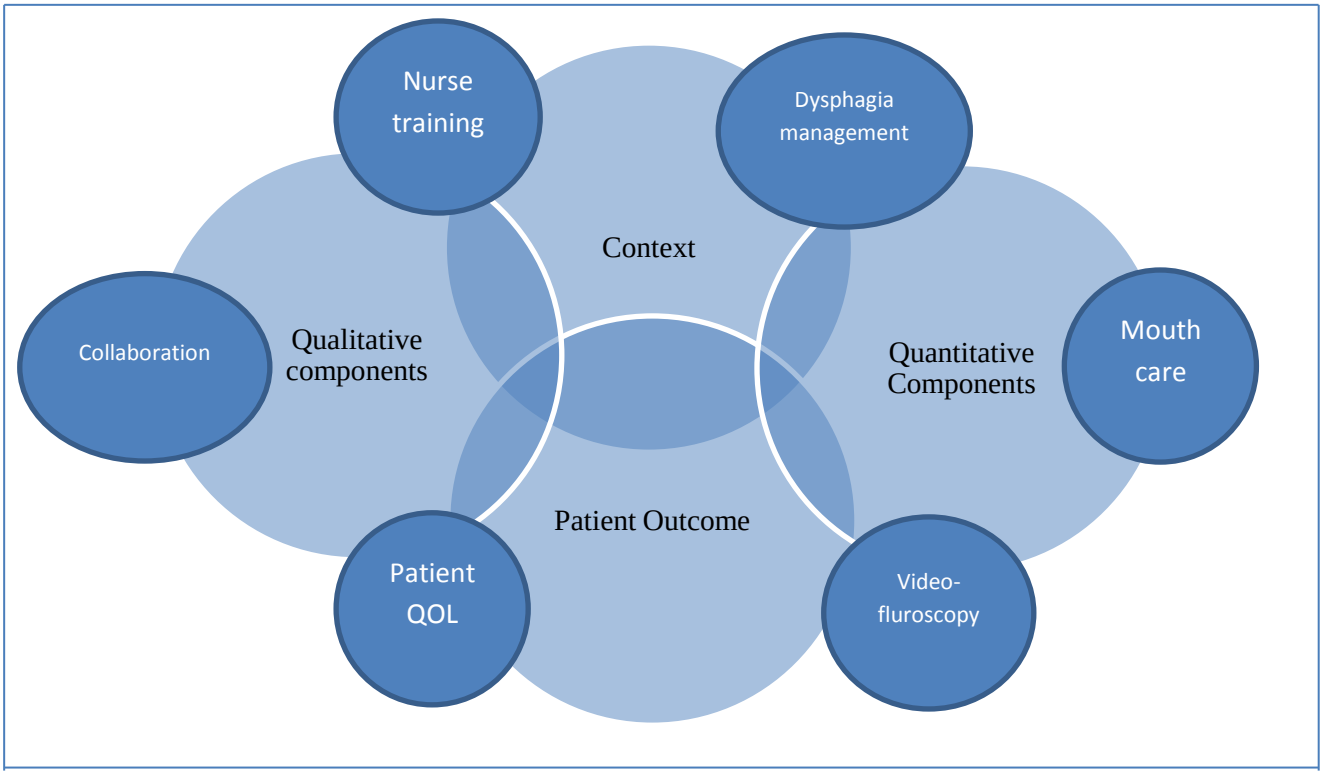

Figure 10: The interplay of variables confirming this study as a complex intervention study

It is acknowledged that clinical research is typically conducted in developed countries (Wendler et al., 2004) with the need for the intervention often required in developing countries. Developed countries given their status have access to finance, resources and are able to accommodate scientific methods for research purposes. However, the argument prevails, that it is for these very reasons that the proven interventions are not readily feasible or appropriate in a developing context because of the lack of finance, resources and other contextual variables. Wendler et al. (2004) caution that researchers and clinicians in developing countries must be mindful not to fall prey to using and accepting 'evidence' considered to be less than the world-wide best just because it is a developing country when the very same evidence would be unethical in a developed country. Evidence refers to the consequences of an intervention (a set of actions with a coherent objective to bring about change) and its implementation (Rychetnik et al., 2002). Rychetnik et al. (2002) provide 3 criteria against which to evaluate evidence: Did the outcomes encompass:

- The interests of the participants i.e. those delivering the service and those receiving it.
- Unanticipated and anticipated effects of the intervention irrespective of benefit. Research that reports only the intended outcomes of a study may fail to identify other positive or negative consequences.
- The efficiency and effectiveness of the intervention.

As with any health care institution anywhere in the world, there are numerous processes, people and interactions that are in operation. The historical backdrop of South Africa has resulted in significant socio-political change for many people in the country, some positive and some less positive. This change has opened up the doors of public health care to individuals who previously found health care inaccessible, resulting in an influx of more patients but without the necessary human and infrastructure supports, the attempts at transformation and redress have in some ways unfortunately adversely affected the status public health care finds itself in, from the perspective of the patients as well as the staff employed at these institutions. The nature of the current study required collaboration with nursing professionals if it had any chance of proving to be feasible. Given the scenario presented above and professional responsibility to engage in evidence-based practice via engagement with research, careful consideration of how to approach nurses to be participants of this process was required. Careful discussion with nurses of their role and position within the hospital generally and for purposes of the study contributed to them being involved in

tailoring the research process which was beneficial in preventing anticipated barriers. These underlying considerations aligned with the necessary requirements for action research.

The sensitivity of dysphagia and its intervention dictated that the researcher (me) should possess the clinical skills and knowledge to implement the intervention. Table 6 (p. 53) provided evidence of the lack of quantitative dysphagia research in South Africa. However, the increasing prevalence rate of dysphagia and dysphagia-related pathologies in South Africa motivated the need to intervene. Purely qualitative or descriptive dysphagia studies are insufficient to address the needs of patients with dysphagia or the burden being faced by the health care system. A combination of qualitative and quantitative methods to guarantee contextual understanding before embarking on quantitative investigations, or vice versa provided an attractive and attainable solution to a seemingly insurmountable task.

5.4 The need for ethnography

In defining the research question and conceptualising how to get the necessary information, it was clear that ethnography was needed. Observational methods to understand a phenomenon is regarded as the gold standard given that it provides direct access to what people do, as well as what they say they do. This was conceded by Becker and Greer as early as 1957, and has been supported by various researchers since (Murchison, 2010). Murchison (2010, p. 4) for instance defined ethnography as "*a research strategy that allows researchers to explore and examine the cultures and societies that are a fundamental part of the human experience.*" By facilitating the studying of people and cultures outside of a controlled environment, the implications of studying cultural phenomena in action is explicit. Nurse routine, nurse culture, their inter-professional interactions, nurse interactions with patients and nurse interactions amongst each other necessitated an ethnographic component to answer the *how*, *when* and *what* of the different interactions.

Ethnography has its roots in early anthropology since the end of the nineteenth century beginning of the twentieth century (Murchison, 2010). Whilst often used as a comparative measure for other sources of qualitative data collection, ethnography despite possessing methodological advantages in health related contexts is considered under-used because of its time consuming nature (Green & Thorogood, 2009). Green and Thorogood (2009) proceed to say that any attempt to intervene health behaviour and culture necessitates the researcher viewing the context through the eyes of the people involved, which in this study was the

nurse. Ballinger, Yardley and Payne (2004, in Marks & Yardley, 2004, p. 110) have acknowledged that prolonged fieldwork and ethnography have become less sustainable in today's context but it is "*precisely this strangeness and novelty at the beginning period of a study that enables the researcher to make the most acute and sharply focused observations.*" The ethnography provided rich detail and understanding of the context and people. Observations, interviews and conversation were used (Murchison, 2010).

Hammersley (1998) has recommended that for ethnography to be considered a valid method it should contain most of the following features:

a) Study of people's behaviour in everyday contexts rather than under conditions specified by the researcher. *I observed the general daily routines within the different wards at different times in the day on any day of the week, including weekends. The following were observed; ward rounds, nurses completing their routines, patient mealtimes, dieticians, physiotherapists, occupational therapists and speech-language pathologist intervening with patients and different interactions and communications between the professionals and nurses. I did not contrive any situation for the benefit of the study and made all attempts for my observations to occur within routine, everyday interactions. The observation included an environmental assessment.*

b) Data are gathered from a range of sources. *Data was gathered from observations interviews with nurses, doctors, allied health professionals and patients. I ensured that field notes, audio and video recordings were used to record the outlined routines and interactions. This was validated with information from the participants during the informal and semi-structured interviews.*

c) The approach to data collection is 'unstructured'. *This was achieved and the process was unexpectedly less difficult than anticipated. The nurses within a few days of me being in the ward knew who I was and why I was there. Being familiar to the hospital in my role as clinical supervisor for student training on a weekly basis over the previous two years, some nurses were already familiar with me being in the ward. Hence, when my study commenced my now daily presence became a norm. I did not go in with any predetermined plan of what to do, aside from knowing that I needed to observe different wards, various routines and interactions, at different times of the day and with various levels of nurses and health care professionals.*

d) The focus is generally a small number of cases or a single group of people. *It was impossible for me to specify at the outset the number of nurses that would be involved in*

my study however I was able to specify two groups of participants i.e. the nurses and the patients with dysphagia.

e) Data analysis involves interpretation of the meanings and functions of human actions taking the form of verbal description. Statistical analysis may play a subordinate role. *The data from the study was analysed using both thematic analysis and thematic content analysis presented via verbal description, definitions and explanations (Hammersley, 1998). As a mixed method study, nonparametric and descriptive statistical procedures were conducted to achieve the quantitative aims of the study, namely use of the Fisher's exact test and the Wilcoxon two tailed test. Qualitative and quantitative data were equally valuable in the study.*

I have thus far provided a description of the quantitative and qualitative methodological considerations that were necessary to undertake the study. Below are the overarching methodological theories that were used to direct the chosen method for the study, namely action research and knowledge translation.

5.5 Action research cum knowledge translation

The knowledge-to-action process model by Graham et al. (2006) underpinned the method for the study as it encompassed action research as a means to achieve translation of knowledge into action. Each step of the model encompasses knowledge translation and draws the attention of the user (of the model) to the different variables and factors necessary for consideration to facilitate this process e.g. selection, tailoring and implementation of intervention, monitoring the use of knowledge, and so forth (refer to figure 8). In phase one, the involvement and collaboration with nurses, nurse managers and matrons to:

a) Define a way of training that would be successful,
b) Discussion on how to adapt and modify the mouth care training to ensure that it would address the needs of all categories of nurses that may be involved in the study and
c) Advice on incentives that may enhance participation, were some examples of mutual planning and joint decision making that ensued. These discussions with different levels of stakeholders enabled identification of barriers that were likely to impede implementation of mouth care of patients with dysphagia, and together we were able to modify the protocol so that it could be used easily and quickly, but competently.

Monitoring and evaluation of the outcomes was completed independently by myself, after which nurses were again consulted and provided information regarding the continuation of implementation, the consistency of implementation and completeness of implementation. Where necessary, adaptations were made and the intervention continued. This process (i.e. use of action research and implementation of the knowledge-to-action process model) seen in figure 8 continued for the duration of the data collection period until the completion of the study.

In the previous section, I described how my study aligned with the knowledge-to-action process model (Graham et al., 2006). Figure 11 shows how the action research characteristics proposed by Street (2003) were addressed in the knowledge-to-action process model.

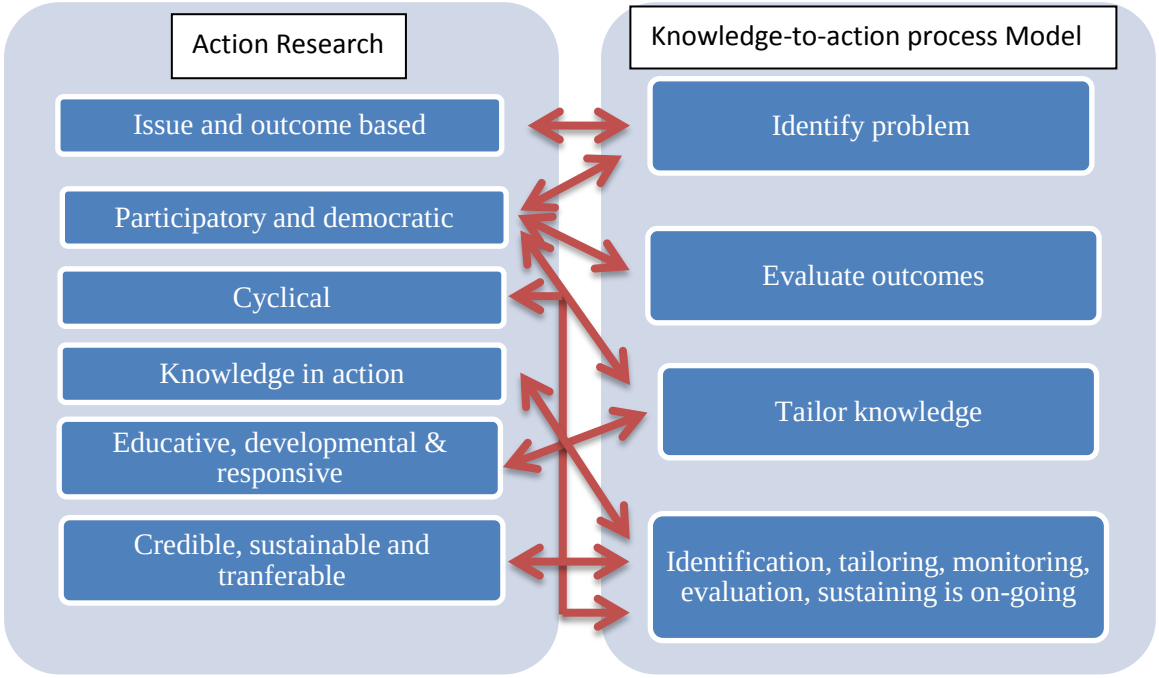

Figure 11: Link between action-research characteristics (Street, 2003) and the Knowledge-to-Action Process Model (Graham et al., 2006)

Although the link shown in figure 11 appears to be complicated, it is easy to follow. The diagram shows the link between the action research characteristics proposed by Street (2003) and how these are encompassed within the knowledge-to-action process model by Graham et al., (2006). In showing this, I aim to highlight that action research and knowledge-to-action follow similar principles and processes, suggesting similarity. Below I explain how the action research characteristics were addressed in my study.

1) **Issue and outcome based**: Joint identification of gaps in clinical practice that were common to speech-language pathology and nursing were identified. Mouth care was agreed on. Mutual goals and outcomes for improvement in mouth care were set. For the nurse this included improved implementation of mouth care in terms of procedure and regularity. For me, the speech-language pathologist, prevention of aspiration pneumonia was the outcome measure.
2) **Participatory and democratic:** Nurses, nurse managers and matrons were included in the design and implementation of the mouth care training and the combined input of myself and the nurse participants was considered in modifying and adapting the protocol and the training when obstacles or difficulties were encountered.
3) **Cyclical:** As noted above the entire process was cyclical and continued for the duration of data collection.
4) **Knowledge in action:** Based on the ethnography and data collection during phase 2, acquired information and knowledge was continually being acted on, tailored (modified) and implemented.
5) **Educative, developmental and responsive:** It was necessary for the intervention to be capacity building and for it to provide the participants as well as myself, the researcher, with new information, better understanding and improved clinical skills. The intervention had to fill a gap in theory and/or clinical practice for all invested stakeholders. Basic mouth care was covered as a theoretical course for nurses during their training. The implementation of mouth care for the study provided greater explanation, detail, structure with supporting rationale and recommendations.
6) **Credible, sustainable and transferable:** All necessary measures were taken to establish credibility of the intervention i.e. the mouth care and free water dysphagia intervention patients with dysphagia and sustainability – involvement of the nurse at the outset facilitated this process for mouth care. As the resident speech-language pathologist was not directly involved in the study because of her work commitments, sustainability of the free water dysphagia management was not expected to be achieved at the conclusion of the study. However, mouth care for patients with dysphagia has been sustained and transferred now to geriatric patients as well.

Summary

This chapter provided insight into why a mixed method design was necessary to address the aim of the study. I highlighted how ethnography and action research were appropriately suited to investigation in a public hospital. The importance for nurses and patients to be active participants in an intervention study was described. The chapter ends with a review showing the link between action research and the knowledge-to-action process model, providing validation of this model and action research as an appropriate theoretical basis for the study.

CHAPTER SIX: METHODOLOGY

Overview

This chapter provides a description of the study setting, the chosen research design, a description of the two groups of participants (nurses and patients with dysphagia) and the sampling method for each group. The need for a retrospective record review to confirm participants for a pathology matched comparison group is discussed. The ethical and contextual considerations, and data collection with a description of the data analysis process is also provided. The chapter ends with a description of how trustworthiness and reliability of data was confirmed.

Research Question

How do we reduce the knowledge-to-action gap i.e. facilitate knowledge translation, in dysphagia management when using a free water protocol in a public hospital in South Africa?

6.1 Primary aim

The primary aim of the current study was to investigate if implementation of a free water protocol by collaborating with nurses in the oral (mouth) care component would have a positive and sustained outcome for dysphagia for patients with stroke or traumatic brain injury, in an acute government hospital setting in Gauteng, South Africa.

This aim was addressed by exploring the objectives below.

6.2 Specific objectives

1. To determine nurse perception on the different aspects of the free water protocol specific to nurses i.e.:
   1.1 Mouth care
   1.2 Feasibility of mouth care
   1.3 Water provision to patients
   1.4 Training
   1.5 Collaboration
2. To ascertain the dysphagia outcome of free water provision by comparing the study and comparison group in terms of:
   3.1 Occurrence of aspiration pneumonia,

3.2 Amount of water intake and

3.3 Length of hospitalisation.

3. To gain insight into doctors, nurses and allied health professionals view of their role in the free water protocol and their overall impressions of the protocol for the management of dysphagia.

4. To explore the impact of dysphagia on the patient by evaluating his/her quality of life using a standardised measurement tool, the SWAL-QOL.

6.3 Outcome measures

Table 11 provides a description of the outcome measures that were used to measure the objectives listed above.

Table 11: Objectives and outcome measures for the current study

Objective	Outcome Measure
To introduce a mouth care protocol using a training framework	Effective implementation of mouth care in terms of procedure and period. Evaluated using visual inspection, video recordings, face-to-face interviews and review of documentation.
Implementation of mouth care	Clean mouth prior to water intake and after meal consumption. Evaluated using random observations, video recordings, and review of documentation.
Monitor for absence of aspiration pneumonia	Healthy lungs and no evidence of aspiration pneumonia. Evaluated via videofluroscopy.
Amount of water consumed	No dehydration. Manual calculations based on recording by nurse.
Length of hospitalisation	Manual calculation of length of hospitalisation in days.
Patient quality of Life	Compliance with mouth care. Patient involvement in management and consequent compliance with dysphagia recommendations. Perceptions of the impact of swallowing on his/her life as measured by the administration of the SWAL-QOL.

The outcome measures allowed me as the researcher to track and compare progress before and after implementation of the different aspects of the intervention. This is seen in table 11 above. Tracking progress with the outcome measures provided evidence of the success of each objective and overall information to support the attainment of knowledge translation in dysphagia management for the South African public health care context.

6.4 Research design

For reasons provided in previous chapter on methodological considerations, the sequential exploratory mixed method design was selected for the study. Figure 12 provides a detailed description of the design and shows the method for the qualitative and quantitative component.

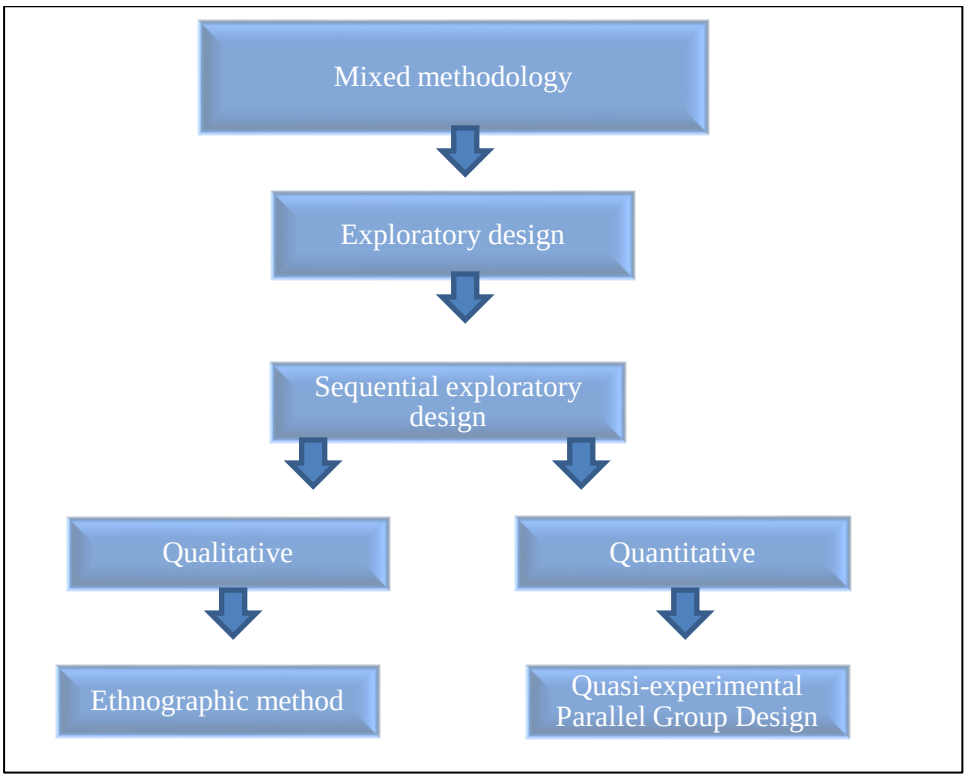

Figure 12: Flowchart description of the research design

Figure 12 provides visual clarity on how the mixed method, which followed a sequential exploratory design, comprised a qualitative and quantitative component. For the qualitative component, ethnography was used. Rationale behind selection of a mixed methodology, sequential exploratory design and ethnography have been provided in the previous chapter. It is touched on again briefly, below. The quantitative component was explored using a quasi-

experimental parallel group design. The quasi-experimental parallel group design is described below.

Figure 13 shows how the selected methodology translated into the data collection process.

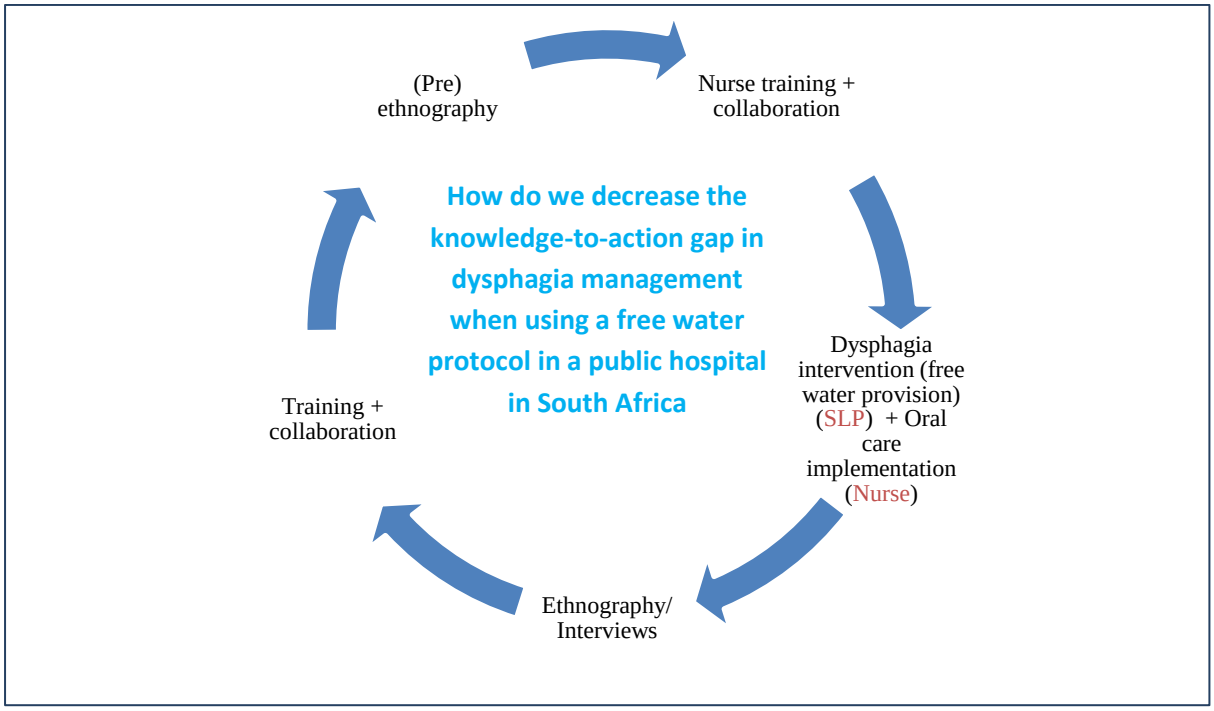

Figure 13: Integration of quantitative and qualitative component to address the research question.

Figure 13 shows visually the interaction of the qualitative and quantitative components of the study. Within the cycle is included (but not shown) the retrospective record review (described later) that was used to select the participants for the comparison group, and the final comparison of dysphagia results between the two groups. All aspects of the qualitative and quantitative enquiry together contributed to answering the research question.

6.5 Phases of the study

Phase 1: Qualitative phase – Ethnography

This phase commenced with ethnography of the study site. Ethnography provided an understanding of how things worked in the hospital and ward/s, why they worked that way, individual preferences, routines and rituals, things/people that went against the norm and why. This information was vital in planning how to devise a training protocol to address the aim of the study whilst ensuring it was a capacity-building task for the participants. The qualitative phase also included the information obtained from the informal and semi-

structured interviews, observations and video-recordings, which at times overlapped with phase 2. The ethnography contributed toward the trustworthiness of data obtained during the interviews as it allowed me to corroborate the information from the interviews. The video recording provided similar contribution.

Phase 2: Quantitative phase – Quasi-experimental parallel group design

Phase 2 involved direct hands-on intervention with patients with dysphagia employing a quasi-experimental design involving two groups. It was quantitative in that direct measurements of variables were undertaken with objective testing procedures and comparisons. Repeated measures of the dependent variables (listed below) in the study were systematically documented (Horn & Heerboth, 1982). Concurrent change in the dependent variables with introduction of the independent variables, i.e. mouth care training and water administration, were surmised (Horn & Heerboth, 1982). A parallel group design was used, comprising two groups. The study group participants received the treatment (free water and oral care) and the comparison group did not receive the treatments. Analysis involved comparison of the two groups of participants (Whitehead, 2000; Matthews, 2006; Stevens et al, 2001).

6.6 Variables in the study

It was necessary to define the dependent and independent variables in the study, as variables are considered central to empirical research (Schiavetti & Metz, 2006). Independent variables may be conceptualised as the condition or criterion that causes a change (Schiavetti & Metz, 2006). For this study, mouth care and water provision i.e. the free water dysphagia management protocol were the independent variables that were expected to prompt change in dysphagia status for patients.

Independent Variables

a. Mouth care

b. Water administration

Dependent variables are the measures used to observe the effect/s of the independent variable (Shaughnessy, Zechmeister & Zchmeister, 2000, p. 210). For the current study change in nurse completion of mouth care, patient compliance and satisfaction, mouth care, water

consumption and recovery from dysphagia without occurrence of aspiration pneumonia, were expected.

Dependent Variables:

a. Nursing adherence

b. Mouth care and hygiene

c. Patient satisfaction

d. Amount of water consumed

f. Occurrence of aspiration pneumonia

g. Recovery period from dysphagia

The possible complications that could arise from dysphagia mismanagement alerted me of the need to proceed with caution. Conducting a randomised control trial or quasi-experimental study, which would require application and withdrawal of an intervention, in this case water provision and mouth care, was not possible. I therefore selected to run a quasi-experimental design, using two parallel groups of dysphagic participants: one that received the free water dysphagia intervention + regular mouth care (study group) and a pathology-matched group (comparison group) that received the 'traditional' dysphagia intervention, no 'free water' and inconsistent mouth care. Refer to pg. xx for a definition of traditional as used in this thesis.

6.7 Sampling

Nurses: Nurses were recruited using random purposive sampling. Random purposive sampling facilitated purposeful selection of all nurses tending to the dysphagic participants as it was perceptions of their experience and involvement in the different aspects of the study that was targeted (Patton, 1990).

Patients with dysphagia: There were two cohorts of patients with dysphagia who were participants in the study, namely the study group and comparison group participants. The groups are described individually.

Study group: Participants belonging to this group were the patients with dysphagia who received free water dysphagia management, the intervention under investigation. These patients were recruited using consecutive sampling. Consecutive sampling involves selecting individuals who agree to participate, provided they meet the inclusion criteria until the number of participants required have been recruited (Maxwell & Satake, 2006). Consecutive

sampling, a non-probability sampling technique allowed investigation of all the stroke and traumatic brain injured patients presenting with dysphagia at the hospital for the study period. This provided a good representation of the overall population in a reasonable period while reducing sampling bias (Maxwell & Satake, 2006).

Comparison group: A retrospective record review was conducted to identify patients who received dysphagia intervention. Consecutive sampling was then used selectively to choose patients that met the stipulated inclusion criteria until the number of participants required were selected (Maxwell & Satake, 2006).

Doctors and allied health professionals: The respective doctors and allied health professionals managing the participants of the study group were invited to participate. Purpose sampling was used, as these professionals were specifically selected based on their intervention with the patient.

6.8 The sample

6.8.1 Sample size

Nurses: There were 139 nurses recruited as participants in the study. All nurse participants received mouth care training and all were involved in the intervention process.
Patients with dysphagia: There were 23 patients with dysphagia in the study group and a pathology- matched comparison group with 23 patients with dysphagia.
Doctors and allied health professionals: Three doctors, two physiotherapists and one dietician were interviewed based on their involvement with the study group participants.

A large sample size for both the quantitative and qualitative components were more representative of the nurse and dysphagic population respectively, and limited the influence of outliers or extreme observations. A larger sample size is required to produce results among variables that differ significantly (Patel, Doku & Tennakoon, 2003). In a qualitative study while a large sample size provides a better picture for analysis, with the focus on depth and richness of detail being the goal, a smaller sized sample allows the researcher to attain this goal (Patton, 1990).

6.8.2 Description of the sample

Nurses and patients with dysphagia comprised the study sample. As has been mentioned, the patients with dysphagia were further divided into two groups, the study group sample and the comparison group sample. The nurse participants will be described first.

Table 12 below provides a list of the inclusion and exclusion criteria that were used to recruit nurses to the study.

Table 12: Nurse participant inclusion and exclusion criteria

Nurse Inclusion Criteria	○ Age: not specified. ○ Gender: Male and female ○ All nurses working in the clinical environment. ○ Any site of qualification i.e. agency, university trained, college trained.
Nurse Exclusion Criteria	○ Persons working as 'nurses' on a voluntary basis within the hospital.

Inclusion Criteria: Nurses

All nurses working within the clinical environment were invited to participate in the study, i.e. Professional Registered Nurse, Registered Staff Nurse, Auxiliary Nurse (Enrolled Nursing Assistant), Student Nurse. It was not necessary for there to be any level of knowledge or experience with mouth care, as the training protocol developed would suffice in detail and explanation. Participants would have different levels of knowledge and expertise and the planning of the training considered this.

Exclusion Criteria: Nurses

Individuals without any formal training in nursing or not in the process of receiving training, working in the hospital in a voluntary capacity, were excluded from the study.

Patients with dysphagia

The inclusion and exclusion criteria were similar for both groups of patients with dysphagia to allow for statistical group comparisons. The criteria applied are shown in table 12 below.

Table 13: Inclusion and exclusion criteria for patients with dysphagia

Dysphagic Patient Inclusion Criteria	○ Age: 45- 80 years. ○ Gender: Male and female. ○ Diagnosis: Dysphagic stroke or traumatic brain injured in-patients. ○ Type of dysphagia: Oropharyngeal. ○ Cognitive status: Oriented, alert and able to follow simple one-level commands
Dysphagic Patient Exclusion Criteria	○ Previous history of stroke or traumatic brain injury. ○ Previous history of dysphagia, aspiration or aspiration pneumonia. ○ Oesophageal dysphagia. ○ History of cancer and/or history of exposure to chemotherapy, radiation or related surgery.

Inclusion criteria: Patients with dysphagia

An upper limit of 80 years was based on studies suggesting an increased risk of swallowing disorders with normal ageing as a result of poor dentition, oral phase problems resulting from loss of tongue connective tissue and pharyngeal phase changes such as increased pharyngeal transit time and prolonged upper oesophageal sphincter relaxation time (Morris, 2006; Wilkins, Gillies, Thomas & Wagner, 2007). Thus, as far as possible it needed to be ensured that age over and above the stroke or TBI was not the reason for the presentation of dysphagia in the population under investigation. It was vital that patients presented with oropharyngeal dysphagia, as the role of the speech-language pathologist with this presentation is unequivocal. An informal screening of the patient's level of alertness, orientation and language was completed, as intervention would require the patient with dysphagia to understand and execute simple commands, e.g. open your mouth, wait – hold it in your mouth and swallow when I ask you to, etc. Patients who did not meet this criterion were handed-over to the resident speech-language pathologist for management.

Exclusion criteria: Patients with dysphagia

It was necessary to exclude patients with a previous history of infarct or trauma, as it would be difficult to isolate acute from residual symptoms and effects. A diagnosis of acute dysphagia was important to rule out any previous dysphagia intervention, which may have influenced the prognosis of the protocol under investigation as well as impact on patient

compliance because of previous therapy. It was important to consider that patients presenting with signs of oesophageal dysphagia may require the services of a speech-language pathologist only secondary to medical intervention and surgery. These patients were also handed-over to the resident speech-language pathologist for intervention and monitoring.

Criteria for doctors and allied health professionals

It was not necessary to stipulate inclusion and exclusion criteria for these participants, aside from the need for each to be involved in the management of any of the patients with dysphagia who belonged to the study group. These professionals were employees of the institution.

6.9 The site



Figure 14: Properties within and surrounding the perimeter of the hospital site

Helen Joseph hospital was the site for the study. At the commencement of my study Helen Joseph hospital was categorised as a Secondary Level Hospital. In 2012, it was converted to a

Tertiary Level hospital by the National Department of Health with implications for provision of more specialised services, financial budget, and availability of resources (human and equipment) improving at a policy level. Secondary and tertiary level hospitals and health care are described in chapter 2, with a quick reference definition at the beginning of the thesis. Helen Joseph hospital was named after Helen Beatrice May Fennell, who was born in England and resettled in South Africa. Starting out as a teacher, she moved on to become a social worker and eventually a vocal political activist during the apartheid era in South Africa. The Helen Joseph hospital was established in 1968 as J.G. Strijdom hospital. It was renamed on 1 April 1997 as Helen Joseph hospital as a tribute and acknowledgement of the contribution Mrs Helen Fennel Joseph made to the liberation struggle in South Africa during the apartheid era.

The hospital is located within an urban context in Westdene, Johannesburg. Westdene is fairly close to Johannesburg's city centre with the properties in the area surrounding the hospital, heavily lined with barbed wire against the rise of crime in the area. This is seen in figure 14. The hospital is accessed by patients from a lower and middle-income financial bracket. It is an adult only in-take hospital and as such accommodates many pensioners.



Figure 15: The patient entrance to the hospital

The hospital has 10 internal medicine wards, with two being admission wards. It has a 480-bed capacity and the medical intake averages 45-50 patients per day. Helen Joseph hospital also has an outpatient facility with the following clinics: hypertension, diabetic, GIT, haematology, HIV, neurology and renal clinic. Of significance is that Helen Joseph hospital hosts the Temba Lethu clinic, which is the largest anti-retroviral site in the country, and it

also hosts a recognised Tuberculosis Focal point (Sithole, 2009: Personal communication). Helen Joseph hospital is now one of three tertiary academic hospitals in Gauteng.

6.10 Study procedure

Figure 16 provides a diagrammatic representation of the steps taken during data collection. Below the figure follows a more detailed description of each step.



Figure 16: Procedure followed for the current study

6.10.1 Ethical considerations

A fundamental feature of the study is that the experimental units were people (Matthews, 2006). In compliance with WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects (accessed June 2012) and the University of Witwatersrand Human Research and Ethics Committee (Medical), there were several ethical considerations necessary initially, during and upon completion of my study that I adhered to:

a) Acted in the best interest of the participants and considered participant's health and needs first,

b) Protected the health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of all participants,
c) Ensured that my intervention was based on scientifically sound principles and reasoning,
d) Exercised appropriate caution during the research process,
e) Obtained approval from the necessary ethics committee prior to commencement of the study,
f) I carefully considered the risks and benefits associated with the intervention and planned accordingly,
g) Participation by the nurses and patients with dysphagia was voluntary and non-participation did not have any consequences on their job (for nurses) or them receiving treatment (for the patient with dysphagia) respectively,
h) Took all necessary precautions to protect the confidentiality of patients,
i) Sought and obtained all necessary approval from the site (management structures) of the hospital (study site) and
j) At the conclusion of the study, all participants as well as hospital managers were informed of the outcome of the intervention and the potential benefits or not of the researched intervention.

6.10.2 Ethical approval

Ethical approval to proceed with the study was obtained from the University of the Witwatersrand Human and Ethics Committee (Medical). The ethical clearance certificate is attached as Appendix 1. Information letters to the chief executive officer, clinical executives, matron, nurses and dysphagic patients were provided. These are available in Appendices 2 to 7. They were respectively invited to participate in the study and were given time to consider their decision. The nurses and patients with dysphagia were informed that they would be required to sign two consent forms, one indicating their agreement to participate in the study, and a second indicating their agreement to be video-recorded (Appendix 8 and 9 respectively). It was impossible to assure confidentiality or anonymity for the nurses as they got to know which of their colleagues were participating in the study, I did assure the nurses that their names and any identifying information would be excluded in the write up of the dissertation or in any publications that would arise from the study. Information from both the informal discussions and semi-structured interviews were cleared for inclusion in the study.

Nurses were informed that information exchanged during these discussions could be included in the write-up of the study, but were assured that their names would be kept confidential.

6.10.3 Access to the setting

Gatekeepers of a setting according to Atkinson-Grosjean (2006) are those who believe they are the power brokers (in control) and so have authority to either grant or refuse access. The chief executive officer and the clinical executive managers (Allied Health and Medical) were informed of the study. They were considered the hospital management and permission for me to proceed with the study was granted. Logistical arrangements and specific details of the study were discussed, such as the transportation of the patients to a private hospital facility for the videofluroscopy study to be completed. Various meetings were held with different levels of organisational leadership. It was also necessary for me to meet, establish rapport and seek permission and approval from the nurses and patients. "*Although consent may be given by the ethics committee entry to the field is not guaranteed. The researcher has to negotiate with the relevant 'gate-keepers' in order to gain access to the informants and the setting itself*," (Holland, 1993, p. 1464). It was important to be mindful that acceptance and approval was necessary to attain at the outset from the respective managerial structures as a way of predict foreseeing implications for cooperation from the actual participants. To gain acceptance, I talked to different nurses and the nurse managers. During these discussions information provision, posters, hand-outs and mouth care booklet was dispensed to supplement verbal information about the study. Following a discussion with the matron, it was agreed that all nurses receiving the training on mouth care would be provided with accredited certificates.

6.10.4 Information provision and consent from the stroke and traumatic brain injured patients

The information letters to the patients with dysphagia required tailoring in consideration of the neurological, language and cognitive effects of the stroke or brain injury. Information letters were provided in easy to understand language and terminology using short sentences. Pictures with verbal explanation were used to enhance understanding. For patients unable to sign consent, verbal consent and thumbprints were accepted. Caregivers were involved in the information provision and recruitment process when necessary. All information pertaining to rights and responsibilities of the patients were addressed. Patients and caregivers were given

time to consider their decision before consenting to participate. Patients were also required to sign a separate consent form indicating their agreement to be video-recorded.

6.10.5 Nurse involvement

It was not possible to anticipate with any certainty what the commitment and interest level from nurses would be. As with the patients, the nurses were provided with all relevant information pertaining to the study, their role in the study and responsibilities. They were assured that non-participation would not have any impact personally or professionally. They were given time to consider the invitation.

During the pilot study it emerged that unintentional coercion on my part may have occurred in my attempt to recruit nurses to participate in the study. Prior to the pilot study, as part of my information provision protocol, I consulted with various matrons to get an impression of nurse participation, working values, etc. During these discussions, the matrons in keeping with my discussion on dysphagia and mouth care, brought up the difficulties they experienced with getting nurses to complete mouth care on patients. It was established that completion of mouth care would have mutual benefits in that it would address requirements for the study as well as imperatives of the matron for this aspect of nursing care to be completed. Having obtained this insight, during the first pilot study on mouth care training, I made attending nurses aware that the matrons were aware of my study and that they were keen for nurses to be involved from a mouth care perspective. Therefore, by providing insight into the matrons' support for the study and for nurses to be involved in the study, the nurses attending the training may have felt pressured to consent to participate. When faced with the reaction (visual and verbal) from the nurses, I made every attempt to assure them that the matrons would not get any feedback of who did or did not attend the training and who did or did not agree to participate. Hence, by guaranteeing their anonymity they felt more comfortable and less anxious.

6.11 Data collection

Duration: Ethnographic observation of the context began in 2008 when I first started supervising students at the hospital for an adult dysphagia clinical practical as part of the University of Witwatersrand supervision programme. This was done on a once weekly basis from 8am until 12pm. My data collection commenced in May 2010 and ended August 2010.

Ethnographic observations pertaining to the study specifically started in January 2010 until May 2010. More intensive, daily observation was conducted during the first 3 weeks of May to consolidate previous field notes and recordings obtained since 2008. Patient recruitment and data collection continued until mid-August 2010.

Several different data collection methods were necessary to achieve the aims. From a qualitative perspective, the use of different methods ensured validity of the obtained data as it allowed crosschecking and validating that the same information/message was being conveyed irrespective of how and where it was gathered from (Marks & Yardley, 2004). For example, information obtained from the semi-structured interview was confirmed by the video-recordings, which was confirmed with the informal interviews and then evidenced in patient outcome. The paragraphs below provide detail of the methods used with rationale.

6.11.1 Interviews

As the most logical, common and frequently used technique to gather research information in exploratory studies, interviews were used in the current study (Gray, 2009; Grbich, 1999). It was necessary to gain information on the perspectives, understandings and meanings of the nurses and patients with dysphagia of their lives and experiences (Grbich, 1999). Grbich (1999) defines three face-to-face interview structures, namely: informal, guided (semi-structured) and structured. The use of interviews in the current study served three purposes, namely:

- Information gathering about one's knowledge, values, preferences and attitudes,
- To test out hypotheses or identify variables and their relationships, and
- As an accompaniment to other techniques to follow up and clarify issues

(Cohen & Manion, 2000).

Informal and semi-structured interview formats were used (Grbich, 1999).

Informal interview structure: This method was appropriate for the study for several reasons. It was necessary to obtain 'true' as opposed to 'appropriately acceptable' responses from the nurses regarding their role in the intervention under investigation so I could obtain a clear view of culture of nurses and nursing at the hospital, therefore casual conversations with spontaneously generated questions during the conversation were apt (Grbich, 1999). An informal format with its open-ended 'structure' was able to offer necessary flexibility while

simultaneously allowing the nurse to offer detail and clarity (Gray, 2009). Logistically it was the most viable option as conversations and discussions about mouth care, training, work and patients happen on the spur of a moment and cannot be paused for fear of halting and tainting the response/feeling being expressed at that time by that nurse. This was supported by Grbich (2003, p. 93) who noted that this "off-the record" information/data is closer to the truth than the recorded responses. This format also provided a gateway for discussion of larger topics and concerns that I sometimes observed but were not always forthcoming from the nurse/s. As cautioned by Gray (2009) I took care to avoid directing and/or influencing the responses from the interviewee.

Semi-structured/Guided interview structure: A semi-structured format was essential for the study as there were pertinent areas that required exploration and responses from all interviewees, such as feasibility of doing mouth care a minimum of three times a day in conjunction with other vital nursing routines. The need for a core set of questions that required answering aligned with the format of a semi-structured interview (Gray, 2009). Using this format also allowed me to alter or change the order of questions, and to probe views or opinions (Gray, 2009).

6.11.2 Video recordings

To guarantee a rich and detailed description of all data collected, the use of visual data to enhance the information derived from the interviews was invaluable (Grbich, 2004). It also provided visual information on interactions and non-verbal behavioural aspects that were missed. One of the major disadvantages of the video recording within the study was that it was not a permanent video so there was always the question of how to prevent, posing and acting by those being videoed (Grbich, 2004). I was able to alleviate this disadvantage to some extent by purposefully not videoing the faces of the nurses. Some nurses requested this specifically and I used this to my advantage. Nurses were more likely to be natural if their faces were not on camera. The audio-content on the video footage assisted with reliability of notes taken during discussions and observations. Inevitably limited facial expression was captured which was unfortunate. Several mouth care training sessions, nurses implementing mouth care on patients, nurses assisting patients with feeding, and patient-nurse and patient-researcher discussions were recorded.

6.11.3 Field notes

Despite the challenge of not always gathering a full and accurate account of the setting, the interactions and people in the setting, field notes coupled with video-recording provided a significant advantage (Ballinger, Yardley & Payne in Marks & Yardley, 2004). I took care to ensure that all incidents and situations were recorded at the time of observation or immediately thereafter to prevent the possibility of not recalling it later (Bailey, 1996). The environmental description, interactions, routines, and general atmosphere within the wards was recorded.

6.11.4 Retrospective record review

Retrospective data within a health care context is often termed a chart review, as the data source is a patient's medical record (Hess, 2004). As a pre-test post-test design was not suitable for ethical reasons pertaining to dysphagia management issues, a comparison group was used with the participants selected via a record review. A limitation of retrospective data is that information is recorded for reasons other than research (Hess, 2004) often resulting in incomplete notes, inadequate detail or unexplained results. Retrieved records that had these omissions were excluded. All comparison group participants received traditional dysphagia intervention by resident speech-language pathologists employed at the hospital.

6.12 Traditional dysphagia intervention for the comparison group

Traditional management refers to the routine procedures and protocols employed by speech-language pathologists when intervening with patients with dysphagia. As per hospital protocol, patients suspected with dysphagia have to be seen within 24 hours of referral. A limitation across public hospitals in South Africa, are the late referrals and often lack of referral until the day of patient discharge. The result for some patients that were included in the comparison group meant later intervention, inability of the speech-language pathologist to capitalise on the very acute presentation of dysphagia, and inability to prevent secondary effects and co-morbidities and worsening medical condition of patient. Hence, as with this study, this may often be out of the control of the resident speech-language pathologist of the hospital. Common trends that were noted across the files reviewed included:

- Patients were placed on thickened liquids.
- Mouth care was regularly requested.
- It is unclear if the speech-language pathologist/s completed mouth care.

- On occasion dysphagia management was restricted because of poor oral care of the patient.
- Patients on nasogastric tube were requested to have mouth care.
- It was difficult to ascertain specific therapeutic management strategies. Patients appeared to be re-evaluated every time they were seen to determine if they were coping with a particular consistency. Specific management strategies seemed to have been recorded inconsistently.
- The supra-glottic swallow manoeuvre and patient position during feeding were recommended on occasion.
- It was unclear to what extent patients were involved in their dysphagia intervention.
- Often requests for NGT insertion were made repeatedly before the tube was inserted. In the interim the patient continued to be fed orally despite concerns of aspiration with the patient.
- When aspiration was suspected, recommendations for temperature monitoring were requested from nurses.
- Some notes of the speech-language pathologist/s suspecting that the patient in question was consuming liquids despite recommendation for no thin liquids. Notes were unclear on how this was monitored or followed-up.

N.B. It must be noted that it is possible that more was done with the patient than was recorded in their file. However, based on what was recorded, the above was noted. It is therefore impossible to say with certainty if assessment and management were any more or less detailed than what was documented by the respective speech-language pathologist.

6.13 Dysphagia intervention (free water protocol) for study group

I provided the dysphagia management to the participants of the study group. I consulted with the patients daily. The research assistant and I were both involved in water provision and were both involved in monitoring mouth care provision by nurses. Both the research assistant and I would ensure that between us, we would observe a minimum of one meal a day for each patient receiving intervention at the time. All dysphagia management was conducted at the patient's bedside. The participants proceeded from soft to liquid to solid foods. The participants were not restricted from water intake except at meal times and half an hour after a meal. To prevent influence of extraneous variables such as un-rinsed mouths prior to water

intake, aside from myself and the research assistant only the nurse managing that patient for the day provided the patient with water. Appendix 11 and Appendix 12 respectively are the mouth care and water provision protocol used in the study. Dysphagia management ended when I was sure that the patient was able to manage a minimum of two consistencies of food – this was dependent on the underlying pathophysiological difficulty. All patients in the study group were followed-up telephonically at the end of week one and the end of week two after discharge. If necessary in the interim, they were seen by a speech-language pathologist at a hospital close to their place of residence. Table 14 below provides detail of the major differences in dysphagia management between the study group and the comparison group.

Table 14: Key differences between the study group and the comparison group

Traditional dysphagia (Comparison group)	**Free water protocol (Study group)**
1. Restricted liquid intake.	1. Water consumption encouraged.
2. Mouth care inconsequential.	2. Strict mouth care protocol – priority.
3. Thickened liquids recommended.	3. No reliance on thickened liquids.
4. Patient's view on diet modification not given priority.	4. Patient satisfaction and approval with diet modification is considered.
5. Patient quality of life not considered priority.	5. Quality of life viewed as essential to ensuring patient's adherence to diet modification.

As opposed to making pre- and post-intervention individual comparisons, whole group comparisons were conducted. These comparisons allowed exploration of the existence of a functional relationship between mouth-care + free water consumption (independent variables) and occurrence of aspiration pneumonia (dependent variable) (Connors & Well, 1982).

During all meals, patients were assisted into an upright position in their bed or chair. For dependent patients, the nurse assisted with eating. As part of the training on mouth care, aspects of safe swallowing and feeding were included, with the understanding that these nurses would be involved in mealtimes with patients. I focused on nursing incorporating the following strategies when assisting patients at mealtimes:

- Confirm that the patient is getting the correct food consistency according to my recommendations before you start feeding.

- Pacing of feed – ensure that the food is not given hastily. The patient must have sufficient time to chew and swallow. Avoid rushing the patient to eat 'quicker' as this may cause anxiety and possibly choking (prandial aspiration).
- Amount of bolus: The amount of food offered on the spoon or fork should suit the competency of the patient. Avoid too much or too little food as it may impede the ability to chew effectively.
- Observation of chewing and swallowing before the next bolus: Ensure that the patient has finished chewing and swallowing what is in his/her mouth before the next spoonful is given. Make a note if you think that the patient is having difficulty with the type of food being fed.
- Positioning: The patient must not be fed lying down. Try to get the patient into as upright a position as possible – with even a pillow under his/her head.
- Patient level of wakefulness for the meal and responsiveness to the meal: Stop feeding if patient does not seem to be coping with chewing and swallowing, if patient is falling asleep while feeding or patient seems confused.
- Inspection of mouth after the meal: Ensure that all the food has been cleared from the patient's mouth after the meal. Get the patient to take a sip of water and rinse and spit out.

Temperature charts were monitored daily and I consulted with physiotherapists (whenever available), who checked the status of the lungs and the patients cough. Each of the patient's doctors was aware of the patient being part of the study and enquired about patient and study progress either via notes in the patient's medical chart or verbally.

The study group participants were informed that either the nurse, research assistant or myself would give him/.her water to drink throughout the day. They were informed that they were not allowed to drink or take water by themselves, as it was necessary to record how much of water they drank for the day. The respective person recorded each episode of water consumption. No liquid restricted diet was recommended for any of the study group participants. Texture modification such as puree and soft foods were included in management. During the course of intervention, it was necessary on different occasions for patients to be transitioned from an oral to a non-oral feeding regimen and transitioned from non-oral to oral feeding thereafter. During the period of enteral feeding, these patients

remained in the study and continued to receive regular mouth care. Water consumption was suspended only if the patient was deemed medically or cognitively unstable.

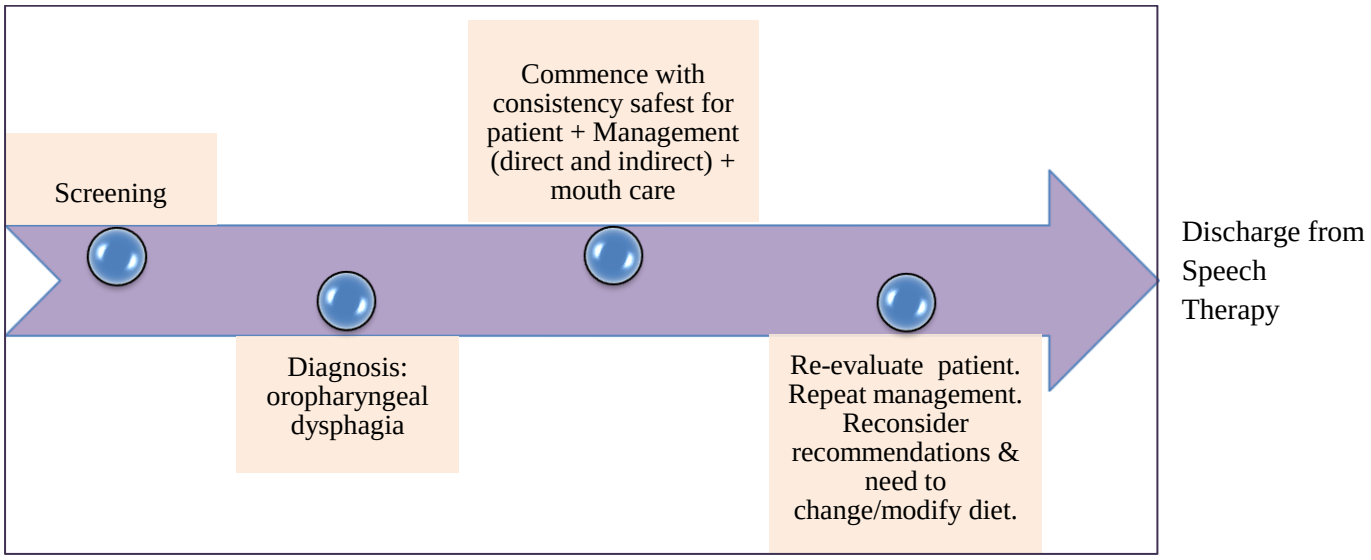

Figure 17: Dysphagia intervention protocol

The protocol that was followed for dysphagia intervention is depicted in figure 17 above. The patient first received a dysphagia and language screening to determine his/her compliance with the pre-determined inclusion and exclusion criteria. Upon diagnosis of oropharyngeal dysphagia, the patient was given information about the study and invited to participate. Patients that did not consent, were referred to the resident speech-language pathologist, with whom they continued to receive management. Consenting patients commenced with dysphagia management from me, which included recommendations of appropriate diet consistent and a combination of direct and indirect treatment techniques. As has been mentioned previously, the patient was also counselled about mouth care and water provision to enlist their compliance with the regimen and to get feedback from them and include them in decisions about their swallowing. Daily re-evaluations of the patient's swallowing ability and ability to cope with specified diets was done. Modifications were made accordingly.

Dysphagia management stopped when it was determined that the patient was able to manage two consistencies of food safely. The decision to discharge the patient was a mutual decision by the doctor and me. Prior to discharge the patient received a videofluroscopy to determine lung status, evaluation for aspiration pneumonia and tolerance of the different foods orally. Helen Joseph hospital did not have the necessary equipment for videofluroscopic studies. It

was therefore necessary for this procedure to be completed at a private health care facility in Johannesburg, Gauteng. Prior arrangements were made with the transport department and the Medical Clinical Executive of Helen Joseph hospital to transport the patients by ambulance with a nurse to the site for the videofluroscopy to be conducted. I was present for each of these studies. The site for the videofluroscopy was the Donald Gordon hospital situated in Parktown, Johannesburg. The procedure was conducted at the x-ray department. The cost of the procedure was covered by funding that received by the Carnegie Foundation, New York for the study. The radiologist and I were involved in the procedure. Different food and liquid consistencies were provided and the swallow pattern and patient's ability to cope with each monitored. The videofluroscopy was performed in the lateral as well as antero-posterior view, at a 45°, 60° and 90° angle. Reflux was also probed with patients in inverted supine position after water consumption. Prior to the videofluroscopy each patient had an x-ray to determine status of the lungs. All reports were signed by the radiologist upon completion. Results of the findings were discussed with the respective patient's doctor the following day, at which time the patient was then discharged.

6.14 The data

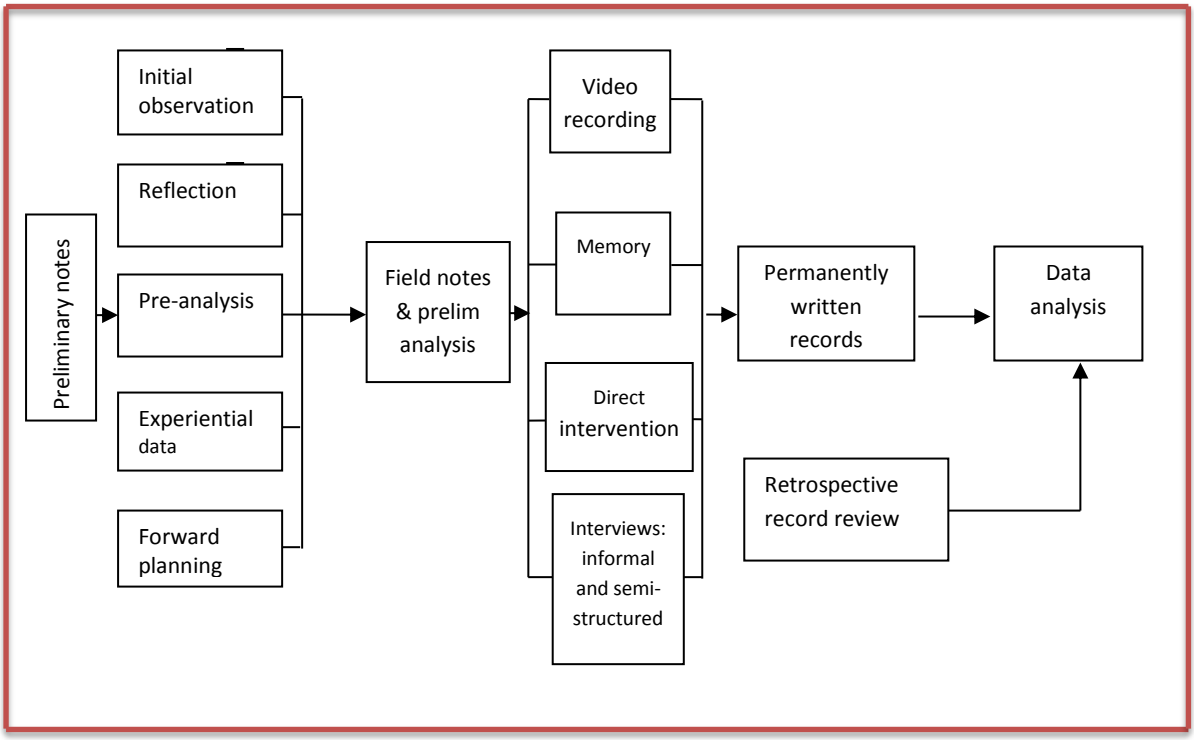

Figure 18: Process of data collection (Gray, 2009)

My data-gathering process aligned with the model described by Gray (2009). This is illustrated in the figure 18 above. The figure illustrates that data was collected via several sources and avenues. I considered the documenting of field notes to be invaluable as real-life situations and interactions were recorded which allowed me to have understanding of perceptions of the nurses from the interview. I was able to surmise perceptions regarding workload and feasibility of the intervention. It also captured vital patient-caregiver interactions and this information was used for validity checks for the information patients provided on the quality of life questionnaire as well as allowing the crosschecking of compliance and adherence to the management protocol.

6.14.1 Transcription

Transcription was used to extract data into textual form (Lee & Fielding in Hardy & Bryman, 2006). The study contained large volumes of data obtained from multiple sources in multiple forms. Care was taken to ensure against the unintentional glossing over of the seemingly 'insignificant/latent' details/responses *and* people (Miles & Huberman. 1994). The analysis of the data proceeded with the identification of themes aligning with categories or topics (Lee & Fielding in Hardy & Bryman, 2006). I considered the research aims that needed to be answered and consequently approached the transcription to enable attainment of that information (Davidson, 2009, p. 42).

6.14.2 Transcription of video- audio recordings

The verbal content of all informal and semi-structured interviews were transcribed verbatim. The video recording provided information that allowed me to establish if mouth care implementation aligned with the protocol and training received, and it was used as a reliability check for information obtained during the informal and semi-structured interviews. Discussions occurring during the video-recording sessions were also transcribed verbatim. Coding and thematic analysis was completed after transcription. Transcription and analyses followed the systematic guide provide by Braun and Clarke (2008) which commenced with familiarisation with the data and ended with a completed report.

6.15 Data analysis

The ethnography framing the study provided an understanding of the hospital culture: the professionals, the patients, interactions and routines. Aligning with ethnography, it was

necessary to portray, understand and add the etic view of nursing culture to the emic perspective of the nurse participants (Halloway & Todres, 2003). After review of the literature it was clear that thematic analysis offered the most flexible and accessible approach to analyse the qualitative data.

The quantitative data analyses were carried out using the Statistical Analysis Software. The 95% confidence level was used throughout, unless otherwise specified. Covariates of age, gender, race and diagnosis were used. The Fisher's exact test was used to determine if there were any non-random associations between the listed covariates between the study and comparison group. ANOVA was used to determine if there was any difference in the mean ages of the different race groups in the study. The Wilcoxin two-sample test, Kruskal-Wallis test and Spearman's rank correlation was used to make within-group comparisons for the study group between the listed variables. Skewness of the data (large variation) prevented the use of parametric procedures, hence non-parametric statistical procedures were used.

As a mixed method study it was necessary to ensure that analysis proceeded based on the aims of the study and the overall purpose of the study (Onwuegbuzie & Teddlie, 2003). Thus as will be seen, qualitative and quantitative data is presented and analysed sequentially, with an integrated discussion at the end (Onwuegbuzie & Teddlie, 2003). In conducting analysis for the mixed method it was acknowledged that neither the qualitative nor quantitative data dominated aligning with the research question (Creswell, 1994; Tashakkorie & Teddlie, 1998). A "sequential qualitative quantitative analysis" of data was used (Tashakkorie & Teddlie, 1998, p. 128). As the researcher I had the option of writing up each set of finding separately, and then discussing them in an integrated manner thereafter as was recommended by Onwuegbuzie & Teddlie, 2003.

Thematic analysis

It was necessary to commence with a thematic description of the entire data set before commencing with the hospital and nurses as a group of professionals. Thereafter a thematic description of the ward and nurses working within that ward before finally focusing on nurses as individuals within the ward.

Inductive Thematic Analysis: Inductive thematic analysis was used for data from the study. The identified themes linked closely to the data itself, and aligned with a bottom-up approach (Patton, 1990). During the coding process, I did not attempt to try to fit the codes into a pre-existing coding frame hence the analysis was data-driven (Braun & Clarke, 2008). This was particularly important for my study given the volumes of published work (nationally and internationally) on nurses, nursing culture and nursing as a profession. Based on the literature, personal experience and exposure it was difficult going into the study without preconceptions or assumptions. Although not necessarily negative or positive, immersing myself within the wards and amongst the nurses was 'cleansing' and forced me to shake off these additional layers so that I could provide a valid and unbiased etic account of the hospital context. After the data were transcribed responses were grouped together if they shared common features. This was followed by the identification of what features aligned and themes describing the information being conveyed were identified.

Level of analysis: An important consideration for a researcher is the level of analysis one would like to achieve. Boyatzis (1998) explains that analysis could either stop at an explicit semantic level, or proceed to a more latent interpretive level. I chose to go beyond the explicit descriptive level of data to try to investigate and identify underlying ideas, assumptions, conceptualisations and ideologies that contributed to the semantic content of the obtained data (Braun & Clarke, 2008). Thus, once data was arranged in categories at a descriptive level, deeper analysis was conducted to understand the reasons behind a particular response.

It was also necessary to not ignore hidden themes within responses. There were occasions when a particular theme added valuable insight and understanding to interaction patterns and observed behaviours to particular groups of nurses. These themes, termed latent themes were not evident at an explicit level and at times only with a small number of nurse participants. Latent themes were explored to ensure that the perceptions and work ethos of all nurse participants in the study were considered.

6.16 Reliability, validity and trustworthiness

Data from the ethnography, semi-structured and informal interviews as well as video and audio recordings were compared and checked against each other (Hammersley & Atkinson, 2007). Information and inferences from different sources were validated against information videoed. Respondent validation occurred during the course of the interviews with nurses and

patients, where summary of responses were presented to the respondents to confirm that an accurate picture of their responses was obtained. As a mixed method study, Bazeley (2002) noted that mixed methods are neither more nor less valid than other specific approaches to research. Validity may be attributed to the appropriateness, thoroughness and effectiveness of the chosen methods in their application to the research (Bazeley, 2002). In the chapter on methodological considerations, rationale was provided for choice of the pragmatic approach, with limitations of traditional research methods highlighted for the given study.

Barnes (2012) identified three examples of types of legitimation (validation and trustworthiness) he believed was valuable for evaluation in mixed method studies: a) sample integration legitimation, b) inside-outside legitimation and 3) weakness minimisation legitimation. Weakness minimisation legitimation i.e. the extent to which the strengths of one method are used to address the weakness of the other (Barnes, 2012) evidence has been provided in table 10. A rationale for the use of a pragmatic paradigm was provided given the need to investigate qualitative and quantitative aspects to address the overall aim of the study.

For inside-outside legitimation i.e. the degree to which the researcher integrates responses from the participants and the researcher (Barnes, 2012), personal reflections during the ethnography of nurse-observed interactions have been included. In addition, direct transcriptions taken from the participants either during the interviews or from video-recordings of discussions with them have been included with my reflections on the information being conveyed, either from an experiential perspective or supported by literature. Hence, evidence in this form validated the themes that were identified. Further, responses from multiple nurses alluding to the same theme have been provided as evidence to support particular emerging themes.

The completion of multiple pilot studies also contributed to the validity of the findings. The research assistant as well as an independent qualified speech-language pathologist reviewed the transcribed data and crosschecked emerging themes for validation. Trustworthiness of responses was inferred when multiple participants provided responses aligning to similar beliefs, perceptions, or levels of knowledge and understanding.

The audio-recordings of the interviews, video recording and observations completed the triad of data gathering sources that contributed to the trustworthiness of data capturing.

RESULTS

The results that follow are presented in three separate chapters. The first of these, i.e. chapter seven presents the results of the pilot studies that were conducted.

Chapter 8 provides the results of the qualitative aspect i.e. Phase one of the study. This focuses on the ethnography, the nurses and their participation in the study.

Chapter 9 provides the results for the quantitative aspect of the study, i.e. Phase two. This chapter focuses on the dysphagia intervention, the patients with dysphagia and the dysphagia management they received using the free water protocol. The outcomes for this group of dysphagic participants is compared against dysphagia outcomes for the comparison group, who received traditional dysphagia management.

CHAPTER SEVEN: RESULTS OF THE PILOT STUDIES

Overview

This chapter provides an overview of the steps followed during the pilot studies with results. It was important to determine the most ideal and feasible manner to invite nurses to be participants in the study as significant participation from the nurses was required. An understanding of the role nurses filled in a public hospital, the position they assumed and the circumstances under which they worked guided the selection and refinement of the different pilot studies conducted. This is seen in figure 19 below. A description of the process followed to gain the trust, respect and participation of nurses is described, with a general discussion of the barriers and facilitators that were encountered during this process.

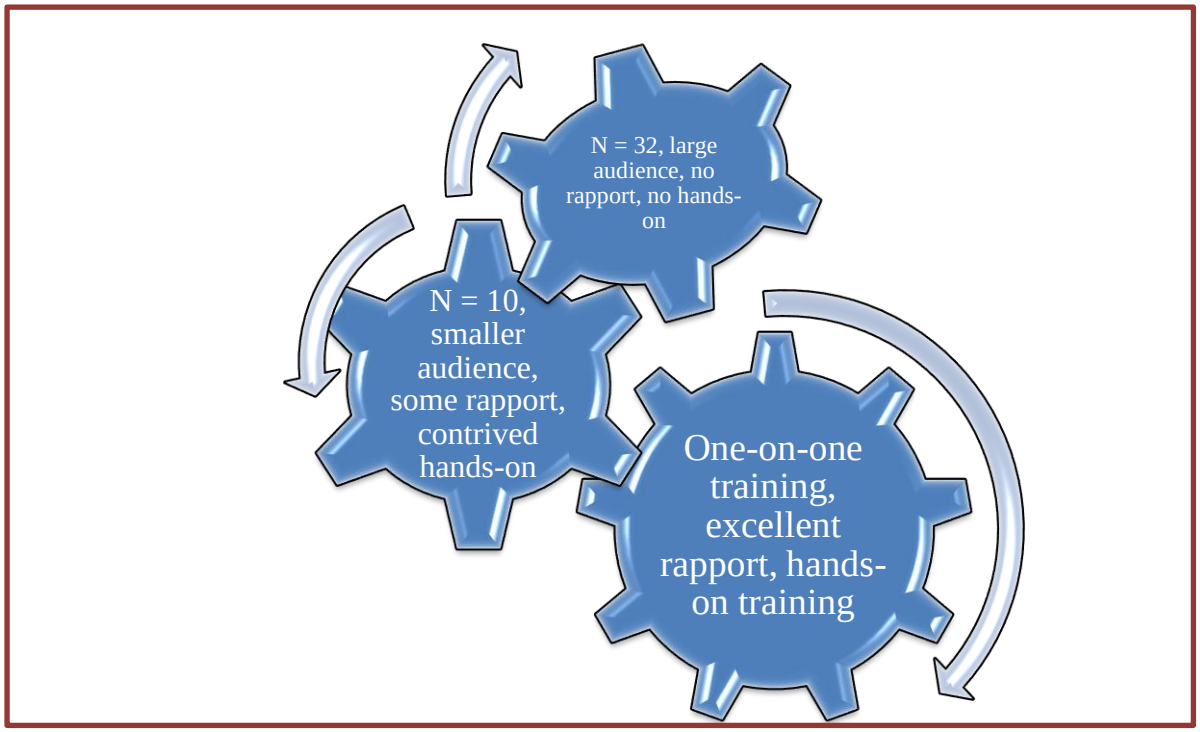

Figure 19: Diagrammatic representation of the pilot studies as the training for nurses bacame more refined (from large group to individual training)

While I was aware that I was still at the pilot study phase of my study, I had to consider the long-term implications of the training protocol developed and ensure that it would be sustainable and feasible in the given context after my exit. At the completion of the pilot

study phase, several reasons led me to believe that the training was feasible and it would be sustained in the given context:

- One-on-one training was quicker than large group training.
- There is less need for planning, preparation and coordination. There was no need to consider logistical variables such as venue, time for training, or audience participation.
- Improved understanding with better opportunity to address concerns and get clarification.
- More direct opportunity for trainer feedback.
- Hands-on experience with opportunity for conducive feedback.

The final pilot study, which transitioned from large group training (pilot study one) to one-on-one training (pilot study four), seen in figure 19 above was effective and quick. Once trained, there was transference of mouth care implementation to other patients, alleviating the need for further training. I viewed the one-on-one training model relevant for the study, stakeholder needs, contextual needs and it aligned with the knowledge-to-action process model (Graham et al., 2006) that facilitated sustainability and ensured capacity building with maintenance of skills that could then be used with all patients. However, the generalisation of mouth care to all in-patients was not an aim of my study and remains untested.

Pilot study one: Training the group

After consultation with the matron responsible for accreditation and training at Helen Joseph hospital, three consecutive days were chosen during which information provision, training and question and answer sessions were held. Allied medical staff (physiotherapist, dietician and occupational therapist) also displayed interest in the workshop and attended. Thirty-two nurses participated in the first pilot study workshop.

My 'training' comprised a power-point presentation on dysphagia with practical demonstration to supplement the information provided. The training workshop commenced with biscuits being passed around for the nurses to chew. The nurses were requested to observe how long they chewed for before swallowing, what oral structures were being used, saliva production and taste. I also asked them to be aware of how long it took them to swallow after they had chewed the biscuit. An interactive discussion of all of these aspects followed. Thereafter I used the power-point presentation to provide a theoretical basis for the prior discussion. Diagrams, pictures, notes and points were incorporated. There was good

audience participation. Nurses asked questions during the course of the presentation. I discussed the association of stroke and traumatic brain injury to swallowing difficulties and described the importance of mouth care for all patients with special attention given to those patients with swallowing difficulty. Complications, focusing on aspiration pneumonia were discussed in detail. Some comments and questions from this session included:

Nurse #5: "If only half the body is paralysed is it the same with the tongue.....does it mean then that when we feed we should place the food on the other side?"

Nurse #9: "I didn't realise that pneumonia was so dangerous. Therefore, for the patients who are finding it difficult to eat, I must try to not give them things to drink because a liquid is more dangerous than something to eat? It is also important to look into their mouths after, to make sure that nothing is left behind?"

Nurse #1: "But you know, those patients with head injury, they don't let us touch them or are not nice. They will not let us do anything. I don't want the patient to hurt me or bite my finger if it's in his mouth. What must I do then – it sounds too difficult?"

The responses suggested that the information being disseminated was being processed and it seemed to be serving a triple purpose; clarification of previous understanding, it was informative and it was unsettling as noted in the questions and concerns raised.

I acknowledged the comments and answered all questions. I found it useful to redirect some questions back to the audience. This assisted in making the discussion cohesive and maintained the interest of the nurses. Having provided a rationale, I proceeded to discuss the study and its aims. The role of the nurse participants in the study was described. I described all paperwork necessary for the study and informed nurses of their rights and responsibilities if they agreed to participate. I showed them the mouth care booklet that was compiled (Refer to Appendix 12). The booklet also contained details about the study, when mouth care would need to be done, when the patient would need to be given water, etc. The nurses were informed that this booklet could be kept with them and could be used as a quick reference whenever needed. There were immediately questions around time commitment and balancing workloads as was expected. The body language of many nurses changed, some moved forward in their chair as they waited for me to answer the questions being asked. I observed that some nurses were shaking their head some started to look at each other and were shrugging their shoulders.

Nurse #1: "How long will this take? Some patients are stubborn and don't cooperate, they don't see that we're trying to help them."

Nurse #6: "We have many duties in the ward. How many times will we have to do this?"

It was important to express empathy but I had to be honest about time and workload commitments that were necessary for the study. I answered the questions honestly and transparently. I reiterated the rationale for doing mouth care and revised what may likely happen to a stroke patient who did not have his mouth cleaned and who was choking on water and food when being fed. I focused on the long-term implications for the patient. I also related the relevance of the study (mouth care and water provision) for the nurse, such as quicker medical recovery by patient due to increased hydration and increased appetite, decreased length of hospitalisation, likely reduction of co-morbidities such as aspiration pneumonia and improved patient compliance at mealtimes.

I made a critical mistake during the workshop. I had believed that informing nurses that I had already spoken with the chief matron and several other matrons for consent (which they provided), it may help to appease some of the pressure the nurses may feel about committing to study and providing frequent mouth care. However, in hindsight and on reflection on the course of events, I realised that my comment in this regard was not viewed in the manner intended. I could see that the nurses felt more pressure to commit and agree to participate in the study, not because they actually wanted to, but because of the "pressure" from their superiors. A nurse made a comment in this regard, *"So what will happen if we don't feel that we have the time to take part? Will the matron know who takes part and who doesn't? Because I am not sure that I want to do this yet?"*

On further analysis of the responses, it was apparent that with this example alone, the potentially harmful effects of lack of communication and top-down approach by management was revealed. While it is believed that the decision and agreement from the matrons may not have been an intentional lack of consideration, this example did reveal two things: a) lack of consultation with nurses for their input and 2) poor translation of a decision made at a management level to action by the people doing the work i.e. the nurses. This example further illustrated how unilaterally decisions are made by management structures in health care. It is clear that these managers have a job to do, and so make decisions aligning with that need.

How this translates into action is a consequence they deal with later and only if it emerges as a problem.

I assured the nurses that participation was voluntary and that non-participation would have no adverse consequences for them. It was clear from this early in the study that nurses were a vulnerable group of professionals because they believed that they did not ultimately have a choice in what they did and the duties they fulfilled. Everything they did was via instruction to them, and there was little room for them to negotiate or refuse. During the workshop, it was apparent that there was safety in numbers i.e. nurses looked at each other to confirm that others had a similar view to them, and if reading support from fellow-nurses they felt more confident. However, if it seemed that their view had little or no support from other nurses present they would remain quiet and not voice their thoughts or concern. This was observed when I saw nurses looking around the room at each other and shaking their heads in agreement or disagreement, depending on what was being said.

I went on with the demonstrations of how the mouth should be cleaned using videos and pictures. I explained the equipment needed and reassured the nurses that I would provide all utensils such as the toothbrush, toothpaste, suctioning tubes, tongue brush, mouthwash, etc. Unfortunately none of the nurses were willing to be used as a model for demonstration purposes. This was something I had not anticipated as being a problem and did not have an alternate plan. Upon reflection, I recognised that having such a large audience was a disadvantage. Maintaining and ensuring attentiveness during the training was difficult. It also prevented me from establishing any kind of personal relationship hence there was no opportunity to dispel some of the dismay being projected by some nurses at the thought of being asked to do additional work. I could see that training proceeding in this fashion was not ideal or optimal. Despite the lack of a volunteer for demonstration, I continued without an actual demonstration of the mouth care protocol. The nurses were then given time to consider if they wanted to participate in the study. I passed around a page for the nurses to evaluate the workshop and training held and they were asked to write down their details if they wanted to be participants. They were informed that when a dysphagia patient in their ward was recruited I would then contact them and consent forms would be signed at that stage.

My reflection: Introducing the study and describing the level of commitment that would be needed from the nurses immediately caused a shift in attitude and the initial interest that was displayed. There was genuine concern around increasing workload and balancing duties throughout the day. It did not matter that I had approval from the hospital management or the matrons if the nurses themselves were not convinced to participate. I was able to see that the nurses felt that they were being dictated to by superiors, but it was also observed that they lacked the confidence to actually speak up when necessary. While they outwardly displayed confidence and bravado within a group context I was not sure that this display would be similar if I spoke to them on a more personal level. Their initial positive reaction to the information indicated a genuine interest to improve patient outcome and help the patient.

Limitations

- The group was too big – limited sustained attentiveness and opportunity for one-on-one interaction.
- There was no opportunity to practise mouth care on a 'live' participant.
- Obtaining consent for participation was not practical.
- I was unable to evaluate nurse understanding of the information provided.
- I was unable to predict when a nurse would get a patient with dysphagia in his/her ward.
- My approach to the nurses was very much top-down. There was a need for a more concerted effort of shared planning and consultation with nurses in the ward as they were the end-users of the planned intervention.

To ensure continued support from the resident speech-language pathologists it was necessary to keep the head of department abreast of the study. After a period of reflection and analysis it was time to proceed with the second pilot study. I discussed my plans with the head of the speech-language pathology and audiology department. I would do the training ward by ward, commencing with the ward referring the most patients with dysphagia to the speech-language pathology department. This would allow me to do training with a smaller group of nurses and would allow me to avoid some of the shortcomings observed from the previous pilot study. With support from the head of department I proceeded.

Pilot study two: Ward-based training

After reviewing the list of ward referrals, I selected a ward that I would start the training in based on number of patients referred. After consultation with the nursing manager on duty, we together decided on a suitable time during which the training could occur that would accommodate all the nurses in the ward. The nurse manager agreed to oversee the running of the ward during the period of the workshop so as not to compromise patient care. We also discussed the content of information provision and the actual training process. A group of ten nurses (one male) participated in the training. Space limitations within the ward did not leave much choice of where to run the workshop; it was held in the tearoom. Some nurses had to stand. I explained why I was there. I noticed that the male nurse present had also been present at the first workshop. I discussed the study, the rationale behind it and role of the nurse as a participant. I emphasised the rights of the nurse if he/she agreed to be a participant and provided an opportunity for questions. Some nurses asked questions as I went through the details of the study, but many remained quiet. Unlike with the first pilot study, to gain more participation and engagement in this pilot study I asked questions such as, "*what kind of training did you receive on how to do mouth care?", "how often would you do mouth care for a patient?"* and *""do you think mouth care is necessary?"*

The nurses were quite vocal in response to the training they received. They reported that they did not receive any formal training; if they were lucky then they got to see or practise mouth care as a student, but otherwise they had little information on the procedure. It became immediately apparent that there was a mismatch in the information I received from teaching staff at the different training institutions and the nurses themselves. I left the nurses alone for a few minutes to give them the opportunity to decide if they wanted to participate. Thereafter consent forms were signed, the booklets were handed out and I explained to the participants that they would receive certificates after they completed the training. I continued with the demonstration on mouth care with the nurses that consented. I completed the demonstration on two patients, one needing suctioning, and one not needing suctioning. There was genuine interest in the mouth care with valid questions about possible difficulties they may encounter.

Nurse #49: "But if the patient is not cooperative, especially with the ones with head injury, how should I do it because the patient doesn't know you're trying to help them?"

As with the previous pilot study the questions were answered honestly. I showed the participants where the signs above the bed would be and where the forms in the file would be for them to complete. I emphasised the need to complete the forms every time mouth care was done and every time the patient was given water. I also informed the nurses that I would be checking the forms daily to ensure that it was completed. I then explained that I may sometimes video-record how they were doing the mouth care for my study. Some nurses requested that their faces not appear in the video.

My reflection: The group was cohesive. There were strong collegial bonds and good camaraderie and it was clear that many of the nurses had been working with each other for some time. There were some student nurses in the ward as well. Being a smaller group, I was able to remember everyone's name which the nurses commented on in interviews held with them later.

Nurse #42: "You feel appreciated when someone, other than your friends, remember your name. It shows that they care when they remember your name, like you and Pam (Assistant) did. It makes you feel happy and also happy to do the work."

Many responses received reflected that respect and regard/acknowledgement was not something nurses received often from allied health or medical staff and it was insightful to see that these values were important to them. There was a need to instil and build on these in my study. Many nurses lacked confidence as they were not offered concrete feedback or appreciation for their contribution to patient improvement (to the extent that they wanted). This was vital to consider for every step of my study. I was not too concerned that not all the nurses in the ward consented to participate. I had anticipated this from the outset.

Review of the video recording revealed that the nurses were more relaxed and comfortable as compared to the first pilot study. Questions and comments about the training and study were discussed. When questions were asked about who received training and how often mouth care was done, initially body language, expression and verbal responses seemed to indicate nervousness. However, the responses quickly became more confident and louder as dissatisfaction with the training surfaced.

One nurse #36 commented: "I think we're not sure if we can say this but I don't know if all of us know how to do the mouth care. The matron often comes and asks us about it. We try especially for the patients who can't brush their teeth themselves, but if the patient is independent, we ask them to clean their own teeth and mouth."

Some of the nurses were not comfortable saying they did not know what to do, while some were quite vocal about this. Levels of experience and training varied from one nurse to the next and this also needed to be accommodated in the training. After providing the nurses with the necessary information, I gave them time to consider the invitation to participate in the study. Five nurses agreed to participate.

Flaws with this manner of training were identified. I realised that I was actually working backward. This pilot was done on a Monday. When I started the training, I did not enquire if the ward still had the patients with dysphagia that were on the list given to me by the head of the speech-language pathology department on the previous Friday, indicating that there were five patients in this ward with dysphagia. Having received the list from the resident speech-language pathologist on Friday, I had made an assumption that the patients would still be there on the Monday. Unfortunately, of the five patients three were discharged over the weekend, and two were transferred to another ward. Hence, I had no patient with dysphagia to conduct the mouth care demonstration on. As luck would have it, the ward did not have *any* patients with dysphagia on that day. The Sister reported,

> *"It's Monday, our in-take day is tomorrow and Thursday, so I'm sure we will get new stroke patients then. I'm sorry, but for now, I can't think of anyone in the ward who is having difficulty with swallowing. The other stroke patients we have are fine, and anyway, you can't use them from what you said because they've been here since last week. Anyway, I think the two may be going home soon."*

I realised that I needed to go to each ward and find out when their in-take day was. For now, the nurse participants were eager to start, but there were no patients. Also with cubicle nursing, where a nurse was assigned to specific cubicles for the day, it meant that despite being willing and consenting to participate, there was no guarantee or way of knowing if each of the consenting nurses would eventually be managing a patient with dysphagia. Whilst there was more opportunity to practice the mouth care with and without suctioning on 'non-dysphagic' patients that were in the wards, there was the risk of nurses forgetting what had

been discussed during the training when they did get to nurse a patient with dysphagia. It is possible that the training book provided would have overcome this barrier, but I was unwilling to have nurses rely on the training book for recall. It was clear that I had to work the other way around i.e. get the patient first and then train the nurse. Secondly, the space was problematic – the training was conducted in a very small room, making it difficult for me to manoeuvre around and access all nurses.

At the end of pilot study two I concluded that one-on-one training after recruitment of the patient with dysphagia would be most appropriate. The daily rotation of nurses further complicated the training process and needed to be accommodated as the same nurse would not necessarily be allocated to the same patient the next day.

Pilot study three: Referral-based pilot study

As I commenced with the third pilot study I felt optimistic that nurse training was possible and that the nurses would engage positively. For this pilot study, after consultation with the head speech-language pathologist and audiologist it was agreed that I would wait for referrals to the speech department and I would then follow-up on recruiting participants fitting the inclusion criteria. I was assured that referrals would not be problematic and statistical records reviewed in the speech-language pathology department suggested that there were adequate numbers of patients referred for me to meet my target number of dysphagic participants. On the day of the pilot study, I arrived early at the speech-language pathology and audiology department and waited for a referral for a dysphagic patient to come through telephonically. There were no referrals made to the department that day or the next.

It was necessary to pause and regroup if I wanted to avoid further pitfalls in patient recruitment. It appeared that doctors and nurses were not referring stroke and TBI patients on admission to their ward but only later upon identification of a swallowing and/or speech difficulty. I consulted with several ward sisters who were aware of the study on what the best way forward would be. We discussed that I wanted to intervene as early as I could with the acute stroke and head injured patients, within 24-hours of admission. The sisters reported that different wards had different in-take days. An in-take day was the day when the ward received patients from the two admission wards in the hospital. The two admission wards temporarily housed patients after admission or from casualty, before they were transferred to the ward aligning with their medical condition. Hence, by identifying the in-take day of the

necessary wards, screening could be accomplished within a day of admission and recruitment thereafter. This coupled with the cooperation of the sisters from different wards made me feel more at ease about the feasibility of a pilot study.

Pilot study four: Patient-centred training

That night and over the next few days, I re-evaluated the previous pilot studies. Better equipped with information and advice from the sisters of the wards I planned the next pilot study taking into consideration why the previous ones were not successful. My plan was as follows:

- First identify the patient with dysphagia
- Identification of the nurse/nurses working with that patient for the day
- Provide individual training with practice and demonstration
- Training would need to be done daily due to nurse rotation
- Interview/s to be completed at the end of each day

I knew that first I had to screen and recruit the patient and then the nurse. As per the previous pilot studies, I provided the necessary information about the study and informed the nurses of all ethical rights and responsibility within the study. I then invited the nurse to participate in the study. Following consent, training on an individual basis was conducted with practice and demonstration on the patient already identified. This appeared to make the experience more concrete and real. Valid questions were voiced and problems with difficulties around patient compliance were immediately addressed. The need for suctioning was also immediately addressed. I thus went from ward to ward, equipped with knowledge of when each wards intake day was and screened the stroke and TBI patients admitted on that day. When I obtained my five participants for the pilot study, I stopped. The manner in which this pilot study was proceeding was logical and feasible. Each nurse participant was able to order mouth care packs for the patients. These remained at the patient's bedside for the duration of their dysphagia intervention until discharge from the hospital. Identifying charts were displayed above the patient's bed identifying them as belonging to the study. Signs of aspiration (for nurse/doctor and caregivers) and the protocol to be followed by the nurse (for nurse and doctor) were also placed above the patient's bed. Participants were thus easily identifiable. A further advantage of this selected protocol was that in the event of a nurse not being trained/given information on what the study entailed, the protocol was clearly visible

and together with verbal explanation from the previous nurse, it would allow nurses to continue with the necessary feeding and mouth care protocol if necessary. This only happened under extreme circumstances if I was otherwise occupied.

The interviews at the end of each day revealed that the nurses were interested. Nurse participant #60 commented: *"My friends want to know what I am doing. They are very interested but also they want to know why they can't do it. I told them about the patients but maybe you must explain to them. (laughing) – I think they are jealous because I told the one that I was going to get a certificate for my CV."*

The provision of certificates was an attractive incentive. By the end of the pilot study phase, it was becoming apparent that nurses that did not have stroke or TBI patients in their cubicle as well as the night nurses were becoming resentful of not being provided the opportunity to participate and hence not get a certificate and learn something new. Unfortunately, there was no solution to this obstacle, as I had to adhere to the protocol and confines of the study.

Dysphagia intervention began immediately upon patient recruitment and included mouth care and water provision. Five participants with dysphagia were involved in the pilot study phase.

Table 15: Patient demographics

Patient	Age	Gender	Ethnicity	Pathology	Duration of dysphagia intervention	Duration of hospitalisation
Pt. 1	27y	Male	Black	CVA	6 days	10 days
Pt. 2	32y	Male	Black	TBI	13 days	21 days
Pt. 3	±32y	Male	Black	TBI	7 days	10 days
Pt. 4	64y	Male	White	CVA	4 days	5 days
Pt. 5	64y	Female	Black	CVA	8 days	11 days

Demographic information is provided in table 15 above. Generally, the stroke patients received a shorter duration of intervention and hospitalisation than did the TBI patients.

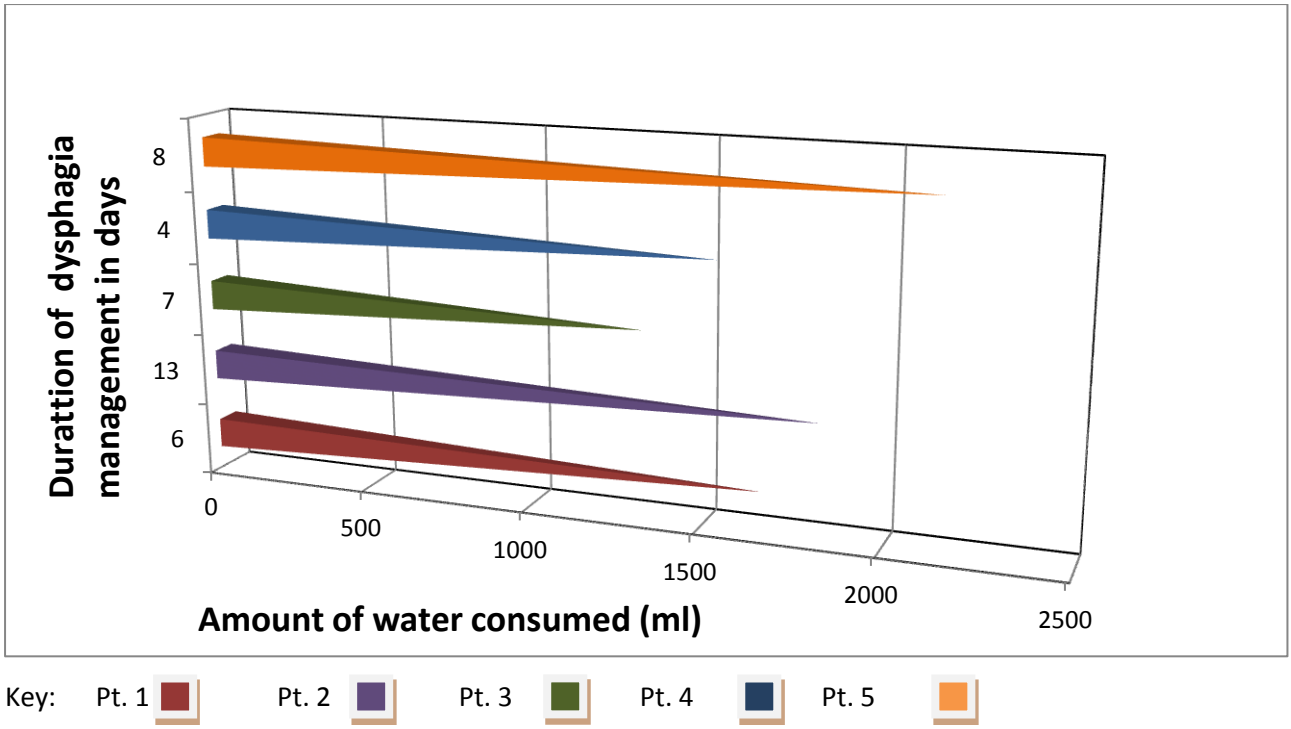

Figure 20: Duration of dysphagia management and amount of water consumed over the management period

Figure 20 depicts water consumption in relation to the duration of dysphagia intervention received. It can be seen that patient 1, seen for 8 days consumed just over 2000ml of water with patient 2 who received the shortest duration of intervention (4 days) consuming just under 1500ml of water. While statistic measures were not completed, it is evident that the amount of water consumed was not reflective of the length of dysphagia intervention and hospitalisation. (Upon completion of dysphagia intervention, each participant in the pilot study was discharged from hospital. The length of dysphagia intervention therefore aligned with the period and length of hospitalisation).

Table 16: A summary pertaining to swallowing difficulty and consequent management for each patient

Patient	Diagnosis	Background Information	Dysphagia Assessment Results	Dysphagia Management Plan
Pt. 1	Left CVA	RVD positive, on ARV's. Right facial nerve palsy.	Oropharyngeal difficulty – difficulty with bolus transition and initiation of swallow reflex. Odynophagia extending to oesophagus.	Thin, clear liquids. Medical management for candida. Transition to thickened then soft foods.
Pt. 2	TBI	Subdural haemorrhage and cerebral contusions. On NGT, but pulling it out. Uncooperative.	Oropharyngeal difficulty – intact chewing but pooling in buccal cavity. Inconsistent following of instructions. Coughing after liquids and wet sounding voice quality.	Soft diet, with tactile and verbal cueing. Heightening of oral and tongue sensation. Water provision only under supervision.
Pt. 3	TBI	Severe head injury and cerebral oedema. Post-traumatic seizures and facial fractures.	Oropharyngeal difficulty. Incoordination of swallow reflex and delayed initiation of reflex. Patient also complained of pain when chewing related to the sustained facial fractures.	Thermo-tactile sensation. Diet modification and postural changes.
Pt. 4	Left CVA	Signs of regression. Dysarthric. Medically unstable.	Oropharyngeal difficulty. Extended oral preparatory phase and difficulty with initiation of swallow reflex.	Diet modification – thick consistency to increase oral sensation, simultaneously decreasing oral preparatory time.
Pt. 5	Left CVA	Dense right hemiplegia, type II diabetic.	Oropharyngeal difficulty - inadequate clearing with some pooling in oral cavity. Pooling in valleculae was queried. Wet voice quality.	Consistency changes coupled with effortful swallow manoeuvre. Sensation on tongue and oral cavity. Multiple swallows.

Table 17: Videofluroscopy results for each patient

	Liquid		Nectar Thick		Thickened/Puree		Soft		Solid		
	Erect	**supine**	**erect**	**supine**	**erect**	**supine**	**erect**	**Supine**	**erect**	**supine**	**Conclusion**
Pt. 1	+	+	+	+	+/-	+/-	+/-	+/-	-	-	NA
Pt. 2	+	+	+	+	+	+	+	+	+	+	NA
Pt. 3	+	+	+	+	+	+	+	+	+	+	NA
Pt. 4	+	+	+	+	+	+	+	+	+/-	+/-	NA
Pt. 5	+	+	+	+	+	+	+	+	+	+	NA

NA = No Aspiration + Managing Well - Not yet managing

As is evident in table 16 and 17 at the end of their period of intervention, all five dysphagic participants received a videofluroscopy. All the results were favourable i.e. x-rays showed that the lungs were clear. All the patients were managing a minimum of three consistencies well and none showed signs of aspiration with any of the three consistencies. This was a successful result. All five participants received regular mouth care before and after each meal as revealed by the recording made by the respective nurses. They were also encouraged to and provided with water by their attending nurse. Amounts consumed were documented. Each nurse ensured that the patient rinsed out his/her mouth in accordance with the protocol prior to drinking the water. This result suggested that with regular and consistent mouth care after each meal and before the intake of water, coupled with appropriate dysphagia management, free water provision did not seem to result in aspiration pneumonia. It was necessary for dysphagia management as well as the mouth care to be conducted consistently. It was not an aim of the pilot study to monitor how much of water each patient consumed, however the recordings made by the nurses indicated that they were giving the patients water at every opportunity they could. The pilot study revealed that conducting the mouth care regularly by nurses was feasible, as was their ability to regularly give the patient water to drink. The accompanying administration and paperwork which was essential to monitor this process was also completed by the majority of the nurse participants with care and appropriately. Overall, the results of the pilot studies suggested that it was feasible to pursue the main study but I was aware to not predict results as the main study would involve many more patients with dysphagia, many more nurses and require greater monitoring.

Conclusion of the pilot studies

The pilot studies were vital in identifying a time efficient and effective mode of mouth care training for nurses. Upon confirmation of the protocol, effective implementation of mouth care by nurses and provision of water at the stipulated times coupled with individual patient specific dysphagia management by myself, suggested positive dysphagia outcomes and appeared to minimise opportunities for acquiring co-morbidities such as aspiration pneumonia. It was necessary to involve the nurse participants in the planning and refinement of the pilot study and this collaboration suggested positive benefits for implementation and knowledge-transfer. Overall findings suggested that a larger-scale study was feasible. One-on-one training was feasible and offered an effective way transferring knowledge of mouth care into action in an easy to understand format. Free water dysphagia management appeared to also have potential for use with stroke and traumatic brain injured patients presenting with

dysphagia. Results of the pilot studies suggested that there was good recovery from management with improved patient compliance. Mouth care and water consumption did not appear to result in aspiration pneumonia for the aspirating patient.

CHAPTER EIGHT: RESULTS OF THE MAIN STUDY

PHASE ONE: NURSE COLLABORATION

Overview

This chapter presents the result of phase 1 of the main study. Observations made during the ethnography and themes that emerged from the various interactions between and among the different participants will be described. The perceptions of nurse participants toward the training they received and their implementation of mouth care are described. Nurse perception around their role in the free water protocol is critically evaluated. Despite the ethnography not being an aim of the main study, results thereof are presented at the outset as this provides a background against which to understand the findings that follow. In addition, the ethnography informed the training and dysphagia management that were part of the intervention.

8.1 Ethnography: The hospital site

The layout of wards at Helen Joseph hospital is similar to that in other public hospitals in South Africa. Each floor has a maximum of four wards which are numerically numbered from the bottom up.The wards each have patient cubicles that accommodate either four or two patients, with a maximum of ten cubicles per ward. Each ward also has toilet and bathroom facilities, a sluice room, kitchen, and medicine room, store room and staff tearoom. A fairly recent development in the secondary and tertiary government hospitals in Gauteng was the establishment of private wards, called Folateng Wards within these facilities. Helen Joseph hospital being a tertiary level hospital has a Folateng ward. These wards are for private or patients on medical aid. Service provision, interior design and decoration of the ward and resources available mimic that of a private hospital setting and contrasted sharpely with the visual image of the public ward across the aisle from the Folateng ward. It was therefore vital to exclude patients from the Folateng ward in my study to ensure uniformity of procedures, protocols, utensils and staff ethos.

My observation of the wards

As touched on briefly in the introduction chapter, I began attending Helen Joseph hospital with final year speech-language pathology and audiology students in 2008 to see adult patients with dysphagia. I considered this the commencement of my ethnography although

my role was not that of a researcher at the time but rather as a clinical supervisor. The observation below reflects my observation in the role of researcher.

The wards were a hubbub of activity from as early as 7am to late afternoon with a cessation of activity toward the afternoon. Nurses, doctors, patients and other people were moving around, some lost and trying to locate where they were, and others with clear purpose and direction. In between the cleaning of the ward and the passage of the food trolley there was an element of order and logic that could be discerned.

Day one, ward one, cubicle one: 7h45 – nurses are dishing up porridge. One nurse has started feeding a patient who seems to have a hemiplegia. The nurse serving the porridge goes to a patient and rearranges the pillow and then props the patient up, leaving the porridge bowl on the patient's lap. Everyone is busy and the patients are concentrating on breakfast, some more than others. One patient remains asleep and the nurse serving the breakfast leaves his bowl at his bedside.

Day one, ward one, cubicle two: 8h15 – All the patients have finished their porridge, two were assisted. The lady with the tea/coffee trolley comes around asking patients if they wanted any. Most patients respond by saying yes, and give information on milk and sugar requirements. Two patients are undecided and the tea-lady moves on to the next cubicle.

Day one, ward one, cubicle three: Some of the breakfasts are still at the bedside, the patients are too ill and do not seem particularly interested in the food. One patient, a lady who seems to be in her mid-50 is disoriented. She is wearing a nappy, has a pyjama top, but no bottoms on. She has a sheet that is being used to cover her. It is obvious that she is not comfortable and tries pulling and fighting with the sheet to cover herself better, but it seems like the more she tries to cover up the more uncovered she gets. I observe this for at least eight minutes. There are two nurses in this six-bed cubicle at this time. One nurse is reading and writing in the very same patient's file as the other nurse feeds a patient on the opposite end of the cubicle. The nurse making notes is aware of what the patient is trying to do, but does not make any move to assist, hence my deliberation to assist. She every so often says to the patient, *'what do you want?' or 'what are you trying to do?'* after which the patient stops tugging at the sheet for a few seconds before resuming. The patient is unable to cover herself completely or adequately because she seems to have a right hemiplegia and is half lying on

the sheet, making her task impossible. After eight minutes it becomes clear that no help is forthcoming from the nurse so I move from my corner and pull the sheet out from under the patient, while she lifts herself up using her left hand holding on to the side rail. She expresses gratitude, and for at least 30 seconds thereafter continues repeating, *'thank you', thank you so much, this is better'*. I tell her it was a pleasure and move on to another cubicle with the nurse making the notes staring after me. I consider what impression I may have made on her and wondered if she considered what impression she made on me, given that she did not know who I was.

Day four, ward one: 9h15 – The nurses (three) are busy with the routines and basic nursing care rituals. One nurse checks the pressure, while another does the temperature and sugar checks and documents the recordings. As the two nurses are busy with this the sister comes into the ward heading for one of the patient's files. She looks into the file and starts talking rapidly under her breath, then starts to get louder as she 'shouts' at the nurse doing the blood pressure querying why she did not report the previous reading indicating high blood pressure. She continued that the patient was in danger and medically unstable. She went on for the next four minutes scolding and reprimanding the nurse for not knowing and hence not following protocol and not understanding the implications of her actions. The sister seemed unaware and unconcerned that I, the other nurses and patients were also in the room, and there was no consideration to discuss the incident with the nurse in private to avoid embarrassment, etc.

Several things stood out for me when reflecting on and analysing these and other elements of the ethnography and information from other data sources. (Depicted in the figure 21 below).

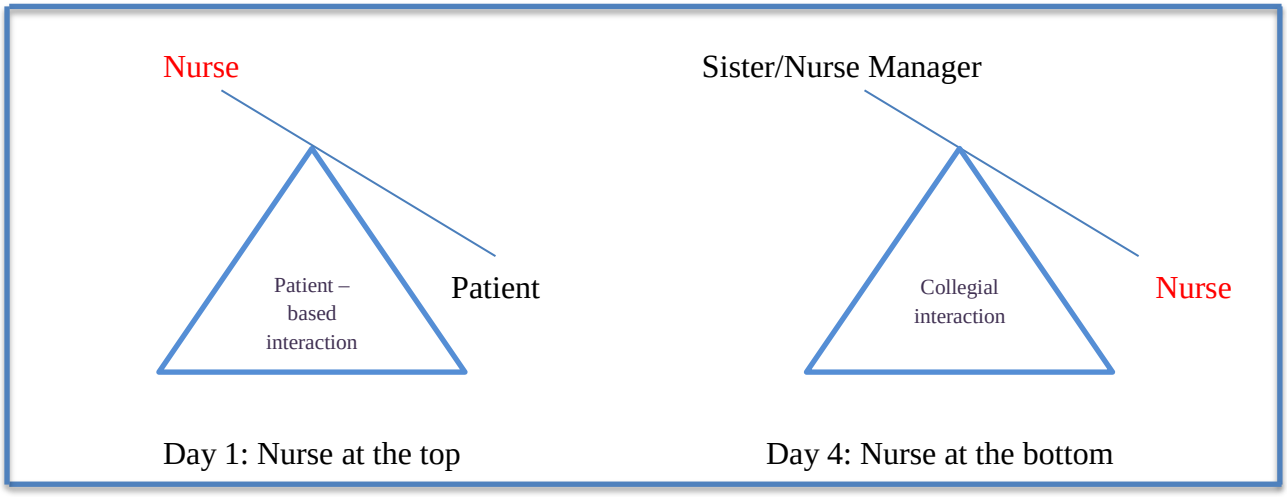

Figure 21: Diagrammatic representation of the different positions nurses assume relative to context and conversational partner

Nurses could be seen as riding a see-saw. Depending on whom they were interacting with at a given moment, the scales could be tipped either in favour of or against them. In conducting the ethnography I attempted to understand what variables, factors and/or circumstances tipped the scales in either direction for this group of professionals and what was necessary to strike a balance to facilitate a more collegial, collaborative and pleasant working environment to enable optimal service delivery to the patient. Some of the more negative themes that emerged from the ethnography of nurses included:

- Affirmation of power or authority
- Lack of empathy and sensitivity
- Compliance

The positive themes included:

- Adherence
- Ownership
- Contentment (which may also be viewed negatively depending on one's perspective)

Affirmation of power and authority

There were particular types of interactions where nurses asserted their power and authority. These situations most frequently involved patients, followed by interactions with health professionals (not doctors) and finally interactions with other lower ranking nurses. It was frequently observed that a nurse, who in one interaction would be the authority, could just as quickly be humbled into subservience in the next interaction, as the communicative partner/s changed.

Situation one: Nurse - patient interaction

In situation one above (figure 21), the nurse is seen as be the person in control and directing a situation and she determines to a large extent the outcome of the situation/interaction. Whilst there is no overt display of power, there is no mistaking the hidden influence of the nurse's power in the situation. Reasons for this imbalance of power may include: familiarity of routines and rituals within the ward, knowledge of where things were in the ward, and knowledge of who everyone in the ward was may have some contributory reasons for the imbalance. Equipped with experiential insight, the nurse is probably most comfortable with her own knowledge and skills to position herself optimally in an interaction with the patient/caregiver, doctor or allied health professional. The routine nature of the work and

consistency of rituals such as bathing, feeding times, or dispensing of medication enforces the manner in which nurses do take control in their interactions in the ward and these nurses then consequently also give orders in a very routine manner.

It was surprising that despite the widespread common knowledge of the poor image of nursing (Jewkes et al, 1998) when faced with a potentially 'reputation damaging' situation, few if any attempts were made to either prevent further damage to the image of nursing or try to change the perception/image of the patient/observer by some nurses. A lack of concern of the impression created was apparent during the initial stages of my observation. This trait while not completely alleviated did change positively for many of the nurse participants in the study as the study and their involvement in it progressed.

Situation 2: nurse-nurse interaction

In the figure (21) above, the nurse who is at the top of the ladder in the nurse-patient interaction now falls to the bottom of the ladder in a nurse-nurse interaction, where the nurse at the top of the ladder is a nurse with a higher rank or qualification. The changing position of the nurse links to the unspoken rules and rituals that exist within a ward, where all members of the ward, including the patients instinctively know their roles and what is expected of them (Holland, 1993). Aligning with the themes of power and authority affirmation, the swap in roles is dependent on the nature of the discourse as well as whom the communicative partners are in that interaction. Analysis of the interaction confirmed that discourse amongst nurses could be classified as either friendly or as collegial. Thus in the nurse-nurse interaction referred to in the excerpt there is a level of politeness and reservation evident from the lower ranking nurse, setting this interaction apart from nurses of similar ranking chatting to each other in the tearoom during their tea-break.

Lack of empathy or compassion

During my initial observations in the wards, there were particular significant events that transpired. A common thread that surfaced across these events was the seeming disinterest displayed by nurses when faced with distress or hopelessness being expressed by a patient. During the ethnography it was observed that despite having the opportunity and ability to help, this was not offered by the nurse as was the case in the initial transcription above. While this lack of care appeared to stem from a need for the nurse to show her authority in the interaction, this need seemed to reduce significantly in my interactions with the nurses as the

study progressed. Probable reasons for this may be the greater recognition and respect nurses were shown as vital members of the health care team and in the study. In the situation described below, one starts to get a glimpse of the vulnerability of nurses. Despite a lack of compassion emerging from interactions where patients were medically vulnerable or unstable, (e.g. patients having difficulty breathing, patients being suctioned) interviews from nurses later confirmed that this lack of sensitivity, in part, stemmed from a need for the nurse to protect herself. Sub-themes of protection and coping emerged from these nurse-patient interactions and were identified as reasonable contributing influences to the emotionless response to an otherwise emotional situation. Examples of such situations were described for nurses during the informal interviews with them, for me to gain understanding of their perspective. It was confirmed by different nurses that by adopting an attitude of lack of empathy and an almost 'uncaring' emotion for the obvious distress of the patient in such interactions, provided protection for their own psychological and emotional well-being.

Me: "You were really busy today. I'm sure you must be exhausted – the ward was busy?"

Nurse #55: "Yes it was quite busy, but I'm used to it so I'm not that tired. Anyway it's only 2 o' clock. I'm only finishing at seven tonight."

Me: "What was happening earlier with that patient, the one that needed to be suctioned? I heard you and XXX being very stern, but I didn't understand – did he do something wrong because he looked really sick and like he was in pain when you were suctioning him? Why didn't you stop or make him feel better?"

Nurse #55: "You know what the problem is, we have a job to do. If we had to feel sorry for the patient every time they were in pain or complained and asked us to stop, we would not get anything done. Sometimes it's painful for them even when we change their napkin. But we can't let that affect us. I do feel very bad, but if I let them see that then they will take advantage and then I think we (nurses) will start to fall apart. We don't have a choice. I know that people say nurses are bad and unfeeling, but they must know that we are doing this because we care and like to help people. But if we don't help ourselves, who is going to help us. We just can't feel sorry for every patient because then we will be crying with them. (thinking)... but there are some nurses... I watch them and wonder, *"why did you become a nurse – you don't really care or feel for the patient?"*

Compliance

While not a major theme amongst the more qualified and higher ranked nurses, compliance was found to be a recurring pattern of behaviour evident among the student and auxiliary nurses. The manner of interaction, voiceless when reprimanded and general agreeability was

evident during the observations. This was later confirmed by these nurses during the interviews. Similar patterns of discourse and interaction were observed between the lower ranked nurses and allied health professionals. It was uncommon to observe student nurses conversing with medical professionals. Interestingly, with patients the compliance was replaced by concern and eagerness to help amongst the same group of nurses.

In addition to compliance defining many of the communication interactions of the lower ranked nurses, it was evidenced in the observations and interviews with older male nurses as well. The ratio of male to female nurses may have had a role to play in this regard with male nurses feeling overwhelmed by the sheer number of female nurses. Hence the male nurse perception of not having a loud enough voice so 'why bother' – resulting in a quiet acceptance of their role.

Ownership

Ownership as described here related to nurses taking ownership for their errors or being afforded the opportunity to take credit when due. Ethnographic observation allowed me the opportunity to view this from both sides. There were many instances when nurses were reprimanded or admonished in the presence of colleagues or other professionals. There was no 'covering up' of the mistake at this level. During these situations, the discomfort and sometimes anger of the nurse being reprimanded was tangible however s/he was not given a choice and had to accept ownership of the situation. There was little discussion over reasons for the 'mistake' and the nurse was not given a voice to disagree with the perceptions of the nurse doing the reprimanding. This may be viewed as 'forced ownership' as it involved no discussion and there was no opportunity to provide a different viewpoint to provide further clarity on the matter being discussed.

Nursing sister: "Did you do the vitals this morning for Mrs X?'

Nurse #63: "Yes. Is…"

Nursing Sister: "Why did you not report to me that her pressure was so high? Why? And I see that it is still high now again."

Nurse #63: "I…"

Nursing Sister: "You know that the patient could have had a new stroke because of you, she is sick – do you understand what it means if the patient's pressure is high? Do you know that you have to report it to the sister in charge? It is my responsibility, and now because of you

the doctor is shouting at me."

Nurse #63: "I'm sorry, I didn't know that I had to do that. Nobody…"

Nursing Sister: "I did tell you that, anyway isn't that what you learn at college?"

Nurse #63: "I'm sorry."

During an informal interview with the nurse being reprimanded, she reported that she was a student and very new, and unaware of the rules, and all her responsibilities.

"I think I'm in big trouble now with the Sister. She is really mad at me. I feel stupid because the patient could have died because of me, but I don't know why nobody ever told me that I had to tell someone if the pressure is high. I know that it is dangerous, but I thought that maybe when the doctor comes he will read the charts and sort it out."

The ethnography revealed that there were clear channels of miscommunication and glaring gaps in the communication between the higher and lower ranked nurses. It was also interesting to monitor how one theme merged into another. By asserting authority and control over the lower ranked nurse, the sister precipitates an atmosphere of compliance and docility which as stated above, she may perceive as positive in that she is getting 'her job done'.

Ownership for patient improvement was afforded to other members of the medical and allied health professionals and almost never to nurses. These instances were however rare. In most observed interactions where a patient was being discharged, either from a service or from hospital, patients did not display noticeable gratitude or acknowledgement for the service/s received, but instead relief for being given the chance to leave (and go home). Within the given context, patients were largely not vocal unless upset or disagreeable. In instances where praise or gratitude was expressed, this was limited as noted above, and reserved for the doctor and sometimes the physiotherapist. The role that a nurse played in the patient's recovery appeared insignificant and unrecognised, even from other professional colleagues. Thus, there was no opportunity for the nurse to take ownership of her role in the positive patient outcome despite having had the most hands-on contact with the patient.

Interestingly, when something did not go as planned and the nurse appeared to be responsible, the patient and more so their caregiver/s, were quite vocal in expressing their anger about the 'poor treatment' or 'mistreatment' they received.

Job security

This was particularly evident amongst many of the more middle-aged but lower qualified nurses. When engaging them in informal discussion, they expressed no desire to study further or move to a different hospital. They were content that they had a job, they knew what to expect from the job and what was expected of them, and were not seeking change in their routine. This sub-group of nurses were particularly concerning during the ethnography as I could not predict their response to the study generally and more so their participation in it if necessary.

The nurse in the transcript below typified this feeling in that while she was not particularly happy at work she was not unhappy, and was content to come to work, get through the day and get home. Her body language coupled with her need to not want to engage in conversation conveyed a lack of interest. From the 'conversation' it was observed that while she is not happy with what or how continuing professional development courses are run, she also refuses to grab on to opportunities that come her way.

Me: "Hello, how are you?"

Nurse #102: "Fine – (shrugging shoulders)"

Me: "You may have seen me around the wards for a few weeks now. I'm a speech-language pathologist and I'm doing a study with stroke and head injured patients. Nurses are also part of my study – I train them in mouth care which they then complete for the patients in my study. Do you think you get good opportunity to study and attend courses here at the hospital?"

Nurse #102: "Yes there are courses, but not everyone gets to go and they are not always very practical."

Me: "Have you attended any of them?"

Nurse #102: "Ya – one or two, but ….you know. It is all stuff you should know already anyway."

Me: "Depending on how things go, I may come back to you and ask you if you would like to be involved in the study. Would you…(nurse interrupts)."

Nurse #102: "We'll see. Anyway it's tea time now – can you come back later. I need to go and have a cigarette and a cup of coffee. I don't want to stick around here."

Me: "Okay sure we can chat later when … (nurse walks away before I complete saying what I wanted to)."

Summary of ethnography

The ethnography enlightened me in several ways. It forced me to be more realistic about the working conditions of nurses and the state of public hospitals (when viewed from a daily perspective). My silent optimism that things were not as harsh for nurses and patients (as I had heard and read) plummeted as I completed the initial observations. Nurses appeared to face incredible challenges and appeared to work under extremely stressful and logistically and structurally flawed conditions. It seemed that faced with what looked to be an unchanging and uninspiring situation for many hours of the day, nurses needed an outlet. There did not appear to be one, hence associated emotions seemed to be directed toward the patient on occasion. Their frustration (venting) was observed in their manner of interaction and communication amongst themselves (of similar rank) and with each other (of different ranks) as well as in their completion of rituals with patients. Thus from my observations it appeared that nurses working in an acute public hospital were a diverse and multidimensional group of professionals working within a complex environment that was bound and constrained by rules and rituals to ensure job completion regardless of extraneous variables. The ethnography allowed me some insight into why this ethos prevailed. Upon 'completion' of the ethnographic component I was aware of the need to fine-tune how I was going to intervene to ensure that I realised my goal for dysphagia management in this context. As a speech-language pathologist who worked in a hospital previously I had some insight into the challenges and needs of the speech-language pathology profession in South Africa. Equipped with clinical and researcher-derived knowledge of the challenges and needs of nurses working at Helen Joseph hospital, I chose not to pursue a top-down model to introduce my study and the proposed intervention. Thus in addition to the above stated aim for dysphagia intervention, the ethnography allowed me to work toward fostering improved collaborative partnerships between speech-language pathologists and nurses so that they would be capacity building and learning opportunities for both professionals. The ethnography highlighted that the framework necessary for intervention was most likely a bottom-up approach that would align with action-research principles. The ethnography allowed me to address some components of the model by Graham et al. (2006) e.g. identification of the gap/problem (mouth care), adapting knowledge for the context, assessing and identifying the barriers to knowledge use, etc. that would be beneficial in the training.

8.2 .1 Nurse perception on Mouth Care

Table 18: Demographics of nurse participants

	Gender		Age range	Racial classification				Qualification		
	Male	Female		B	W	C	I	Professional	Auxiliary	Student
Nurses	12	127	18 – 61	116	9	7	7	60	74	5

Key: B – Black W – White C – Coloured I - Indian

Table 18 reflects the demographics of the nurse participants. Of the 139 nurse participants in the study, gender, age, racial profile and qualification varied as is evident in the table. It can be seen that a majority of the sample was female and black. The distribution between professional and auxiliary nurses was fairly similar (Auxiliary and professional nurses have been defined on pg. xvii).

The mouth care protocol stipulated that mouth care be done before and after each meal and before the provision of water. In addition to the manual completion of mouth care, the administrative component required the nurse to record each completed mouth care session. I reviewed these recordings daily and when necessary intervened when records were incomplete. Crosschecking the records, information from observations and information from the interviews completed my triad of data collection sources. The use of multiple sources allowed me to verify information informed from one source against information from a different source. For all but three patients, the recordings were completed comprehensively. Below are some comments from the nurses in their recording of mouth care.

Table 19: Examples of nurse's notes for mouth care

Difficulties	Compliance
"Unable to spit. Had to use suctioning"	"Patient cooperative"
"Mouth bleeding"	"Patient able to move tongue around and spit out"
"Unable to open mouth. Teeth clenched. Had to force open"	"Successful – patient cooperative"
"Patient not cooperative"	"Able to complete suctioning successfully – patient tolerated well"
"Unable to clean tongue well. Patient refusing."	

The array of comments when patients were and were not compliant with the mouth care from one nurse to the next as well as from one session to the next with the same nurse assured me that the comments were a true reflection of what ensued during the mouth care procedure with the patient. I felt confident that the recordings were not merely a 'cut and paste' from one session to the next. For the three nurses with incomplete records, reasons for this were explored during informal discussions with them.

Nurse 1 interaction

Me: "I see that for lunch today you recorded that you completed the mouth care for Mr X, but then you recorded no for after lunch–what happened?"

Nurse #29: "I was very busy because I still had to give the other patients their food. I told Mr X to wait and I will come back to help him, but he said he was hungry. So I made sure he rinsed and gargled before he ate, and then I gave him his food and carried on giving out the rest of the lunches. He was finished eating by the time I got back."

Me: "Did you check if his mouth was clean when you got back or did you ask him if he cleaned his mouth after he was finished eating?"

Nurse #29: "No, he is very independent. He doesn't really need help and he's getting better. So I recorded no, because I didn't think he would have anything left. He always finishes his meal. He's always hungry."

Nurse 2 interaction

Me: "So tell me what happened, I see that you didn't clean the patient's mouth? Did you forget, what happened?

Nurse #21: "No I remembered that I had to do the care after he eats. But then I went to lunch and the other nurse that was covering for me, I think she forgot. Then when I gave the patient some water later when I came back, I saw that there was no care after he ate lunch. So I cleaned his mouth before I gave him water to drink and I recorded no for after his lunch."

Me: "That is good. It is very, very important to remember that the patient's mouth must be cleaned and rinsed especially before they drink water because we don't want any left-over food and bacteria to get into his lungs if he chokes. But it is also very important to remember to clean a patient's mouth after eat. Especially with the stroke patients who do have difficulty swallowing, the food sometimes gets left in their mouth and the patient doesn't know, and later if they swallow badly, they choke and the bacteria from that leftover food can go into the lungs. Was there anything left in his mouth when you cleaned before he drank water?"

Nurse #21: "No, not really. There were tiny bits that were left on the tongue. But I asked him to gargle and spit out."

Me: "That's excellent. I'm really happy you did that before giving him the water. Good job.

You were also right to record a 'no' for after lunch. A 'yes' record is what I want, but I also want to know the truth."

Nurse #21: It is good to know that you are watching what we are doing. I want to help the patient, that's what I'm here for. But sometimes we all make mistakes and the Sisters sometimes don't check or know, and when they do know, they scream at us. It is good that you ask our opinions because we are the ones doing the work with the patient, so we know what is easy and what is difficult."

Nurse 3 interaction

Me: "How did the mouth care go yesterday, what happened?"

Nurse #83: "I was very busy yesterday. I was rushing and Nurse Y fed my patient for me. I think she did ask the patient to rinse out before he ate – yes it's written yes. I'm not sure what happened after. I was busy."

Me: "I know that it gets really busy, but it's very important for the mouth care, more especially after the patient eats and before they have water to drink. I want to make sure that no bacteria get into the lungs from their mouth, if they choke. The only way to do this is by getting the patient to clean their mouth. It is especially important for patients who have a stroke or head injury. I see that you gave the patient some water at 14h20. Was there anything in his mouth when he rinsed out before drinking the water?"

Nurse #83: "No."

Me: "Good. Thank you. I know that it is sometimes difficult, but I want you to tell me when it is difficult. I need to know this too – is it because you are busy, or is there too much to do, or is there another reason. If I know why you can't do the mouth care then can I try and help."

The transcriptions above illustrate that time and the priority of other routines, were contributing reasons for incomplete recording. It was encouraging that negative attitude and perceptions of the study being 'extra' work was not a finding as was expected. Further discussion of the findings are presented in chapter 10.

The nurses were eager to participate in the interviews and were happy to discuss their role in the study. On reflection I believe that the informal interviews were more conducive as they commenced as a conversation or chat within a natural context, the nurse was at ease and less guarded about his or her perceptions and views. Whilst aware of the need to maintain confidentiality of the content of the interview, I did not attempt to rearrange the setting or make the situation contrived, as I wanted the discussion to occur as naturally as possible. When concerned that other people were around us, I would casually start walking away from

the group, but continue talking to the nurse. The transcript below was from a nurse who was faced with a dilemma and required some assistance from me. The discussion started out in the tearoom and ended at the patient's bedside.

Me: "So how has the mouth care been going?"

Nurse #56: "Mr Y is not really letting me clean his tongue. He lets me brush his teeth, but he keeps gagging every time I use the tongue cleaner. Can you show me what to do – I'm going to him now." *(We walk toward the cubicle of the patient)*

Me: "Hello Mr Y. How are you today? Have you had lunch? (Patient nods yes). Good – was it tasty? Can you open your mouth for me I want to have a look before we clean?"

Observation – Some residue on tongue. Minimal pocketing in left lateral sulci, posteriorly.

Me to Nurse: "Show me how what you would do first and let's see what gets difficult."

Nurse continues with brushing teeth. Patient spits out. She proceeds with water to rinse, and patient rinses out mouth. Nurse then puts more toothpaste on brush to clean tongue. As she gets to the middle of the tongue, the patient starts to gag, preventing her from cleaning the tongue sufficiently.

Me: "Okay, let me try something. Let's start at the front, okay so this is how far you can go, before he starts to gag. Some people have a gag reflex that is very forward."

Nurse: "Yes, I know when I brush my son's tongue he does the same thing."

Me: "What do you do at home?"

Nurse #56: "I can't get the brush to go very far back, so I ask him to put toothpaste on his tongue, and take some water and rinse his mouth to make sure it is clean."

Me: "Why do you do so much, is his tongue dirty? How old is your son?"

Nurse #56: "Well he's 3 years old. I took him to the doctor, because he had marks on his tongue, and it always looked dirty, like white patches. They were different every day and I thought I wasn't cleaning it enough."

Me: "What did the doctor say?"

Nurse #56: "He said not to worry. It wasn't any infection or anything. What did he say it was??? *(trying to remember...)*...a map, no, no a geography tongue...

Me: "A geographical tongue..."

Nurse #56: "Yes, that's it….a geographical tongue. He said that not a lot of people have it, but it doesn't always look nice. So as my son grows up, he mustn't stick out his tongue. That's why I make sure I teach him to clean it properly, so it doesn't look dirty and patchy."

Me: "Okay, so let's try the same thing with Mr Y. I think though, instead of using toothpaste on his tongue, we can use the mouth wash. I will leave some here for him. Let's try it and then look at his tongue again."

This interaction was one of many where nurses who faced a particular challenge or difficulty when doing the mouth care tried to fall back on personal experience to problem-solve the difficulty. This type of experiential insight was especially prevalent amongst nurse participants in the middle-age group i.e. 32-45 years. Nurses who were younger were often not experienced enough to know what to do and as a result were more dependent on my help.

Overall nurses were positive in their comments about implementing mouth care. I posed the following question/s to the nurses to address their perceptions on implementing mouth care and then the feasibility of continuing, past my involvement:
"Tell me how you feel/felt doing the mouth care," and based on the response I would lead into a question such as, *"So from what you said, do you think you could do mouth care for all stroke and head injured patients, even all patients, every day, even after I leave – will it be possible – why and why not?"*

Two of the major themes that were identified were:

- Duty
- Patient safety

A latent theme that arose was indifference, which will also be discussed below.

Theme: Duty

A majority of the nurses commented that mouth care was part of their job requirement – it was their responsibility, especially for dependent patients. These nurses were also critical in their comments about the training they received on mouth care, saying that despite knowing they should be doing it they were never really trained or shown how it should be done. They added that responsibility for doing it actually lay with the 'night nurses' and not with them, the day nurses. An important observation that most nurses made was the lack of monitoring or priority given to mouth care within nurses daily routine. A majority of nurses said that because nobody checked to see if it was or was not done unlike temperature, blood pressure and input/output recordings that were charted in the patient's medical file, they did not do it. Hence, it often took secondary importance, if at all. It seems that the lack of documentation played a significant role in the need to do mouth care. A few comments related to the fact that aside from speech-language pathologists and on the rare occasion doctors, no other health or

medical professional had the need to look into a patient's mouth. In terms of priority, mouth care according to many nurses was at the bottom of the list, especially when compared against something like oxygen and saturation levels, and they commented, that even these were often not monitored.

Theme: Patient safety

The nurses who commented that mouth care was part of their job description expanded their explanation to say that basic nursing care addressed the quality of life aspects of a patient which included completion of the activities of daily living for dependent patients and they believed that this included tooth brushing. Many comments were received that alluded to mouth care contributing to patient safety. I believe however that this insight came after the training and explanation of the association of bacteria in the mouth to aspiration and aspiration pneumonia. It was important to observe that nurses now had a more accurate understanding of this relationship. When compared to several discussions that occurred during the training with some nurses it was clear that at that time, there was limited, if any understanding of the medical reasons for a clean mouth, it was only understood from a hygiene and smell perspective. When asked about their completion of mouth care, some of the comments received were:

Nurse #41: "It wasn't as long as I thought it would be. Once you did it a couple of times, it got easier."
Nurse #52: "It actually takes only a few minutes. The more often you do it, the better you know what to do and what not to do. You almost know what to do to get the patient to listen and do what you want. You can learn to read the patients and know who is going to give you problems."
Nurse #24: "It's easy with the patients that are independent. They do it themselves. You just have to make sure you check their mouths, or if you can, watch them a few times before you let them do it themselves."
Nurse #63: "I learnt a lot. I didn't really know what to do with mouth care, but now that I am doing it, it is so easy. You do get those difficult patients, who are not very compliant, but most patients are too sick, and let you do what you need to. I am looking forward to getting the certificate too."

The table above reflects some of the positive responses. In acknowledging that mouth care was part of their job description despite not having received formal training on how to do it,

many viewed it now as a learning opportunity and way to improve their skills and knowledge. Although I am unable to say this with a hundred percent certainty, it appeared that provision of mouth care positively influenced the interpersonal relationship between the patient and nurse. For the few negative relationships, the level of cooperation from the patient played a role.

A latent theme: Indifference

When analysing the transcripts it was interesting although concerning to see that it was 'easy' for some nurses to leave a task incomplete because of poor patient compliance. When comparing the efforts made by different nurses to engage patients and get tasks completed, it was evident from the responses, that while some nurses would persevere and look for other ways around the problem even if it meant adopting a stricter, scolding stance toward the patient, other nurses would attempt the same task possibly twice and if unsuccessful, note it as such and move on. This behaviour demonstrated some level of a lack of insight into the implications for an incomplete task.

Nurse #1: "Everyone needs to have their mouths cleaned. Sometimes you do get the patient whose mouth stinks, and when you try to help them they get angry. They don't think that we are trying to help them, and so I just stop, especially when I'm tired and had enough."

Nurse #77: "The mouth care is important but it is not always easy especially when you don't have what you need. You are here now, but when you are gone, then who will give us the toothpaste and mouth wash and brushes. It is important but I am not sure how it will go once you are gone. All the nurses are really happy to do it now, but I hope it will carry on (shrugging shoulders and shaking head)."

The excerpt from Nurse #1 also makes one aware that nurses are faced with high levels of fatigue and given the number of hours at work it impacts on work performance and burn-out, identifiable in the response from the nurse. Despite these challenges, many nurses do retain their level of enthusiasm and perseverance as can be seen from the transcript below.

(In response to the nurse's implementation of mouth care)

Nurse #56: "It is important but it is not always easy with those uncooperative patients. They fight you because they don't understand that you are trying to help them. But I am strong and help them anyway. It is what I like to do."

There were however a handful of nurses who were less positive. Their 'complaints' about completing the mouth care related to patient's lack of compliance, being too busy and difficulty getting mouth care packs.

Nurse #52: "It is not long to do. But when you have a patient who is not cooperative, then it takes time. For me, Mr W was not easy – he was difficult. It especially became difficult when I had to hand-out the lunch then come back to him, and he would take so long. I just think with patients like him, it's not easy. They make it difficult because they can't see that you're trying to help them."

Nurse #102: "I did it because you asked me and you explained why it is important for the patient. I know that. But I don't know – I just don't think we can manage this with patients all the time. I think it will be difficult. Maybe if we only did it for the dependent patients and not for those ones on NG tubes, maybe then, but I don't know..."

Nurse #111: "You know there's a shortage of everything in the wards, linen, pyjamas, blankets, and even the mouth care packs. You need the forceps for the gauze – I don't want to stick my fingers in the mouth. Sometimes I tried like you said to use the tongue depressor to take out food that was stuck, but the hospital makes it difficult when they expect you to do the best for the patients, but they don't give you what you need."

The sub-themes that emerged from the negative perceptions toward mouth care included time constraints, poor patient compliance and lack of resources. All these are valid and significant concerns as they depict the reality of the ward situation in public hospitals.

In summary,

All of the nurses interviewed said that they believed that mouth care was important for all patients, but more especially for those who were dependent and thus unable to clean his or her mouth independently. Their knowledge of the relationship between poor mouth care, bacteria, difficulty swallowing and resulting aspiration pneumonia was evident after the training. They were all able to understand and see the implications for length of hospitalisation and general medical recovery of the patient. However there were negative and positive perceptions toward their completion of mouth care, with more nurses reporting that implementation was not as bad as they thought it would be. These nurses found that it got easier with experience and familiarity and they found that it did not take more than a few minutes to complete the paperwork attached to it.

A majority of nurses agreed that mouth care fell within their job description. The three nurses who perceived implementation negatively felt that the demands in terms of time and lack of resources contributed toward difficulty implementing a relatively easy protocol. There were themes of care and compassion that were identified as driving forces behind nurses completing not only the mouth care, but their jobs generally. A concerning latent theme that emerged was that of indifference and a failure to persevere. This was also observed during several interactions when conducting my ethnography and has already been described.

A note on suctioning

Video-recordings provided evidence that nurses were correctly completing the mouth care according to the developed protocol. For patients that required suctioning, the protocol took longer to complete largely because some of the suctioning points at the patient's bedsides were not always functioning. For these patients, a portable suction machine was used effectively. I noted that availability of a functioning suction point may affect the knowledge-to-action transfer of mouth care implementation and it had the potential to unnecessarily increasing the time required to complete mouth care. I made a point of observing nurses doing mouth care with patients requiring suctioning, where the suction point worked. I specifically recorded the length of the procedure and compared it to mouth care done on a patient not requiring suctioning. To ensure that my comparisons were reliable, several observations were completed. On all occasions, mouth care on the patient requiring suctioning was shorter by 3-4 minutes (when the suction machine was functioning adequately). When reviewing the video recordings it was clear to see why it was quicker – less 'compliance' was required when doing suctioning, there was no need to engage patient cooperation, patient was not required to spit out, or rinse mouth and spit as the nurse was able to accomplish suctioning using her right hand while administering the water with her left hand. There was however, a need for the nurse to ensure that the patient did not swallow before the suctioning was done.

8.2.2 Perceptions on feasibility of mouth care in the given context

Given the positive response from most nurses about their role in implementing mouth care, I found it easy to transition to this question. I queried the following possibilities:

- Mouth care for all stroke and head injured patients,
- Mouth care for all patients with dysphagia, even after my exit,
- Feasibility of doing mouth care on all patients in the hospital.

The information from the informal and semi-structured interviews provided valuable insight. Information during these was validated by video-recordings as well as reviewing documentation. This again provided some comfort that the responses from the data obtained seemed to be valid.

The feasibility of completing the mouth care was assessed by:

1) investigating if nurses were completing the mouth care in line with the stipulated protocol (based on video-recordings and direct observation),
2) exploring if the actual protocol was easy to follow and understand (based on feedback from the interviews); and
3) completion of related paper-work.

Based on the results of these investigations, feasibility from a time and workload perspective was established.

The mouth care protocol

Video-recordings were random. They were done throughout the day with different nurses for different meals and with different patients. Mouth care sessions implemented and videoed were compared against the protocol used in the training. A review of video recordings confirmed that the protocol and procedure was followed. For many nurses it was clear that they were hesitant, anxious and nervous as they started. These feelings (as confirmed in discussion with them after they were finished) stemmed from it often being their first attempt and the fact that they were being videoed. They reported feeling more confident and less nervous as the session progressed. Patient cooperation level influenced this as well. All parts of the oral cavity were cleaned while ensuring that no toothpaste or food residue was being swallowed. For those patients requiring suctioning, although the protocol stipulated that two nurses should be involved, this was not possible on most occasions. The nurses therefore adapted and completed the task by themselves if another nurse was not available to assist them. Overall there were minor changes and tailoring of the protocol based on patient variables however these modifications in no way impacted the outcome of the procedure.

Perceptions of the protocol

There was agreement from the nurses that the protocol was thorough. While a few nurses believed that the protocol was a little long, they also agreed that it would not be beneficial to exclude any step. There was also agreement that there was a visible change in the appearance

of the oral cavity after the mouth care, and that patients reported that they were able to 'taste better' after. A significant number of nurses commented that patients who were initially 'difficult' become more cooperative and willing after a few sessions, and as one nurse commented: "Patient W would open her mouth as soon as she saw me entering the room and sometimes it wasn't even because I was there to clean her mouth *(laughing and shaking her head)*." Based on this statement and the responses of several other nurses, it was gathered that patients either tolerated the mouth care (because they had no choice) or were grateful and looked forward to it. Overall this resulted in an improvement in their quality of life which I viewed as a positive outcome.

Nurse #52: "I don't think you need to include anything else - everything is discussed and so we just followed that. In the end it cleaned the patient's mouth and that's what's important."

Nurse #23: "It was a little long and sometimes I had to make slight changes depending on the patient. They are not always easy to work with especially the first few days when they get admitted."

Nurse #76: "The mouth care was very detailed. I think the only problem for me was when the suctioning point did not work, and the book said to use two nurses also - I didn't really need anyone to help me."

Nurse #34: "It was a good procedure because it included everything that was necessary."

Nurse #35: "It was easy to do the mouth care - it covered everything. I like the tongue cleaner - I didn't know there was something like that. But the steps in the book were easy to follow and do."

The responses suggested that nurses were happy with the actual protocol used. There were some comments related to time and feasibility which have already been addressed, but overall the protocol used was effective in its objective i.e. a clean mouth free of residue, and hence bacteria.

8.2.3 Perceptions of water provision

As with mouth care, the nurses were required to record the times they gave patients water and the amounts given and consumed. Nurses were also asked to describe their role in having to give patients water to drink more frequently than they normally would. As the study progressed it became clearer that understanding the medical benefits of drinking water and staying hydrated contributed significantly to nurses complying with this aspect of the study.

Nurse #52: "I understood from the training that giving the patient enough water helps the

body to get better, just like eating food. So although it takes a few minutes, I made sure I always gave my patients enough water."

Nurse #95: "Having enough water is very important for a person to get better. With the patients being sick it is even more important so I made sure that I gave the patient as much water as often as I could."

Nurse #102: "Giving the patient water was easy and I know how important it is so the patient does not get dehydrated."

None of the nurse participants reported or suggested that water provision was not beneficial for the patient, hence their agreeability to provide the water. However, some nurses did comment on the feasibility of this task and again the issue of time arose.

Nurse #100: "The water was easy the only thing that took extra time was the patient rinsing out his mouth before."

Nurse #2: "It was a little difficult to remember when I got busy, and I know you reminded me a couple of times. I know that it is important to drink enough water."

Nurse #22: "It was no problem. I just came by after each meal and gave the patient water, especially because he couldn't drink anything when he was eating, I'm sure he was thirsty."

Nurse #121: "Sometimes it was difficult when I got busy and then I forget to come back to the patient."

It was interesting and although not probed directly, there were a few comments suggesting that it was not the water provision that was time consuming but the need to ensure a clean mouth prior to water provision that took time. These nurses realised that there was no option to change this procedure.

Nurse #100: "The water was easy the only thing that took extra time was the patient rinsing out his mouth before. I know that it needs to happen that way but it just takes longer."

Nurse #128: "Giving the water was easy, because we are told to do that. The only difference now is to make the patient clean their mouth before they drink the water. It wasn't too much longer, but they had to rinse and spit out."

There was an understanding that stroke and head injured patients experienced difficulty swallowing and were susceptible to the risk of aspiration. Many of these patients were not independent and the responses from the nurses showed insight into their role in maintaining patient hygiene. Completing the necessary forms were not viewed as being problematic,

although some nurses did comment that during periods when the ward got busy it was easy to forget to either give the patient water, or complete the form. This was a further consideration for sustainability. If there was no or poor monitoring of nurses completing mouth care and providing water to patients, to what extent would it be completed or given attention by nurses?

8.2.4 Perceptions on training

In exploring nurse perception on training, I initially probed perceptions of continuing professional development courses [CPD] offered within the hospital thereafter exploring nurse's perceptions of the mouth care training they received. My question to nurses during the interview was: *"So tell me what you feel about the training and CPD for nurses at the hospital."* Several positive and negative themes emerged from the responses summarised in table 20.

Table 20: Themes emerging from nurse perception on training within the hospital

Positive	**Negative**	**Neutral**
- Learning opportunity - Improved patient care and service provision - Opportunity for certification - Improved knowledge of other professions - Mouth care: practical, allowed application to other patients, patient improvement.	- Lack of commitment and interest - Not feasible - Time constraints - Current CPD – not practical, not compulsory - Poor image that needs to be changed	- Within job description - Students – in training

Generally with regard to training a majority of the responses indicated that training was important and necessary as it provided an opportunity for learning. This opportunity for learning they observed resulted in improved patient care.

Nurse #3:"I like learning new things and being better. For me training by other professionals is a good thing. I think we can learn from each other, and why not, if we want to help the patient?"
Nurse #52: "I believe it is important to always learn and be trained in new things in nursing."
Nurse #64: "Nursing is a profession to help people and to help people we have to know what

is new and what is different. Medicine changes all the time, so we too as nurses have to get trained in the new things so we are able to offer the best service."

The responses confirmed that some nurses had good insight into the need for accuracy with procedures and protocols. While they had some insight into how they were performing, a few nurses believed that by introducing more practical training and mentoring programmes it would assist with identification of when procedures were not being conducted correctly. The following response was indicative of this:

Nurse #3: "Like I said the training is good and important not only to help patients, but this way we also learn what we are doing wrong and so we can learn new and better, and correct ways of doing things. We don't always realise or know that we are wrong, and it so happens that sometimes others need to inform us…"

Nurse #32: "Like you trained us and showed us that just by cleaning the mouth it can help the patient on so many levels. I can't imagine how many other things we think we already know, but in fact we actually still can learn and know more about. That for me is why training is needed."

Many of the nurses believed that more training was necessary and that training would be beneficial if it came not only from other nurses, but other professionals. This would allow the nurses to then also improve and expand their knowledge on the roles of other professionals.

Nurse #3: "I like learning new things and being better. For me training by other professionals is a good thing. I think we can learn from each other, and why not, if we want to help the patient?"

Just as nurses believed that training from other professionals would be of value for them, they felt that training for these other professionals was also necessary.

Nurse #3: "... Training is important, not just for nurses but for all people who work in the hospital with patients."

In the discussion of their perceptions about the mouth care training they received most nurses were positive in their comments stating that it was practical, provided new information that many assumed they had already and that this knowledge would be beneficial for their future

practice. They were confident in their knowledge and could apply this to other patients needing mouth care. The fact they would be receiving a certificate for this boosted their confidence in their ability to do mouth care.

Nurse #52:"We need more training - like the mouth care. I was supposed to know it, but I only learnt it when you showed me."

Nurse #21: "I love it. The training we got now was lovely and to get a certificate to show that you have learnt it and are doing the mouth care correctly is lovely. It's also good for my CV because other people can see exactly what you have been trained in."

Nurse #45: "The training for the mouth care was really good. I learnt something new and now I can use it for other patients who I can see have difficulty with swallowing."

Overall, the negative themes portrayed a sense of hopelessness. Their responses were reserved and guarded. These nurses spoke almost on behalf of the other nurses, or gave a response of 'their observation' of the situation.

Nurse #77: "I think it is very, very important. However it is not always easy to make the young, less experienced nurses see this, and if they can be convinced, then it will be something to celebrate…"

Nurse #103: "... not everyone is interested and not everyone thinks it is important. I'm not sure how this can be changed."

Nurse #55: "Although it is important, not everyone is interested and not everyone thinks it is important. I'm not sure how this can be changed."

It was curious that many nurses answered the questions from a third person perspective in what seemed like an attempt to avoid taking direct responsibility for the response made. Hence, their responses were made to appear as a reflection of what *they* observed to be happening in the ward/hospital but not what they felt.

The issue of lack of feasibility due to time constraints arose again. The fact that training and CPD was not compulsory was a point of contention for some nurses. They believed that this contributed to lack of motivation and willingness to attend.

Nurse #128: "...The training the hospital holds is good, but it doesn't happen all the time and depending on how busy it is, not everyone can go every time. There needs to be a good

schedule made so everyone has the opportunity to learn and maybe it needs to be compulsory."

Nurse #89: "I try to attend the training the hospital offers, but I often find it difficult. If there was more training in the ward that may be easy and work better…." *and later* "….yes - like I said I have attended some courses and found them helpful. But we must just get to do what we get trained in. We must be given the time to actually practice and do it."

The need for short, practical and hands-on courses with practical demonstration appeared to be what the nurses wanted. It was reassuring that the mouth care training fulfilled this criterion. Thus it was viewed favourably by a majority of the nurses. With the mouth care, while the general sentiment suggested that it was practical and could easily be applied to other patients, I acknowledged that part of the reason for its success was because of my presence within the wards. This was based on responses from many nurses suggesting a need for more monitoring with a genuine interest in improving their competency via monitoring. They were clear that it was important to maintain some kind of monitoring system for nurses to ensure continuity of care and practice of what was learnt. Lack of this kind of unobtrusive monitoring they believed would result in nurses giving up and eventually stopping practise/use of the newly learnt procedure. One nurse commented that this was part of the reason why nurses had a bad reputation amongst the other medical and health professionals in the hospital. Lack of commitment and often lack of evidence of their caring for patients was a rumour that many nurses were unconsciously fuelling. One nurse (#74) was insightful to recognise the need for a change in work performance commenting that, *"….if the nursing profession is to survive the public view on us we have to stop and change now so that we save ourselves. Nobody else will…."*

Nurse #45: "If we don't push ourselves to learn new things, other people are going to take over and the nurses will continue to have a bad name. If we start and we show the doctors and the families that we know what we are doing and we care, then even the matrons will see it. We must all remember why we chose to do nursing."

The neutral comments pertained to aspects falling within the nurse job description. There was therefore an implication that training was expected regardless of personal preference. Further as a caring profession nurses already had an understanding that patient care was their overall goal, and if professional development courses and further training allowed them to achieve

this goal, then it was something that had to be done regardless of their personal views on the matter.

> Nurse #111:"Nursing is a profession to help people and to help people we have to know what is new and what is different. Medicine changes all the time, so we too as nurses have to get trained in the new things so we are able to offer the best service,…"
>
> Nurse #24: "It is part of our job...."

The nurse sample included five student nurses. While the question on training was not particularly relevant for them as they were still in the process of training their responses were of interest as it was reflective of their previous work experience and reflected their age.

Table 21: Demographics of student nurse participants

Student	Age	Previous Experience
1	38	Volunteer at primary health care clinic
2	23	Debt collector at ABSA
3	18	None – scholar
4	28	Nurse assistant at Brenthurst Clinic
5	20	None – unemployed

The two older student nurses with some previous history of working in health care were able to provide more detailed answers with their responses reflecting greater insight into health care barriers. Thus their responses revealed understanding and insight based on their experiences and expectations.

> Nurse #111: "Nursing is a profession to help people and to help people we have to know what is new and what is different. Medicine changes all the time, so we too as nurses have to get trained in the new things so we are able to offer the best service."

In contrast the responses of the younger nurses showed their lack of experience and knowledge.

> Nurse #50: "Well I am still a student. Everything is still new and I am still learning. I am lucky that I got to also learn the mouth care while I was here for my practicals. I don't think

the other students got to do it." Nurse #63: "As I am a student at the moment, I am learning and getting training here - this is my practical. It is interesting."

I was able to recognise the importance of capitalising on the enthusiasm of the student nurse and providing positive role models with positive feedback seemed essential to maintain this enthusiasm. Positive regard and engagement in a non-discriminatory manner seemed to have the potential to influence how student nurses would view their profession in years to come, given the less than positive working conditions they were currently working in.

8.2.5 Perceptions on collaboration

The nurses were divided in their views on working together with all medical and allied health staff at the hospital. Table 22 reflects the positive and negative themes that emerged from their responses.

Table 22: Positive and negative perceptions on collaboration

Positive	Negative
• Patient care and improvement • Improved communication/ interpersonal relationship and respect for each other: nurse, doctor, health professional, family and patient • Equal role in patient improvement or deterioration • Improved knowledge of the roles of other professionals	• Bad reputation and assumption of blame rests with nurses • Lack of respect: doctor – nurse and family-nurse • Influence of previous bad experiences • Superiority of medical staff over other hospital employees generally • Time constraints hamper communication

A majority of the nurses believed that it was impossible to separate training from working together.

Nurse #3: "Like I said if we are going to teach other new things it will mean that we have to work closely together and get to know each other. I see this as being a good thing to happen. It needs to happen here because it needs to get better here."

Nurse #111: "I can't see how training would happen without different professionals working together. They both go hand-in-hand."

Many nurses believed working together would facilitate improved patient care and quicker patient recovery. Working together implied regular communication amongst team members and all members taking equal responsibility in patient progress.

Nurse #3: "I would like to work with the different professionals and the families because I think if we all work together then we can get the patient to recover better and maybe quicker."

Nurse #52: "I think the training and working together goes together. I've seen how by working together I understand better what's happening with the patient and why certain things need to be done. I am sure it is the same for you. So for this too I think it is important to work together."

Nurse #50: "It is nice to know a little about what we all do. It makes me understand the patient better and even deal with the families better, because I know more about what is going on with the patient so I can answer some of the questions."

Summary of nurse perceptions

It was encouraging to observe and hear that nurses were enjoying their role in the study. During my observations and informal conversations with nurse participants, many reported that their colleagues who were not in the study were envious of them. It seemed that receiving a certificate at the completion of their participation was an attractive incentive and that many nurses were upset about not being afforded this opportunity. This was confirmed when two nurses approached me directly, *"We want to get certificates too. Why are only some nurses learning how to do the mouth care and not everyone? How did you choose?"* This suggested that there was discussion of the study 'in the corridors'. During the interviews nurses commented that they appreciated my daily presence in the wards. Overall, the results suggest that the completion of the mouth care and the provision of water were viewed positively by those nurses who participated in the study. The nurses were eager to participate in training, but were clear that training should not end with them, but include other allied health and medical professionals as well. By making training a multidisciplinary effort there was opportunity for shared learning and this would facilitate greater inter-professional collaboration. While perceptions on the mouth care training and water provision were positive it is unclear how different the response may have been without the incentive of the

CPD certificate and without the monitoring. This aspect will be discussed in greater detail during my discussion on sustainability in the next chapter.

8.3 Doctor and allied health staff perception on the free water dysphagia intervention

Time and logistical reasons limited the number of returned and completed questionnaires received. Three doctors, two physiotherapists and one dietician returned the questionnaire.

Table 23: Demographics of doctor and allied health participants

Profession	Years of experience	Gender	Race
Intern – year 1	1 year	Male	Black
Intern – year 2	2 years	Female	Black
Medical Officer	3 years	Male	Black
Physiotherapist	1 year	Female	Indian
Physiotherapist	1.4 years	Male	Black
Dietician	4 years	Female	Black

It is evident from the demographic profile in table 23 that the staff that completed the questionnaire were recently qualified and were of similar experiential level with equal numbers of male and female respondents. The responses from the participating professionals were positive and encouraging. Despite their reported lack of any direct involvement with the study they acknowledged and agreed that the patients responded and recovered well from their dysphagia. The doctors were complimentary that none of their patients developed aspiration pneumonia and were particularly happy about the videofluroscopy studies that were conducted. All participants noted that the study did not require them to be involved any more than they usually were with patients and similarly did not require them to communicate or collaborate additionally with either nurses, health professionals or the patients themselves. None of the participants reported any limitations. They commented on the importance of ensuring that mouth care was done prior to water intake which they agreed had overall benefits for the patient.

On analysis of the results, despite the positive feedback received from all interviewed professionals, it was concerning that none expressed the need for more communication and

discussion amongst professionals or saw this as a way to facilitate improved patient management and recovery. It was clear that all professionals were still content to work in isolation and while not opposed to discussing patients, did not seek each other out to discuss the patient. It was sufficient to raise questions and queries in their written notes in the patients file and get answers similarly. This was in opposition to the sentiments of the nurses who believed that there is need for more and greater discussion amongst staff for the benefit of the patient.

CHAPTER NINE: RESULTS OF MAIN STUDY

PHASE TWO: DYSPHAGIA MANAGEMENT

Overview

The result and outcome of the dysphagia management that was provided will be presented. In reading the results of the dysphagia management I refer you to pg. 123 (Methodology Chapter) which outlines the protocols of management followed based on the recommendations of various authors and researchers. Details of the study and comparison group will be provided. I draw some distinction between the dysphagia management for the study and comparison group to show the association of type of management to the resulting patient outcome. To keep the results succinct and relevant to the aims of the study, only pertinent results of statistical analyses will be provided in this chapter. Appendix 23 contains a more comprehensive report of all statistical analyses conducted. To address the aims of the study several within and between group comparisons were completed. Results of the questions below will be provided in this chapter.

Description of the sample of dysphagia participants

There were equal numbers of male and female participants in the study. There was no significant difference in the gender composition between the participants of the study and comparison group. The Fisher's exact test revealed that there was a significant, strong association between race and group ($p = 0.003$, Phi coefficient = 0.54). While there was no significant difference in the mean age between the two groups ($p = 0.16$), the distribution of ages in the study group was much wider than that in the comparison group. There was no significant difference between the pathology composition of the study and comparison group as revealed by the Fisher's exact test ($p = 0.75$). Overall there were more stroke (70%) than traumatic brain injured patients in the study group across the study and comparison groups: stroke n = 32, traumatic brain injury n = 14 with similar distribution of each pathology in each group.

The mean age of the females in the study (53.7 years) was significantly higher than that of males (42.2 years). This was linked to pathology i.e. participants presenting with traumatic brain injury were younger than patients diagnosed with stroke and there were more males with traumatic brain injury than females. There was a significant, moderate association

between gender and diagnosis (p = 0.0031). Amongst the females, a higher number were diagnosed with stroke as opposed to traumatic brain injury and vice versa for males. The mean age of the traumatically brain injured patients (33.6 years) was significantly lower than the mean age of the stroke participants (54.3 years) (p < 0.0001). ANOVA revealed that there was no significant difference in the mean age between the different racial groups, with the Fisher's exact test revealing that there was no significant association between race and diagnosis, both as was expected.

9.1 Dependent variables

9.1.1 Between group comparison for aspiration pneumonia

Across the groups there were seven identified participants presenting with aspiration pneumonia. The Fisher's exact test showed that there was a significant, moderate association between the occurrence of aspiration pneumonia and group: all seven patients were participants of the comparison group (p = 0.0092). This is seen in figure 22.

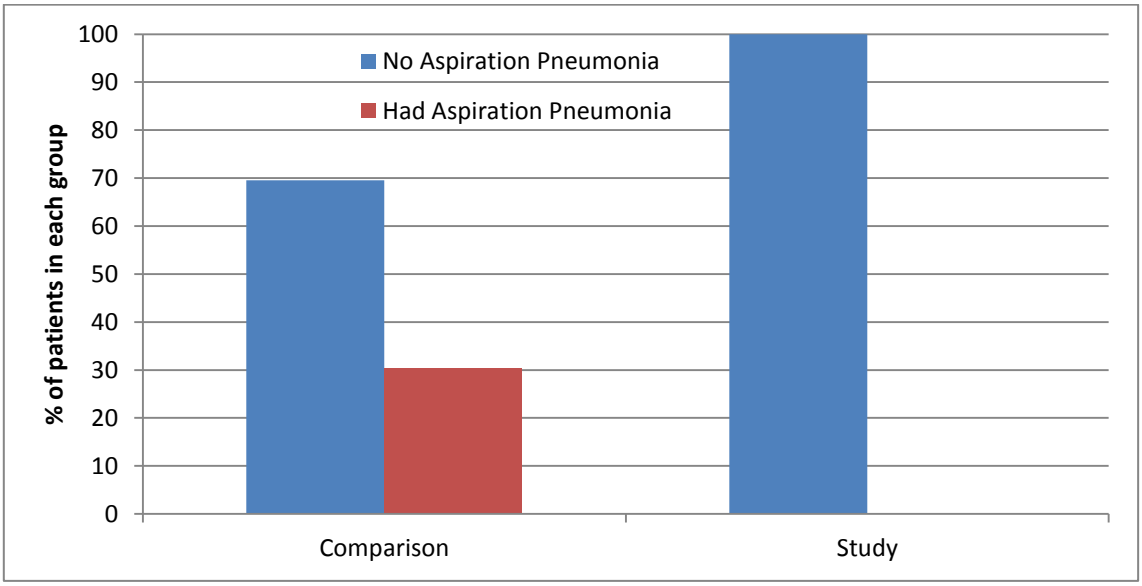

Figure 22: Presence of aspiration pneumonia within the study and comparison group

There were no occurrences of aspiration pneumonia in the study group making application of logical regression analysis impossible. The Fisher's exact test of aspiration pneumonia and the comparison group was the only analysis possible, which showed a significant moderate

association (p – 0.0092) with a Phi coefficient of 0.42 when controlling for age, gender, diagnosis and amount of water consumed per day of intervention.

9.1.2 Between group comparison of duration of intervention

The skewness of the distribution of the days of intervention for the comparison group seen in the figure (23) below, made it necessary for non-parametric analyses to evaluate for differences between the two groups. The Wilcoxon two-sample test showed that there was no significant difference in the mean duration of intervention between the study and comparison group (p = 0.078). Study group mean = 12.6 ±3.3 days, comparison group mean = 23.4 ± 9.6 days. The distribution was positively skewed as a result of a few patients remaining in hospital much longer than most other participants. This is seen for the comparison group in figure 23.

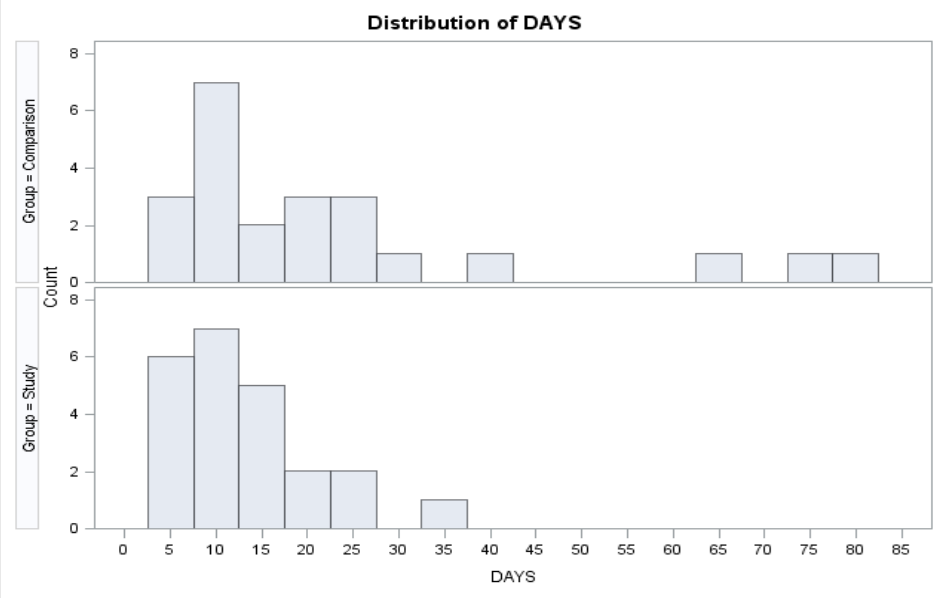

Figure 23: Distribution of days of intervention for both groups

Analysis was done to determine if there was a significant difference in the duration of intervention between the study and comparison group, controlling for race, gender and diagnosis. This was initially done without controlling for amount of water consumed per day. The analysis was done by using a General Linear Model (GLM) with duration of intervention as the dependent variable to compensate for the skewness in the frequency distribution of this variable and thus meet the assumptions of the technique. The overall model for duration of intervention was not significant (F = 1.06; p = 0.40). However there was a significant

difference in the mean duration of intervention between the two groups, while controlling for gender, race, age and diagnosis (F = 5.73; p = 0.022). It is apparent that controlling for the listed covariates was important. None of the covariate independent variables were significant.

The analysis was then completed including amount of water consumed per day of intervention, in addition to the other covariates. The overall model for duration of intervention was not significant (F = 1.66; p = 0.14). However, there was a significant difference in the mean duration of intervention between the study and comparison group (similar to the finding above), while controlling for gender, race, age, diagnosis and amount of water consumed per day. The effect of the covariate, amount of water consumed per day was also significant (F = 4.50; p = 0.041).

9.1.3 Between group comparison of amount of water intake

Analysis was completed looking at the relationship between the amount of water consumed and the duration of intervention. For the study group, it was expected that the longer the duration of intervention, the more water would be consumed. Overall the comparison group consumed more water than the participants in the study group. This was an unexpected finding but nevertheless interesting as it supported the rationale of the study. This is discussed in the next chapter.

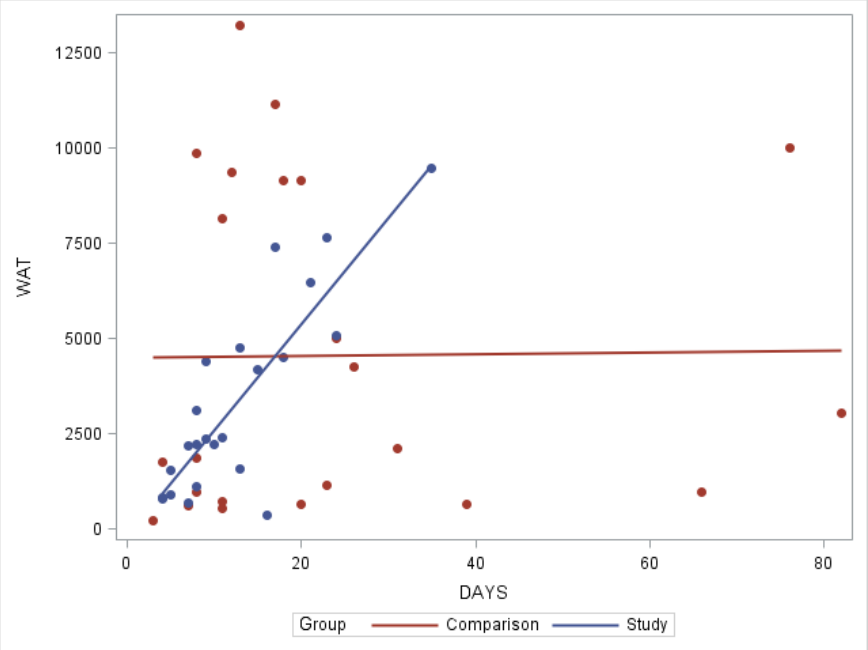

Figure 24: Relationship between water consumed and days of intervention for the study and comparison group

For the study group, there was indeed a significant, positive correlation between these variables i.e. water consumption increased as the duration of intervention lengthened (correlation coefficient, $r = 0.84$; $p < 0.0001$). This is evident in figure 24. However for the comparison group, there was no significant correlation between these variables ($r = 0.014$; $p = 0.95$), showing that the total amount of water consumed by patients did not increase with increased duration of intervention. Given the relationship between the duration of intervention and water consumption, and the different lengths (duration) of intervention for different patients, comparisons should be based on the average amount of water consumed per day by a patient, and not the total amount of water consumed by a patient. Thus further analysis was done in terms of amount of water consumed per day of intervention.

9.1.4 Between group comparison of amount of water consumed per day

The distribution of water consumed per day was skewed for the comparison group, hence non-parametric analysis was necessary. The Wilcoxon two-sample test revealed that there was no significant difference in the mean amount of water consumed per day between the participants of the study and comparison group ($p = 0.30$). Study group mean = 257 ±47ml/day, comparison group = 312 ±153 ml/day.

Analysis was done to determine if there was a significant difference in amount of water consumed per day between the study and comparison group, controlling for age, race, gender and diagnosis. The analysis was done using a GLM with amount of water consumed per day of intervention as the dependent variable to compensate for the skewness in the frequency distribution of this variable and thus meet the assumptions of this technique. The overall model for water consumed per day was not significant ($F = 0.95$; $p = .48$) neither was there any significant difference between the study and comparison groups controlling for the covariates ($F = 0.06$; $p = 0.80$). None of the covariate independent variables were significant.

9.2. Supplementary within-group comparisons

To determine if there was a significant difference between the stroke and TBI groups with regard to duration of intervention, controlling for age, gender, race, cognitive status and amount of water consumed per day, a GLM with duration of intervention as the dependent variable for reasons described above was completed. The overall model for duration of intervention was not significant ($F = 1.26$; $p = 0.33$). There was also no significant difference

between the stroke and TBI group controlling for the listed covariates (F = 0.03; p = 0.88). None of the covariate independent variables were significant.

Summary of intervention for the comparison and study group

Table 14 in the methodology chapter describes the differences in dysphagia intervention for the study and comparison group. Results of the statistical analyses conducted revealed a significant moderate association between occurrence of aspiration pneumonia and group – seven patients with dysphagia from the comparison group had aspiration pneumonia. There was no significant difference in the duration of intervention for participants of the study when compared against the duration for the comparison group. Overall, the comparison group participants consumed more water than the study group participants. A statistically significant positive increase was seen for the study group, the amount of water consumed increased as the duration of intervention increased. A similar trend was not seen for the comparison group, despite the overall large consumption of water. Implications of this finding for non-compliance and disregard of recommendations for no thin liquid are highlighted.

As with the study group, each patient in the comparison group received individual assessment and management strategies dependent on the underlying cause of the swallowing difficulty. The progress notes kept in the speech-language pathology and audiology department provided details on the intervention provided to each participant. It was evident that for the oropharyngeal difficulties all the selected patients were put on liquid restricted diets i.e. thickened liquids. However, the speech-language pathology notes indicated that this recommendation was not always adhered to. The speech-language pathology notes revealed that for several patients there were repeated requests for the patient not to be given liquids. It was clear that this recommendation was not being followed, either by the staff or the patient's caregivers. For two patients, the speech-language pathologist reported that the patient was consuming tea, cool-drink, etc. independently as observed by nursing staff, despite the patient being counselled not to. Only four of the participants from the comparison group had barium swallows and this it appeared was only after several motivations were made for the procedure to be done. While several recommendations were made for this procedure for other patients, notes indicated that the machine was not functioning for a period of time.

A majority of the patients (19 of 23) were discharged with recommendations on position during feeding, pace of feeding and for the patient to remain on thickened liquids only and no

thin liquids. Compliance with these recommendations are queried in view of the poor compliance seen whilst patients were still in the ward under supervision of the nurses and speech-language pathologist. Further, records revealed that three patients were re-admitted from two to four weeks after discharge with diagnosis of aspiration pneumonia.
The above information reveals gaps in practice and several areas that may benefit from improved communication, education and monitoring.

During my interview with the head of the speech-language pathology and audiology department these findings were discussed. She reported that many patients were transferred to her hospital from the nearby tertiary hospital, and these patients were often already very sick with poor prognoses. [Helen Joseph hospital was a secondary level hospital for the period during which the comparison group patients were in-patients]. There was often a patient exchange agreement between secondary and tertiary level hospitals, depending on the specialisation of services required for the patient.

Speech-language pathologist: "We get the really bad patients. Very often they are so sick, many of them come in with NGTs or they need PEGs. It's difficult because at that stage there is not much we can do. I'm not sure medically but the prognoses of these patients are bad. Although we work as fast as we can, there is so much of red tape, that by the time the patient can have a PEG inserted, they very often pass away. Remember that while we wait for the PEG, they very often are being fed orally because they have pulled out NGTs and then the doctors refuse to reinsert. Here the nurses don't insert NGTs."

Me: "So do all patients have barium swallows before the PEG is inserted?"

Speech-language pathologist: "We try. But the machine is often broken. Also, the radiologist is not very experienced and is not always sure what to look for. Very often he gives up and says that the patient is not cooperative, but he doesn't understand that these are patients with hemis, so they can't stand. I often do what I have to, but it's difficult to do what's necessary."

Key: NGT - nasogastric tube (non-oral feeding method via the nose)
PEG - percutaneous endoscopic gastrostomy (non-oral feeding method via the stomach)
Hemi's – patients with hemiplegia

The report by the resident speech-language pathologist is concerning on several levels. It is clear the priority that medical impairment assumes with any patient. However, it remains unclear how patients with dysphagia being transferred from one facility to another are being managed and what the accountability for the speech-language pathologist at each of these institutions is. It is apparent that there are many rules and policies beyond the control of the

speech-language pathologist employed at a hospital that dictates how patients are managed. It is particularly within these confines that the role of a speech-language pathologist is tested and under scrutiny. While it remains difficult to ensure that protocols are being followed, it appears that there may be need for expansion of roles, and greater strides to question protocols. A possible way around questioning service delivery may lie with a need for speech-language pathologists to provide managerial structures with evidence of patient outcome (good and bad) as a way of motivating for change. Moving away from the very defined parameters of 'what can one do in the given situation?' may open up new and unanticipated opportunities. For instance inefficient inter-professional communication and poor ownership of patient progress may be alleviated by committing to a more partnership model of service delivery. It appeared that patients in the comparison group were not always referred to the speech-language pathology and audiology department on the day of admission. The referral based on the information obtained from the medical files, did not seem to come from a constant source, e.g. the nurse or doctor. Notes suggested that referrals were often coincidental via a health professional who suspected a communication or swallowing impairment via his or her interaction with the patient. The time frame for a referral could be anything from days to weeks after the patient was admitted. I discussed this with the speech-language pathologist as it had ramifications for early intervention.

Speech-language pathologist: "Unfortunately the team work here is not very good. There are particular doctors who are excellent and know us by name, but it's difficult with the new interns. It is very frustrating when a patient who cannot swallow properly and needs an NG tube gets referred to the dietician. XXX [dietician] is excellent, she will call us immediately if there is such a referral. But this is not with all the dieticians. It's the same with the physio's and OT's..... When you get to a patient and you see that they should have been referred to you days before it is frustrating and you wonder why nobody called you sooner?"

The report from the speech-language pathologist confirmed that teamwork was not ideal at the hospital. Despite the need for multidisciplinary management of stroke and traumatic brain injured patients to address the differing needs of these patients attempts at communication and closer working seemed limited. Documentation suggested that patients were unfortunately at the receiving end of the short-comings of the different health care professionals. Given the less than ideal literacy level among many people in South Africa (STATSSA, 2012), particularly those of lower-socioeconomic standing who experience difficulty accessing adequate education and employment opportunities, greater efforts toward

capacitating these patients is still needed for many in South Africa. Hence, implications for change to be initiated by health care professionals in the interim. As speech-language pathologists we are placed in a prime position to take advantage of leading this initiative to explore ways to improve and enhance existing partnerships with other health professionals in the management of dysphagia.

9.3 Patient quality of life (QOL)

The responses from the SWAL-QOL did not appear to be a true representation of the swallowing ability of many of the participants in the study group. The questionnaire was administered to each participant after their period of dysphagia intervention, following completion of the videofluroscopy. Generally the information from the SWAL-QOL was believed to be limited in comparison to the depth of information obtained during my informal daily interactions with patients. These discussions provided useful insight and detail which allowed me to understand the extent to which swallowing impairment did or did not impact their life. As a standardised tool, it seemed that the SWAL-QOL was not linguistically or culturally appropriate from a content perspective for the present study. Questions pertaining to issues of finance, affordability, caregiver implications and importantly the priority of swallowing safely in the context of other 'challenges' the patient may be dealing with, which came up during the informal discussions with patients, may have had greater significance for the patients with dysphagia attending this hospital.

Statistical correlations were not viable due to the sample size hence the results are presented descriptively. The following categories were described (McHorney, 2006):

Table 24: SWAL-QOL categories evaluated

SWAL-QOL category	
Burden	Eating duration
Eating desire	Symptom frequency
Food selection	Communication
Fear	Mental health
Social	Fatigue
Sleep	

The effects of the impairment, poor literacy levels and some linguistic limitations required me to assist with the completion of all questionnaires. Two patients specifically who had minimal understanding and expression of English, were unable to read or write in English. As I assisted the participants, some reported that they did not understand some of the words, and some were unsure of what some questions meant. This was not always due to the impairment sustained, but the complexity of the question from a language (English) perspective. It appeared that many were not actually thinking about the question and the different choices, but would often respond to the question posed, with the last choice given to them. For example:

"Most days, I don't care if I eat or not"

CHOICE: very much true, quite a bit true, somewhat true, a little true, not true at all

The answers for most questions by the patients were: "not true at all."

Hence, the validity of the responses was queried. The categories social, symptom frequency, food selection, and mental health and fatigue categories while likely to give the most useful information, appeared to be most problematic.

Information in table 25 below suggests that the majority of participants noted that a swallowing impairment assumed a low burden in their life. This response was evident for all patients over the age of 40 years with some variation in responses for those participants below 40 years of age. Some of the reasons that may have contributed to the obtained responses, may be related to the priority of eating safely amidst other responsibilities they had to manage at home. In reporting that his/her swallowing impairment was not 'the end of the world," or 'it's really not that serious', they were drawing comparisons against now being unemployed or without their weekly wage as a result of their hospitalisation.

Some of the responses from the participants did not correlate with the symptoms of dysphagia that I identified or with previous discussion held with them regarding their swallowing pattern. For example, while I would identify throat clearing as a symptom, this was not identified as a problem, hence not a symptom by the patient. Thus in view of the majority of favourable responses (resulting in the high overall patient score) for each category, I was hesitant in accepting patients responses on the SWAL-QOL. It is also probable that the patients attending the hospital may have been limited in the frequency and type of social interactions they would engage in such as going out to restaurants or buying take-away foods. Consuming meals in the company of unfamiliar or irregular family, based on discussion with

different participants, was not typical. Although the patient may have been part of a large family, the family is known and familiar with the routine and rituals of the patient and would consequently be understanding. Similarly the patient would be 'comfortable' coughing or clearing his/her throat in their presence. Thus further evidence of the unsuitability of the questionnaire for the present study.

The use of the questionnaire was therefore considered a limitation on my part for the current study, as this was not included during the pilot study to determine if it would be suitable for the context and participants. On a more positive note, it does suggest the need for development of a more linguistically and culturally appropriate swallowing quality of life tool, that may even been specific for use in public hospitals in South Africa for patients presenting with dysphagia of neurogenic origin.

Table 25: Results of SWAL-QOL

	Burden	Duration	Desire	Frequency symptom	Food selection	Communi-cation	Fear	Mental health	Social	Fatigue & Sleep
Total patient response score	170	169	261	1404	184	200	379	460	467	490
Total raw score	230	230	345	1610	230	230	460	575	575	575
Results suggest	Sw is not a burden for most patients	Sw difficulty did not increase length of time needed to complete a meal	Most patients were still interested in eating	Most reported none of the listed symptoms	The sw difficult has not affected their choice of food selection	Most patients have no difficulty with communication	Most reported no fear toward eating or drinking	Most have no fear toward their sw difficulty	Most reported that their social loves were not affected by the sw diff	The sw difficulty did not make them more tired or cause them to have difficulty falling asleep

Key: Sw - swallowing

Summary of dysphagia result component of the free water protocol

The positive outcome for the patients with dysphagia in the study group receiving the free water intervention is significant for the dysphagia-practising speech-language pathologist in South Africa. While the results did not show a statistically significant difference in terms of water consumption and duration of hospitalisation between patients receiving traditional and free water intervention the results suggested clinical significance. Over and above the benefits of minimising the opportunity to acquire aspiration pneumonia, having a clean mouth, a patient feeling comfortable to open his/her mouth to a health care provider and being able to actually taste what was eaten seemed to be significant findings from the study. Showing respect to the needs of patients and attending to their basic demands appeared to improve satisfaction of the service offered and seemed to positively influence their quality of life (Farneti & Consolmagno, 2007).

While the standardised SWAL-QOL tool was not deemed appropriate for this study, it provided valuable information with implications for the development of a more linguistically and culturally appropriate tool. Despite the reports by the patients that a swallowing difficulty was not particularly concerning, it would be relevant to understand and contextualise this swallowing impairment with other life routines and rituals.

CHAPTER TEN: DISCUSSION

Overview

The discussion provided in this chapter will link the findings presented in the previous two chapters. The results will be discussed in an integrated manner and will highlight how the findings of phase 1 are interlinked with that of phase 2. Positive, negative and unexpected findings will be discussed with supporting literature. At the end of the discussion, I will provide additional information pertaining to how sustainability of the intervention was addressed.

10.1 Integrating the qualitative and quantitative data

As the researcher, the ethnographic data evoked feelings of sadness, compassion, amazement, joy and anger. In terms of inter-professional relations, much of what transpired and was observed, aligned with existing literature (Jewkes, Abrham & Mvo, 1998; Ansari & Phillips, 2001; Zwarenstein & Reeves, 2002). A lack of respect and limited if any communication with the nurse on equal footing to that of the health care professional was noted. The observed inter-professional interactions reflected a similar pattern of engagement: basic greeting, brief interaction, business-like manner, ending with a dictation of what needed to be done for the patient.

There appeared to be no place for any social or personal inferences that may have had the potential to significantly alter how capacitated each communicative partner felt at the end of the interaction. Nurses felt disempowered and like they did not have a ‘voice’ outside of their own peer group (Manias & Street, 2001). Depending on their rank, nurses could not attend ward rounds, and hierarchy dictated that they should not discuss patients with medical staff directly, all discussions were facilitated through messages in the patient’s medical file or delivered to the respective medical professional via the professional nurse in charge of the ward. Not surprisingly there was a perception that their position in the hospital was to merely do what everyone else recommended. With no platform for these feelings and perceptions to be discussed openly, it resultantly surfaced in the way they interacted with other professionals and patients, how they carried out their routines and how often and to what extent they went beyond the call of duty for the benefit of the patient (Jewkes, Abrahams & Mvo, 1998). Nurses felt that their struggles were not being heard, their difficulties and stress not being

taken seriously and were feeling generally unappreciated. The nurses role in the study was given importance. The observed outcome from nurse involvement in the intervention undertaken provided support of a realistic and feasible opportunity for nurses enhanced participation in patient care and increased autonomy, as recommended by Manias and Street (2001), something that nurses sought. With their implementation of regular mouth care, nurses were more directly involved in patient care and at the time of discharge, the nurse/s involved with that patient, were given feedback of the videofluroscopy results and the s/he was able to 'see' the outcome of the regular mouth care and free water provision to the patient. Nurses were held accountable for their role in patient improvement, something that appeared to motivate and provide incentive for them to continue similarly with other patients they were managing.

Offering greater incentives and opportunities to health professionals has been documented to promote better engagement and motivation (Pillay, 2009). For the nurses participants the majority of whom responded positively to the intervention under investigation, they sensed an opportunity to improve their skills, learn something new and be rewarded. Simultaneously however, there was a minority few nurses who in comparison were content, unmotivated and almost resigned to the position they found themselves in. Ascertaining if joy, happiness or motivation existed in the work context for these nurses was difficult.

Almost from the start of the ethnography I was struck with a sense of there being almost sub-groups of nurses who seemed to belong together. As the study progressed this perception was confirmed leading me to conclude that there were pockets of nurses whose work ethos and views differed based on, work ethic, interest, age, rank, where they resided, beliefs or practice. This was supported by Hofstede (1984); De Cooman, Geiter, Pepermans, Du Bois, Caers & Jegers (2008) and Knafo & Sagiv (2004) who noted that one's work values and performance may be linked to personal values and belief systems, emotions, culture, tradition and interest. Moving beyond the importance of intrinsic factors only, findings from the current study seemed to offer an alternate view. The crucial role of external variables such as recognition, respect, reward, management styles, interpersonal relations and communication styles were highlighted as having *greater* effect in shaping or guiding work performance of the health professional. This has been supported in the literature (Shortell et al., 1994; Adams & Bond, 2000; Gilson, Palmer & Schneider, 2005; Mathauer & Imhoff, 2006).

In line with observations that work ethos, values and commitment vary according to context and other variables, Tronto (1999) cautions that ethical dimensions of caring change similarly in response to the setting. In response to the various stakeholders that share responsibility for patient outcome seen in figure 25, Tronto (2010, p. 159) also concurred that it is imperative that institutional culture cultivate and reinforce caring amongst employees and to remember that "…*satisfying consumers may not be the same thing as providing care adequately*." As speech-language pathologists and nurses in South Africa, valuable lessons in caring that were displayed in the study did appear to have positive multifaceted benefits.

For a majority of nurses, a change from the normal routine, acknowledgment for their contribution and an opportunity to demonstrate their resolution to patient care; were some of the reasons that prompted eager participation in the study. Routine, hierarchy, 12-hour shifts, little respect, and no acknowledgement dominated the sentiments echoed by nurses during the initial ethnography. Contrastingly outcomes from the training and intervention implementation reflected care, work ethic, willingness and capability. This finding suggested that the free water protocol seemed to offer an avenue to improve service delivery given the protocol's reliance on mouth care and free water provision over and above direct dysphagia management. It also requires collaboration and communication between speech-language pathologists, nurses, medical doctors, and associated health professionals with an overall more comprehensive management of dysphagia (Altman, 2011). In view of the requests for cooperation, communication and collaboration by nurses in the study, it would make little sense if speech-language pathologists under public employment working in the area of dysphagia did not take advantage now of this hand being extended by nurses. To embrace this opportunity speech-language pathologists need to be willing to meet nurses halfway and concede the expertise of each professional within the hospital.

From the perspective of speech-language pathology as a profession there seems to be a need for greater flexibility, improved and better self-insight and self-criticism with less resistance to embrace changes in work routine in order to break the stalemate that seems to exist between speech-language pathologists and other professionals. As has been noted in the thesis, similar resistances to embracing change have been documented across professions (Brown, Crawford & Darongkamas, 2000). However as was seen with the results of some comparison group participants with compromised lung status due to aspiration pneumonia, implications of a work ethos that is not flexible and or insistence on a generic routine such as

mouth care to be completed only by the nurse, will result in poor patient outcome. Results of the comparison between traditional dysphagia management protocol and the free water dysphagia management protocol confirmed that in its existing form, a traditional protocol is not ideal and does not seem to be achieving the outcomes we assume they are.

The aspects of free water management that were not included in traditional dysphagia management included regular mouth care after every meal, free water except at meal times and greater regard for the patient and not just the dysphagia – these aspects are what set both these protocols and the consequent outcomes apart (Panther, 2005). The lack of published literature on quality of life aspects in patients with dysphagia as a result of stroke or traumatic brain injury, together with the information from the retrospective record review documented by the speech-language pathologist suggested that quality of life seems to be given lip service in traditional models of management. Therefore while unable to say conclusively what the compliance with recommendations by patients was, the incidence of aspiration pneumonia, increased fluid intake and re-admission to hospital (as was documented in the medical records) suggest that it was not ideal. It seems that hospital structures and systemic rules play a contributory role in the poor follow-up of patients after they are discharged form hospital (Cullinan, 2006). The need for professional responsibility and accountability to ensure adequate patient monitoring and follow-up after hospital discharge must be pursued. This too appears to be limited but requires further investigation.

The data in its entirety suggested that passion, initiative, sincere interest, theoretical knowledge of dysphagia with regard for evidence-based practice, a commitment to holistic management, knowledge of professional boundaries and an open attitude to team work or collaboration are characteristics that seem to be missing from the traditional dysphagia management model of practice reviewed. Continued application of principles and procedures that were used a decade ago, may no longer be relevant or suitable for the patient population we now encounter (Duncan et al., 2005). Herein lies the challenge for us to question our traditional models of practice. Equally relevant however, is to guard against implementing ‘new’ techniques that have not been validated for the patient population we manage, as the potential to do harm exists (Grol & Wensing, 2004; Zipoli & Kennedy, 2005).

Based on the analysis of the results from the quality of life assessment, the SWAL-QOL, it appears that the following variables may be some of the factors that contribute to the use and

successful implementation of a technique/standardised test in one context/country over another;

a) linguistic understanding - which in South Africa may be problematic given that a majority of practising speech-language pathologists do not share linguistic competency of a majority of patients they manage,

b) the often lack of caregiver support - members of the household may be working,

c) poor understanding of the consequences if the strategy is not used - health literacy and often illiteracy of many patients attending public hospitals and

d) poor monitoring of service provision by professional bodies and employer institutions.

Barnes (2012) recommended that evaluation of a study, more specifically a study using a mixed methods framework may be determined based on whether or not the outcome/s were achieved. In evaluating outcomes, I believe the following were addressed:

i) Mouth care training: This was successfully achieved and shown in the effective and efficient implementation of the trained protocol on patients, which together with the dysphagia protocol facilitated positive patient outcome. Video-recordings and observations of nurses during their implementation of mouth care with patients provided evidence of this.

ii) Implementation of mouth care: This was achieved and demonstrated in the positive patient outcomes as well as visual inspection of patient's mouths after meals, documentation in paper-work and video-recordings. The absence of aspiration pneumonia on videofluroscopy suggested that there was no entry of oral bacteria into the lungs, either because of no aspiration or good oral hygiene. These patients underlying difficulty was oropharyngeal dysphagia with aspiration.

iii) Aspiration pneumonia: No patient in the study group presented with evidence of aspiration pneumonia at the end of their intervention period. This was measured objectively via videofluroscopy. Seven participants from the comparison group were documented to present with aspiration pneumonia.

iv) Water Consumed: The comparison group participants consumed a greater amount of water than the participants from the study group, implying better hydration. Medical safety status and compliance of participants in the comparison group is queried, as suggested by the findings and the recommendations documented in the file, which are conflicting. For the study group, there was a significant, strong positive correlation between amount of water consumed and duration of

hospitalisation confirming that amount of water consumed increased as length of hospitalisation increased. Concerns around hydration were eased.

v) Length of hospitalisation: Although there was no significant difference in length of hospitalisation between the two groups, the average length of hospitalisation for the comparison group was longer (mean=23.4±9.6 days) than that for the study group (mean=12.6±3.3 days).

vi) Patient quality of life: Despite the limited information obtained from the standardised tool, patient-researcher interactions and discussions as well as patient compliance (with mouth care and water consumption) were suggestive of patient participation and involvement in decision-making in their intervention. Compliance with recommendations seemed to imply agreement, with implications for quality of life.

In view of the information provided the results suggest successful clinical achievement of the listed outcome measures. Based on the three gaps in dysphagia management that were identified in the introduction, the first to establish a contextually grounded dysphagia management protocol based on evidence; was addressed for the study context. The study showed that it may be feasible to implement the free water protocol in different hospitals in South Africa. Particular conditions need to be considered. The second gap that centred around limited collaboration in dysphagia management despite understanding of its benefits. This was also addressed in the study. The third gap relating to mouth care implementation was achieved in relation to nurses as well as the speech-language pathologist, who was subsequent to her involvement as the research assistant in the study, employed as a staff member at Helen Joseph hospital. She thus continues with free water provision and monitoring and involving nurses in mouth care for patients with dysphagia.

When viewed holistically, the findings demonstrate that it is possible to implement a free water protocol to manage neurogenic oropharyngeal dysphagia in a public hospital in South Africa. Further, when compared against the traditional model of dysphagia intervention, patient outcomes in terms of improvement of the dysphagia, lack of aspiration pneumonia, decreased length of dysphagia intervention and resultant decreased length of hospitalisation, improved hydration and mouth care all seem to align with implementation of a more holistic model of intervention such as a free water protocol. Off-spins from the protocol include increased communication and team work between nurses, speech-language pathologist and

doctors; increased understanding of patient and caregiver backgrounds resulting in feasible and realistic recommendations which enhance patient/caregiver compliance with recommendations and a decrease in hospital re-admissions for reasons pertaining to swallowing difficulty. Further a participatory model of training with potential for sustained implementation of the core elements of the training was observed in the study.

10.2 Knowledge translation in dysphagia management using the knowledge-to-action process model – highlighting collaboration and action research imperatives

This thesis has shown that knowledge translation to address a knowledge-to-action gap requires active collaboration between the researcher and knowledge-users and when achieved, the benefit of knowledge translation are results that extend beyond the lifetime of the research project (Kothari & Wathen, 2012). In conducting the study it became clear that successful practice of dysphagia intervention i.e. assessment and management has particular guiding principles that should not be compromised, irrespective of context or environment (Kathard, 2005; ASHA, 2002). As undergraduate students, we learn about ethical practice, working for the benefit of the patient, not compromising quality of care and the dangers of 'bad' management. Literature supports the findings of the study which seem to indicate that as we work and get comfortable with work contexts, rules, shortages, and administrative red tape, we can start to compromise on what we do, how far we push ourselves and in the decisions we take (Dodd, 2007). It is necessary to guard against becoming speech-language pathologists (professionals) who seem content, accepting and lacking the passion we once had for the profession and our jobs (Dodd, 2007; Moskos & Martin, 2005; Anderson, 2012).

Unfortunately given the slow pace over which this transition can occur before becoming apparent, there may be resultant in gaps in clinical practice. In an area such as dysphagia where monitoring of patient outcome is not documented, it may be that only through research investigation that this 'gap' is identified. For contexts where research is not prioritised such caveats may go unidentified resulting in avoidable compromise of service delivery. This thesis has shown that this unintentional transition of 'passion' to 'complacency' is a possible reason for the less than optimal protocol being used for dysphagia management with patients. Documented patient outcomes of patients receiving traditional dysphagia management supported this, and has been discussed above.

An area of deficit within the speech-language pathology degree and other health professional degrees are guidelines or information on how to bridge the knowledge-to-action gap after qualification (Jerlock, Falk & Severinsson, 2003; Kazdin, 2008; Baumbusch et al., 2008; Weller, 2004). Hongoro & McPake (2004) note that this should be highlighted in resource-constrained contexts, such as South Africa, that faces increasing medical complexity of patients, unmatched resources to accomplish efficient service delivery and a somewhat disjointed health care structure. The findings seem to suggest that not only within speech-language pathology, but also within nursing, and to an extent within other allied health disciplines despite agreement on the value of: routines (mouth care), the value of water and food intake for any medically ill patient, the professionals working together for the benefit of the patient; as professionals we lack guidelines or direction on how this knowledge can be translated in clinical practice (Hongoro & McPake, 2004). Responses suggested that in addition to lacking knowledge and experience of how this knowledge translation could be achieved, external variables within the institution/country compound this challenge. Thus a gap in *how* to effectively use an intervention may in addition to other factors, be hampering strides to apply knowledge and effective interventions in developing countries (World Report on Knowledge for Better Health, WHO, 2004).

Garner, Meremikwu, Volmink, Xu and Smith (2004) and Santesso and Tugwell (2006) agree that developing countries unfortunately do not have the luxury of money and resources at its disposal for ineffective treatments, nor the costs associated with ineffective treatments. This has implications for all health professions. It remains unknown if as a professional corps, speech-language pathologists employed in government health institutions fully grasp the state of service delivery in public health care. As was seen in the current study, the use of strategies and techniques practised in an inefficient and ineffective manner places additional burden on already overstretched services and staff (Haines, Kuruvilla & Borchert, 2004). For the management of dysphagia, implications for increased medical compromise or risk thereof for the patient should be a concern but one that seems to either be ignored or not fully acknowledged by speech-language pathologists. Unfortunately neither ignorance nor poor self-insight is favourable.

Choosing an appropriate model for knowledge translation that is able to address a diverse range of needs is important. The study has shown that the knowledge-to-action process model (Graham et al., 2006) seems to be suited to the public health care context needs in South

Africa. The knowledge-to-action process model resonates with action research and involvement of end-users during the initial stages. In this study, the role of nurses in the pilot studies and their input in refining the training from large-group training to one-on-one training allowed them, as the end-users of the training to take ownership for how the training was done, and what it consisted of. Their participation enabled an understanding of the importance of mouth care by allowing them to see the benefit first-hand for patients with dysphagia and ultimately the value of the training that they received. This process, facilitated engagement from the nurses and at the same time, afforded me as the researcher, some measure of assurance that mouth care could be sustained after the completion of the study.

Zwarenstein & Bryant (2003) warn that achieving collaboration with nurses for example, should not be at the cost of increased levels of stress and frustration for the nurse. This was carefully guarded against and avoided in the current study. Secondly, as in any other profession, collaboration between nurses and speech-language pathologists should not be seen as an attempt to shed responsibility of dysphagia from the speech-language pathologist to the nurse as in so doing it may promote perceptions of authority by speech-language pathologists over nurses in public hospital contexts in South Africa (Dowling et al., 1996). A potential risk of collaboration that warrants consideration in the South African context, is the risk of shifting responsibility for care from the speech-language pathologist to the nurse without provision of necessary support, training and acknowledgement (Colvin, Fairall, Lewin et al., 2010). Active engagement and embracing a mind-set that moves from "all-knowing" to "I'm here to learn too" on the part of the different allied health professionals, in this case the speech-language pathologist is a core requirement.

Direct support, one-on-one training, and monitoring structures were revealed to be valued and necessary components of knowledge creation, knowledge action and ultimately knowledge translation (Molfenter et al. 2009) for this context. Haines et al., (2004) agree that effective communication may enhance the utilisation of interventions. Aligning with a bottom-up approach, as with findings from my study, Baumbusch et al., (2008, p. 131) found an incongruence between linear, unidirectional and passive flow of information from research to practice and achievement of knowledge translation. The need for face-to-face contact, and a more interactive participatory style of research, with involvement of end-users in the process, was found to result in improved partnership when caring for patients with dysphagia (Dobbins et al., 2009).

Direct communication, participative and joint decision making and mutual respect seem to be some of the necessary pillars for action research in the South African public health context. As this study showed, these enabling strategies were relevant in a context dominated by work apathy, some perceptions of poor or non-existent work culture and high levels of stress, fatigue and poor resources (human and physical) (Coovadia et al., 2009). According to Cornwell and Jewkes (1995, p. 1667) "*research strategies that emphasize participation are gaining greater respectability and attention within mainstream health research in developed and developing countries*." I consider engagement of stakeholders from all levels of hospital structure a prerequisite to achieving knowledge translation in public health care. For this study, it included different levels of hospital managers, hospital personnel, matrons, nurses, administration staff, ambulance drivers, allied health professionals, doctors and patients. This may differ for other research imperatives. Each person fulfilled a role in the research undertaking, and without his or her participation the aims of the study may have been compromised. Within a developing context, diffusion of responsibility from one (professional/person) to more supports action research principles and forces one to take ownership and responsibility for his or her role in patient progress. The consequent empowerment that ensued with this process amongst the different stakeholders provided further confirmation that a knowledge-to-action framework had hidden benefits that may not be initially visible. In a developing context, as has been mentioned above, it is necessary for the research to take precautionary steps to ensure that this diffusion of responsibility does not inadvertently, *take away responsibility* (Zwarenstein & Bryant, 2003).

During the early period of the country's transformation after the disbanding of apartheid, the South African government recognised the potential value and need to undertake research. It was believed, that this would facilitate our growth and development as a skilled research capacitated country as long as research imperatives were directed towards the needs of the majority of the South African citizens (Health Research Policy in South Africa, 2001). The recognition by the National Department of Health of a gap in research in South Africa provided support of a growing awareness and recognition of the need for more context sensitive research that would have meaning and relevance for South Africans. The free water management protocol was shown to have value for the patients at the chosen hospital site. The adoption of the knowledge-to-action process model (Graham et al., 2006) was able to facilitate holistic planning and careful consideration of confounding and facilitating variables that proved beneficial from a time and logistics perspective.

As was discussed above, for a minority number of nurses in the study greater autonomy was not desirable. Thus, knowledge translation was not a successful outcome for these individuals because of personal choice. When aiming for knowledge translation in a complex and diverse context it is important to remain cognisant that not all participants or end-users may have the same enthusiasm for research or change, irrespective of known benefits. Personal preference and choice are two of many reasons that present as barriers to achieving knowledge translation (Mitton, Adair, McKenzie, Patten & Perry, 2007). Santesso and Tugwell (2006) provided support that for new evidence and routines that are not consistent with existing values, routines and principles may not be easily accepted, if at all by some.

Nurses level of involvement in daily operations within the ward, interactions or lack thereof with other medical and health professionals and routines with patients places them in a prime position to identify areas that require improvement and to identify clinical questions. An Editorial in the Lancet (Holman, 2012) reported that the promotion and engagement with evidence-based nursing via action research provides an ideal opportunity for countries in transition (such as South Africa) to scale up the quality and quantity of service provision. The often tenuous relationship between nurses and other health professionals in acute health care contexts as was evident at the commencement of this study, may present as a challenge to engaging participation for research purposes in other public hospital contexts, highlighting the value of qualitative methods in knowledge translation imperatives. Lack of transparency and scepticism from all parties, time constraints, inability and/or unwillingness for all to participate, unintentional negative consequences as a result of participation, participants unprepared for the research process, and availability of funding may be variables (or pitfalls) that can impinge on successful participation (Cornwall & Jewkes, 1995). Meyer (2000) however cautioned against judging change (from the research undertaken) solely in terms of size of change achieved or the immediate implementation of the solution/s, but to consider the lessons learnt from undertaking the research.

A significant lesson learned from the current study was the value of collaborative reflection and dialogue in confirming the most effective and efficient way in which to conduct nurse training. By applying the different elements of the knowledge-to-action process model, modifications transitioned smoothly with minimal negative perceptions on training, collaboration and implementation (Elliot, 1991). As a researcher it is therefore necessary to be cognisant of all variables and to question what for you, would constitute success. For this

study, success was nurses implementing mouth care with minimal (if any) prompting and evidence in the form of positive outcomes for the patient with dysphagia after the period of intervention.

The perceptions by the allied health and medical professionals, while positive with regard to the intervention undertaken, was less than optimal around possibilities of greater collaboration or multidisciplinary involvement with patient care. Reasons for this less than ideal view of collaboration seemed to centre around time, patient load, insecurity, lack of confidence, limited knowledge or inexperience and comfort with the familiar. When engaging in training with nurses it was learnt that mutual goal setting, perceptions of increased investment of time and effort with positive patient outcomes, relinquishing power, acknowledging nurse contribution to patient improvement, and some measure of flexibility on role execution were factors that aided collaboration (El Ansari, Phillips & Zwi, 2004; Long et al., 2003). Marks (1994) documented that historically nurses in South Africa were taught to see themselves as subordinate to doctors and other health professionals. The minimal attempts by nurses to communicate with doctors during the study showed some evidence of this. However, the disinterest by doctors and health professionals to make more effort into areas of collaboration may well be motivated by their perceptions of authority over nurses within the health care context and their insecurities related to relinquishing power. This assumption would however would require formal investigation.

The findings from this study have shown that moving beyond what we know or working in areas outside of our comfort zones as speech-language pathologists we have the potential to achieve more and do more and better for the patients we see, particularly in the area of dysphagia. The success or failure that may ensue from a collaboration attempt may always loom large and remain an uncertainty until actual steps to attempt collaboration are taken (El Ansari, Phillips and Hammick, 2001). This fear however is probably what hampers many collaborative partnerships, but the confidence to try is may be what defines one as a caring health practitioner and what may separate one from the mediocre. Shields (article in press) stresses that caring should not be regarded as only a nurses' responsibility.

As a health care practitioner, it becomes necessary for speech-language pathologists to recognise the benefit and value of holistic intervention that extends beyond alleviation of the medical symptoms (for dysphagia). Too few staff, time, poor use of existing staff resources,

'it's not my job syndrome', ineffective delegation, habit and denial have been listed by Kalisch (2006) as contributory factors to missed care. While written with reference to nursing, findings from the current study suggest that these variables may be applicable to the speech-language pathology profession as well. The results of traditional dysphagia management suggested that it is likely that limited inter-professional interactions and rapport may have resulted in miscommunication, non-compliance with recommendations, disregard and a general lack of ownership or accountability for either patient improvement or regression on the part of the speech-language pathologist as well as the nurse (Coovadia et al., 2009). Forte and Fowler (2009) and Carlson, Pilhammar and Wann-Hansson (2010) believed that the answer to fostering favourable future inter-professional collaboration may lie in the education of students where they learn the boundaries and expertise of different professions as well as their own. Modelling behaviour and practice you advocate as a professional, may provide opportunity for it to filter through to those professionals whose clinical skills require improvement.

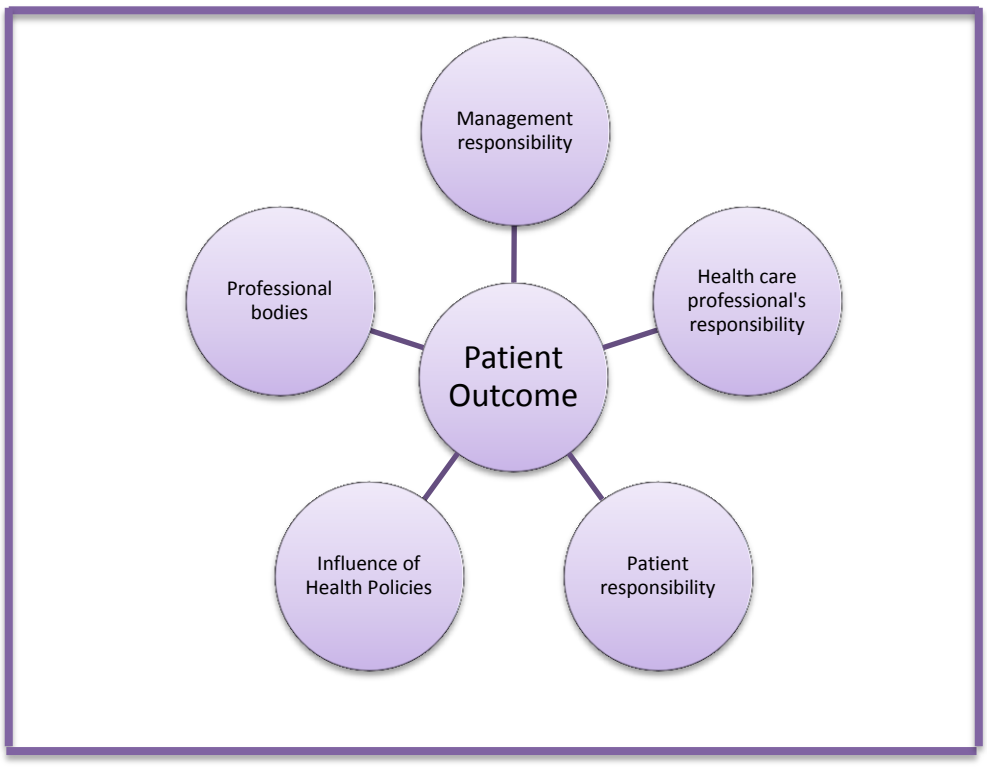

Figure 25: Factors sharing responsibility for patient outcome

As reflected in the figure above, multiple stakeholders share the responsibility for patient outcome. It appears that several of these components may be contributing to the manner in which current models of intervention are practiced. Some concur that a lack of rigorous

monitoring in developing countries of what constitutes service provision by particular professionals is on-going and is unfortunate (Dodd, 2007; Haines et al., 2004). Notwithstanding the diffusion of responsibility, as a professional corps we need to assume and recognise our responsibility: be insightful of what we do or what we are not doing, be cognisant of the needs of the country and our capacity to address these needs and not use the current disparity in public health care as an 'excuse' to not improve.

It is optimistic to believe that we can work in isolation or a state of ignorance and still profess to meet the needs of the population we serve or the country we work in. The intrinsically related politics of health care cannot be removed from whom we see, how long we see them for, to what level with intervene and resultant outcomes. Politics dictate much of what happens in health and adherence to rules and regulations is an expectation of those employed in government institutions. At the same time however we must take care to not become complacent and too accepting. Using the political strives to our advantage, engaging in more research initiatives (as per the government's agenda) and being innovative in how we address our service delivery imperatives will require greater effort. We stand on the brink of transformation of the profession and missing this opportunity to take the profession forward to a higher level in all aspects of management may have implications for the future position of speech-language pathology. South Africa is ripe with potential for change, improvement and transformation. Abiding by principles of ethical practice, engaging in collaborative partnerships and research, ensuring translation of research into clinical practice and minimising knowledge gaps brought about by context and pathology may alleviate existing despondency and imperfect models of practice. Only by arming ourselves with evidence of the effectiveness and efficiency of particular models of assessment and/or management, will we be in a position to negotiate with institutions and government for improved service delivery, however we see appropriate (Dodd, 2007). Thus we may be able to influence the political climate and its responsiveness to the profession to some extent.

10.3 Evidence-based research and evidence-based practice in dysphagia management in a developing context?

As a profession within the international arena, speech-language pathology is young (Dodd, 2007) and in South Africa it has been around for less than a century (Swanepoel, 2006). It is no surprise that research and evidence-based practice are relatively new but challenging imperatives for speech-language pathologists to embrace. Many speech-language pathologists

are still establishing a niche for themselves as well as the profession within the health care and literature spheres in South Africa. The inadequacies and limitations of South Africa for ideal clinical practice based on evidence have been discussed. Therefore not unlike other professions, the time delay between research and practice in speech-language pathology is significant even in the international arena (Dodd, 2007). The difference internationally is the increasing pace of emerging research evidence relevant for evidence-based practice which appears to be doubling every decade (Hess, 2004). While this is promising, the slowness of speech-language pathologists to give attention to evidence-based practice is concerning (Ratner, 2006; Vallino-Napoli & Reilly, 2004). An understanding of the variables, which may or may not be unique to public health and a developing context, may facilitate a novel way of conceptualising research in speech-language pathology for these contexts.

Another important factor to consider when undertaking dysphagia research in a developing context, is the patient and pathology mix these contexts face, which ultimately affect generalisation and implementation of findings (Dodd, 2007). This heterogeneity can make research appear daunting. For this study it was important to be mindful that participant criteria were not too rigid to prevent the sample from being representative of the typical presentation. The results obtained led me to propose that there were different groupings of nurses. These groupings were fluid and overlapping, and commonality with one group did not mean exclusion from another. For example, a nurse could be 50 years old and share features or traits typical of that generation, but she could at the same time, by a student nurse and so share experiences that group experienced. I therefore maintain that it may be difficult to generalise the *findings* of this study to a different hospital that also shares the title of public hospital within a developing context because of the specific characteristics of each hospital. What this study does add are the processes and methods that were used as they may be able to provide direction for future studies.

From the perspective of the patient whilst the post-colonial focus has been on transforming health care, hardships and struggles persist for patients belonging to the public health sector with the hardship having only transformed at face value – new and different hardships have replaced the old, existing struggles: "..a *two-tier health care system continues, with discrimination in access to care on economic grounds replacing the racial discrimination of the past*," (Benatar, 2004, p. 82). The media has played a significant role in influencing public perception (Moloney, 1997) of public health care which is associated with 'poor and

sub-standard' health and service provision due to amongst other reasons, decisions made at the macro level without consideration for the people functioning and resources available at the grass-roots level. It is therefore necessary that in pursuing evidence-based research a top-down model is avoided.

For the speech-language pathologist working in a *public teaching* hospital, greater strides to capitalise on opportunities and resources this context offers may be welcomed. By viewing research as being symbiotic, it will provide a means of ensuring that clinical practice is informed by research and research is guided by clinical practice (Dodd, 2007, p. 126).

As a health professional in this context it remains important to recognise that the fundamental principles of patient quality of life are interwoven into the Batho Pele Principles and the Patient's Rights Charter. For instance, consultation, access, courtesy, information, openness and transparency and value for money may be considered to be some underlying principles of quality of life, and are Batho Pele principles. Similarly the Patient's Rights Charter (Department of Health, 1999) explicitly outlines the rights of patients and emphasises the importance of upholding and ensuring their quality of care within the institution.

The information from the record review with reference to quality of life or related aspects such as counselling with patients, discussions with caregivers, was limited. Reasons for this can only be assumed. Nevertheless, the consequent results of each treatment group was testament of the value of patient-therapist interactions in intervention. Holland (1993) agreed that the type of care provided to a patient in the ward is based on medical understanding of illness due to a disease process, hence medical intervention, whereas patients themselves may concentrate on caring aspects of healing that they undertake from a traditional stance. Richman (1987) concurs that not all cultures separate physical illness from other kinds of misfortune, which may likely be the case for some cultures in South Africa. Should a quality of life tool be developed for this context of people, nurse involvement in the completion of this tool may be another avenue for mutual collaboration between the speech-language pathologist and nurse. Greater understanding into the lifestyle and culture of South Africans may provide insight in compiling such a dysphagia quality of life tool that would be more appropriate and relevant for this context.

In an article appearing in the Mail & Guardian (May, 2011), Mahmood Mamdani challenged researchers in Africa to question whether models, interventions and research derived from the dominant Western experience trivialise research conducted elsewhere (as in Africa) because of the likelihood of it to not conform to reported Western findings. He cautioned against devaluing research or intellectual production in Africa. In the light of the dearth of contextual empirical evidence this warning has special significance to researchers in minority health professions and more especially the end users of the research, i.e. the clinical health care professionals and patients. Over and above the tremendous burden on academics and researchers to engage with research, embracing findings, implementing the results clinically and a willingness to be flexible and change patterns of practice is a crucial responsibility for the practising clinician (Logemann, 2008). An inclusion of combined research collaborations between different professionals is an area that seems likely to have beneficial outcomes for developing countries, as this study has shown.

Implicit within the characteristics of patients accessing public health services and their involvement in research imperatives in a developing country, is the vulnerability of these patients. Many articles have focused attention on the ethics of conducting research in developing countries (Dans & Dans, 2000; Emanuel, Wendler, Killen & Grady, 2004). A common underlying thread in all these publications is the need for protection of participants in developing countries, issues around consent, linguistic and cultural diversity of the participants and context, and for research to be responsive to the needs of the country and people. The United Nations Educational, Scientific and Cultural Organisation [UNESCO] report in 2004 estimated that 27% of total researchers in the world were from developing countries (UNESCO, 2004). South Africa as one of the more developed countries in Africa holds promise for research to identify more cost-effective approaches to management and assessment in dysphagia for instance. This knowledge may prove invaluable for other less developed or developing countries. Engaging with research may be viewed as an engine for economic growth (Fathalla, 2004). From a socio-political perspective it may provide policy makers with much needed information on how to make best use of existing resources and curb further expenditure (Fathalla, 2004). Thus this study has shown that there is need for an expanded role of the speech-language pathologist, incorporating an awareness of the political landscape of South Africa whilst investigating avenues via which research and more efficient services can be achieved within the confines imposed by policies.

As speech-language pathologists working in South Africa, we could consider ourselves to be in the right place at the right time. We are part of a young, and fairly untainted profession that holds promise for much growth and improvement if we are willing to move beyond what we 'know' works and be willing to explore possible better ways to address patient needs whilst maintaining the scientific basis of the profession. As a country, we are ideally placed on the brink of socio-political change and enhancement with the proposed introduction of the National Health Care Plan for public hospitals. If we could summon up the courage to market ourselves, whom we see and what we do, we may be able to attain unexpected benefits from new policies being introduced by the government. From a health care perspective, we are ideally placed to conduct research and training given the diversity of medical pathology and the interest being shown by developed countries wanting to invest finances and resources in South Africa, all with due regard for ethical conduct (Burgess & Sulzer, 2010).

Although the current study did not include a cost-analysis perspective in the analysis of the data, the evidence from the study group that clinically revealed the study group participants had a shorter duration of hospitalisation than the comparison group, seen in figure 21, suggests some cost-saving to the institution with a more focused and efficient manner of management. Speech-language pathologists in South Africa need to exercise caution in '*uncritically accepting new fashions in clinical practice*" (Dodd, 2007, p. 127), but at the same time be willing to implement initiatives that may require some level of commitment. Haines et al., (2004) note that there are few studies that have investigated how professional behaviour can change in low-income countries, and is an area requiring investigation in South Africa.

The study confirmed that despite the connotation of immense effort and change that accompanies evidence-based practice, methodological working that commences with identification of gaps in clinical practice, and theory into how these gaps may be reduced with research, can amount to improved clinical practice based on contextual evidence. This study may be considered an initial attempt of this for dysphagia management.

A note on sustainability: Providing feedback after analysis of results

Significant to my study, was the Communication of Health Research sub-section of the Health Research Policy (2001, p.16) of South Africa, which is defined as "*a communication*

strategy that disseminates information and ensures that the benefits of research are systematically and effectively translated into practice." As one of the final requirements of effective knowledge translation are the measures the researcher puts in place to ensure sustainability of the investigated intervention.

At completion of my study, a meeting was held with the hospital Chief Executive Officer, medical and allied health Clinical Executives and nursing matrons. My research assistant subsequent to her involvement in the study was offered employment at the hospital. She attended the meeting as a permanent member of staff. Her employment contributed significantly to the continuity of mouth care implementation after my exit from the hospital. Her presence also provided an element of monitoring that was requested by many nurse participants in the study.

At the feedback session there was interest in extending compulsory mouth care to other categories of patients such as geriatric patients. From a clinical perspective this cohort of patients in addition to requiring assistance with activities of daily living, were also reported to present with poor dentition, inadequate oral hygiene, slow eating, and food residue after meals. The CEO of the hospital expressed agreement that my weekly return to the hospital as a clinical supervisor for students, provided an element of monitoring for patients with dysphagia specifically which was beneficial.

Summary

I have attempted to critically evaluate existing literature and position my study amidst the array of published information as a complex intervention study. A discussion of how the knowledge-to-action process model (Graham et al., 2006) was able to facilitate knowledge translation in dysphagia management for the chosen public hospital is provided. The information provided will suggest that irrespective of the challenges and limitations faced by health professionals working in public hospitals, research that culminates in evidence-based findings that are sensitive to the needs of the patient and professionals alike is needed and may be attained. My discussion will acknowledge that transformation, politics, social and financial redress as well as cultural beliefs have influenced individuals and professional groups in some way. As a speech-language pathologist, how these variables have influenced, shaped and directed current practice has been discussed as I have touched on dysphagia as an

area of vulnerability within speech-language pathology as a result of socio-political influences and the consequent response by the profession at large. I have proposed that how we practice is suggestive of what we believe our role is in health and how we position ourselves as professionals in South Africa. For a large part, I do not believe that this position is ideal. The discussion supports that failure to initiate change or ignorance of the subtle scientific deterioration of our profession in South Africa, if not addressed may have negative implications for future practice, sustainability and regard by other professions and the lay public. While limited to one site, the study has shown that a starting point may be collaboration amongst health professionals within an institution. I have attempted to show that supporting and practising principles such as respect, open communication, trust, confidence, and positive regard by speech-language pathologists and nurses, undesirable attitudes and perceptions believed to be 'cast in stone' may be changed for the better. Ultimately, the importance of practicing principles of action research within public health care settings in South Africa is supported as the words of Dr. Victor E. Frankl (unknown) ring true, "*When we are no longer able to change a situation - we are challenged to change ourselves*."

CHAPTER 11: CONCLUSION

Overview

This chapter contains the final thoughts on the study that was undertaken. The overall findings are presented, with my personal reflections on the research process as well as the outcomes of the study. Lessons that were learned in undertaking this study is included. The various implications that arose from the study are discussed as I show how this study contributed to existing literature on the subject of dysphagia and knowledge translation in the South African context.

11.1 Conclusion

It is likely that as you read the results of phase one you were initially faced with a 'less than positive' image of nurses and nursing care in South Africa, as was I. You may have started to question any kind of empathy or consideration you may have been inclining toward after reading the literature review chapters on nursing in South Africa and the South African health care context. As the author of this thesis, I followed my instinct to allow you, the reader to experience the tide of emotions and perceptions as I experienced them as I embarked on this journey. My initial contact as a *researcher* with the patients and nurses was eye opening (despite my many years working in this context) as I realised that I now had to document everything, and that nothing could go un-captured. However my perspective seemed to change constantly until the very end of the study with unexpected findings and interactions. During the course of data collection, my research assistant and I were constantly taken aback and in awe of the nurses involved in the study based on their keen regard to participate and make a difference, and more especially for their sense of compassion for the patients welfare that was often hidden behind a mask of duty and routine and which could so easily be missed by an outside observer.

Working in a medical setting, dysphagia assessment and management likely constitutes a significant percentage of the speech-language pathologist's caseload (Threats, 2007). This study is about dysphagia and how it is being managed in public hospitals in South Africa. It specifically looked at introducing an existing theoretically validated protocol, the free water protocol and investigated what conditions and modifications were required for it to be

implemented successfully i.e. achieve knowledge translation, in a public hospital in South Africa. Having established a manner of implementation, the effectiveness and outcomes of the free water protocol were compared to that of traditional dysphagia management protocols.

Specialists in adult dysphagia in South Africa are few in number. There are many qualified speech-language pathologists who are compelled to intervene with patients presenting with dysphagia but who would not call themselves experts in the area, as they are often new graduates or have limited experience. Implications of this include lack of monitoring of how and what dysphagia practice constitutes with poor or limited mentoring for inexperienced clinicians. Consequently there remains little evidence of what is being practised, poor monitoring of what happens to the patient once he or she is discharged from hospital, uncertainty of the different strategies and protocols being used and the outcomes of these, poor documentation of how strategies and techniques are implemented, and generally poor accountability and ownership of service provision. While such practice is not acceptable within any sphere of speech-language pathology, for dysphagia the implications are even more pronounced given the adverse consequences that may arise from poor intervention. This scenario is not ideal and is likely a significant contribution to variation in practice, management based on anecdotal evidence and clinicians then grabbing on to 'new' interventions when these may not be suitable.

From the many knowledge gaps present in dysphagia intervention in South Africa, three were identified in the management of dysphagia that resulted in the current study:
1) A poor understanding of the contextual, logistical and human variables that were likely impeding or facilitating optimal dysphagia service provision in South Africa,
2) Poor implementation of mouth care in public hospitals in South Africa which is a vital component of dysphagia management and
3) Implementation of dysphagia management according to internationally defined resources, situations and variables.

The findings of this study have sadly confirmed what was suspected – for dysphagia management, we seem to be doing a disservice to ourselves, the patients we serve and the institutions that employ us. There is a need for us to move away from a separatism mind-set to that of partnership, particularly when working in public health care in a developing context. By moving away from our traditional protocols and comfortable boundaries of

management, ahead lies limitless opportunity to improve what we do and how we do it. Engaging in research that address our patient's needs as well as that of the health care institutions that employ us, we may be able to clarify our profession's scientific basis and promote the management of dysphagia on sound scientific principles. The free water protocol that was investigated seems to hold much promise for managing dysphagia in public hospitals. Engagement of nurses in a partnership model can facilitate effective and sustainable implementation of the free water protocol. The underlying need for engagement and commitment from the speech-language pathologist to steer the process as well as his/her ability to adapt aspects of the protocol to suit contextual needs cannot be over-emphasised.

Although the original aim in undertaking this research was to bridge identified knowledge-gaps in dysphagia management, enhance collaboration and improve clinical practice with evidence, there have been other clinical spin-offs. Aspects of service provision have been identified that require investigation. These will be discussed in greater detail below. Monitoring of service provision has revealed gaps within the practice of speech-language pathology as well as nursing. Surprising findings pertain to the nurse response to the study, which unlike many other studies on nursing in South Africa, revealed good engagement, value for patient care and improvement, and a desire for greater inter-professional collaboration. Some findings resonated with previous studies, such as levels of disrespect, lack of ownership and disregard between different professionals, however these were from a handful of nurses. Notwithstanding the regular enquiry and attempts to assist with particular aspects of the study by doctors, there were suggestions that the pace and load in public hospitals are significant obstacles to either steering or initiating multidisciplinary management of patients with dysphagia.

Implications for research to therefore adopt more mixed methods frameworks may hold the key for future research from developing countries that may result in practice based on relevant evidence. Context plays a significant role in the severity and complexity of one's medical presentation. Thus, for the speech-language pathologist working in this context, as for other health professionals, a realisation that only managing the medical symptomatology of dysphagia, for example, may make little difference to the overall presentation of the pathology if the extraneous variables are not considered. Thus a move away from a purely medical model of management, to a more holistic bio-psychosocial model (as proposed by the WHO-ICF model) when managing dysphagia, as was shown in the study, may do more to

address the vicious cycle depicted in figure 1, than managing the pathophysiology in isolation.

Recognising and applying knowledge-to-action models that enable knowledge translation may simplify work for researchers but requires commitment at every level to ensure successful translation of research into clinical practice. Preparation of end-users to implement findings is a necessary component of evidence-based practice. The ability to modify a protocol such as the free water protocol to meet the needs of the context lies in the hand of the speech-language pathologist. The study showed that a model of collaboration and action research are processes that can be helpful in achieving this.

Given the limited knowledge many professionals have of each other and their respective scopes of practice, involvement in education and training, as was conducted in the current study may be a cost-saving and time-saving way to address service delivery imperatives. The study provided support of the need to ensure that the interests of a) the nurses who were responsible for a component of service delivery as well as b) the patient with dysphagia who was receiving the mouth care and dysphagia management, as well as c) mine, as the researcher and speech-language pathologist were all considered and addressed. This core consideration in an intervention study should be prioritised above all other. The study process revealed that the free water protocol may be feasible for a public hospital context. Actual implementation of strategies and techniques to address the underlying pathology daily for a specified amount of time and the involvement of the patient to use behavioural strategies with every meal was vital. In drawing conclusions for this study, the relevance of the considerations by Rychetnik et al. (2002) were realised. In disclosing unanticipated outcomes, anticipated outcomes, limitations and successes of the intervention undertaken, studies such as the one undertaken provides a platform for future dysphagia research, and on a broader level evidence-based contextual research that could be beneficial to the profession.

The need to acknowledge that dysphagia may manifest in activity and participation limitations as well as psychosocial consequences (Threats, 2007) in addition to the more familiar and acknowledge medical and pulmonary consequences amongst dysphagia practising speech-language pathologists in South Africa was highlighted by the study, hence the proposal of an expanded role of the speech-language pathologist working with this pathology. Aligning with the stance taken by Threats (2007, p. 332), management of the

participants in the study group reinforced that broader and more holistic perspectives on dysphagia enables "….*intervention that best honours the health care ethical tenets of both autonomy and beneficence.*" Central to this broader perspective, the vital role patients play in their own progress and recovery was recognised. It was seen that involvement of patient's and/or caregivers in decisions around intervention, did improve patient adherence and compliance, and ultimately enhanced the effectiveness of management (von Wühlisch & Pascoe, 2010).

At the conclusion of the study, I remain undecided on how I view current speech-language pathology practice. I am swayed by the history of the country and the influence of the political climate on health care as I realise how this has culminated in the current work ethos of practising speech-language pathologists. On the other hand though, I remain critical and disappointed with the level of contentment and acceptance many speech-language pathologists working in public hospitals appear to display toward their work and intervention with patients. There is a need to revisit what the profession of speech-language pathology stands for, and for each speech-language pathologist to acknowledge his/her role in the profession. The study has confirmed that the potential for advancement has to rest on all our shoulders to ensure that we can be proud to be speech-language pathologists. Therefore a commitment to enhance dysphagia service provision and capacitate less experienced speech-language pathologists working in public hospitals by engaging in public-academic partnerships to share the knowledge such as I have gained from this study, will be an on-going aim.

11.4 Personal reflections

Literature reiterates the need for qualitative researchers to be free of preconceived ideas or assumptions about the context or people when entering a site.

As an outsider to 'nursing', I was able to observe the reality of working within an under-resourced context from a disrespected and unacknowledged professional alignment over the duration of the study. It was possible to gain insight into attitude, communication and interactions as these were clearly distinct and dependent on who the conversational partner/s was/were; and what the topic of conversation was. The value of non-verbal cues within these interactions was suggestive and indicative of the content and 'formality' of the conversation.

There were distinct layers of hierarchy within nursing which are necessary as with any other profession, to maintain stability, work order and a line of communication. The context at the time of data collection, with that cohort of nurses and with specific protocols and procedures followed were the ingredients that when combined produced the observed result/outcome.

Similarly levels of hierarchy existed between the different medical and allied health professionals of the hospital. While patterns of engagement appeared to be more relaxed and conducive between these different professionals (doctors, physiotherapists, dietician, nurse) and me as the researcher, it was not observed to be so amongst themselves as employees of the same institution. The observed interactions were less friendly, more formal, with little room for banter and familiarity. I am unable to conclusively say why this may have been so.

As important as the speech-language pathologist's role is to engage in and undertake research (and relevant research and not just for the sake of a qualification, but to impact the survival and standing of the profession on the same platform as other health care professions), it is equally important for practising clinicians to remain vigilant and critical of emerging research before accepting the results as a 'new gold standard'. One has to guard against textbook like guidelines and protocols, especially working in the South African context given the diversity of patients, pathology, circumstances and variables in-play with any one patient. The hazards of blindly applying protocols from one context to another need to be monitored and safe-guarded against, for the benefit of the patient and his/her quality of life.

I firmly believe that this type of generalisation has numerous untold hazards and adverse consequences attached to it that may not be immediately visible, but may be identified upon closer inspection. The evidence to support this belief (over and above previous clinical experience) was explicit in the current study. Aligning with this finding, Busse (2012) in an editorial cautioned that studies conducted in one country and then generalised, should be questioned based on the applicability and transferability of findings and procedures. For the current study, despite the positive outcome there were uphill battles within the study context that needed attending to, to facilitate this favourable outcome. These included initial nurse disregard and in some instances opposition, administrative red-tape around hospital access as well as access and 'completeness' of medical records to name a few. In listing some of the obstacles encountered I aim to highlight that there may be specific nursing sub-groups that existed at this hospital and which is/was different to the sub-groups I encountered and

observed where I worked previously. Throughout my data collection, I constantly reflected why it was that some nurses took the mouth care implementation on in their stride and why some did not.

During my observations as I moved from one ward to the next it became apparent that while there was a level of similarity between the different wards, there were also subtle differences that made one ward stand out from another. These differences included the interpersonal relationships between nurse managers and nurses, interpersonal relationships amongst the nurses, personalities of the staff in the ward, receptiveness to 'outsiders', neatness and orderliness of the ward and cohesiveness of the staff in the ward. I was able conclude that a nursing perspective did exist at a macro (institutional) level, as well as at a micro (ward) level.

Darch and Underwood (2005, p. 78) introduced two key components to organisational compliance which I found relevant to understand the behaviour of the participants in the study, and which I believed supported my belief of the existence of pockets of nurses: that of *capacity* to comply and *willingness* to comply. I found it valuable to make this differentiation with the participants of the study as it provided a rationale for understanding behaviour and work ethic, which inevitably is influenced by a multitude of factors as seen in the figure below.

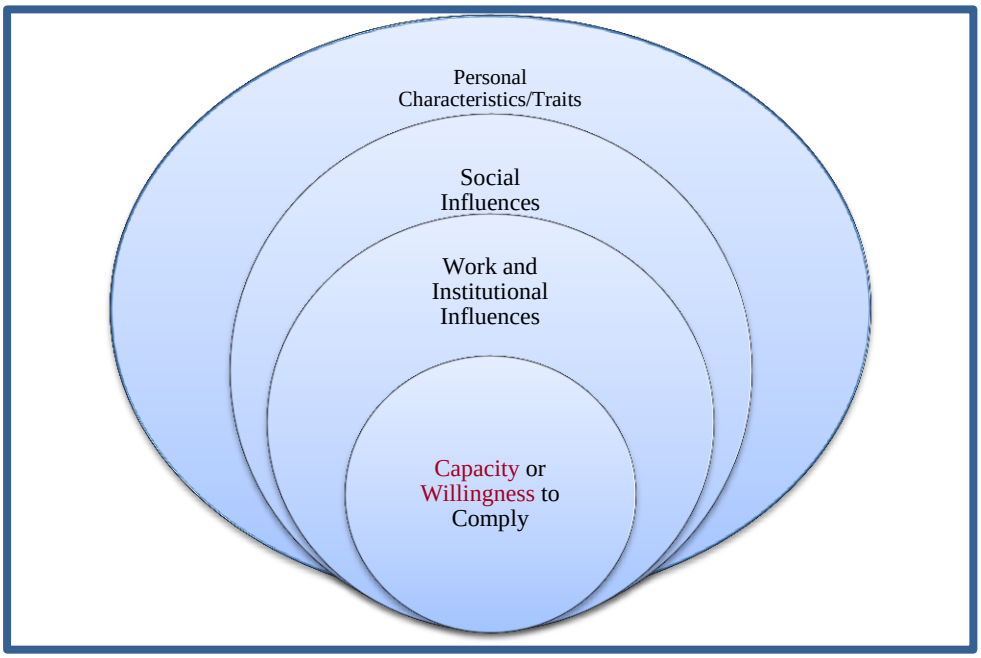

Figure 26: External and internal factors influencing nurse behaviour and work ethic

Going back to my argument on the need to be cautious with generalisation, the existence of these sub-groups of nurses implied that it was likely that for the given context, with due consideration of variables within this context, the study was feasible. Whilst not discounting the possibility of the protocol being feasible in other public hospitals there would need to be consideration of the variables unique to that context that may impact outcome. Rust and De Jager (2010) outlined leadership and management failures, management capacity problems, understaffing, increased patient loads, reduction of support staff (cleaners, porters, etc.), and lack of staff discipline as some of the variables that are considered unique to South African public health care and hospitals. I would like to propose that similar sub-groups exist within the speech-language pathology profession as well that need interrogation and understanding that may aid progress of the profession.

Myburgh, Solanki, Smith and Lalloo (2005) conducted a study investigating patient satisfaction with health care providers in South Africa, and while it may be considered a little out-dated, they found that when comparing the 1994 patient satisfaction survey results against the 1998 results an increase in satisfaction was found for all racial categories. It would be valuable to ascertain satisfaction levels currently, almost 20 years post-apartheid. Thus by intervening appropriately at the level of the institution, it may be possible to influence and positively impact patient perception as well as employee satisfaction and compliance. On searching through the volumes of published literature on nursing, I was struck by the comments of Coovadia et al. (2009, p.829), "*From the 1950s, persisting to the present day, a popular image of nursing has been that they are cruel. The roots of this image lie partly in deliberate attempts to position African nurses in the struggle for colonial hegemony.*" Whilst glimpses of this type of hegemony was evident and possibly still prevail with particular nurses, the overall impression upon completion of the study was one of admiration and empathy with a new found respect for their contribution to the health of people.

By the end of the study, or end of intervention for patients from the study group, it was clear that positive nurse-patient relationships had developed for many of the patients. There were good communication exchanges that reflected mutual trust. This allowed patients to share information that they would not previously have done as they felt comfortable and secure with the nurse (Timmerman, 1991). The nurses were able to form a positive bond with the patients via their interactions involving mouth care and feeding. Haddock (1996) believes

that this is associated with the concept of dignity on the part of the nurse, who in establishing this interpersonal relationship was able to take care of the physical and psychological needs of the patient. While this type of positive interactions and open communication did not develop amongst all nurses with their patients in the study group, the majority of nurses who were able to attain this, were the nurses who were enthusiastic about work, the study and who believed that there was need for nurses to transform the poor image they had into something more promising. Mutual satisfaction (nurse-patient, nurse-speech-language pathologist, speech-language pathologist-patient) provided inspiration for all end-users and lay the foundation for a supportive, proactive and professional work-driven environment (McQueen, 2000). The results of the study suggested that a majority of the nurses in the study were ready to expand the extent of their involvement with patients in the intervention process as a way to foster greater collaboration and to address needs of the patient and gain respect form the other health and medical professionals. Herein lay the benefits of an action research oriented approach to conducting research in public health contexts.

The entire research process has been an eye opening and enlightening experience. The most ‘exciting’ part of the research process has without doubt been the data collection period. Despite it being an emotional rollercoaster ride not knowing what to expect from one day to the next, or not knowing if you are going to be able to handle what comes your way, I was kept invigorated and challenged. I had a responsibility to my institution, my research funders, my supervisors, my profession, the hospital as the study site and most of all my participants. The engagement with the nurses and patients were especially significant. I had gained trust and acceptance of many nurses and I had to ensure that their voices and desires were heard by their managers and the public.

In contrast, as expected based on clinical experience, the traditional model of dysphagia management did not inspire hope or dispel fears that dysphagia management was not resulting in the anticipated positive outcomes. The levels of anticipation and foreboding I felt at the commencement of the study had turned to excitement and commitment during the data collection period, and to sadness and pride as I left. I exited the study site as a supporter of nurses and with confirmation that improved dysphagia management is possible to the benefit of the patient and speech-language pathologist. As a team, nurses and speech-language pathologists have a journey ahead that can have untold benefits, it just needs commitment from practising nurses and speech-language pathologists working in acute care settings. For

dysphagia, I will endeavour to ensure that this partnership grows and that the standard of dysphagia practice grows from strength to strength.

In summary, the results suggested that a free water protocol may be successfully implemented (positive dysphagia outcomes) in an acute public hospital context with adherence and compliance with particular guidelines. When compared against the traditional model of dysphagia management the outcomes from the free water protocol seemed to be more valid, reliable and had better prognosis for the patient with dysphagia. Secondly, the results of the study seemed to suggest that it may be impractical and impossible for the speech-language pathologist to work in isolation when managing dysphagia. For management to be holistic and to fulfil quality control requirements, collaboration appears to be essential. For this study, it was necessary for speech-language pathologists to collaborate with nurses. Mouth care, which was a component of the protocol, fell within the domain of the nurse. Despite the challenging and vulnerable position nurses in public health care find themselves in in South Africa, the results of the study suggested that positive collaboration may be achieved between the speech-language pathologist and nurse with probable positive benefits for both these professionals as well as the patient, who sits at the epicentre of dysphagia management.

The value of action research within a health care context as demonstrated with the current study included the active participation of staff, open-ended objectives and high levels of commitment from me as the researcher as well as from the participants to the research problem and to active learning. Action research appears to be an optimal avenue via which to address the knowledge-to-action gap present in the clinical practice of dysphagia management and intervention. It is able to hone in on and accommodate each end-user's knowledge and experience to result in significant and relevant findings. There have been numerous action research studies specifically within the nursing profession (Booth, Tolson, Hotchkiss, & Schofield, 2007; Breda et al., 1997; Greenwood, 1994; Hart, 1996; Meyer, 1993). Useful information to aid and improve practice, education, management and general professional improvement (in nursing) have resulted (Coghlan & Casey, 2001). It is likely that greater undertaking of such initiatives in professions such as speech-language pathology and in different contexts may in time result in similar positive outcomes for the profession with added insight of contextual understanding.

The research process has taught me that even with the best laid plans, and favourable outcomes from an intervention study, appropriate dissemination, traditional practices and resistance to change is inevitable (El Ansari et al., 2004). Many reasons may underlie resistance but with an appropriate model to identify the source of the resistance, clinical practice can improve. In South Africa the political, economic and social inequalities do not provide a suitable basis from which to conceptualise change (Cassels, 1995). For dysphagia management it was important that the strives to implement change with nurses (in terms of implementation of mouth care) and with speech-language pathologists (use of a free water protocol) occurred after consultation with them as end-users. Skipping this step in the process may have resulted in similar inequality that existed prior to the study.

11.4 Implications

The culmination of this intervention study has transpired in different implications. These are discussed below.

11.4.1 Training Implications

Mouth care is a simple, quick and easy procedure but is one that nurses and speech-language pathologists alike, would rather not do. There are implications for the undergraduate training curriculum of both nursing and speech-language pathology to expand to include theoretical underpinning of mouth care, influence of gram-negative bacteria in development of lung infection and the role of oral flora in aiding this adverse consequence, amongst the general population and specifically for individuals with dysphagia.

11.4.2 Clinical implications

The results of the free water dysphagia intervention strongly suggest that such a protocol may be feasible in other acute public hospitals in South Africa. For successful implementation clinically there is a need for measures to be put in place. These include:

- Defining outcome measures for each patient.
- Diligent mouth care.
- Intensive dysphagia management.
- Patient involvement in their intervention.
- A strict adherence to recommended diet for the patient and monitoring thereof.
- No thickened liquids.

- Water provision only by specified persons and only following mouth care.

Realistically it is impossible for the speech-language pathologist to accomplish these aims in isolation. The impetus to therefore move away from an individual model of practice to one of partnership using collaborative processes involving other professionals and patients themselves. Greater monitoring of patient outcomes for dysphagia with reflection on effectiveness and efficiency of management protocols being seems needed. The need for improved documentation of assessment and management undertaken for patients will facilitate improved understanding of efficiency of intervention.

Mouth care needs to be taken on clinically by practising dysphagia speech-language pathologists. As noted in the dissertation, mouth care does fall within the job description of the nurse. However, this does not always transpire, reasons for which have been described earlier. Hence, with a theoretical understanding of the implications of poor oral hygiene in aspirating patients with dysphagia, there is a professional obligation for the speech-language pathologist to ensure that mouth care is a priority before any intervention for dysphagia (by themselves) proceeds. Modelling implementation of desirable clinical practice will not only have benefits for the patients with dysphagia, but may facilitate improved communication and cooperation from nurses.

The clinical implications to initiate links between the speech-language pathology department and Dental Schools is positive given the findings of the study and the potential to improve oral care not only from a dysphagia perspective, but also for reasons of quality of life.

A speech-language pathologist working in a public hospital has the advantage of having access to patients, pathologies and medical resources to engage in research, whilst remaining obligated to ethical practice. A speech-language pathologist working in academia has access to literature, electronic data bases and theory to guide research initiatives. Improved partnerships and collaborations between these speech-language pathologists from different contexts may have many positive implications not only for research in dysphagia, but other aspects of the speech-language pathology profession, that may assist in solidifying the status of the profession as being scientifically based, and will also promote improved relations between these groups of speech-language pathologists.

11.4.3 Research implications

Several research needs were identified in the study, some directly related to dysphagia, and others to the speech-language pathology profession generally.

The benefit of mouth care suggests that there may be other populations presenting with dysphagia who may show benefit from oral hygiene and care. For instance persons residing in residential care facilities and frail care centres may be one such cohort. Training for staff at the facilities and research into facilitators and challenges within these facilities is needed.

Research to confirm the priority and views of research amongst speech-language pathologists working in public hospitals, what informs their practice and barriers and facilitators they may encounter working in public hospitals will provide insight into perceptions around evidence-based practice. This information may be able to assist with planning effective knowledge translation for different pathologies relevant to contextual and patient needs. In addition, a deeper investigation into the research ethos at the different pubic hospitals by management structures may provide useful information in understanding how this ethos is disseminated to speech-language pathologists and other professionals at the grass-roots level, and may likely provide reasons for why research imperatives are or are not considered by the end-users at the grass-roots levels.

Investigations at hospital sites and departments that do engage in multidisciplinary management of patients to determine why the multidisciplinary model works for them, who the professionals involved are, the steps that were taken to establish the multidisciplinary model of management, which pathologies it works well for and which not, how team involvement is sustained and how has it changed or improved patient outcome and treatment efficiency are needed. Information gained from such research investigations may enable other institutions to learn and initiate similar imperatives in their own institutions. It may further provide a source of inspiration for speech-language pathologists who encounter difficulty setting up these teams, with knowledge that it can be attained and the process involved.

There are implications of further research into general prevalence studies to determine prevalence of dysphagia in South Africa, and the incidence of dysphagia with specific pathologies in South Africa, comparison of prevalence between rural and urban populations, and the different intervention strategies that may be beneficial for patients from each context.

Given the lack of research into quality of life of patients with neurologically acquired dysphagia, this is potentially an additional area that could benefit from improved understanding. Compilation of a quality of life scale appropriate to the needs and circumstances of patients from different socio-economic groups, cultures and linguistic backgrounds in South Africa is necessary.

With the study showing benefit of nurse-speech-language pathology partnership, it would be useful to conduct a survey among speech-language pathologists and nurses to probe their perceptions of working with each other for the benefit of the patient with dysphagia. Such investigations will provide insight that can be used as necessary to engage each professional in such partnerships.

A general survey to determine the demographics of current speech-language pathologists employed at public hospitals, to understand what level of expertise and experience can be found in public hospitals will provide valuable information when evaluating research needs according to the hospital site. Further identification of 'specialists' with expertise in dysphagia based on years of experience, areas of expertise and availability of these lists electronically may allow inexperienced speech-language pathologists to receive mentoring and support via electronic-means when necessary. Discussion of cases, assessment and management decision via electronic means may offer necessary support to young professionals.

A comparison study to determine if there is any difference in the patients presenting with dysphagia at secondary and tertiary level hospitals, and match this to the speech-language pathologists employed at these institutions in terms of experience and expertise is required from the perspective of patients. This will also have implications for the need of mentors and supervision for less experienced speech-language pathologists.

11.4.4 Policy Implications

Results of the current study need to be disseminated to educators of nurses and speech-language pathologists to rationalise the inclusion of mouth care as a compulsory component of undergraduate training. As with other aspects of training, if taught, reinforced and examined (clinically and theoretically) by lecturers, it is likely to transpire in implementation by the said professional upon graduation and in practice.

Decentralisation of health was one of the reform programmes adopted by the post-colonial government as a means addressing transformation imperatives (McIntyre, Muirhead & Gilson, 2002). Thus while there is a National Department of Health, each hospital has its own manager, financial budget, and imperatives, that overall need to align with that of the National Department of Health. There has been a shift in leadership in hospitals toward managers with a more commercial or managerial history (Pillay, 2008). How this is done, is largely decided by the management structures within the hospital. This structure holds potential benefit for the inclusion of mouth care as one of the vital routines that need to be completed by nurses. If adopted as a policy by the department of health, it opens up greater possibilities for the importance and practice of mouth care to be adopted at a national level. Hence, this will result in improved oral hygiene of all hospitalised patients and an improvement in their quality of life with positive spin-offs for patients with dysphagia.

The study has highlighted the importance of front-line staff, nurses and speech-language pathologists alike to have an active role in research. If driven from a policy level, there may be less obstacles encountered. Not only must policies be put in place, but the monitoring of the implementation of these policies would require equal attention. It is probable that institution-level management structures as well as professional bodies may play a more significant role in these monitoring imperatives, especially within public health care that offers an ideal context for research. Policies that call for engagement of front-line staff in research imperatives will further facilitate knowledge translation not just at a policy level but at the grass-roots level where it is most needed (Baumbusch et al., 2008).

11.4.5 Theoretical Implications

The potential for research into sub-specialities of speech-language pathology in South Africa is promising, given that many areas have remained minimally explored, such as dysphagia.
Based on experience with this study and lessons learned, I have proposed a model that may inform potential clinicians and researchers of core considerations that may be necessary when conceptualising an aspect of research.

The model seen in figure 27 below aims to align with knowledge translation and which I found relevant for the current study. Investigation for application to other sub-specialities of speech-language pathology is still required. The model proposed aims to enable clinicians/researchers to answer four questions around a potential area of investigation:

- What?

  This entails a thorough needs analysis and identification of the area requiring investigation, improvement or refining.

- Who?

  This represents identification of all relevant end-users and stakeholders central to the area requiring investigation, improvement or refining.

- Why?

  There needs to be transparent and explicit benefit and interest of the proposed investigation for each of the stakeholders and end-users identified.

- How?

  One needs to consider the manner in which the proposed investigation will be conducted, in addition to how success will be measured and thereafter monitored.

The model proposed in figure 27 is based on the knowledge-to-action process model, and visually presents an easier flow of aspects that need to be considered in undertaking an intervention based study in a hospital context. In considering each component of this proposed guiding framework, regard for context remains a high priority. Implicit within the consideration of context are variables such as resources, personnel, logistics and work ethos each of which may be considered to be either facilitators or challenges to the identified area of investigation/improvement or refinement.

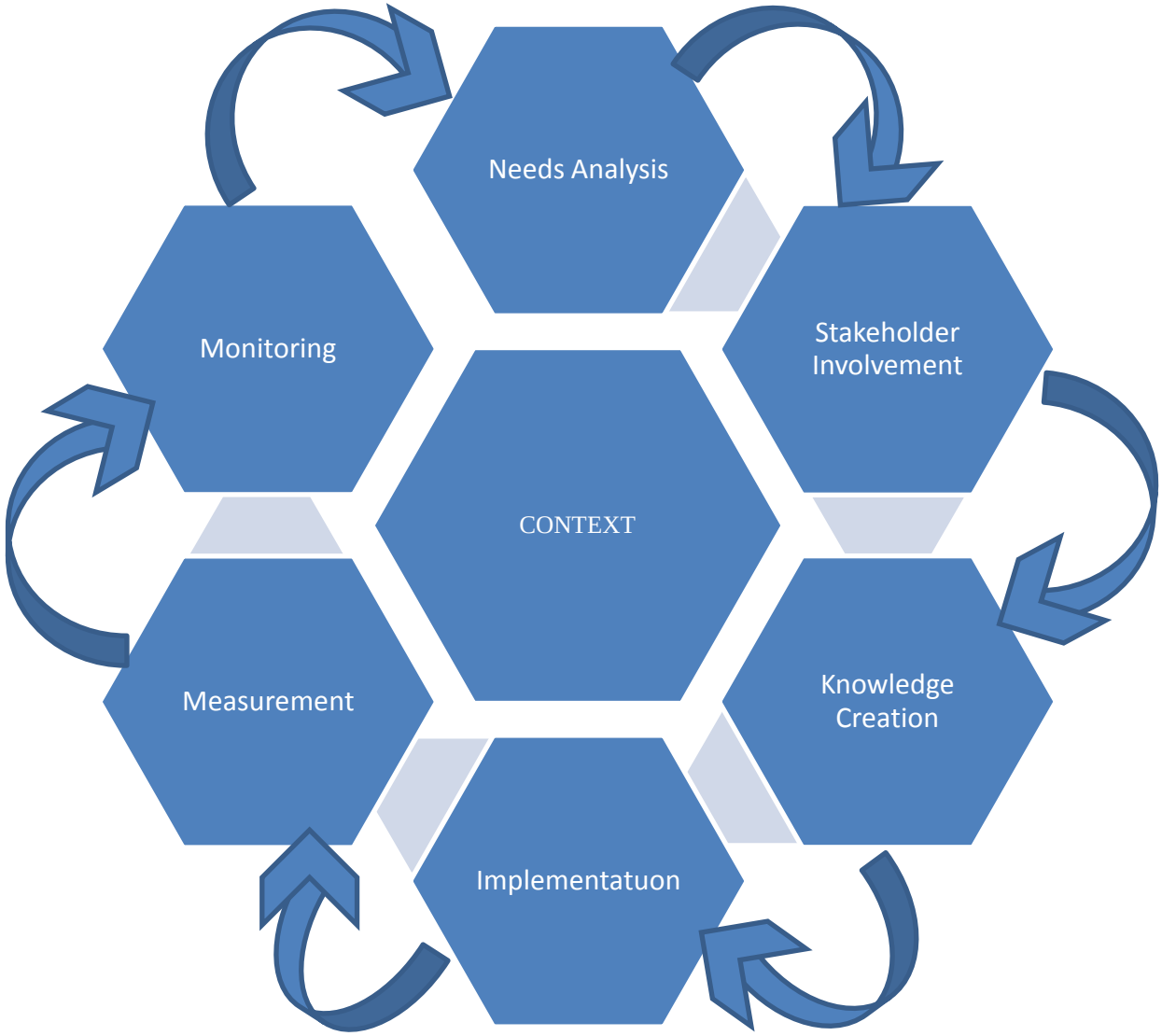

Figure 27: Aspects for consideration during conceptualisation of improvement in service delivery or research imperatives

11.5 Final Thoughts

Dysphagia assessment and management remains an interesting and fulfilling sub-speciality of speech-language pathology to work in. A public hospital context in a country like South Africa may impose unexpected challenges that may adversely impact the effectiveness and efficiency of dysphagia intervention. The challenge to remain insightful of one's practise whilst maintaining a balance between employee (government) and professional obligations (speech-language pathology) requires skill and is an on-going requirement as long as one remains a public (government) health employee. It is hoped that some of the information provided in this thesis may assist one in maintaining this balance between clinical practice, research and context. The model may provide some initial insight into identifying aspects of service delivery that may not be running ideally, and provides a basic guideline of variables that may be worthy of consideration when conceptualising how an aspect of service delivery may be improved, tailored or evaluated. I believe that a pragmatic approach that optimises knowledge-translation in dysphagia assessment or management is a necessity in a developing context and should be the direction of future research.

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APPENDICES

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Jaishika Seedat

CLEARANCE CERTIFICATE	**M091166**
PROJECT	The Feasibility of Implementing the Frazier Free Water Protocol (FFWP) in a South African Acute Medical Setting-Addressing the need for Evidence Based Practice in Dysphagia
INVESTIGATORS	Ms Jaishika Seedat.
DEPARTMENT	Speech Pathology & Audiology
DATE CONSIDERED	2009/11/27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 2009/11/30 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof C Penn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

APPENDIX 2

SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

School of Human & Community Development

Faculty of Humanities

University of the Witwatersrand

Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

Date: _____

ATT: Chief Executive Officer/Clinical Executive
Allied Health
Helen Joseph hospital

RE: Permission to Conduct Study at Helen Joseph Hospital

Hello. My name is Jaishika Seedat. I am a speech-language pathologist, working at the University of the Witwatersrand. I qualified in 1996 and worked at Johannesburg Hospital from 1997 – 2007, primarily with adults. I am currently registered to complete my PhD. My area of interest is dysphagia in the adult population. The title of my PhD is: Feasibility of Implementing the Frazier Free Water Protocol in a South African Acute Medical Setting: Addressing the Need for Evidence-based Practice in Dysphagia.

Assessing and managing dysphagia/swallowing problems comprise a significant portion of the workload of a speech-language pathologist. The area of dysphagia is a particularly contentious issue due to the risks associated such as choking, aspiration pneumonia and mortality. Thus experience when assessing and managing dysphagia is stressed. Dysphagia is lacking an underlying evidence base to support practice. For my proposed study, I would like to assess the feasibility of implementing a protocol (Frazier Free Water Protocol) that originated in Dallas, Texas; and that is being used at the Frazier Rehabilitation Institute with success to manage patients presenting with dysphagia.

There are 3 principles underlying the protocol, namely, safety of water, hydration and patient compliance.
Safety of water: Aquaporin channels in the lungs allows for absorption of small amounts of water. However oral care and absence of gram negative bacteria in the mouth must be ensured so that the water, if aspirated, is free of bacteria, and can thus be safely cleared without leading to aspiration pneumonia.
Hydration: Dehydration has been documented to lead to a host of negative health conditions including change in drug effects, infection; poor wound healing, pressure sores, decreased urinary volume, urinary tract infections, confusion, lethargy, constipation, altered cardiac function, acute renal failure, weakness and declining nutritional intake. This ultimately affects the rehabilitation process, length of hospital stay and inadvertently results in increased

hospital costs. Thus proper hydration (an aim of the protocol) may facilitate in alleviating these consequences.
Patient Compliance: Studies have shown that patients find thickened liquids unpalatable, leading to non-compliance which may affect occurrence of co-pathologies, resulting in increased length of hospital stays and increased hospitalisation costs. Patient quality of life warrants consideration and needs to be weighed against safety of feeding. This is accounted for in the protocol.

I would like to request permission to conduct this study at Helen Joseph hospital. I have chosen Helen Joseph hospital for the following reasons:
1. It services the adult population.
2. There are a significant number of stroke and traumatic brain injured patients admitted to the hospital.
3. There is a significant number of stroke and traumatic brain injured patients that present with dysphagia at the hospital.
4. The hospital promotes and advocates research and supports the notion of evidence-based practice to inform what one does.
5. The hospital is committed to promoting better health care for all and abides by the Principles of Batho Pele and Patient's Rights.
6. Multidisciplinary teamwork is central to patient management to promote holistic treatment.
7. The population served is representative of the average South African population financially, culturally, socially and linguistically.
8. It is a secondary level academic hospital.

Details regarding the actual study can be obtained from my proposal (attached). Please also find attached all the relevant consent and information sheets. Ethical clearance will be obtained from the Human Ethics and Research Committee (Medical), University of Witwatersrand, prior to my commencement of the study, and all aspects such as confidentiality, justice, beneficence will be adhered to strictly for all involved in the study i.e. participants (patients), nurses and medical staff.

The study will require that I am involved in the assessment and dysphagia management of initially 8 patients (Stroke or Traumatic Brain Injury). Based on the results obtained, I will then continue to then recruit 20 patients into my study, with modifications made to particular aspects after completion of the Pilot study. The resident speech-language pathologist/s at Helen Joseph hospital will not be required to assume any additional work requirements, and there will be no expectation of them for the purposes of the study. During the study, I will be responsible for the dysphagia management of the selected patients, the resident therapist/s will as per normal continue with the communication intervention of these patients. Should they wish to do so, they will be free to observe my dysphagia management. I will adhere to the requirements of the hospital (completing the medical notes, communicating with the doctors and the team involved with each patient, as well as the nurses regarding the patients progress). I understand that I will be assuming part of the workload of the resident speech-language pathologist/s but also understand and accept that I will receive no payment for the services I render. I further commit to providing any additional consumables that I may require, personally at no cost to the hospital. My study will involve collaboration with nursing staff in the medical ward/s that my participants are in. I will, together with approval and consent of the Head Matron involve them in a 1 hour training session on mouth care, for which they will receive CPD accreditation. This will be done at a time suitable for them, without taking them away from their duties in the ward. Thus several training sessions may

be held. It will further involve collaboration with the multidisciplinary team and doctors, in terms of referrals and feedback on the process.

Benefits of the proposed study for your hospital:

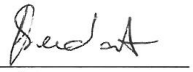
1. Being the first hospital in Gauteng to be involved in Evidence-based Research in Dysphagia.
2. Potentially improving mouth care of patients with dysphagia and thereby reducing the incidence of aspiration pneumonia.
3. With a reduction in aspiration pneumonia and better hydrated patients, decreasing occurrence of co-existing pathologies, decreasing length of hospital stay and ultimately reducing hospital costs (due to shorter hospitalisations, less referrals for tests, quicker and better results in rehabilitation).
4. Improved patient quality of life and better patient compliance with feeding recommendations.
5. Improved understanding by nursing staff of the consequences of poor mouth care.
6. Decreased costs in terms of buying thickeners such as Thick and Easy (R281,00 for a 225gram tin)
7. Increased referrals to speech-language pathology for management of dysphagic patients.
8. Availability of empirical evidence to support the dysphagia management being implemented at Helen Joseph hospital.

Potential Disadvantages

1. Initially more paper work for nurses, which would decrease with time, experience and familiarity.

It is hoped that this request will be viewed favourably and should you require any additional information or clarification, please do not hesitate to contact me at the listed numbers.

Thanking you for your time,



J. Seedat
Speech-language pathologist
University of the Witwatersrand
jaishika.seedat@wits.ac.za
Work: (011) 717 4573
Cell: 082 466 3573

APPENDIX 3

SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

School of Human & Community Development

Faculty of Humanities

University of the Witwatersrand

Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

Date: 9 March 2010

ATT: Matron Peele
Helen Joseph hospital

RE: Permission to Involve Nurses in Study at Helen Joseph hospital

Hello. My name is Jaishika Seedat. I am a speech-language pathologist working at the University of the Witwatersrand. I qualified in 1996 and worked at Johannesburg Hospital from 1997 – 2007, primarily with adults. I am currently registered to complete my PhD. My area of interest is Dysphagia in the Adult population. The title of my PhD is: Feasibility of Implementing the Frazier Free Water Protocol in a South African Acute Medical Setting - Addressing the need for Evidence-based Practice in Dysphagia.

Assessing and managing dysphagia/swallowing problems comprise a significant portion of the workload of a speech-language pathologist. The area of dysphagia is a particularly contentious issue due to the risks associated such as choking, aspiration pneumonia and mortality. Thus experience when assessing and managing dysphagia is stressed. Dysphagia is lacking an underlying evidence base to support practice. For my proposed study, I would like to assess the feasibility of implementing a protocol (Frazier Free Water Protocol) that originated in Dallas, Texas; and that is being used at the Frazier Rehabilitation Institute with success to manage patients presenting with dysphagia.

There are three principles underlying the protocol, namely, safety of water, hydration and patient compliance.
Safety of water: Aquaporin channels in the lungs allows for absorption of small amounts of water. However, mouth care and absence of gram-negative bacteria in the mouth must be ensured so that the water, if aspirated, is free of bacteria, and can thus be safely cleared without leading to aspiration pneumonia.
Hydration: Dehydration has been documented to lead to a host of negative health conditions including change in drug effects, infection, poor wound healing, pressure sores, decreased urinary volume, urinary tract infections, confusion, lethargy, constipation, altered cardiac function, acute renal failure, weakness and declining nutritional intake. This ultimately affects the rehabilitation process, length of hospital stay and inadvertently results in increased hospital costs. Thus, proper hydration (an aim of the protocol) may facilitate in alleviating these consequences.

Patient Compliance: Studies have shown that patients find thickened liquids unpalatable, leading to non-compliance which may affect occurrence of co-pathologies, resulting in increased length of hospital stays and increased hospitalisation costs. Patient quality of life warrants consideration and needs to be weighed against safety of feeding. This is accounted for in the protocol.

I would like to request permission to invite nurses to participate in this study at Helen Joseph hospital. I have obtained medical ethical clearance (certificate attached). Further I have had a meeting with Ms N. Sithole, Mr D. Mogale and Dr G. Kirby to discuss the study and the roles of the doctors and transport department for the participants. Approval has been obtained. I would therefore likely to kindly request a meeting time with you to discuss involvement of some of the nurses from the medical ward in my study. Details regarding the actual study can be obtained from my proposal (attached). Aspects such as confidentiality, justice, beneficence will be adhered to strictly for all involved in the study i.e. participants (patients), nurses and medical staff.

Briefly, the study will require that I am involved in the assessment and dysphagia management of initially 8 patients (Stroke or Traumatic Brain Injury). Based on the results obtained, I will then continue to then recruit 20 patients into my study, with modifications made to particular aspects after completion of the Pilot study. The resident speech-language pathologist/s at Helen Joseph hospital will not be required to assume any additional work requirements, and there will be no expectation of them for the purposes of the study. During the study, I will be responsible for the dysphagia management of the selected patients, the resident therapist/s will as per normal continue with the communication intervention of these patients. Should they wish to do so, they will be free to observe my dysphagia management. I will adhere to the requirements of the hospital (completing the medical notes, communicating with the doctors and the team involved with each patient, as well as the nurses regarding the patients progress). I understand that I will be assuming part of the workload of the resident speech-language pathologist/s but also understand and accept that I will receive no payment for the services I render. I further commit to providing any additional consumables that I may require, personally at no cost to the hospital. My study will involve collaboration with nursing staff in the medical ward/s that my participants are in. With your approval and consent, the nurses will be involved in a training session on mouth care. This will be done at a time suitable for them, without taking them away from their duties in the ward.

It is hoped that this request is favourably viewed. Should you require any further information or clarification, please do not hesitate to contact me.

Thanking you for your time,

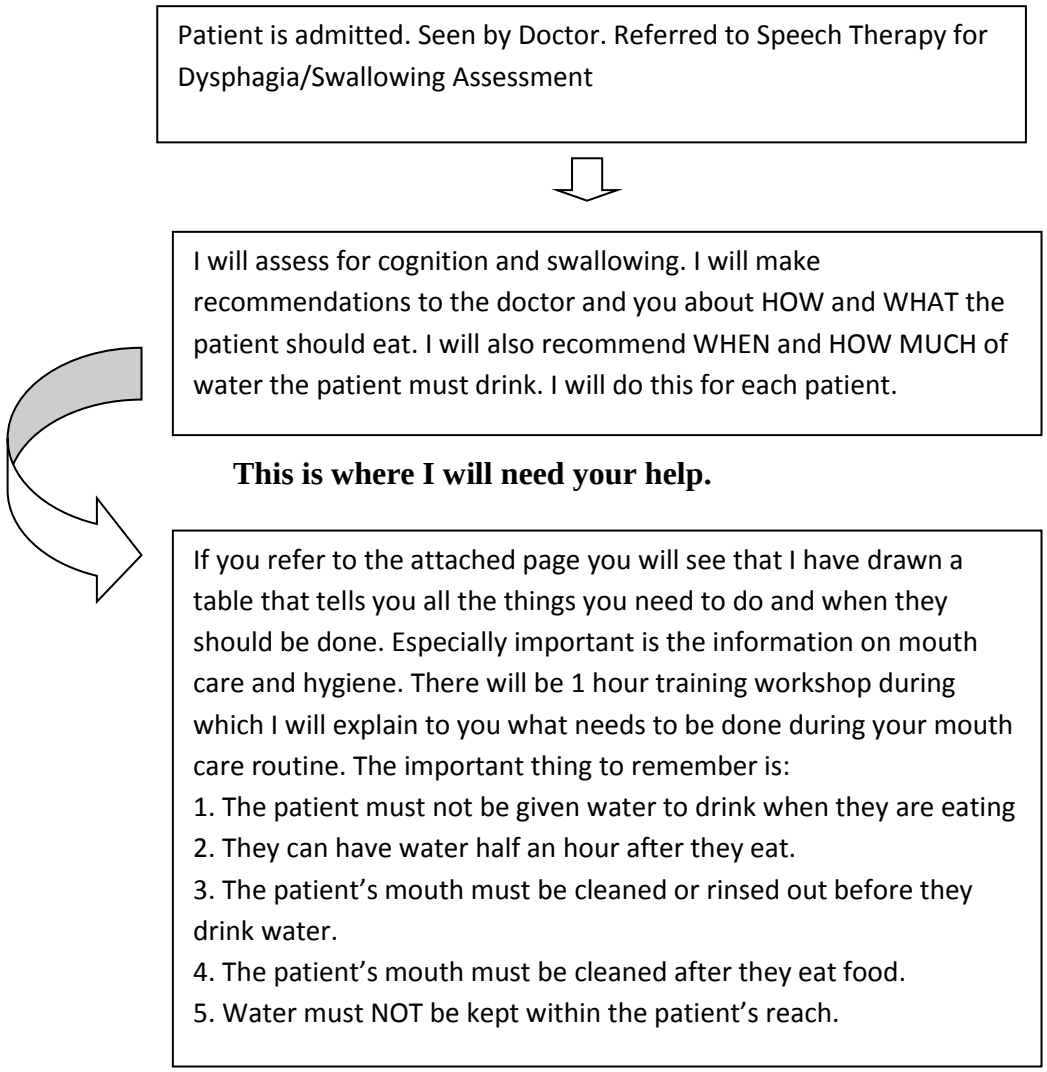


Jaishika Seedat
Speech-language pathologist
Jaishika.seedat@wits.ac.za
Tel: 011 717 4573
Cell: 082 466 3573

INFORMATION TO NURSES

Hello. My name is Jai. I am a speech-language pathologist. I am working at Wits University. As you may know that a speech pathologist works with people that have communication and/or hearing difficulties. We also assess and manage dysphagia or swallowing difficulties, which is what I am especially interested in. I am interested in doing research with stroke and traumatic brain injured patients that have swallowing difficulties. There is a protocol called the Frazier Free Water Protocol that was developed in the USA that speech-language pathologists are using to treat their adult patients who have swallowing difficulties. I want to determine if speech-language pathologists could use this protocol in South Africa, in an acute hospital setting, such as the one you are working in.

For me to determine whether this is feasible I need your assistance. The role of the nurse is very important in the protocol. I will now give you information of how the research study is going to work, and how and when you will be involved if you agree to be part of the study. As I mentioned the study will look at patients with stroke and traumatic brain injury.



You will need to make recordings of:

1. How much water the patient drinks that you know of (It is important that the patient does not get dehydrated).
2. Temperature recording (Temperature spiking may suggest that the patient is aspirating). This will be as per your normal routine.
3. Weigh the patient every morning.

Mouth Care Training

In the Mouth Care Training I will discuss the advantages and disadvantages of poor mouth care and hygiene, how mouth care is being and should be done. It will be an interactive workshop during which you can ask questions, clarify issues and comment on what you think will or will not work. I will be giving you handouts that you can use and refer to when necessary.

Your Rights

If you agree to be part of the study and receive the training, your name will be confidential on all paperwork necessary for the study. It will not be published or made public in any way. If you agree to be part of this important study, but at some point feel that you would like not to continue, you will be free to withdraw from the study. This will have no implications for your job security, your status within the ward and hospital or affect your normal duties in any way. You right to withdraw from the study will be respected.

If you agree to be Part of the Study

If you agree to be part of the study you will be required to sign a consent form indicating that you agree to be part of the study (bottom of the page). There may be times when I will be video recording what happens in the ward. Therefore you may at some point also be videoed. You will need to give consent and agree to the videoing for the purposes of the study. I will be present at the hospital every day as I will be managing the patients with the yellow wristbands. Therefore it may happen that I will sometimes watch how things are running in the ward with these patients, how the mouth care is being done by you, how often the patients are requesting for water, how they manage their food, how many visitors the patient gets and what happens during visiting hours. If you have questions at any time, please feel free to ask me. I will discuss with you how each patient is progressing at the end of each day. I understand that you are busy with different duties throughout the day and I am interested in seeing whether this new protocol will help patients recover faster and thus stay for shorter periods in the hospital. There may be difficulties you experience with this and I am interested in learning what these are; and together maybe finding a solution and a way for it to work as it does in America.

Your Role in the Study

If you are involved in the study it will be important to remember: Those patients that I will be assessing managing will have notices above their beds. Therefore, the mouth care and forms

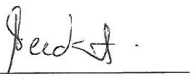
that you complete will only be for these patients. The other stroke and TBI patients (with no notices above the beds) will as per normal routine, be seen by the speech-language pathologist at the hospital – you will follow the normal protocol for these patients, in terms of intake/output/temperature/mouth care and water provision. You must not change anything you would normally have done for these patients.

For those patients with the signs

1. You will need to do the mouth care/mouth rinsing (will be discussed in workshop) before they drink any water.
2. They can drink water at any time EXCEPT when they eat and not for HALF AN HOUR AFTER THEY EAT.
3. You will need to do mouth care/rinsing AFTER they eat.
4. You will need to record:
   a] how much of water they drink every time they drink water,
   b] their weight every morning
   c] their temperature as per your normal nursing routine.

At the end of the study I will have an interview with you to discuss how you managed, what went well, what did not go so well and what you think needs to change.

If you have any questions or need me to explain in more detail, please ask me now. Thank you for your time.



Jai Seedat
Speech-language pathologist
082 466 3573
Work (011) 717 4573

INFORMATION TO PATIENT

This information sheet will be read with the investigator, together with the specially adapted participant consent form with pictoral aids.

INTRODUCTION

Hello. My name is Jai Seedat. I am a speech-language pathologist doing my PhD at Wits University. The document you are reading is an information sheet. In it I will describe the reasons for why the study is being done, how it will be conducted and what will be required of participants who are willing to volunteer. I will read this document with you in conjunction with a specially adapted form with pictures that will help to make the information clear to you. You can ask questions at any time about any aspect of this study. When we have finished reading the information sheet and talking about the study, I will make sure you have understood everything that we have spoken about by asking you some key questions and giving you more time to ask questions or clarify any information. I will give you time to think about our discussion. I will return a little later to ask if you have made a decision about participating. If you agree, I will ask you to sign a form that shows you consent to participating. You will then be given a copy of the form you sign to keep.

WHAT HAPPENS WHEN YOU HAVE A STROKE OR BRAIN INJURY

When a person has a stroke or injury to the brain different things may be affected – there may be difficulty moving the arms and/or legs, there may be difficulty with talking and understanding, there may be memory problems, or there may be difficulty with eating and drinking.

Eating is important because it gives the body nutrition and strength to get better. Drinking liquids is important so that you do not get dehydrated. You will remember that I have done a swallowing assessment on you already and it showed that you have a problem. This means that it is possible that sometimes when you eat or drink it goes down the wrong way and so not everything is going into the stomach. Some of what you eat or drink may be going into the lungs. If this is not treated, it can cause more serious problems and complications like pneumonia.

REASON FOR THE STUDY

There are many ways to help with eating and drinking difficulties, but none of the ways that we use have been tested and proven to work with people from South Africa. Most of the treatments have been tested on people from overseas countries, such as America, England and Australia. A new

treatment was developed by a lady, Kathy Panther in the United States. This treatment called the Frazier Free Water Protocol (FFWP) is being used to treat adult patients who have difficulty with eating and drinking. Ms. Panther has found that the FFWP works well and has had good results with the patients that are seen at the medical center where she works. I am interested in investigating whether this protocol can also work here in South Africa in a hospital such as Helen Joseph hospital. South Africa is different from America for different reasons such as the languages we speak, the environments we live in, the different cultures and beliefs we as South African people have about illness and life in general. The hospitals and the people working in the hospitals in America are also different to South Africa. All or any one of these differences may be the reason why this treatment may or may not work here. This is what I would like to find out.

As you have had a stroke or have had a brain injury recently, you are being invited to volunteer. If you agree to take part in the study, you will be one of about thirty people who will be asked to participate in the same manner.

THE STUDY AND MY INVOLVEMENT:

When a patient has had a stroke or brain injury such as yourself, the speech-language pathologist would normally not allow the person to have anything to drink because of the risk of it going into the lung and possibly leading to pneumonia. Instead, the person would have thickened water/tea or juice. With the treatment that I will be using you, will be allowed and encouraged to have water at specific times as long as you or the nurses ensure that your mouth and tongue are always cleaned. You will not be allowed to have any other liquids. This is important to remember. It will also be especially important that your mouth is clean at all times, especially before you have water to drink and after you have had something to eat. This is important because sometimes when a person has difficulty eating/drinking, they do not swallow all the food that is in their mouth. When food stays in the mouth and is not cleaned out, it gets bacteria. If any of this bacteria goes into the lungs it can cause a problem we call “aspiration pneumonia”, which if not treated can be dangerous. Depending on what other eating or drinking difficulties you have, I may make other suggestions and recommendations to you and your family. It is also important that your family must not bring you anything to eat and especially to drink. Only the nurse or I will give you food and water because we need to write down how much you eat and drink as part of the study.

WHAT DO YOU HAVE TO DO

The study will take place for as long as your swallowing difficulty is present and you are in hospital. Once it gets better, I will give you a follow-up appointment for one month. When you return after a month, I will ask you questions and do another swallowing assessment to see how you are managing eating and drinking. For the study:

1. I will be doing a detailed interview with you about your eating and drinking. If you choose to participate; I will have need to have access to your medical file. I will be able to get information about your temperature, weight, and any other medical conditions that may affect how you do in the study. I will be requesting your permission to access your medical file. I will get permission from your doctor to make sure that it is safe for you to participate in the study.

2. I will make recommendations about how and what kinds of things you should eat. This information will be written in your file for the doctors and nurses to see. I will also discuss with the nurse of your ward when you should be having water and when and how your mouth must be cleaned. I will put a yellow band on your wrist so that any staff member that sees you will know that you are part of the study. I will also put some charts above your bed that will explain what you can eat, some signs that the nurses must be aware of that may say whether you are having difficulty with what you are eating or drinking and your mouth care routine.

3. I will be seeing you every day while you are in the hospital. I will be present when you eat and most of the times when you drink water. I will also sometimes be with you when the nurses are cleaning your mouth.

4. I may recommend some techniques that you will need to use when you eat and/or drink water.

5. I may sometimes video how you eat and drink or how the nurse cleans your mouth. This will give me information as to how it is being done and if it is making a difference to how your swallowing is getting better. Therefore you may at some point need to be videoed. I will request permission to video you. You will need to give consent and agree to the videoing for the purposes of the study.

6. Once your swallowing problem gets better, I will carry out an interview with you, during

which we will discuss the study, your swallowing problem and what was difficult and easy to do from what I recommended during the study.

WHAT ARE THE BENEFITS OF HAVING WATER

I am hoping that by allowing you to have as much water as you want you will not get dehydrated. By not being dehydrated and eating well, your body may recover faster and you will perform and achieve better in rehabilitation. Overall, you should get better faster, therefore you may stay for a shorter period in hospital. This may also result in you having to spend less money for hospitalization and your relatives may spend less money on travelling because your hospital stay may be reduced.

WHAT ARE THE RISKS OF HAVING WATER

As I will present every time you eat and either me or the nurse when you drink, the risks of having water will be minimized. Nevertheless, the following risk can occur: if a large quantity of water that you drink goes down the wrong way i.e. into your lungs instead of your stomach and if this happens when your mouth is not clean, then the bacteria from your mouth may go into your lungs. This means that you will aspirate. Large amounts and depending on what is swallowed may lead to pneumonia. We will know if you are aspirating if you choke or cough when you drink the water. If you do not choke or cough, but still aspirate you may have a fever (we will be monitoring your temperature regularly). Either way will know if you are aspirating. I will arrange for you to have a test called a Barium Swallow immediately. This will confirm whether the water is going into your lungs and aspiration. Depending on the results and if the aspirating has resulted in pneumonia, you will receive treatment by the doctor. I will also change my treatment with you to ensure that you eat safely. If you are concerned about drinking water at any time during the study, you have the right to withdraw immediately.

WHAT HAPPENS IF I WITHDRAW FROM THE STUDY

Should you wish to withdraw from the study at any point, but still have difficulty with swallowing; you will continue to receive treatment for your swallowing difficulty from the speech-language pathologist at Helen Joseph hospital. You will stop having water, which is a thin liquid.

WHAT WILL THE STUDY COST ME

There will be no additional costs to you over and above the cost of hospitalization because of your stroke or brain injury. All utensils needed for the mouth care will be provided by me. All food and water as per routine will be supplied by the hospital.

CONFIDENTIALITY

Due to the nature of the study it is important that the staff involved (doctors, nurses, dietician) is aware that you are participating in the study. Thus while your name will appear on the hospital records, it will be protected on any data published or made public. Your name will not appear on any documents aside from your hospital medical file, unless you specifically want it to. The video material will be destroyed after it has been analyzed, unless you give separate permission to allow me to keep the material for future research purposes.

WHAT ARE MY RIGHTS

1. You have the right to withdraw from the study at any time, with immediate effect with no negative consequences to you or your right to further treatment.
2. You have the right to withhold any of the video material from me.
3. You have the right to see the results of the study.
4. You have the right to contact me at any time with any queries or concerns.
5. If you have any concerns or complaints about the study or me as the researcher, you have the right to contact the Human Research Ethics Committee (Medical) chairperson, Professor Cleaton-Jones or the Research Administrator, Ms. Anisa Keshav on 011 717 1234.

If you have any questions you need to ask me, my contact details are below.

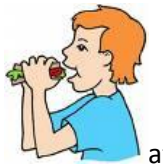
Jai (Cell) 082 466 3573

(Work) 011 717 4573

PATIENT CONSENT FORM

I, _____ (NAME OF PARTICIPANT), the undersigned, agree to volunteer in this study in writing  . In giving consent I understand the following:

1. The research is for a degree – PhD  at Wits University .

2. I will allow access to my hospital medical file . I will be assessed by Jai, the speech-language pathologist for my swallowing  after which the doctor  will decide if it is safe for me to participate in the study. The study will last for as long as I have difficulty swallowing . Jai will see me every day and will make recommendations about what and how I eat and drink  . Jai will discuss this with the nurse  who will also take care to clean my mouth  and tongue .

3. Jai will put a yellow band  on my wrist and signs 

above my bed for the nurses.

4. I may need to be videoed  when eating  or drinking water  or when the nurses  are cleaning my mouth or tongue .

5. When my swallowing  gets better  I will have an interview  with Jai and answer some questions .

6. By having water I should not get dehydrated  and my body may recover faster  so I may stay in hospital for a shorter period of time. Overall my hospital stay may therefore cost me less money . But there are no guarantees.

7. If the water goes down the wrong way  and my mouth is not cleaned, then bacteria from my mouth  goes with the water into my lungs . If this happens over a period of time and in large amounts, it can cause pneumonia.

8. If I feel uncomfortable or am worried  about drinking water, I have the right to leave the study immediately  !

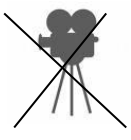
I will continue to receive treatment for my swallowing difficulties from the speech-language pathologist at the hospital.

9. There will be no additional costs to me  aside from the fees I have to pay for my hospitalization because of my stroke or brain injury.

10. The results will be written in a thesis  for a degree. I can have the results of the study after it is complete.

11. My name will be on my hospital medical file  and all the staff  that work at the hospital  will know who I am and that I am part of the study.

12. My name will not be used after the study in any material.

13. I can hold back any video material  from the researcher. The videos may be used in the future for research.

14. I can leave the study at any stage, for any reason and without negative consequences to myself.

15. I can contact Jai at any time to ask about the study.

16. I have read or spoken about this document and the information sheet. I recognise Jai Seedat as the primary researcher for this project and agree to participate in her study.

_____	_____
Participant Name (Print)	Participant Signature
_____	
Date	
_____	_____
Witness Name (Print)	Witness Signature
_____	
Date	

APPENDIX 7

Information Letter to Doctors and Allied Health Professionals

SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

School of Human & Community Development

Faculty of Humanities

University of the Witwatersrand

Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

Date: 1 June 2010

To Whom It May Concern

RE: Information on Proposed Study

Hello. My name is Jaishika Seedat. I am a speech-language pathologist lecturing at the University of the Witwatersrand. I am currently in the process of conducting research on stroke and head injured patients in the area of dysphagia. I am looking specifically at the feasibility of implementing a protocol called the Frazier Free Water Protocol in a South African Hospital. The protocol is being used internationally and advocates the adherence of strict mouth care and hygiene coupled with water intake for patients with dysphagia, under specified conditions from the speech-language pathologist (myself). The protocol addresses issues around dehydration, quality of life, patient compliance and reduced length of hospitalisation. Strict dysphagia assessment and intervention protocols will be adhered to by me with involvement from nursing staff.

Your role in the study will involve referral of all patients admitted for stroke or head injury to the speech-language pathology department. The speech-language pathologist will then notify me of the referrals. Further, during my management some of the patients referred may require videofluroscopic studies, which I have arranged to be done at Donald Gordon Hospital. I have made prior arrangement with the radiography department at Donald Gordon Hospital for the videofluroscopy. The cost of the video swallow will be covered by me. Arrangements have also been made with Mr. D. Mogale for the transportation of these patients. You would need to sign the form requesting the videoswallow. Discussions have also been held with Dr. G. Kirby, who is aware of the study and has given approval. Medical ethical clearance has been obtained.

I am grateful for your cooperation in the study. Should you require further details regarding the Frazier Protocol, please feel free to contact me. A copy of my proposal is available. Should you require any additional information or clarification, please do not hesitate to contact me at the listed numbers.

Thanking you for your time,

J. Seedat
Speech Therapist
Cell: 082 466 3573
Tel: 717 4573
Jaishika.seedat@wits.ac.za

Ms. N. Sithole
Clinical Executive

Dr. G. Kirby

Mr. D. Mogale

APPENDIX 8

Nurse Consent Form

I, _____ agree to be part of this study. I agree to attend the mouth care training workshop and implement what is taught at the workshop with only those patients that are part of the study. I also agree to follow the procedures and recommendations stipulated.

Signed _____ on this _____ day of _____ 2010.

Witness 1: _____

Witness 2: _____

APPENDIX 9

PARTICIPANT CONSENT FORM FOR USE OF VIDEO RECORDINGS

I, _____ (participants name in print), the undersigned give written consent to confirm my participation in this study. In giving consent I understand the following:

1. I will allow the researcher to videotape me while in the ward. This may be with different people at different times in the day.
2. I have the right to withhold any of the video material at any time from the researcher. At the end of the study, Jai will keep the tapes for future research.
3. My name will not be used after the study at any time, unless I want it to be.
4. I have the right to withdraw from the study at any time, with immediate effect without any negative consequences to myself or the study.
5. I have read and fully understood the accompanying information sheet and agree to be videotaped for this study.
6. I can direct any queries to Jai Seedat, the primary research for this study at any time at the details listed on the signature sheet.

_____ _____

Participant Name (Print) Participant Signature

_____
Date and Place

_____ _____
Researcher Name (Print) Researcher Signature

_____
Date and Place

_____ _____
Witness Name (Print) Witness Signature

Jai Seedat: 082 466 3573

BEDSIDE COGNITIVE AND DYSPHAGIA SCREENING

BIOGRAPHICAL INFORMATION

1. Name of Patient: _____

2. Date of Birth/Age: _____

3. Sex: _____

4. Date of Admission: _____

5. Date of Screening: _____

6: Medical History: _____

7. Caregiver information: _____

8: Contact Details: _____

9. Ward: _____

COGNITIVE SCREENING

1. Language: Orientation, Receptive, Expressive Language

CATEGORY	INADEQUATE	INCONSISTENT	ADEQUATE
General Mental Status Orientation - Name - Where are you - Is it day or night			
Reception General Greeting - How are you Commands - Point to the light/door - Stick out your tongue - Squeeze my hand as tight as you can			
Expression Basic Greeting - How are you? I'm fine thank you (expected) Naming - Keys/cup/apple/toothbrush/spoon (pictures)			
Automatic Speech Counting/Days of the Week - 1-10 - Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday			

DYSPHAGIA SCREENING

1. OSME: Visual Examination

CATEGORY	INADEQUATE	INCONSISTENT	ADEQUATE
Lips			
Tongue			
Palate			
Cheeks			
Jaw			
Respiration			
Intelligibility			
Mouth			
Saliva Control			

2. Cough

Productive	Not Productive

3. Voicing Before Swallow: _____

4. Dry Swallow

	Yes	No	Maybe
Multiple Swallows			
Coughing/Choking			
Throat Clearing			
Delayed Pharyngeal Sensation			
Swallowing			
Gurgly/Wet Voice			

5. Voicing Before: _____

6. Puree Texture

	Yes	No	Maybe
Multiple Swallows			
Coughing/Choking			
Throat Clearing			
Pooling			
Swallowing			
Aspiration Suspected			
Voicing After: Gurgly/Wet Voice			
Objective Assessment Indicated			

7. Voicing Before: _____

8. Liquid

	Yes	No	Maybe
Multiple Swallows			
Coughing/Choking			
Throat Clearing			
Pooling			
Swallowing			
Aspiration Suspected			
Voicing After: Gurgly/Wet Voice			
Objective Assessment Indicated			

9. Voicing Before: _____

10. Solid

	Yes	No	Maybe
Multiple Swallows			
Coughing/Choking			
Throat Clearing			
Pooling			
Chewing			
Swallowing			
Aspiration Suspected			
Voicing After: Gurgly/Wet Voice			
Objective Assessment Indicated			

Dysphagia Screening	Pass	Fail

Date: _____

Name: _____

Sign: _____

MORNING		MIDDAY		AFTERNOON		EVENING
☐ Weight ☐ Oral Care ☐ Breakfast – **NO WATER** ☐ Oral Care ☐ Recording	**Water given on request or offered periodically**	☐ Lunch – **NO WATER** ☐ Oral Care ☐ Recordings	**Water given on request or offered periodically**	☐ Snack – **NO WATER** ☐ Oral Care ☐ Recordings	**Water given on request or offered periodically**	☐ Supper – **NO WATER** ☐ Oral Care ☐ Recordings

PLEASE NOTE:

1. **NO WATER** must be given to the patient for half an hour after he or she has eaten. Thereafter patient can be given water.
2. **NO WATER** must be given to the patient with anything he or she eats.

BEFORE the patient has any Water, he or she MUST rinse out their mouth and you MUST clean their tongue.

MOUTH CARE, FEEDING AND SUCTIONING

INFORMATION BOOKLET FOR NURSES



Jaishika Seedat

2010

UNIVERSITY OF THE WITWATERSRAND
JOHANNESBURG

HEALTH COMMUNICATION
PROJECT

Introduction



This is an information booklet for assistant nurses, auxiliary nurses, student nurses and professional nurses. Aside from the patient himself, the nurse is the next most important team member in a hospital. Nurses play the most important role in mouth care.

I am aware that as a student mouth care was covered under hygiene and nutrition – where you learnt about structure and function of skin and its appendages and the gastrointestinal tract. Mouth care [brushing of teeth twice a day, assisting patients on bed rest with mouth care, mouth care of unconscious patients, mouth rinses with medication etc., nutrition related to mouth hygiene (fluoride, apples etc.)] was taught. This information booklet is an extension to what you know already about mouth care and is aimed at providing more detail about the following:

1. **Mouth care and tooth brushing** — why is it important, what happens if not done, who should receive it and how it should be done?

2. **Feeding** - why is it important for stroke patients, oral vs. non-oral feeding of stroke patients, what can happen if incorrect foods and feeding techniques are used, some suggestions.

3. **Suctioning** - importance of suctioning when doing mouth care for stroke patients with feeding difficulty, what happens if patient is not suctioned, how it should be done.

4. **Glossary** of terminology used

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MOUTH CARE





Why is it important?

Digestion starts in the mouth. Research indicates that a clean mouth prevents aspiration pneumonia, gum disease, and helps prevent heart disease. Salivary flow is reduced by some medications and medical treatments. Reduced saliva flow results in less natural washing away of mouth bacteria. Thus reduced saliva and poor or no mouth care will "help" bacteria to grow in the mouth. This may have many negative consequences for people with no medical problems. For those patients with medical problems and difficulty eating and drinking, the problems can become more severe and will be discussed below.

Some positive benefits of mouth care:

- Improved chewing, swallowing, & speaking
- Improved facial appearance
- Less risk for aspiration of bacteria
- Improvement in patient's quality of life



What can happen if not done?

The need for regular and appropriate mouth care and hygiene is clear. The complications that can result if not done are serious. Some of the reasons why mouth care may be poor or inadequate in patients include:

- Inability to complete personal mouth hygiene
- Dependence on staff/caregivers for mouth care
- Active smoking
- Depression
- Use of sedative medication
- Poor feeding position
- Eating and drinking difficulties
- Physical difficulties (e.g. hemiparesis)

Some complications that may arise if mouth care is not done consistently include:

- Bacteria is not cleaned out.
- Patient may present with bad breath (Halitosis).
- Patient will have "bad" taste in mouth.
- Gum disease.
- Food that is eaten and not swallowed will remain in sulci (space between gum and cheek).



Some complications for <u>dysphagic</u> patients include:

- Decreased production of saliva.
- Tongue may become white and thick, "caked" with residue.
- The food that collects may be aspirated and over time will lead to aspiration pneumonia and possibly death.



<u>Who should receive mouth care?</u>



All patients need and should have mouth care for the reasons provided above. It is important to remember that all patients in hospital are there because of some medical reason and so are considered sick. Thus they require medical intervention and monitoring. Even patients that are in intensive care units and who are in comas must receive mouth care.

It is important to note that when we are awake we swallow at least 580 times in the day. When we are asleep, we can go for at least 20 minutes or more with no swallowing occurring. So patients can aspirate when they are not eating or drinking or when asleep. If these patient's mouths are not cleaned after eating and if some bits of food remain on the tongue or in the sulci, this can go down with the saliva they swallow when asleep, directly into the lungs. This is called "silent" aspiration.

With patients in a coma, they are not eating. However their mouths do collect bacteria, and instead of food going down with the saliva into their lungs, the bacteria goes down with the saliva they swallow. This then becomes dangerous and risky.

Therefore ALL patients in hospital for WHATEVER reason MUST HAVE mouth care.

Why nurses?

There have been studies done that show that nurses and caregivers want additional training and information to ensure that:

- Mouth care procedures are adequately done.
- Mouth care procedures are adequately supervised and monitored.
- Frequency/schedule for completing mouth care procedures is trained.
- Frequency/schedule for competing mouth care procedures is monitored to ensure that the current policies and procedures are being followed.
- Training is completed that shows the relationship between poor mouth health and the potential for significant medical complications.

  Caregivers need to understand that mouth hygiene plays a preventative role and may reduce the risk of delivering dangerous bacteria to the lungs (Panther, 2005).

Suggested mouth care procedure



Materials: Depending on the needs of the patient you will need: gloves, flashlight, tongue depressor, toothbrush, toothpaste, basin, mouthwash, mouth swabs, water, tissue, gauze, tweezers and suction machine.

For Independent Patients: Set up with toothbrush/toothpaste, water, mouthwash, and basin. Allow patient to brush, gargle and spit if able to spit and not an aspiration risk. Speech-language pathologist will let you know if it is safe for patient to do tooth brushing himself and if patient does not have difficulty. Patient will still need 1:1 supervision and cues to rinse/spit and *not to drink the water.*





For Dependent Patients: Speech-language pathologist will advise you which patient needs assistance and cannot manage by him/herself. Use a small amount of toothpaste and water. Ensure that suction equipment is plugged in and is being used at all times as outlined in the table below. Foam tipped brush soaked in mouthwash is to be used after cleaning.



Special attention should be given to these patients:

- NPO (patients not on oral feeds)
- Mouth care dependent
- Frequently coughing/choking on own secretions /saliva
- Recently extubated patients
- Patients with tinged secretions

Mouth Care Schedule:



- Every morning, especially prior to any oral intake, medications or water.
- After every meal, to remove any food or liquid particles/residue.
- For the NPO patient, as often as is warranted. Can be performed along with other routine nursing care.
- Rinsing of mouth prior to drinking any water during the course of the day.

Areas in the mouth that need cleaning:

1. Lining of the mouth and cheeks



2. Tongue surface

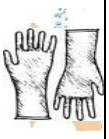
3. Areas around the gums, the upper and lower teeth.



4. Hard and soft palate, back of the tongue and the pharyngeal wall if necessary.



5.  Dentures should be cleaned twice a day and soaked overnight

STEPS	WHY?	TO NOTE!
1. Wash hands and put on examination gloves 	Decreases transmission of germs and body secretions.	Use non-latex glove if patient is allergic to latex.
2. Explain to patient that his/her mouth will be cleaned with toothpaste, mouthwash and water. 		
3. Set up suction equipment.		
4. Check to see that patient is able to spit.	If unable to spit, oral suctioning  equipment must be on stand-by with a nurse.	
4. Assist the patient to a sitting position on bed if health permits. If not, prop	Minimise the potential for	Have nurse 2 available to hold basin for

against pillows and have on hand a basin to spit into if patient able to spit.  If patient unable to spit, prop against pillows and allows easy access with suction machine.	aspiration of mouth secretions.	patient. Nurse 2 must be ready  with suction machine.
5. If patient is unresponsive and/or has clenched the mouth shut, use the mouth prop provided to gently open the mouth. 		Nurse 2 to assist with insertion of mouth prop.
6. Gently brush patient's teeth (using brush provided) to remove any food residue. Hold the brush at 45 degree angle and move back and forth using a vibrating or jiggling motion, from the guns to the crown (top) of the teeth. Clean the biting surface by moving the brush back and forth over them in short strokes.  If the tongue is coated, brush it gently with the toothbrush using a back and forth motion. Brush for approximately one to two minutes (stopwatch provided).		
7. Ask the patient to spit out into the basin provided. If patient is unable to spit, use the suction machine to suction up all the toothpaste and saliva.		Nurse 2 to hold out basin. 

8. Provide patient with a sip of water to gargle and rinse out mouth. 		Nurse 2 to provide water in cup.
9. Patient must be asked to spit out again, and if unable to introduce water to the anterior of the mouth with a syringe and suction immediately. 		Water in syringe must be available. Nurse 2 should suction as soon as tooth brushing is completed and again after water is introduced by nurse 1.
10. Step 8 and 9 should be repeated a minimum of two times.		
11. Provide the patient with 15ml of the mouth wash. Ask patient to sip but not swallow. Gargle and spit out into basin provided. If unable to sip and spit out, introduce mouthwash with foam sponge dipped in mouth was. Must be applied to all surfaces of teeth, gums ad teeth. Suctioning to be done after completion.		Mouthwash must be ready and available for use for independent patients.  Foam tipped brush dipped in mouthwash to be ready and available for use. Nurse 2 to suction immediately after application.
12. Do a visual observation of the oral cavity. Suction any excess saliva that may be present. 		Nurse 2 to suction as directed by nurse 1.

FEEDING



Why is eating the correct types of food and drinking the correct types of liquid important:



When a patient is admitted to hospital, the doctor first assesses and diagnoses the patient. After this assessment the doctor is able to say how the patient is managing eating and drinking based on the case history he obtains either from the patient, the caregiver or family. If necessary, he makes a referral for the patient to be seen by the speech-language pathologist, who will assess the eating and drinking in detail. If the patient only starts having difficulty a little later, it is often the nurse who reports the eating or drinking difficulty to the doctor who then refers the patient to speech-language pathology.

Patients that have strokes or who suffer head injury often have difficulty and need assessing. The speech-language pathologist is able to say if it is safe for the patient to eat orally or not. If able to eat orally, she is able to say what consistency of food the patient can eat safely, and how the patient should be positioned to eat or drink safely. With these patients it is important to remember that ***liquids*** are the most difficult to drink safely – if you see patients managing something as thick as yogurt, they may still have difficulty with water.

What is safe feeding?

Safe feeding is when the food or liquid that is given to the patient goes directly into the stomach without any portion entering the lungs. If any bit of the food or liquid goes into the lungs, it means that the patient has aspirated. There are two ways that the patient can aspirate:

1. ***Observable aspiration:*** You will know that the patient has aspirated because he will



choke or cough and show signs of distress when either eating, drinking or both. You will note that there is an increase in temperature that has no other explanation i.e. there is no presence of any other infection.

2. ***Silent aspiration:*** There will be no observable signs to alert you to the fact that the patient has aspirated. So s/he will not cough, choke or present with any observable signs of difficulty with eating or drinking. You will note that there is an increase in temperature that cannot be explained – the patient does not have any other infection. This can happen at any time: during the day, at night, when the patient is awake or when he is asleep.



Aspiration can happen because:

- the patient cannot manage a particular type of consistency e.g. liquids
- the patient cannot "control" how s/he eats and how much s/he eats or drinks
- the patient needs to be in a certain position when eating or drinking
- the patient needs to use a particular manoeuvre or technique when eating or drinking

The head position, manoeuvre, technique and consistency will be chosen by the speech-language pathologist. Your assistance will be needed to ensure that these are carried out correctly every time the patient eats or drinks. The speech-language pathologist will discuss the eating plan for the patient with you in detail. You can ask the therapist any question you may have or for any clarification that may be needed. There will be signs above the patients bed that will specify what the patient must eat and drink and how. The chart will also say how you need to do the mouth care discussed above. There will also be a yellow chart above the bed that will tell you to encourage the patient to drink water. Please remember that water must only be given to the patient at certain times – the chart on page 19 gives you this information.



ORAL SUCTIONING



What is oral suctioning?

Oral suctioning is the removal of excess food, saliva or retained secretions from the patients' mouth, under the tongue, on the tongue, in the space between the gum and cheeks and back of tongue. If oral suctioning is done during oral care, then saliva, toothpaste and mouthwash is removed to prevent the patient from swallowing any of the above. Oral suctioning can be uncomfortable and painful for the patient. Careful and brief explanation to the patient before starting oral care routine and suctioning; and care taken during the actual routine will allow the patients to be more relaxed and less nervous.

The importance of oral suctioning during mouth care routine:

The mouth flora of ill patients is different from that of healthy individuals and contains



organisms that can quickly cause pneumonia. Patients that have had a stroke or brain injury may have difficulty chewing and swallowing correctly. They may therefore aspirate when eating or aspirate silently when at rest or at night. When they are having their teeth and mouth cleaned, they may not have good control over the water and toothpaste in their mouth, and may therefore swallow this and the bacteria during the cleaning process. It is therefore extremely important that nothing is swallowed – and the only way to prevent this from happening is to suction the patient during the procedure.

Who must receive oral suctioning?

I will discuss with you which patients: 1) need your help with mouth care, 2) can or cannot spit out. For those patients that are able to spit out, there is no need for them to be



suctioned when you are cleaning their teeth and mouth. For those patients who are not able to spit out, you will then have to clean their teeth and mouth and at the same time suction their mouth. Thus, two nurses will have to work with these patients at a time.

Signs of Possible Aspiration Pneumonia

1. **Frequent coughing.** The cough may bring up bad smelling mucous from the lungs. This phlegm may have pus or streaks of blood in it. The patient may also cough up frothy (bubbly) fluid from the lung.

2. **Shortness of breath or noisy breathing** may be seen and heard. The patient's **heartbeat** (**while resting) may seem faster than normal.**

3. **Fever or chills** may be seen. The patient may **sweat** a lot.

4. The patient may report **chest pain** when coughing or taking in a deep breath.

5. The patient may complain of **trouble swallowing** or the feeling of something being stuck in the throat.

6. The patient may report feeling **dizzy, faint or have new trouble thinking (confusion)**. They may feel anxious or upset. They may feel like they **cannot get enough air**. The patient's **skin, lips or fingernails may turn dusky or blue.**

PLEASE CONTACT A SPEECH THERPAIST IF YOU NOTICE ANY OF THESE SIGNS.

Thank you.

Additional Information

Swallowing Problems – Signs & Symptoms

The person may demonstrate any of these alone or in combination:

Symptoms of swallowing problems:

 Chest infections or pneumonia

 Fever

 Weight loss

 Poor nutrition

 Dehydration

Signs of swallowing problems:

 Coughing during or after meals.

 Life threatening choking, restricted breathing.

 Dribbling saliva, food or fluid from the mouth.

 Food residue inside the mouth or cheeks during and after meals.

 Gurgly, or wet voice quality during or after meals or loss of voice.

 Lengthy mealtimes.

 People may fear or avoid eating.

 Spitting out food or pieces of food.

 Several swallows are needed per mouthful.

 Frequent throat clearing during and after meals.

 Watering eyes when eating or drinking.

 Food or fluid comes up into the nose.

 There is a visible effort to swallow.

Breathing patterns may change (e.g. shorter or more rapid breathing).

 Difficulty chewing food.

 Difficulty swallowing medications.

 There can be discomfort during swallowing.

 People may become socially isolated or depressed.

APPENDIX 13

INTERVIEW WITH NURSE

(To be completed by investigator. Clarification and discussion will vary according to information provided by interviewee. Questions are a guideline.)

BIOGRAPHICAL INFORMATION

Number: | | | (For Investigator)

Qualification: _____

Date of Birth and Age: _____

Gender:

Male	Female

Race:

Black	White	Coloured	Indian

Year Qualified and Place: _____

Number of years working at Helen Joseph hospital:

_____

Previous Work History: _____

_____

_____

BACKGROUND INFORMATION

Average number of hours worked a week: _____

Home address: _____

Mode of transportation to work: _____

List current duties: _____

_____

_____

_____

_____

What do you enjoy about your work? _____

_____

_____

What are some of the difficulties you experience in terms of your work? _____

_____

_____

_____

Why did you want to be a nurse? _____

_____

_____

_____

THE STUDY

Do you think the workshop was helpful? _____

_____

What would you change to make it better? _____

_____

_____

Why is mouth care important for patients that have swallowing and eating difficulties?

_____

_____

_____

What were some of the things that were easy for you to do (related to requirements of the study)?

_____

_____

_____

_____

What were some of the things that were difficult for you to do (related to requirements of the study)?

_____

_____

_____

_____

Why was it difficult? _____

_____

_____

What can be done to change this? _____

_____

_____

Do you think that regular mouth care should be done for all patients?

_____

In your experience, do patients generally drink enough water in hospital? _____

Is dehydration and malnutrition a problem in the hospital? _____

Having been part of the study, how important is the role of the nurse for this protocol to succeed and why? _____

_____

_____

_____

ADDITIONAL INFORMATION

_____

_____

_____

_____

_____

_____

_____

QUESTIONNAIRE ADDRESSING FREE WATER PROTOCOL PROCESS (DOCTORS AND ALLIED HEALTH PROFESSIONALS)

BIOGRAPHICAL INFORMATION

Profession: _____
Year of Qualification: _____
No. of years working in present hospital: _____
Gender: _____
Race: _____

KNOWLEDGE

Do you think you had a good understanding of the FFWP? _____
_____
Do you agree with the principles underlying the FFWP? _____
_____
_____

FFWP

To what extent were you involved in the present study/what was your role? _____
_____
_____
How was this different from your conventional involvement with dysphagic individuals? ___
_____
_____
Do you think the FFWP benefitted/did not benefit/was no different than the normal management for dysphagia? _____
_____
_____
What were some of the limitations/obstacles from your perspective with the use of the FFWP with dysphagic patients? _____
_____
_____
What were some of the things that went well with using the FFWP for your dysphagic patients? _____
_____
_____

GENERAL

Additional information
_____
_____
_____
_____
_____

Thank you for completing this Questionnaire!

Contact Details and Follow-Up Appointment

Hello _____. I want to thank you for being part of this important study. You have done extremely well during your stay at the hospital. Please remember all the techniques taught to you when you are eating at home. More importantly, please remember how important it is that you clean your mouth at home as was being done at the hospital.

The mouth, tongue and teeth must be cleaned before and after anything that you eat. This will prevent any bacteria that may be in your mouth from getting into your lungs if you do have a problem.

I will be phoning you on _____ and again on _____ to see how you have been managing with eating.

If after speaking to you I feel that you need to be seen, I will arrange an appointment for you with the speech-therapist at Helen Joseph hospital. Otherwise we will discuss what has been easy and difficult for you to manage eating and confirm that you have been managing to clean your mouth after you eat.

If you need to contact me before your appointment, my number is: (w) 011 717 4573 – where you can leave a message if I am not available and I will get back to you. Otherwise you can contact me on my cell phone: 082 466 3573.

Thank you again and keep well.

Environmental Assessment

1. Average number of stroke patients admitted weekly: _____

2. Average number of traumatic brain injured patients admitted weekly: _____

3. Feeding Times:

Breakfast: _____

- Lunch: _____
- Supper: _____

4. Mouth Care:

- When/How Often: _____
- How: _____

Materials Used: _____

5. Temperature Charting:

When: _____

Additional Information: _____

_____

_____

6. Food Intake Recordings:

- When : _____

Additional Information: _____

_____

_____

7. Feeding Routines:

- Assistance Provided When Needed: _____
- Food Left Uneaten – Why: _____
- Role of Caregivers: _____
- Nurses: How (amounts, speed, utensils): _____

_____

8. Weight Recording:

- When: _____
- Additional Information: _____

_____

9. Referral Procedures:

_____

_____

10. Additional Information:

_____

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Date: _____

Time: _____

APPENDIX 17

Investigator Observation of Patient with Dysphagia

Participant: _____

Date	Interactions/Responsiveness	Visitors	Requesting	Food at Bedside	Additional Notes

APPENDIX 18

Nursing Notes on Water Consumed

Patient: _____

Date	Time	Nurse	Amount of Water	Additional Info

APPENDIX 19

Nursing Notes on Mouth Care Sessions

Patient: _____

Date	Meal Consumed	Mouth Care Before Meal (Yes/No)	Mouth Care After Meal (Yes/No)	Nurse	General

Batho Pele Principles

Eight Batho Pele principles were developed to serve as acceptable policy and legislative framework regarding service delivery in the public service. These principles are aligned with the Constitutional ideals of:

- Promoting and maintaining high standards of professional ethics;
- Providing service impartially, fairly, equitably and without bias;
- Utilising resources efficiently and effectively;
- Responding to people's needs; the citizens are encouraged to participate in policy-making; and
- Rendering an accountable, transparent, and development-oriented public administration

The Batho Pele principles are as follows:

1. **Consultation**

   There are many ways to consult users of services including conducting customer surveys, interviews with individual users, consultation with groups, and holding meetings with consumer representative bodies, NGOs and CBOs. Often, more than one method of consultation will be necessary to ensure comprehensiveness and representativeness. Consultation is a powerful tool that enriches and shapes government policies such as the Integrated Development Plans (IDPs) and its implementation in Local Government sphere.

2. **Setting service standards**

   This principle reinforces the need for benchmarks to constantly measure the extent to which citizens are satisfied with the service or products they receive from departments. It also plays a critical role in the development of service delivery improvement plans to ensure a better life for all South Africans. Citizens should be involved in the development of service standards.
   Required are standards that are precise and measurable so that users can judge for themselves whether or not they are receiving what was promised. Some standards will cover processes, such as the length of time taken to authorise a housing claim, to issue a passport or identity document, or even to respond to letters.
   To achieve the goal of making South Africa globally competitive, standards should be benchmarked (where applicable) against those used internationally, taking into account South Africa's current level of development.

3. **Increasing access**

   One of the prime aims of Batho Pele is to provide a framework for making decisions about delivering public services to the many South Africans who do not have access to them. Batho Pele also aims to rectify the inequalities in the distribution of existing services. Examples of initiatives by government to improve access to services include such platforms as the Gateway, Multi-Purpose Community Centres and Call Centres.

Access to information and services empowers citizens and creates value for money, quality services. It reduces unnecessary expenditure for the citizens.

4. **Ensuring courtesy**

   This goes beyond a polite smile, 'please' and 'thank you'. It requires service providers to empathize with the citizens and treat them with as much consideration and respect, as they would like for themselves.
   The public service is committed to continuous, honest and transparent communication with the citizens. This involves communication of services, products, information and problems, which may hamper or delay the efficient delivery of services to promised standards. If applied properly, the principle will help demystify the negative perceptions that the citizens in general have about the attitude of the public servants.

5. **Providing information**

   As a requirement, available information about services should be at the point of delivery, but for users who are far from the point of delivery, other arrangements will be needed. In line with the definition of customer in this document, managers and employees should regularly seek to make information about the organisation, and all other service delivery related matters available to fellow staff members.

6. **Openness and transparency**

   A key aspect of openness and transparency is that the public should know more about the way national, provincial and local government institutions operate, how well they utilise the resources they consume, and who is in charge. It is anticipated that the public will take advantage of this principle and make suggestions for improvement of service delivery mechanisms, and to even make government employees accountable and responsible by raising queries with them.

7. **Redress**

   This principle emphasises a need to identify quickly and accurately when services are falling below the promised standard and to have procedures in place to remedy the situation. This should be done at the individual transactional level with the public, as well as at the organisational level, in relation to the entire service delivery programme.
   Public servants are encouraged to welcome complaints as an opportunity to improve service, and to deal with complaints so that weaknesses can be remedied quickly for the good of the citizen.

8. **Value for money**

   Many improvements that the public would like to see often require no additional resources and can sometimes even reduce costs. Failure to give a member of the public a simple, satisfactory explanation to an enquiry may for example, result in an incorrectly completed application form, which will cost time to rectify.

APPENDIX 21

The Patients' Rights Charter

For many decades the vast majority of the South African population has experienced either a denial or violation of fundamental human rights, including rights to health care services. To ensure the realisation of the right of access to health care services as guaranteed in the Constitution of the Republic of South Africa (Act No 108 of 1996), the Department of Health is committed to upholding, promoting and protecting this right and therefore proclaims this **PATIENTS' RIGHTS CHARTER** as a common standard for achieving the realisation of this right.

This Charter is subject to the provisions of any law operating within the Republic of South Africa and to the financial means of the country.

A healthy and safe environment

Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection.

Participation in decision-making

Every citizen has the right to participate in the development of health policies and everyone has the right to participate in decision-making on matters affecting one's health.

Access to healthcare

Everyone has the right of access to health care services that include:

vii. receiving timely emergency care at any health care facility that is open regardless of one's ability to pay;

ii. treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;

viii. provision for special needs in the case of new-born infants, children, pregnant women, the aged, disabled persons, patients in pain, person living with HIV or AIDS patients;

iv. counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS;

v. palliative care that is affordable and effective in cases of incurable or terminal illness;
vi. a positive disposition displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance; and
vii. health information that includes the availability of health services and how best to use such services and such information shall be in the language understood by the patient.

Knowledge of one's health insurance/medical aid scheme

A member of a health insurance or medical aid scheme is entitled to information about that insurance or medical aid scheme and to challenge, where necessary, the decisions of such health insurance or medical aid scheme relating to the member.

Choice of health services

Everyone has the right to choose a particular health care provider for services or a particular health facility for treatment provided that such choice shall not be contrary to the ethical standards applicable to such health care providers or facilities, and the choice of facilities in line with prescribed service delivery guide lines.

Be treated by a named health care provider

Everyone has the right to know the person that is providing health care and therefore must be attended to by clearly identified health care providers.

Confidentiality and privacy

Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or an order of the court.

Informed consent

Everyone has the right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and the costs involved, for one to make a decision that affects anyone of these elements.

Refusal of treatment

A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others.

Be referred for a second opinion

Everyone has the right to be referred for a second opinion on request to a health provider of one's choice.

Continuity of care

No one shall be abandoned by a health care professional worker or a health facility which initially took responsibility for one's health.

Complain about health services

Everyone has the right to complain about health care services and to have such complaints investigated and to receive a full response on such investigation.

Every patient or client has the following responsibilities:

- to advise the health care providers on his or her wishes with regard to his or her death.
- to comply with the prescribed treatment or rehabilitation procedures.
- to enquire about the related costs of treatment and/or rehabilitation and to arrange for payment.
- to take care of health records in his or her possession.
- to take care of his or her health.
- to care for and protect the environment.
- to respect the rights of other patients and health providers.
- to utilise the health care system properly and not abuse it.
- to know his or her local health services and what they offer.
- to provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes.

Detailed Statistical Analysis Conducted

The client has collected data for two groups of patients presenting with dysphagia and stroke or traumatic brain injury at a government hospital in Johannesburg:

- Study group (n=23)
  - Data collected by prospective study.
  - Patients treated according to the Frazier Free Water Protocol (FFWP) which included the provision of oral care.
- Comparison group (n=23)
  - Data collected by retrospective record review.
  - Patients treated according to standard protocol which did not include the provision of oral care or free water intake.
- For both groups, patients included in the study were limited to those aged 45-65y, with stroke or traumatic brain injuries only, who were alert and able to follow instructions, able to spit out on command, and were able to speak English. Patients with potentially confounding medical conditions were excluded.

The following data was collected for each patient:

Covariates

- Gender
- Race
- Age in years
- Diagnosis (CVA=stroke / HI=head injury)
- Cognitive score at start of treatment (available only for study group) = measure of injury severity

Dependent variables

- AP = Occurrence of aspiration pneumonia (Y/N)
- DAYS = Duration of intervention (days)
  - This is less than or equal to the duration of hospitalisation since it was not always possible to start patients on the intervention on the same day they were admitted, due to the administrative processes of the hospital.
- WAT =Total amount of water taken in over the intervention period (ml)
- WD = Amount of water consumer per day of intervention (calculated from the above variables: WD = WAT / DAYS) (ml/day).

Research Questions (for these analyses)

- Is there a significant difference in AP between the two groups, controlling for age, gender, diagnosis and WAT or WD?
- Is there a significant difference in DAYS between the two groups, controlling for age, gender, diagnosis and WAT or WD?
- Is there a significant difference in WAT between the two groups, controlling for age, gender, diagnosis and DUR?
- Is there a significant difference in WD between the two groups, controlling for age, gender and diagnosis?
- Within the study group alone, is there a significant difference between the CVA and HI groups, w.r.t
  - DAYS, controlling for age, gender, cognitive score and WAT or WD?
  - WAT, controlling for age, gender, cognitive score and DUR?
  - WD, controlling for age, gender and cognitive score?

Data

The following data files were provided: Patient Data v2.xlsx and Cognitive screener rating.xlsx

Analysis: general

Data analysis was carried out in SAS. Citation: SAS Institute Inc., *SAS Software, version 9.3 for Windows,* Cary, NC, USA: SAS Institute Inc. (2002-2010).

The 95% confidence level was used throughout, unless specified otherwise.

For tables and graphs, see the spreadsheet 'JS_Results.xlsx'.

Data Cleaning
No data cleaning was required.

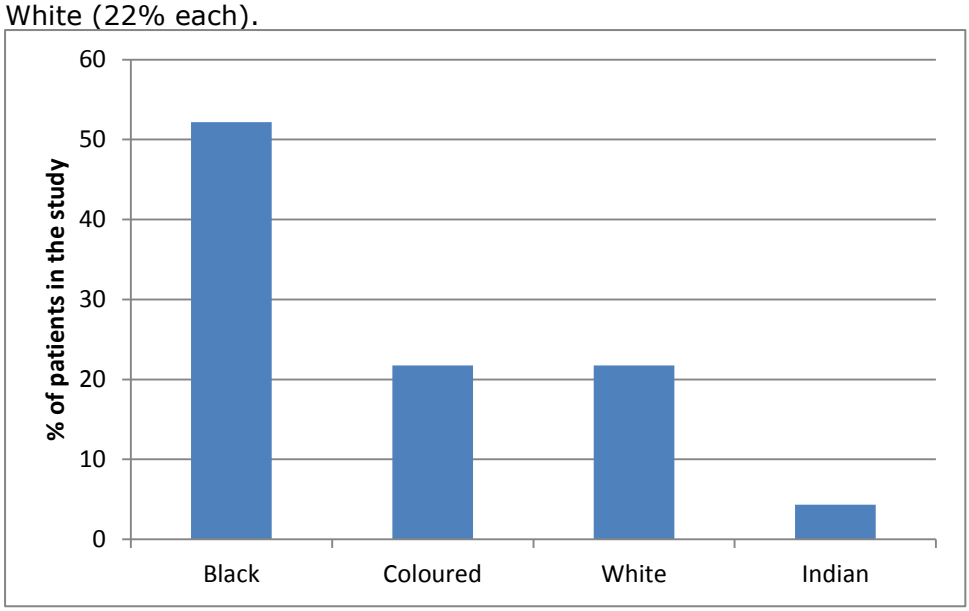
Analysis

Covariates (spreadsheet tab: Covariates)

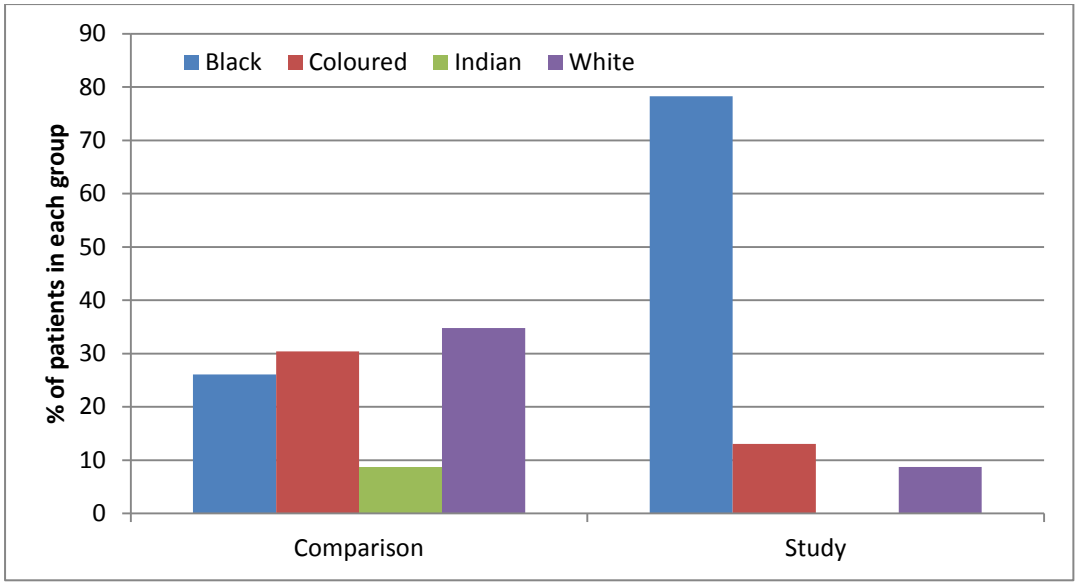
We start by looking at the covariates as a whole and how they compare between treatment groups. Ideally, we would like to show that there is no significant difference between the two groups w.r.t. the covariates.

Gender: There were equal numbers of male and female patients in the study. There was no significant difference in the gender composition of the study and comparison groups (Fisher's exact test; p=1.0). *Tables for this and the other comparisons are in the spreadsheet in case you want them.*

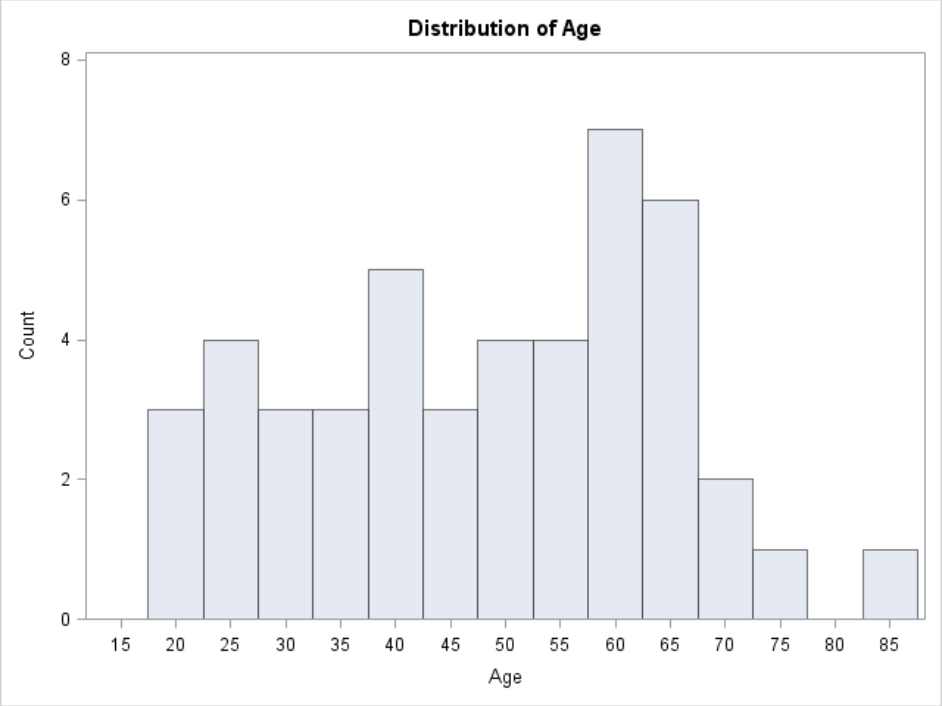
Race: The majority of patients (52%) in the study were Black, followed by Coloured and White (22% each).



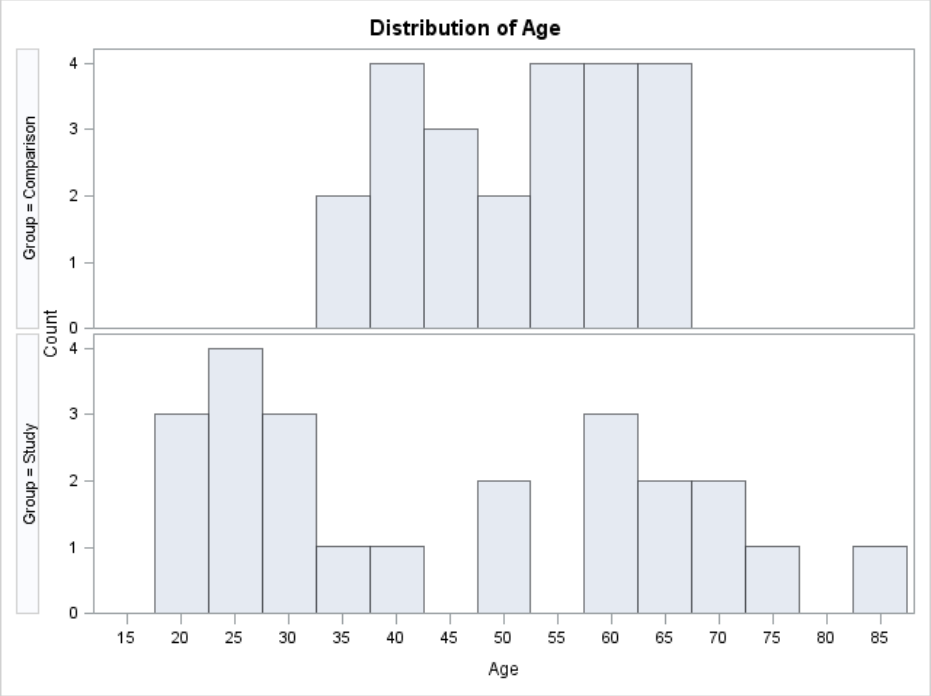
There was a significant, strong, association between race and group (Fisher's exact test; p=0.003, Phi coefficient=0.54), as illustrated below:



Age: The mean age was 48y (sd=17y; median=50y; interquartile range 30-62y). The frequency distribution of ages is shown below. Note that many ages lie outside of the 45-65y age range given in the research proposal.

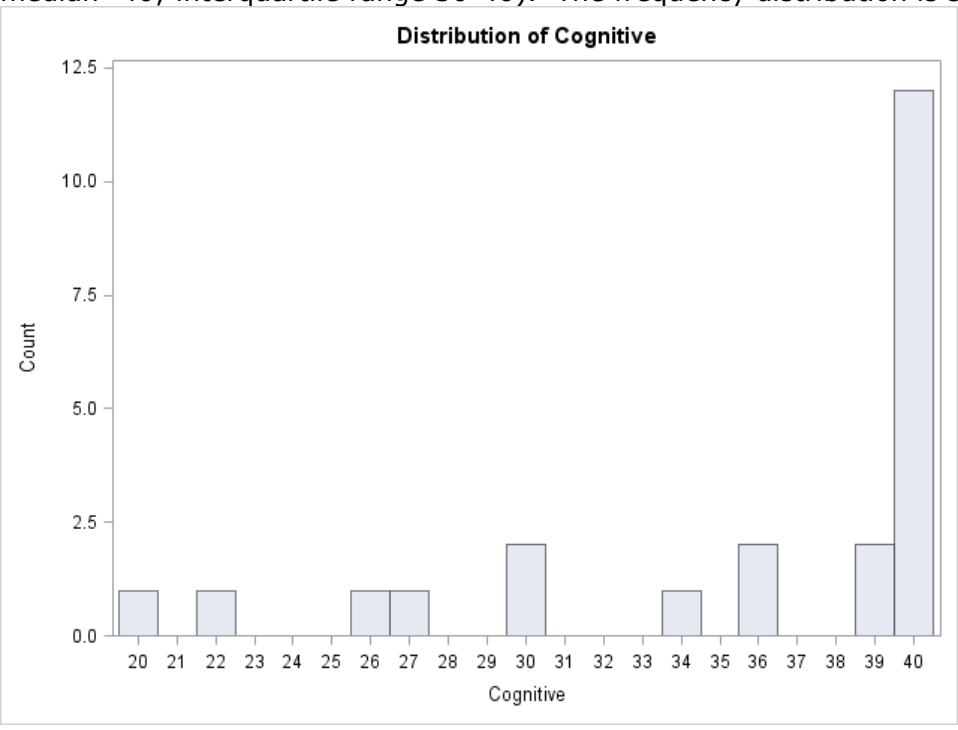


There was no significant difference in the mean age between the two groups (t-test with unequal variances: p=0.16). Comparison group: mean age = 51.5 ± 4.3y; study group: mean age = 44.5 ± 9.0y. *The latter value in each case is the 95% confidence interval.* Note that the distribution of ages in the study group was much wider than that in the comparison group.



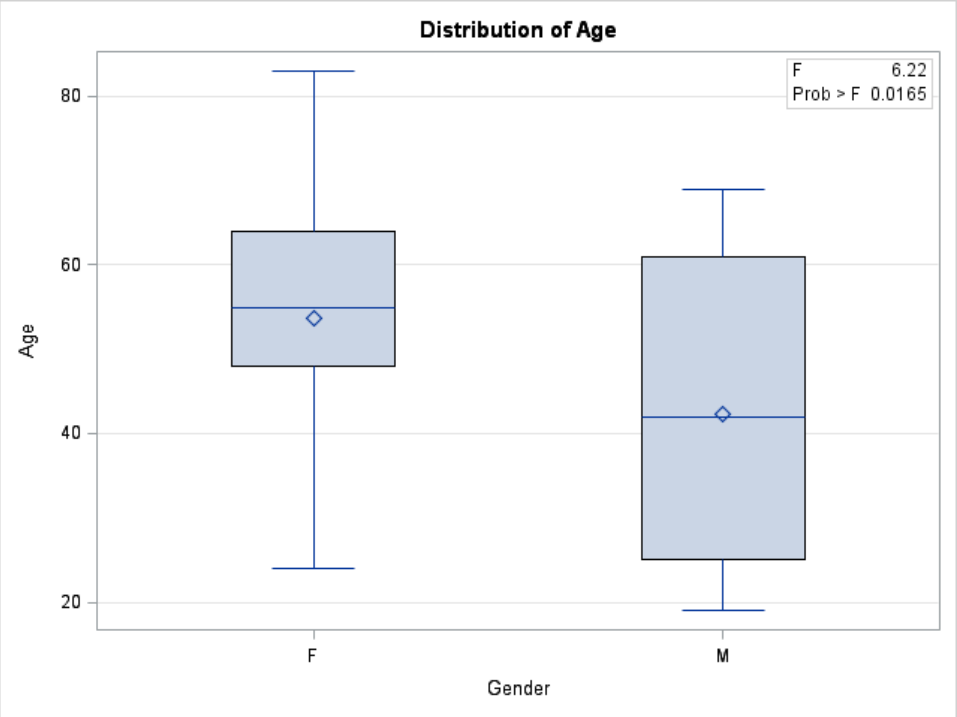
Diagnosis: 70% of the patients in the study had CVA, while the remainder had TBI. There was no significant difference in the injury composition of the study and comparison groups (Fisher's exact test; p=0.75).

Cognitive ability (study group only): The mean cognitive score was 35.6 (sd=6.5; median=40; interquartile range 30-40). The frequency distribution is shown below.

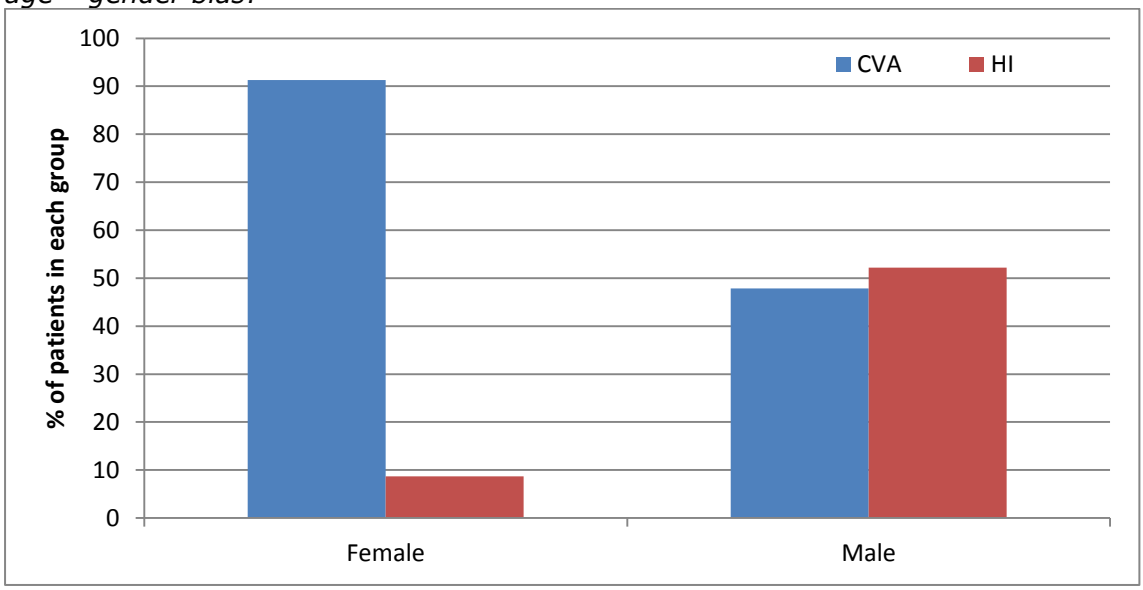


We now look at how the covariates relate to each other:

Gender x Age: The mean age of the females in the study (53.7 ± 6.3y) was significantly higher than that of the males in the study (42.2 ± 7.2y) (t-test with pooled variances: p=0.017).



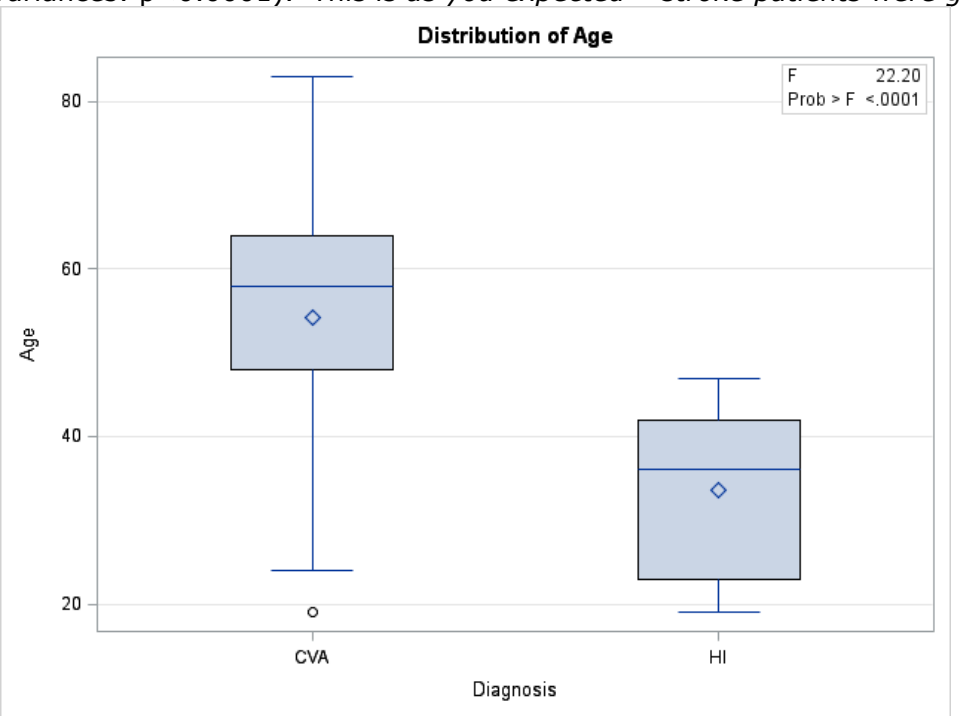
Gender x Diagnosis: There was a significant, moderate, association between gender and diagnosis (Fisher's exact test; p=0.0031, Phi coefficient=0.47). Amongst females, there was a much higher proportion of CVA than amongst the males in the study. *Ties in with age – gender bias?*



Race x Age: There was no significant difference in the mean age of the different race groups in the study (ANOVA: F(3,42)=1.81; p=0.16).

Race x Diagnosis: There was no significant association between race and diagnosis (Fisher's exact test: p=0.14).

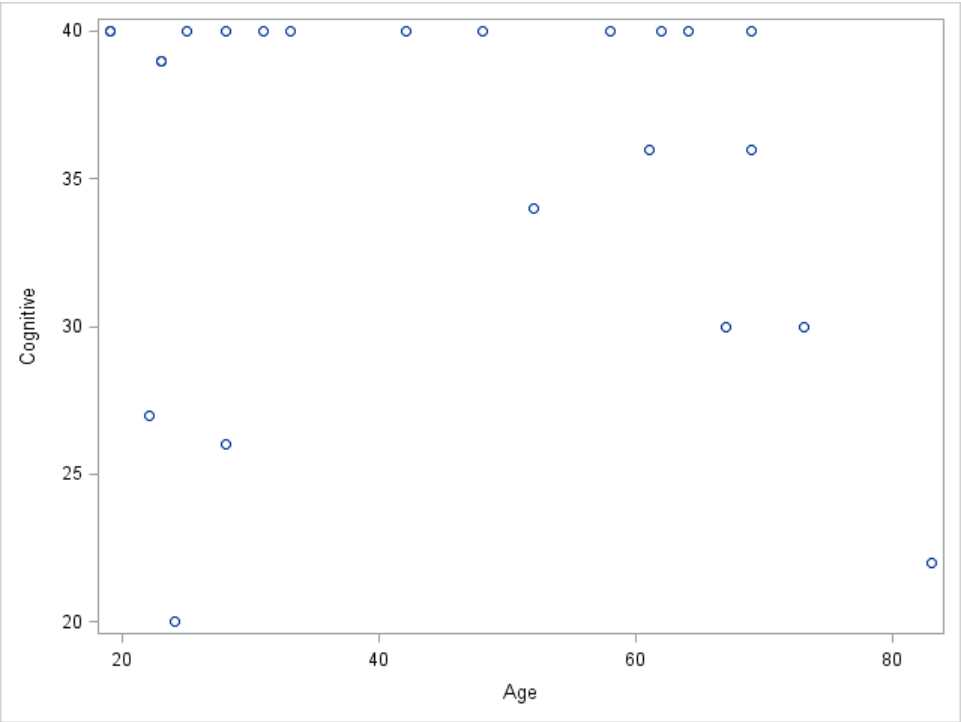
Age x Diagnosis: The mean age of the HI patients in the study (33.6 ± 5.8y) was significantly lower than that of the CVA patients (54.3 ± 5.4y) (t-test with pooled variances: p<0.0001). *This is as you expected – stroke patients were generally older.*



Gender x Cognitive score (Study group ONLY): Given the skewness of the distributions of the cognitive score data (see frequency distribution above), we cannot use the t-test for differences in the mean of cognitive score between the two gender categories and instead use a non-parametric alternative, the Wilcoxon two-sample test. This shows that there was no significant difference in the mean cognitive score between the two gender categories (p=0.71).

Race x Cognitive score (Study group ONLY): Given the skewness of the distributions of the cognitive score data (see frequency distribution above), we cannot use ANOVA for differences in the mean of cognitive score between the race categories and instead use a non-parametric alternative, the Kruskal-Wallis test. This shows that there was no significant difference in the mean cognitive score between the three race groups (B, C, W; no I in the study group) (p=0.97).

Age x Cognitive score (Study group ONLY): The Spearman's rank correlation coefficient of
-0.14 between these variables was not significant (p=0.52). The bivariate plot shows that the youngest and oldest patients were associated with the lowest cognitive scores, but otherwise the two variables were not directly related.

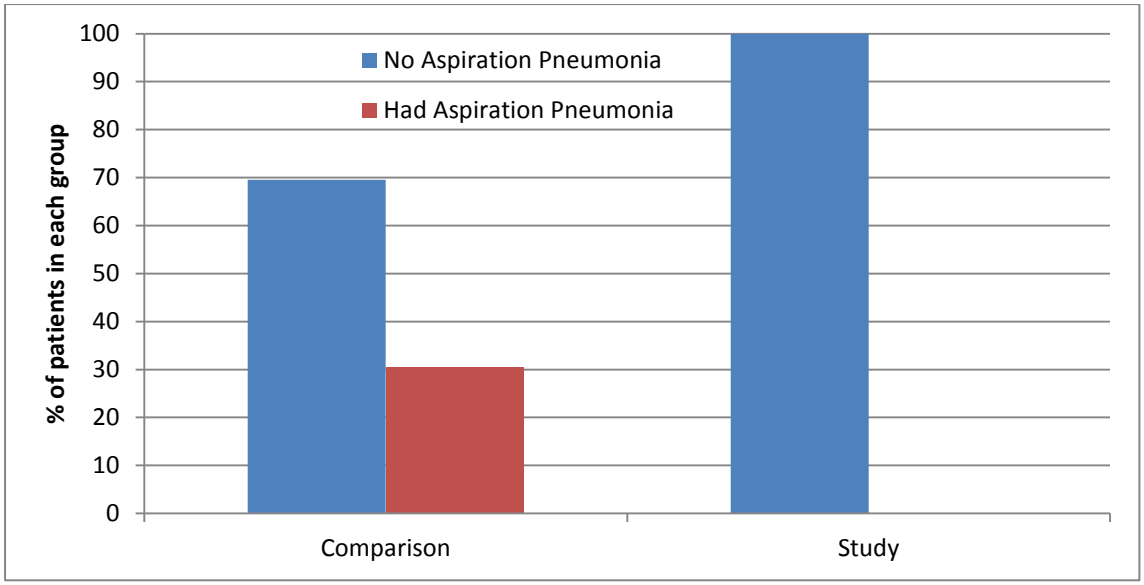


Diagnosis x Cognitive score (Study group ONLY): As above, the non-parametric alternative to the t-test was used (Wilcoxon two-sample test). There was no significant difference in the mean cognitive scores of the HI and CVA patients within the study group (p=0.26).

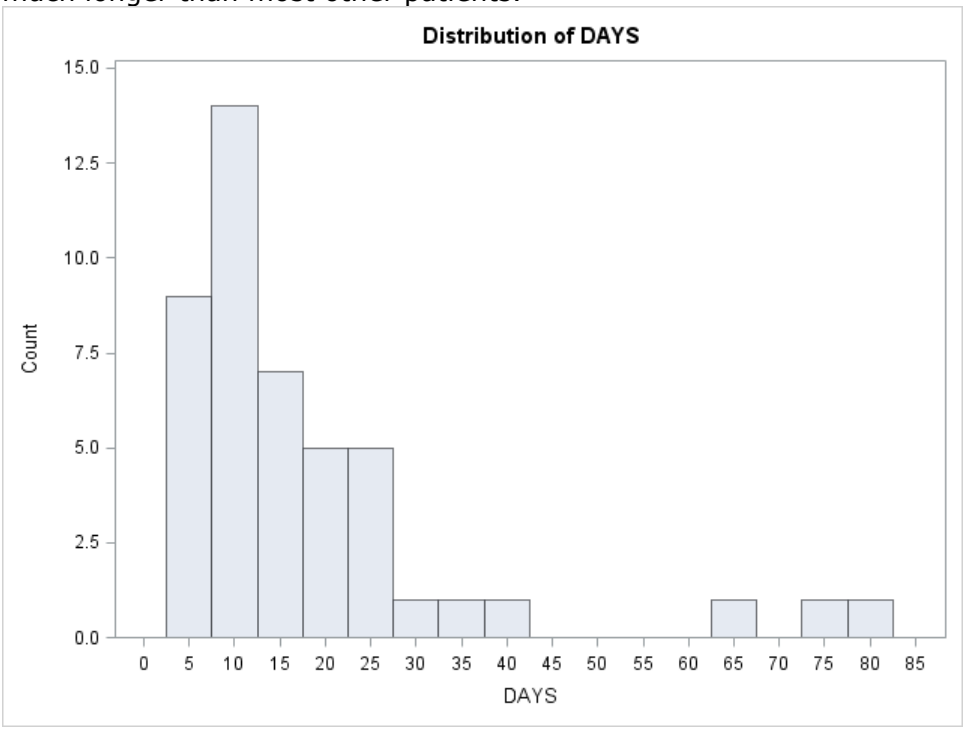
Dependent Variables (spreadsheet tab: DVs)

We look at the proportions (AP) and distributions (DUR, WAT, WD) of the dependent variables overall and per treatment group. Bear in mind though that in the next section we will test for significant differences between groups while controlling for the covariates.

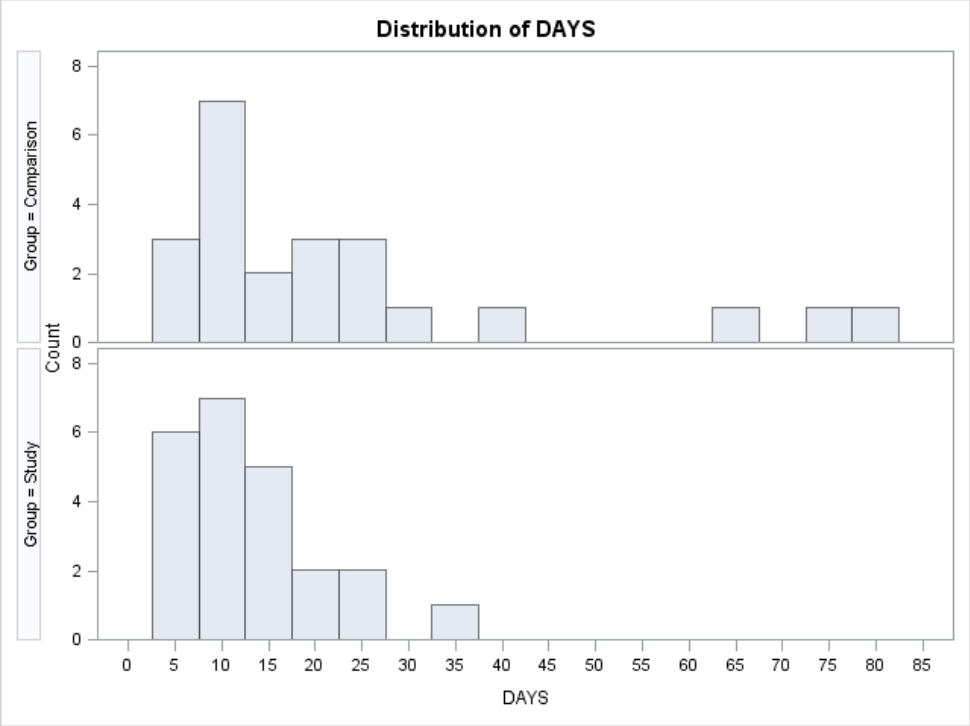
AP: Overall there were 7 cases (15%) of aspiration pneumonia, all of them in the comparison group. Thus there was a significant, moderate, association between AP and group (Fisher's exact test: p=0.0092; Phi coefficient=0.42).



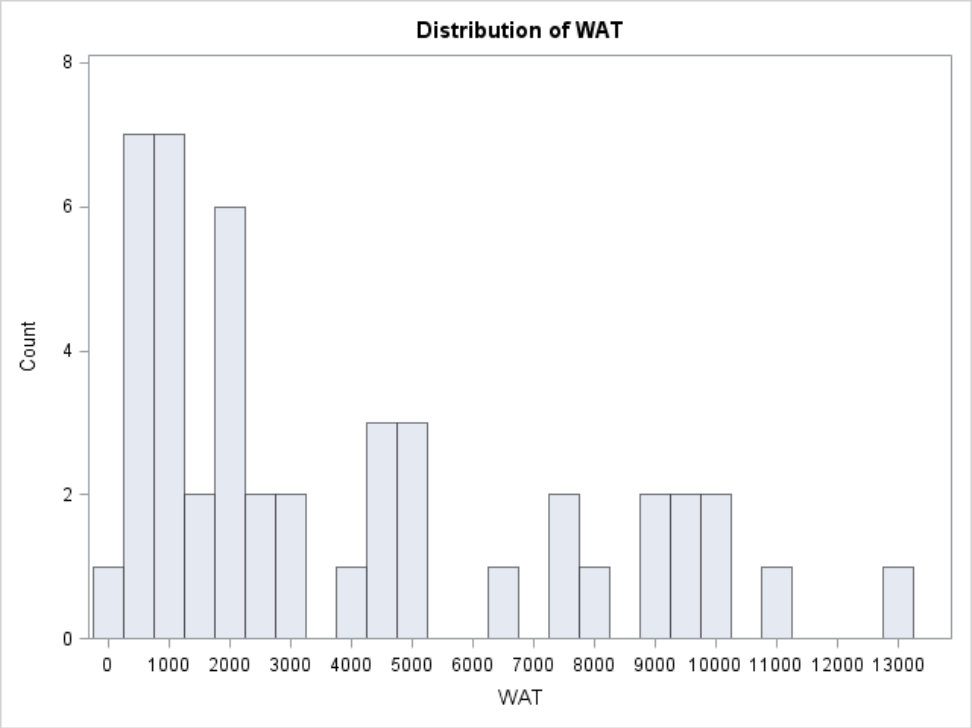
DAYS: Overall, the mean duration of the intervention was 18 days (sd=17 days, median=12.5 days, interquartile range=8-21 days). The distribution of this outcome was positively skewed, as might be expected, with a few patients remaining in hospital much longer than most other patients.



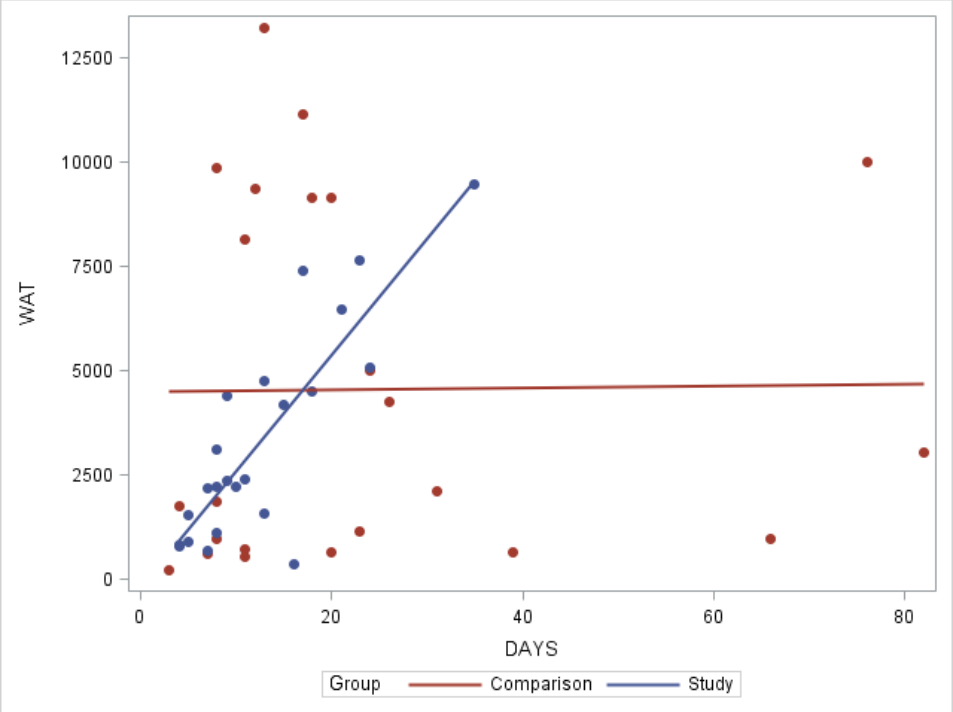
Given the skewness of the distributions of the DAYS data within the two groups (see frequency distributions below), we cannot use the t-test for differences in the mean of DAYS between the two treatment groups and instead use a non-parametric alternative, the Wilcoxon two-sample test. This shows that there was NO significant difference in the mean DAYS between the two treatment groups (p=0.078). Study group: mean=12.6±3.3 days; Comparison group: mean=23.4±9.6 days.



WAT: Overall, the mean amount of water consumed was 3932 ml (sd=3562 ml, median=2300 ml, interquartile range=955-6490 ml).



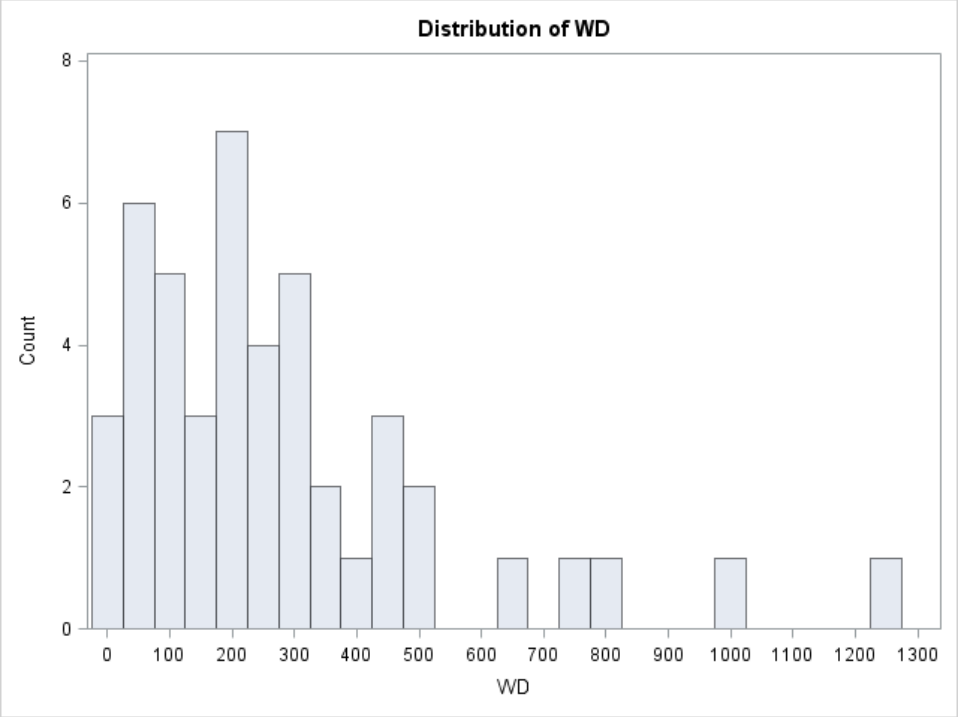
We can also look at the relationship between WAT and DAYS. We would expect WAT to increase with DAYS:



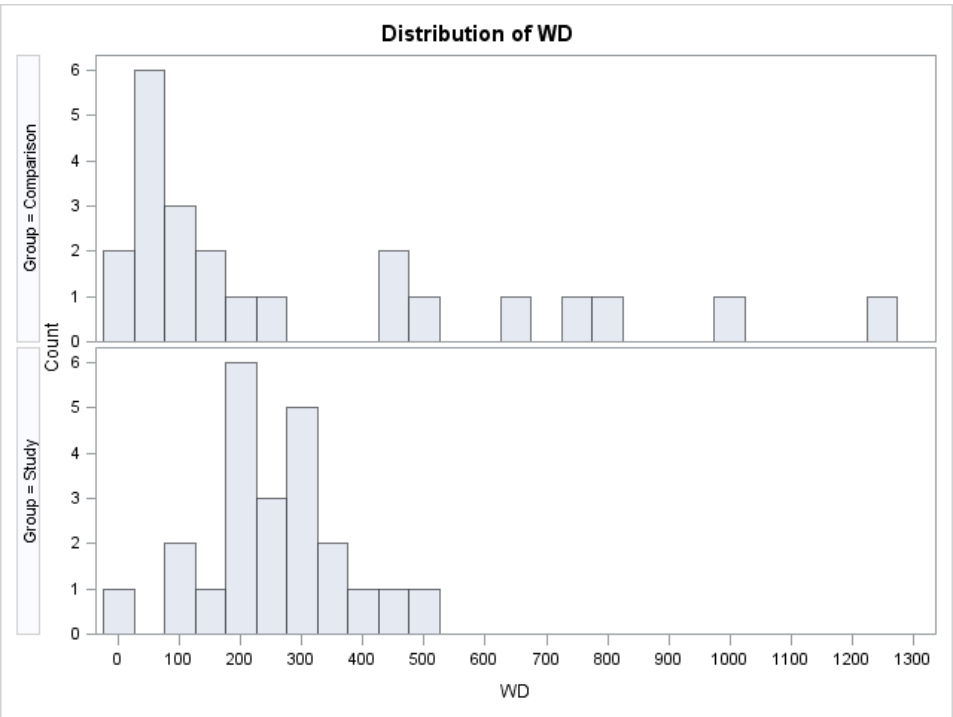
For the study group, there was indeed a significant, strong positive correlation between WAT and DAYS (correlation coefficient, r=0.84; p<0.0001). However, for the comparison group, there was no significant correlation between WAT and DAYS (r=0.014; p=0.95) showing that the total amount of water used by patients did not increase with increased intervention time – which is what we might expect since water intake did not specifically form part of their treatment and would have varied from patient to patient.

Given the relationship between WAT and DAYS in the study group, and the different intervention times (DAYS) for different patients, comparisons should be based on the average amount of water consumed per day by a patient and not the total amount of water consumed by a patient. Thus further analysis will be done in terms of WD and not WAT.

WD: Overall, the mean amount of water consumed per day was 285 ml/day (sd=260 ml/day, median=220.5 ml/day, interquartile range=98-365 ml/day). Note that the minimum amounts (14 and 23 ml/day in the comparison and study groups respectively) are very small!



Given the skewness of the distributions of the WD data within the comparison group (see frequency distributions below), we cannot use the t-test for differences in the mean of WD between the two treatment groups and instead use a non-parametric alternative, the Wilcoxon two-sample test. This shows that there was NO significant difference in the mean WD between the two treatment groups (p=0.30). Study group: mean=257±47 ml/day; Comparison group: mean=312±153 ml/day.



Comparison of the dependent variables between treatment groups, controlling for covariates and other relevant variables
(tabs: DAYS and WD)

Is there a significant difference in AP between the two groups, controlling for age, race, gender, diagnosis and WD?

There were no occurrences of AP in the study group, so we cannot apply logistic regression analysis (this gives a quasi-complete separation of data points). The results of the Fisher's exact test between AP and treatment group (given earlier) are the best we can do.

Is there a significant difference in DAYS between the two groups, controlling for age, race, gender, diagnosis and WD?

As discussed, we look at this with and without controlling for WD. The analysis was done by using a General Linear Model (GLM) with ln(DAYS) as the dependent variable to compensate for the skewness in the frequency distribution of this variable and thus meet the assumptions of the technique.

Excluding WD: The source table is shown below.

Source	DF	Type III SS	Mean Square	F Value	Pr > F
Group	1	3.259	3.259	5.740	0.022
Gender	1	0.058	0.058	0.100	0.750
Age	1	0.000	0.000	0.000	0.983
Race	3	1.202	0.401	0.710	0.555
Diagnosis	1	0.195	0.195	0.340	0.562

The overall model for DAYS was not significant (F=1.06; p=0.40). However, there was a significant difference in the mean DAYS between the two treatment groups, while controlling for gender, race, age and diagnosis (F=5.73; p=0.022). Note that this is a different conclusion to the one we drew when simply comparing DAYS between groups without controlling for the covariates! None of the covariate IVs were significant.

Over a BALANCED model, controlling for gender, race, age and diagnosis, the ESTIMATED mean DAYS for the two treatment groups, together with their 95% confidence interval, are given in the table below:

Group	mean	LCL	UCL
Comparison	17.2	11.6	25.6
Study	9.0	5.2	15.6

Including WD: The source table is shown below.

Source	DF	Type III SS	Mean Square	F Value	Pr > F
Group	1	4.36	4.36	8.38	0.006
Gender	1	0.02	0.02	0.03	0.865
Age	1	0.19	0.19	0.37	0.547
Race	3	1.79	0.60	1.15	0.343
Diagnosis	1	0.18	0.18	0.34	0.564
WD	1	2.34	2.34	4.50	0.041

The overall model for DAYS was not significant (F=1.66; p=0.14). However, there was a significant difference in the mean DAYS between the two treatment groups, while controlling for gender, race, age, diagnosis and WD (F=8.38; p=0.006). The effect of the covariate WD was also significant (F=4.50; p=0.041).

Over a BALANCED model, controlling for gender, race, age, diagnosis and WD, the ESTIMATED mean DAYS for the two treatment groups, together with their 95% confidence interval, are given in the table below:

Group	mean	LCL	UCL
Comparison	17.4	11.9	25.5
Study	8.1	4.8	13.9

(I would write up only one of these results – consider which is the most appropriate.)

Is there a significant difference in WD between the two groups, controlling for age, race, gender and diagnosis?
The analysis was done by using a General Linear Model (GLM) with ln(WD) as the dependent variable to compensate for the skewness in the frequency distribution of this variable and thus meet the assumptions of the technique.

The source table is shown below.

Source	DF	Type III SS	Mean Square	F Value	Pr > F
Group	1	0.07	0.07	0.06	0.803
Gender	1	0.06	0.06	0.05	0.824
Age	1	1.59	1.59	1.43	0.239
Race	3	3.23	1.08	0.97	0.418
Diagnosis	1	0.00	0.00	0.00	0.975

The overall model for WD was not significant (F=0.95; p=0.48). There was NO significant difference in the mean WD between the two treatment groups, while controlling for gender, race, age and diagnosis (F=0.06; p=0.80). Note that this is the same conclusion we drew when simply comparing WD between groups without controlling for the covariates. None of the covariate IVs were significant.

Comparison between CVA and TBI groups within the FFWP study group only
(tab: Study group only)

Within the study group alone, is there a significant difference between the CVA and HI groups, w.r.t DAYS, controlling for age, race, gender, cognitive score and WD?
The analysis was done by using a General Linear Model (GLM) with ln(DAYS) as the dependent variable to compensate for the skewness in the frequency distribution of this variable and thus meet the assumptions of the technique.

The source table is shown below.

Source	DF	Type III SS	Mean Square	F Value	Pr > F
Diagnosis	1	0.008	0.008	0.030	0.875
Gender	1	0.404	0.404	1.250	0.281
Age	1	0.004	0.004	0.010	0.918
Race	2	0.939	0.470	1.450	0.266
Cognitive	1	0.933	0.933	2.880	0.110
WD	1	0.027	0.027	0.080	0.776

The overall model for DAYS was not significant (F=1.26; p=0.33). There was NO significant difference in the mean DAYS between the two diagnosis groups, while controlling for gender, race, age, cognitive score and WD (F=0.03; p=0.88). None of the covariate IVs were significant.

Within the study group alone, is there a significant difference between the CVA and HI groups, w.r.t WD, controlling for age, race, gender and cognitive score?
The analysis was done by using a General Linear Model (GLM) with WD as the dependent variable.

The source table is shown below.

Source	DF	Type III SS	Mean Square	F Value	Pr > F
Diagnosis	1	3383	3383	0.28	0.601
Gender	1	5706	5706	0.48	0.499
Age	1	10198	10198	0.86	0.369
Race	2	27067	13534	1.14	0.346
Cognitive	1	10386	10386	0.87	0.364

The overall model for WD was not significant (F=0.95; p=0.49). There was NO significant difference in the mean WD between the two diagnosis groups, while controlling for gender, race, age and cognitive score (F=0.28; p=0.60). None of the covariate IVs were significant.