



Discipline of Nursing

**School of Population Health and
Clinical Practice**

Faculty of Health Sciences

The University of Adelaide

RESEARCH PORTFOLIO

Stroke prevention and hospital management

(Albert) Man-tat Yip

RN, BHSc, MPHC

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the degree of Doctor of Nursing**

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STATEMENT OF ORIGINALITY

I certify that this portfolio contains no material which has been accepted for the award of any other degree in any university or other tertiary institution. To the best of my knowledge and belief, contains no material previously published or written by another person, except where reference has been made in the text.

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(Albert) Man-tat Yip

Date: _____

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PORTFOLIO OVERVIEW

This portfolio of research is comprised of four main sections:

Section 1. Introduction of portfolio

Section 2. Research study report one:

A descriptive study of lifestyle changes made following discharge from hospital by patients who have suffered a minor stroke or transient ischaemic attack (TIA).

Section 3. Research study report two:

The hospital management of patients with acute dysphagia following stroke.
A retrospective review.

Section 4. Conclusion of portfolio.

INTRODUCTION OF PORTFOLIO

APOPLEXY

Stroke was first recognised nearly 2500 years ago by Hippocrates (460 – 370 BC), a famous Greek physician – ‘the father of medicine’. He called stroke ‘apoplexy’, which means ‘struck down by violence’. In 1658, Johann Jacob Wepfer recognised patients who died with apoplexy had a haemorrhage and blockage of cerebral blood vessels. In 1856, Rudolf Virchow, indicated stroke occurred at cellular level and was caused by cerebral emboli. In 1928 the term ‘apoplexy’ was replaced by the term ‘cerebrovascular accident’ (CVA) the change was supported by evidence of post-mortem examinations (Pound, Bury & Ebrahim 1997). This indicated that health professionals had begun to understand stroke as a disease of the blood vessels in the brain. The lay term ‘stroke’ first appeared in 1599 and appears to have developed from phrases such as ‘the stroke of God’s hand (sic)’, ‘the stroke of God’ and ‘the stroke of justice’, indicating a belief in supernatural theories, and this term has been used in the public arena since 1930s (Chest and Heart Association 1962). In recent decades a new term ‘brain attack’ was introduced to avoid the misconception that stroke is unpredictable. Health professionals wished to convey the message that emergency treatment is required as for ‘heart attack’.

Unlike stroke where the effects may be permanent, transient ischaemic attacks (TIA) or ‘mini stroke’ may provide a warning that severe cerebrovascular disease (CVD) is present. This is when there is a temporary interruption of the brain’s blood flow and the signs and symptoms of stroke last just for a short period usually resolving within 24 hours.

The development and understanding of stroke prevention and care has been slow because of the complex nature of the structure and function of the brain, which is divided into three main divisions: the cerebrum, the brainstem and the cerebellum. Each division contributes different vital functions to the body, via the delicate and complex network of the nervous system. The brain is covered by meninges and requires a continuous supply of oxygen. One-sixth of blood pumped from the heart will supply the brain and one-fifth of the oxygen is consumed by the brain tissue. Without this oxygen

supply brain function is compromised. Therefore the brain is highly dependent on oxygen to support continued cerebral function, including processing information from sensory neurones, coordinating body movements and communication through motor neurones to control particular muscles accurately (Farrell, Smeltzer & Bare 2005).

Stroke is caused by the interruption of blood supply to certain parts of the brain tissue due to a blockage or rupture of blood vessels, and consequently functions of the body may be impaired. The brain is very sensitive to the changes in pressure, due to blockage of the flow of cerebrospinal fluid (CSF), haemorrhage, oedema or a space occupying lesion. Any of these conditions may cause an increase in intracranial pressure (ICP) and due to the limited space within the skull; if this is not relieved, the brain itself may herniate through the foramen magnum.

The blood brain barrier also increases the difficulty associated with investigation, assessment and treatment of the brain. This barrier makes the central nervous system (CNS): brain and spinal cord inaccessible to substances such as drugs, antibiotics and dyes circulating in the blood, preventing them from reaching the neurons of the CNS. The blood brain barrier is created by the low permeability of endothelial cells in the brain's capillaries, which prevents large molecules entering the CSF and is an important protective mechanism (Farrell, Smeltzer & Bare 2005).

The cerebral functions involved in communication, intellectual functioning and in patterns of emotional behaviour and sensory and motor ability are difficult to evaluate and, thus require detailed clinical assessment and observation by health professionals. The Glasgow Coma Scale (GCS) is one of the most common methods used to record a patient's neurological functioning. Questions about the patient's medical history, lifestyle prior and subsequent to the disease are also important in evaluating and risk factors for CVD.

THE HISTORY OF THE TREATMENT OF STROKE

Before twentieth century there were several different theories regarding the cause of stroke, they included humoral theories, supernatural theories, the theory of 'apoplectic

habitué', and moral notions of intemperance and immorality (Pound, Bury & Ebrahim 1997). These theories influenced the perceptions and thus treatment of stroke. According to Pound, Bury and Ebrahim (1997), in the eighteenth century some physicians who supported the humoral theories treated apoplexy with bloodletting to reduce the patient's blood pressure and restore the balance of the humours. Some presumed a stroke was caused by an indigestible meal, so the patients might be stimulated to vomit or an enema was given (Osler 1892-1944). Stroke was a mystery, many believed that it was punishment from an invisible power which attacked people who had sinned (Clarke 1824, Tanner 1854).

In eighteenth century another theory developed, this theory 'apoplectic habitué' proclaimed that some people had an underlying predisposition that made them prone to ill health. Indications of 'apoplectic habitué' were considered to be obesity, 'strait' chests, problems with breathing, very red or pale faces and a short thick neck and large head. Indulgent, luxurious, living was also thought to be a cause of 'apoplectic habitué' with poor circulation increasing the risk of fatal stroke (Robinson 1732). There were a multitude of different lifestyle factors that were attributed to causing apoplexy, these included, diets with highly-seasoned meats and sauces, excess alcohol consumption, use of tobacco, severe physical strain, sexual excitement, constipation, sudden change of the air (cold weather), tight clothing around the neck, too much sleep and warm baths (Robinson 1732, Tanner 1854). Advice given to avoid apoplexy included, maintaining regular bowel movements, a quiet life, a moderate diet and avoidance of smoking and excessive drinking (Clarke 1824).

CARE OF THE PATIENT WITH STROKE

The prognosis of apoplexy was poor and the mortality and disability rate was very high, especially in patients who had persistent hemiplegia for more than three months. It was not until the end of the eighteenth century, that dissection and post-mortem examinations demonstrated the disease was caused by 'obstruction' or haemorrhage associated with the degeneration of the arterial wall (Lawrence 1994).

At the time, there was little agreement among physicians regarding the long-term

treatment for apoplexy. Until 1892 Osler's textbook prescribed massage of the paralysed limbs and using electricity to stimulate the muscles following stroke to maintain nutrition of the muscles and to prevent contractures. In 1935 it was also suggested that patients be instructed to perform passive and active exercises systematically, tendon transplantation and cross suturing of nerves for patients who suffered contractures of limbs was also recommended (Osler 1892-1944). Although these treatments were not very effective and consequently lost favour, they gave paralysed patients' hope and increased their optimism (Pound, Bury & Ebrahim 1997). In 1952 Davidson's textbook also mentioned 'physiotherapy', 'occupational therapy', and by 1965 early 'rehabilitation' was introduced (Davidson 1952-1987). Since the 1950s the establishment of stroke and stroke rehabilitation units has been recommended for care and are recognised as being associated with a lower mortality rate, shorter length of stay in a hospital and better long-term outcomes (Langhorne & Dennis 1998). However, the implementation of stroke units has been limited due to the high cost, related to their establishment and operation. Audits have indicated that in England from 2001/02 only 29% of patients who suffered stroke, were admitted to a stroke unit for acute management and care (Irwin, Hoffman, Lowe, Pearson & Rudd 2005).

At the beginning of the twenty-first century, certain human genetic factors in deoxyribonucleic acid (DNA) were discovered that indicated some people might have a higher risk of certain types of stroke (American Heart Association 2006).

DIAGNOSIS AND INVESTIGATIONS

In the twentieth century, there were several breakthroughs in the techniques used for the investigation of stroke which subsequently improved diagnosis, monitoring and treatment. These techniques included contrast angiography (1920s), indicator dilution technique to measure brain blood flow (1940s), and doppler ultrasonography for evaluating the blood flow to the brain (1960s). Another essential tool for early diagnosis of ischaemic and haemorrhagic stroke, computerised tomography (CT) scanning, was introduced in 1970s, and later positron-emission tomography (PET) scanning was also developed to provide a sectional view which can provide vital

information in relation to brain metabolism. In 1980s magnetic resonance imaging (MRI) was introduced and it further improved the accuracy of evaluation with clear and detailed images to locate the source of the stroke (American Heart Association 2006).

TREATMENT

Advanced investigation methods have greatly helped physicians to accurately diagnose and locate the source and type of stroke. Many treatments and specific surgical techniques have also been developed for prevention and intervention. For example, in 1954 the first carotid endarterectomy was used to remove the plaque deposits from the carotid artery and in 1969 the first operation of artificial heart valves in humans was performed to minimise the risk of stroke caused by emboli (Mackay & Mensah 2005a). In the 1980s early aneurysm surgery was developed to improve patients' outcome after subarachnoid haemorrhage and in the 1990s more effective treatment such as microcoils, angioplasty and stenting were used for aneurysms. In the 2000s neurogenesis (formation of new nerve cells) has been developed, this is an advanced technique which uses transplantation of replenishing brain cells with enhancing growth factors to help regenerate affected neurons (American Heart Association 2006).

Regarding medication, in the 1970s aspirin and anticoagulants were trialled and proved effective in lowering the risk of stroke from chronic atrial fibrillation. In 1990s the first emergency drug to treat ischaemic stroke: tissue plasminogen activator (tPA) was introduced. This drug has the best effect when used within three hours of the first onset of symptoms. Although this drug is very effective in removing cerebral blood clots with maximal reservation of brain functions, certain limitations and problems have altered its efficacy, such as delay in patients seeking medical advice, and inefficiency of health facilities or schedules, so that valuable time and opportunities are lost. Early identification of stroke is important to provide effective treatment, preventing further damage.

The major risk factors for stroke have been gradually recognised over the past 50 years, these include carotid stenosis (1950s), hypertension (1960s) and in the 1970s an unhealthy lifestyle was recognised as a risk factor, including poor diet and, physical

inactivity. Importantly, cigarette smoking was established conclusively as a major risk factor of stroke in the 1980s. In 1978 atrial fibrillation was linked to stroke and in the 1990s studies showed lowering blood pressure also reduced the risk of stroke significantly. Almost 800 million patients between the age 60 and 79 years suffer hypertension worldwide: if the patients' systolic blood pressure (SBP) could be lowered, for each 10mmHg fall there would be a direct reduction in the risk of stroke by about one-third; and if 7% of those with diastolic blood pressure (DBP) over 95mmHg were able to reduce their DBP by 2%, a million deaths a year from stroke could be prevented in Asia alone (Mackay & Mensah 2005a).

One of the first studies about lifestyle changes was commenced in 1972. The 'Stanford three community study' was the first community-based cardiovascular risk education campaign, which involved the change of lifestyle-related risk factors, including physical activity, dietary habits and cigarette smoking. This program showed a 23 to 34% reduction in cardiovascular disease risk, including dietary cholesterol and saturated fats as a result of community-based interventions (Fortmann, Williams, Hulley, Haskell & Farquhar 1981). A large scale 'Stanford five-city project' included stroke reduction and involved a total population of over 300,000 from 1979 to 1992. The project was a quasi-experimental field trial that used more lifestyle-related risk factor interventions through mass media and direct education to the citizens. The project aimed at reducing serum cholesterol levels, improving weight control through dietary change and increased exercise; lowering blood pressure through reduced salt intake, reduced weight and increased anti-hypertensive medication use; and reducing cigarette smoking use through prevention and cessation programs. The results indicate that on average in all five cities there was a reduction of 3% per year of subjects with one or more of the risk factors (Fortmann & Varady 2000).

The World Health Organization also announced countries should cooperate to perform primary health care and encourage healthy lifestyle change projects to minimise the risk factors. This is a cost-effective means to alleviate the health care burden and prevalence of stroke in the future, especially in developing countries, which have almost 75 to 85% of the mortality rate of stroke (World Health Organization 2003).

BURDEN OF STROKE

Although knowledge regarding stroke and interventions has greatly improved in the last century, surveys demonstrate the global prevalence of stroke has increased dramatically and is now shifting from Western developed nations to developing countries. For example: in Britain the absolute numbers of deaths from stroke increased rapidly from 20,000 per year in the 1930s to 80,000 in the 1980s, an almost four-fold increase within half a century (Charlton, Murphy, Khaw, Ebrahim & Davey Smith 1996); however, the mortality rate decreased to 60,000 in the 2000s. There is now considerable evidence indicating that due to globalisation, people in developing countries have adopted unhealthy lifestyles and norms from Western countries. The ageing population is also an important problem as the world population increased rapidly after the Second World War, in addition, people now have longer life expectancy due to the introduction of immunisation and advanced medical care, improved living standards and services in many countries (Oldenburg, Burton & Parker 2004). However, certain chronic illnesses, particularly hypertension, diabetes and heart disease are increasing following the rise in unhealthy lifestyles, increasing the risk of stroke. There is recognition that the increasing incidence of stroke may greatly escalate the cost of health care, and community services and most importantly increase the social burden related to stroke (Palmer, Valentine, Roze, Lammert, Spiesser & Gabriel 2005). Thus effective prevention strategies and hospital care and management are of paramount importance.

Human life is invaluable; however, governments and hospitals have limited resources to expend on health care management and services. Globally, stroke causes 10% of total deaths every year and places a significant burden on health care providers, families and communities due to patients' disability and complications. This is because patients may not be able to continue their previous employment and their families have to care for them at home resulting in reduced community productivity. For example, in 2004 the American Heart Association estimated that stroke would cost a total of US \$53.6 billion, including direct costs (\$33 billion) for medical care and therapy and indirect costs was \$20.6 billion from lost productivity in United States of America (Mackay & Mensah 2005b). Furthermore, the cumulative Medicare cost of treatment of CVD for Americans aged 65 years to death for the risk factors including high blood pressure,

high cholesterol, cigarette smoking, a history of diabetes or previous heart attack was between US \$30,000 and \$76,000 per person, depending on their number of risk factors (Mackay & Mensah 2005b). In regard to the current major preventive measures and treatment of stroke, which are highly dependent on cardiovascular medications, the percentage of total annual drug expenditure on cardiovascular medications has gradually increased from 9.4% to 11% in Organization for Economic Co-operation and Development (OECD) countries between the years 1989 and 1997 (Mackay & Mensah 2005b).

In Australia in 2003 there were an approximate 346,700 stroke survivors and 282,600 (80%) had significant disabilities and needed assistance for activities of daily living (ADL), however only 128,000 survivors (45%) received formal assistance and 169,000 (60%) depended on an informal carer (Senes 2006). In 2002-2003 patients who suffered stroke as a principal diagnosis accounted for 1,073,645 patient days in hospitals and rehabilitation units. Since then the average length of stay for initial hospital care for stroke has been shortened to 12.6 days from 18 days (Senes 2006), this indicates the high admission rate and the rehabilitation required for these patients. Most survivors live at home and half of these require assistance for ADL, only 12% are cared for in institutions. Fifteen percent of all residents in aged care facilities are disabled from stroke. This situation indicates the high demand for formal and informal care. Projections in Australia also indicate that the number of older people with profound disabilities will increase 70% over the next 30 years (from 2006 to 2031), with stroke being one of the main causes. Hence, there will be more challenges for families, friends, volunteers and health care providers (Giles, Cameron & Crotty 2003).

The economic loss and burden on health care resources from stroke is clearly huge and is increasing. However, the burden on the patients, their families and carers is even more significant. The emotional and psychological impact associated with stroke particularly when patients suffer significant physical impairment may be severe. The patient's role in the family and thus the structure may be changed with associated problems involving finance, socialisation, sexuality, communication and behaviours. Patients may also be prone to injury, such as falling, choking and, scalding. These problems can only be alleviated with appropriate support and education for patients and their carers (Hankey 2004, Smith, Lawrence, Kerr, Langhorne & Lee 2003). It is

reported that patients who have a disability and are unable to live independently, have a poorer health related quality of life (Senes 2006). Although stroke can happen at any age, the rate increases significantly with age from about 65 years (Thrift, Dewey, Macdonell, McNeil & Donnan 2000). Patients and carers who have inadequate knowledge and skills may increase the risk of stroke recurrence and deterioration of health. Consequently, more hospital readmissions and more vigorous treatment may be required.

PREVENTION

Stroke is a non-communicable and very preventable disease. Many people recognise stroke as an emergency, however few are aware of the risk factors and signs and symptoms (Senes 2006). Although recognising and understanding these is very important, it is also essential that patients do not delay seeking medical advice when they are first detected. Transient ischaemic attack (TIA) and minor stroke are very important warning signs of major stroke, however, many patients and even some health professionals are not fully aware of this and may not take appropriate actions such as investigation or referral. Studies indicate that about 30% of people with a major stroke have had an earlier TIA and 9% have a stroke within one week, 12% in the first year and then about 7% a year thereafter (Lovett, Dennis, Sandercock, Bamford, Warlow & Rothwell 2003). Therefore, patients who suffer TIA or minor stroke should be important candidates for treatment and preventive measures such as healthy lifestyle modification programs.

Some patients decide not to adopt healthy lifestyles or sustain changes for a short period only (Malfatto, Facchini, Sala, Bragato, Branzi & Leonetti 2000). Since these patients are at high risk of stroke, it is crucial to find out the factors that influence this behaviour. Thus the first study in this portfolio was designed to explore patients' understanding of modifiable risk factors of CVD. It investigated the lifestyle changes actually made following stroke or TIA as well as the factors affecting patients' decisions about whether to make lifestyle changes. The two major factors considered were patients' sources and level of knowledge and their attitudes and beliefs around making changes. In order to assist the patients to minimise the risk of stroke and recognise healthy

lifestyle change as one of their preventive measures, health professionals have to understand the main issues and barriers that cause patients to have difficulties or be unwilling to adopt healthy lifestyle changes.

MANAGEMENT

Stroke is a medical emergency and patients are admitted to hospital for acute care and rehabilitation. Patients who suffer severe stroke may be critically ill, lose consciousness and suffer disability. Health care professionals should provide high-quality stroke care saving patients' lives, preventing complications and promoting recovery, thus the severity of disability can be minimised and length of stay in hospital can be minimised. Nurses are the conduit of all patients' care and they liaise with the multidisciplinary team to provide the best interventions and maintain good outcomes. Stroke care management focuses on rehabilitation to assist patients to restore their ability to care for themselves.

Oral intake is essential for nutrition and hydration, especially in patients being rehabilitated who may require more energy to meet their needs and restore their bodies' resistance (Finestone & Greene-finestone 1999). If patients suffer dysphagia following stroke, this may impede recovery and may cause severe complications. The incidence of acute dysphagia following stroke is high and some patients die from complications (Dennis, 2000). A review of the literature revealed little research has been conducted about the nurses' role in holistic management of patients with dysphagic stroke and the cooperation of the multidisciplinary team. In addition, audits have shown that general stroke care management is not satisfactory and some nurses' knowledge and training regarding dysphagia is limited (Kowanko, Simon & Wood 1999). The quality of hospital care and management may be influenced by policies, collaboration of the multidisciplinary team, protocols, and staff education or training. An in-depth study may assist in evaluating the management of these patients. Thus the topic of the second study in this portfolio was to explore the hospital management of patients who suffer dysphagia following stroke. This was done through a review of medical records to assess the nurses' role and the cooperation of the multidisciplinary team. The results of this study may assist health policy makers and health care providers in the development

of hospital policies and interventions, to enhance the management and quality of care for these patients.

CONCLUSION

The prevalence of stroke is increasing rapidly worldwide at huge cost both financially and in terms of human life. The increasing burden falls not only on health care professionals and families and carers, but will inevitably affect the future health care planning and development. Although in many developed nations the mortality rate from stroke has declined, the morbidity and disability rates are increasing. In addition in many developing countries the incidence of stroke is increasing as associated with unhealthy lifestyles. Hence, governments may be required to spend more on health resources, including medications, and health care facilities for the increasing number of stroke patients with disabilities. However, as stroke is a highly preventable disease, governments may consider increasing community-based programs for health promotion to enhance people's awareness and knowledge of stroke prevention, care and management. These strategies are important to lower the cost and social impact of stroke (Dzator, Hendrie, Burke, Gianguilio, Gillam, Beilin & Houghton 2004).

This research portfolio reports on two studies related to the management and care of patients who have suffered a stroke.

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Research study

Report one:

A descriptive study of lifestyle changes made following discharge from hospital by patients who have suffered a minor stroke or transient ischaemic attack (TIA).

(Albert) Man-tat Yip

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ABSTRACT

Stroke is a preventable disease. Minor stroke and transient ischaemic attack (TIA) are important warning signs of the possibility of a major stroke. Worldwide, stroke is the third most common killer and the largest cause of disability. The incidence of stroke is predicted to increase with the predominance of unhealthy lifestyles and the aging population. The adoption of a healthy lifestyle can reduce many of the risk factors. This descriptive study was designed to explore patients' understanding of modifiable risk factors of cerebrovascular disease. It investigated lifestyle changes actually made, as well as the factors affecting patients' decisions about whether to make lifestyle changes. The two major factors considered were patients' sources and level of knowledge and their attitudes and beliefs around making changes.

A convenience sample of patients who had suffered a minor stroke or TIA was recruited through a major metropolitan hospital. Thirty-five subjects responded to a postal questionnaire. The mean age was 68 years and 37% of the subjects had sustained some disability as a result of the TIA or minor stroke.

The results demonstrated that many subjects had a poor understanding of risk factors of stroke. While smoking was well recognised as a risk factor, subjects showed less awareness of other risk factors, such as excessive alcohol consumption and obesity. Subjects also reported significant confusion regarding diet. Sixty-six percent of subjects depended on doctors as their main source of health information. This may be problematic as the current shortages of General Practitioners has put pressure on doctors to keep appointment times short and reduce the time available for health education.

The main barriers to lifestyle change, were lack of motivation, and inadequate, knowledge, guidance, and support and the inability to access good information. Although 83% of subjects suffered from hypertension, medication was the accepted method of control, few subjects realised the significance of lifestyle factors. Nine percent of subjects were only diagnosed with hypertension after their stroke or TIA and few monitor their own blood pressure, despite the wide availability of home monitoring devices.

From the findings of this study it is concluded that health promotion and education are very important strategies in the prevention of stroke and it is recommended that this kind of education begins in childhood with tailored, age-specific programs delivered to the public over the lifespan. The role of health screening cannot be underestimated in the detection of risk factors such as hypertension and obesity. Early detection makes effective treatment possible and helps prevent the occurrence of strokes, thus reducing the cost to the community. Long-term health strategies such as improving health resource distribution and enhancing health education are needed where patients and their families participate together in comprehensive education programs. It is hoped that this may lead to a shared understanding, which may translate to patients being more supported, and therefore more able, to make the necessary lifestyle changes.

INTRODUCTION

CONTEXT OF THE STUDY

From 1998 to 2002 the researcher worked in the neurosurgical ward of an acute care hospital. During that time many patients who had suffered a stroke were admitted to the ward. Some were previously 'healthy' individuals, who were responsible for the welfare of their spouses, children and sometimes their parents. It appeared that many patients had a poor understanding of the signs and symptoms of stroke and so delayed seeking emergency help or appropriate care (Gupta & Thomas 2002, Yoon & Byles 2002). For these patients, the stroke was a considerable shock to their families, particularly when the patient was critically ill. Unfortunately many did not make a full recovery; some were left with significant disabilities and some died. While the science of neurology has progressed substantially in recent years, often all the health care professionals could do, was monitor the patient's condition and try to minimise the damage to delicate brain cells, preserving the brain function as much as possible (Ingall 2004).

Nearly one-third of stroke victims may sustain disabilities such as loss of sensory and motor functions, poor vision, dysphagia, dysphasia, and cognitive dysfunction. There may also be considerable psychological impact such as depression (National Stroke Foundation 2003). These problems may also have a profound effect on the victim's families in communication with their loved one and helping them with their activities of daily living (ADL). Patients severely disabled by a stroke may need to stay in a hospital for long-term care and require extensive rehabilitation.

Stroke places a huge burden on families and, more broadly, on communities and societies (Forsberg-Wärleby, Möller & Blomstrand 2002, Hankey 2004, Jungbauer, von Cramon & Wilz 2003).

Since the after-effects of stroke can be so severe, dramatically impacting on the quality of life of the victim and their family and costing the Australian government over 1.8 billion of dollars every year, it is important to consider how the risk of stroke can be reduced.

Not all patients initially present with a severe stroke. Many suffer a minor stroke or TIA, that may serve as a warning. Although complete recovery may be expected, there is a significant risk of recurrence if the patient's disease remains untreated and risk factors are not addressed.

To date there is little information available regarding lifestyle changes made by these patients (Jamrozik, Broadhurst, Anderson & Stewart-Wynne 1994, National Institute for Clinical Excellence (NICE) 2002, Goldberg, Burchfiel, Benfante, Chiu, Reed & Yano 1995, Redfern, McKevitt, Dundas, Rudd & Wolfe 2000). Clearly this information is important in developing effective stroke prevention strategies and increasing people's awareness of the risk factors for this preventable disease.

Health care professionals require a better understanding of the lifestyle changes adopted by patients following a minor stroke or TIA so that effective health care strategies may be designed. Effective health promotion may help prevent thousands of strokes each year, reducing the social, emotional, economic costs to individuals, families and communities.

STATEMENT OF THE PROBLEM

Before a stroke occurs, many people may overlook the relationship between unhealthy lifestyle choices and the risk of stroke (Mosca, Jones, King, Ouyang, Redberg & Hill 2000, Emberson, Whincup, Morris, Wannamethee & Shaper 2005). With limited health care funds, most of the resources will be directed to caring for patients who have sustained a serious stroke. Those who have suffered a minor stroke or TIA may receive little attention (Mosca et al. 2000, Tyson & Turner 2000, Redfern, McKevitt, Rudd & Wolfe 2002). However, it is imperative that minor stroke or TIA sufferers understand the risk factors and where possible make lifestyle changes to reduce the risk of future strokes that may have more serious consequences (Daffertshofer, Mielke, Pullwitt, Felsenstein & Hennerici 2004, Fuller, Dudley & Blacktop 2004). From 8% to 37% of patients who have suffered a minor stroke or TIA, are at increased risk of stroke, coronary events or death occurring within five years (FloBmann & Rothwell 2003). Although many studies have indicated the significance of healthy lifestyle changes, there is limited research investigating how these are

implemented, and patients' experience and feedback on lifestyle changes. This study was designed to investigate patients' understanding of risk factors for stroke and factors influencing their decisions about lifestyle changes. It is hoped that the results will provide important information that may be useful in the development of health promotion strategies for this high-risk group of patients.

RESEARCH PURPOSE

The purpose of this study was to gather information about patients who have suffered a minor stroke or TIA, as many of these patients are at risk of suffering a major stroke if changes are not made. A major stroke may result in death or severe impairment. The cost of caring for patients who have suffered a major stroke is considerable. Thus the researcher wished to investigate the factors that influenced patients' decisions regarding the recommended lifestyle changes.

The broad aim was to increase awareness in the health sector about this group of patients who are at high risk of suffering a major stroke; encouraging prevention rather than focusing on cure. It is hoped that a deeper understanding of these factors will be useful to health professionals and policy makers in creating better long-term strategies for prevention of major stroke which places such a heavy personal, financial, medical, social and emotional burden on individuals and the community as a whole.

Specific objectives

The specific objectives were to:

- explore the knowledge patients who had suffered a minor stroke or TIA regarding the risk factors relating to cerebrovascular disease (CVD).
- identify the lifestyle changes adopted by patients following a minor stroke or TIA with the aim of reducing the risk of reoccurrence.
- explore the factors that influence patients' decisions to adopt these changes.

Research questions

What level of understanding do these patients have of the risk factors of CVD?

Which lifestyle changes do they make?

What factors affect their decisions about lifestyle changes?

SIGNIFICANCE OF THE STUDY

It is hoped that the information collected in this study will assist health professionals in understanding patients who have suffered a minor stroke or TIA and inform health strategy planning. In particular patient's knowledge of CVD risk and the factors that influence their decisions to adopt lifestyle changes. It will also provide some useful clues for the development of rehabilitation programs and strategies for meeting this specific group of patients' needs. Therefore, this study may be useful to find possible approaches that may help patients to improve their preventive strategies.

Assumptions

The incidence of stroke is expected to continue to increase in most developing and some developed nations (World Health Organization (WHO) 2002). This is because of the ageing population and the increasing prevalence of obesity, hypertension, diabetes, insufficient physical activity and high blood cholesterol (Australian Institute of Health and Welfare (AIHW) 2004, United States Department of Health and Human Services 2004, Feng 2004). This is a very serious problem predicted to place significant strain on public health care services. The rising number of stroke victims will place an increased burden on already stretched health resources. Modifiable lifestyle factors are the most significant factor. In order to control costs and make effective use of available health resources, logically health care providers and decision makers need to make long-term strategies and focus on a prevention model; one that educates, motivates and supports patients to adopt and maintain a healthy lifestyle.

It was assumed subjects who have suffered a minor stroke or TIA may be more motivated to make lifestyle changes than healthy individuals if they perceive minor stroke or TIA as a warning sign and the danger of recurrence and the possibility of death or severe disability. This may act as a strong incentive to make lifestyle changes.

It was also assumed that the respondents would answer the questionnaire truthfully and that their responses are representative of patients who have suffered a minor stroke or TIA. A further assumption was that those who have not made healthy lifestyle changes were willing to respond to the questionnaire. It was also assumed that the respondents would follow the instructions provided and that if they asked a friend or relative to assist them in completing the questionnaire (due to disability or language) that it was the perceptions and opinions of the respondent that were recorded.

The study was based on the assumption that minor stroke or TIA is a warning that in the future a major stroke may occur.

DEFINITION OF TERMS

Significant terms used in this report are defined below.

Alcohol

For the purposes of this study a standard drink was defined as 12 fluid ounce (fl oz) or 360 millilitres (mls) of either wine cooler or beer (5% alcohol) OR 5fl oz or 150mls of wine (12% alcohol) OR 1.5fl oz or 45mls of liquor (40% alcohol) (Heart and Stroke Foundation 2002b).

Disability

Disability is an umbrella term for impairments and activity limitations. This limitations, restrictions or impairments due to a physical, emotional or nervous conditions which lasts six months or more (Australian Bureau of Statistics (ABS) 2004e, 2005a).

Exercise

Exercise was defined as 30 minutes of moderate activity 6 times per week or vigorous activity at least 3 times per week for 20 minutes each time (Australian Department of Health and Ageing (ADHA) 2005a).

Healthy lifestyle

For the purposes of this study a healthy lifestyle was defined as a way of life that is free from modifiable risk factors.

Hypertension

Hypertension was defined as systolic blood pressure equal to or higher than 140 mmHg and or diastolic blood pressure equal to or higher than 90 mmHg (WHO, 2004b).

Lifestyle-induced health problems

Lifestyle induced health problems are those which result from conscious exposure to certain health-compromising or risk factors (Harris, Nagy & Vardaxis 2006).

Minor stroke

A minor stroke is where recovery is complete or there is little residual disability. For the purposes of this study a minor stroke was defined as, a stroke that requires admission to hospital for a limited period of time (≤ 10 days) and does not necessitate patient discharge to a rehabilitation unit or aged care facility that they were not a patient of prior to admission to hospital.

Motivation

Motivation is 'conscious or unconscious needs, interests, rewards, or other incentives that arouse, channel, or maintain a particular behaviour' (Anderson, K, Anderson, L & Glanze 1998, p.1053). It is used in relation to patients' inclination to make lifestyle changes.

Physical inactivity

The term physical inactivity is lack of any deliberate exercise including walking, sport, recreation or fitness activities, within the two-week reference period or the frequency, duration and intensity of exercise was at a very low level (ABS 2002, 2005a).

Risk factors

Risk factors are those factors that increase the risk of a future stroke. These include both non-modifiable and modifiable risk factors.

Non-modifiable risk factors

These are risk factors over which the patient has no control and cannot be changed. They include inherited defects in blood vessels such as aneurysm and arteriovenous malformation (AVM), family history of stroke, age, gender and race (Skidmore & Katzan 2002).

Modifiable risk factors

These are risk factors that can be reduced or eliminated. They include disorders such as hypertension, diabetes, atrial fibrillation, carotid stenosis, hyperlipidemia, elevated serum low-density lipoprotein cholesterol (LDL), low serum levels of high-density lipoprotein cholesterol (HDL), metabolic disorders such as hyperhomocysteinemia (high homocysteine levels in the blood), obesity and use of certain oral contraceptives. In addition modifiable risk factors include unhealthy lifestyle habits such as cigarette smoking, excessive alcohol consumption, poor diet and not enough physical activity (Mayo foundation for medical education and research (MFMER) 2004, Skidmore & Katzan 2002).

Sedentary lifestyle

This is defined as a lifestyle characterised by a low physical activity level (Harris, Nagy & Vardaxis 2006).

Stroke

A stroke, cerebrovascular accident (CVA) is 'an abnormal condition of the brain characterized by occlusion by an embolus, thrombus, or cerebrovascular haemorrhage, resulting in ischaemia of the brain tissues normally perfused by the damaged vessels...' (Anderson, K, Anderson, L & Glanze 1998, p.302).

Transient ischaemic attack

Transient ischaemic attack (TIA) is a temporary episode of cerebrovascular insufficiency may cause neurologic dysfunction commonly manifested by a sudden loss of motor, sensory, or visual function. Symptoms may last shortly and rarely continue for hours. Complete recovery generally occurs but may serve as a warning of impending stroke (Smeltzer & Bare 1996).

SUMMARY

The impact of stroke is immense. Not only does the high mortality and morbidity rate impact on victims, but it also affects families, friends, communities and society as a whole. Inaccurate records of the number of people who suffer a second stroke, together with limited resources means that the importance of prevention may be tragically underestimated. Although stroke is a preventable disease and lifestyle modification has a significant effect on minimising the risk of recurrence, there has been little research regarding this issue. Health care providers, as yet, have not had sufficient information about patients' perceptions to implement appropriate prevention strategies. Current health care strategies focus on treatment of major stroke and provide limited health promotion to support this group of patients. This may have significant implications for future demand on health care services.

This study evaluated the knowledge of patients who had suffered a minor stroke or TIA and sought to identify any lifestyle changes they had made since their stroke or TIA. In addition, it sought to identify factors that had influenced their decision-making. This information may be of use to health professionals in developing appropriate preventive strategies; particularly centred around supporting existing patients to adopt healthier or lower risk lifestyles.

LITERATURE REVIEW

INTRODUCTION

In many countries stroke is among the most common causes of death and is the largest cause of disability (National Stroke Foundation 2003, WHO 2002). Patients who have suffered a stroke may be left with disabilities, requiring long-term care and assistance from their families. This condition not only increases suffering of the patients themselves and their families and reduces their quality of life, it also increases the burden on the community by decreasing productivity and escalating the cost of health care and social support systems (de Looper & Bhatia 2001, Forsberg-Wärleby, Möller & Blomstrand 2002). Although the mortality rate has declined in the last few decades, the number of stroke victims is increasing every year (ABS 2005b). Possible reasons for this are unhealthy lifestyle norms in the Western culture such as poor diet, cigarette smoking, binge drinking, and sedentary behaviour.

In many developing and low-income countries, globalisation has promoted the adoption of unhealthy lifestyles resulting in more people suffering strokes, disability or ultimately death (WHO 2004a, AIHW 2004, Sacco, Benjamin, Broderick, Dyken, Easton, Feinberg, Goldstein, Gorelick, Howard, Kittner, Manolio, Whisnant & Wolf 1997). For example in Cambodia, Malaysia and Bangladesh, the prevalence of smoking has increased particularly in the female population (American Cancer Society 2003). In 2003 the Tobacco Control Country Profiles (TCCP) reported that in 1995, more smokers lived in low and middle income countries (933 million), than in high-income countries (209 million); and about 35% of men in developed countries smoked, compared with almost 50% in developing nations and almost two-thirds in China (Shafey, Dolwick & Guindon 2003). According to the findings of WHO in 2004, 80% of CVD now occurs in low and middle-income countries. If this trend continues, CVD will be the leading cause of death in developing countries by 2010 (WHO 2004a). Prevention is an important and cost-effective means of reducing the cost of chronic diseases such as CVDs. Governments and health industries in many nations would do well to cooperate on primary health care initiatives, sharing their experiences and making long term policies and plans to control the increase in strokes and other CVDs.

According to the International Classification of Diseases (ICD-10) cerebrovascular disease (160-169) is classified as a disease of the circulatory system (WHO 2005b). Stroke is caused by two major mechanisms, ischaemia (83%) and haemorrhage (17%) (Englewood 1997) (Figure 1).

Figure 1: Rates for all types of stroke

NOTE:
This figure is included on page 10 of the print copy of
the thesis held in the University of Adelaide Library.

Sourced from: Stroke Brain Attack Reporter's Handbook. Englewood, Colo: National Stroke Association 1997.

Ischaemic stroke is caused by decreased circulating blood supply to the neurones and a resulting lack of oxygen and glucose for brain cell metabolism. This type of stroke accounts for the majority all strokes with about 62% caused by cerebral thrombosis and 38% caused by cerebral embolism. Cerebral thrombosis is when a blood clot forms within a cerebral artery damaged by atherosclerosis. This results in a blockage of blood flow. Cerebral embolism is when an embolus (clot) comes from the heart or the cervical portion of the carotid artery and is carried through the blood stream, subsequently blocking a portion of the circulation to the brain (Englewood 1997).

Haemorrhagic stroke is caused by the rupture of a blood vessel in the brain (Hyperdictionary 2003). Most haemorrhagic strokes result from an aneurysm or a n

arteriovenous malformation (AVM) within the brain that ruptures causing blood to flood the surrounding brain tissue. Haemorrhagic strokes are caused by a bleed either over the surface of the brain (subarachnoid haemorrhage) or into the brain (intracerebral haemorrhage) where bleeding begins from deep blood vessels in the brain and causes localised pressure, damaging brain tissue and disturbing blood flow (National Health and Medical Research Council (NHMRC) 1997). Some brain tissue injury is caused by biochemical substances, which are released from blood cells causing further destruction of brain cells (Brain Injury Society 2005).

THE PREVALENCE OF STROKE

The ABS indicates that 'the prevalence rate of cardiovascular disease (including cerebrovascular diseases) increases with age, peaking at 40% for people aged 65 years and over' (ABS 2004f). Many risk factors stem from unhealthy lifestyle habits. Although health departments claim that there has been a reduction in the number of people with modifiable risk factors that are a hazard to their health, the proportion of overweight and obese Australians is still increasing from 36% in 1990 to 44% in 2001. In 2004 the percentage of male adults who were overweight or obese was 54.4% and for females was 38.2% (ABS 2004a, 2004b). It appears that a poor diet, especially diets high in fat, cholesterol and salt and a low consumption of fruit and vegetables are common (AIHW 2001).

In 2003, a WHO survey found cardiovascular diseases resulted in 16.7 million deaths, constituting about 29.2% of total global mortality (WHO 2004a). Every year stroke cause 5.5 million deaths and are the largest single cause of disability with 20 million survivors around the world. Stroke has become the third highest killer after heart disease and cancer (WHO 2004a).

In Australia in 2003 60% of patients who suffered from stroke were aged 65 years and over, thus the ageing population is an important factor contributing to the increasing stroke rate. In 2004 the Australian population reached 20,111,300. The median age was 36.4 years with South Australia having the highest median age of 38.5 years. Moreover, the number of people aged 65 years and over increased by 2.3% to over 2.6 million. This group comprised 13% of the population and the proportion of people

aged 65 years and over is expected to increase from 12.4% to 13.1% in 2005 (ABS 2004d). According to the Australian Bureau of Statistics, in 2051 27.1% of the population will be aged 65 years and over and the median age will also rise to 46.8 years (ABS 2004c). The trend of population ageing is increasing.

A stroke often occurs suddenly and has serious outcomes which may include death or severe disability for approximately two-thirds of victims (National Stroke Foundation 2003). In Australia in 2003, 12,240 people died of stroke (9.3% of all deaths) and about 70,000 suffered a disability caused by stroke and are living in the community (AIHW 2004, 2005a, ABS 2004e, 2005b). According to the AIHW national mortality database in 2005, the number of male stroke victims is higher than female. Although the mortality rates for stroke have declined consistently in both sexes in recent decades, the death rates were 25 per 100,000 males and 17 per 100,000 females among people aged 0-79 in 2000 (AIHW 2005b) (Figure 2).

NOTE:

This figure is included on page 12 of the print copy of the thesis held in the University of Adelaide Library.

Sourced from: AIHW National Mortality Database (Australian Institute of Health and Welfare (AIHW) 2005b).

Figure 2: Death rates for stroke, ages 0-79

However, AIHW in 2004 showed that 'over the last decade the prevalence of heart, stroke and vascular conditions rose by around 18.2%' (AIHW 2004, p.18). Every year over 40,000 Australians suffer a stroke: about 30% make a complete recovery, 25% die in the first month and 45% are disabled and need long-term care (AIHW 2004). However, reports have indicated that patients presenting with a minor stroke or TIA

are not being recognised and treated appropriately (Goldstein, Bian, Samra, Bonito, Lux & Matchar 2000, Smith, Lawrence, Kerr, Langhorne & Lee 2003). A 1998 study by Petty, Brown, Whisnant, Sicks, O'Fallon and Wiebers' reported a recurrence rate of only 2% to 4% within one month. Subjects for this study were recruited one week following their initial stroke. Thus episodes that occurred within the first week were not recorded. However, in 2004 Coull, Lovett and Rothwell reported the rate of recurrence of minor stroke and TIA was 8% for the first week and up to 18.5% for the first three months. Another possible reason for the difference in reported recurrence rates could be varying definitions of stroke and TIA. Underestimation of the recurrence rate may impact on the distribution of resources and research conducted on the issue. Rapid recovery may lead victims to view their condition less seriously. In fact a minor stroke or TIA may serve as a warning of an impending more serious stroke. If taken seriously, this information may provide patients with the necessary motivation to make healthy lifestyle changes.

The number people in the population who have suffered a minor stroke or TIA may be underestimated, this may be because some patients ignore symptoms and do not seek medical advice (Gupta & Thomas 2002). With a TIA it is likely that for some patients the signs and symptoms may resolve before they see a General Practitioner (GP) and therefore their condition remains undiagnosed. In addition to this, patients with little knowledge about stroke may not report important symptoms to their doctors. This may mean that they are not referred to a hospital for further investigations or provided with appropriate health information on how they can reduce their risk factors (Lovett, Dennis, Sandercock, Bamford, Warlow & Rothwell 2003).

In hospital-based studies, minor stroke and TIA may also be under-represented due to the focus on high acuity admissions (Shah & Cooper 1995). In addition, patients are often admitted for a short period of time (usually one to two days) for observation and investigations. Some patients may think that since they have made a full recovery that they are cured and no follow up is required. Although health care resources used for saving acute major stroke victims and rehabilitation of severe disability patients are first priority, it is also important to reduce the new incidents and recurrence of stroke.

Anecdotal evidence suggests that patients who have suffered a mild stroke or TIA with little intervention, do not receive comprehensive follow up, but may only be referred to their GP. This means that their access to education programs and information regarding their condition may be limited (Chaturvedi & Fe mino 1997, Filippi, Bignamini, Sessa, Samani & Mazzaglia 2003).

The causes of stroke relate to genetic, behavioural, physiological, social, economic and cultural factors (de Looper & Bhatia 2001). Risk factors such as hypertension, diabetes and high blood cholesterol levels may go undetected, meaning that patients may not be aware of the risk of serious disease. In addition, patients may not recognise the early signs and symptoms of a stroke or TIA and may delay seeking treatment. Although in Australia, the mortality rate has been reduced by about 60% since 1950, stroke is still common and remains a leading cause of long-term disability in the adult population (de Looper & Bhatia 2001). This is especially true in the ageing and lower socioeconomic groups.

LOWER SOCIOECONOMIC GROUPS

People who live in the most disadvantaged socio-economic areas are at higher risk of cardiovascular disease (AIHW 2004, Jakovljevic, Sarti, Sivenius, Torppa, Mähönen, Kuulasmaa, Tuomilehto, Puska & Salomaa 2001) and the related mortality rate is double that in wealthier areas (AIHW 2001). This may be due to the lower socioeconomic groups having a higher rate of cigarette smoking, obesity, diabetes and history of cardiovascular diseases and also being less likely to visit physicians and receive in-hospital services (Kapral, Wang, Mamdani & Tu 2002, Centers for Disease Control and Prevention (CDC) 2005).

THE COST OF HEALTH CARE

Nearly \$1.8 billion is spent caring for stroke victims in Australia each year. During 1997, the total cost relating to strokes (excluding subarachnoid haemorrhage) was estimated to be \$555 million, and the lifetime cost was estimated to be \$1.3 billion. Based on these figures, the average cost per patient during the first 12 months was \$18,956 and over a lifetime \$44,428 (Dewey, Thrift, Mihalopoulos, Cater, Macdonell, McNeil & Donnan 2001).

Obviously the huge cost of ongoing health care and social support for stroke victims is a major incentive to put energy and resources into stroke prevention strategies. In 2001–2002, there were 40,251 hospitalisations where stroke was the principal diagnosis, which made up 0.6% of all hospitalisation (AIHW 2004). From 15.4% in 1993–1994, hospitalisations for stroke (include TIA) increased to 22.1% in 2001–2002. The average length of stay, however, dropped from 18 days in 1993–1994 to 12 days in 2001–2002 (AIHW 2004). These improvements were mostly due to the recognition of risk factors and health professionals starting to encourage patients to make lifestyle changes. Knowledge gathered from advanced investigations in stroke units helped professionals improve the ways treatments were implemented (Webb, Fayad, Wilbur, Thomas & Brass 1995). Also, more medications have been used to control blood pressure, cholesterol levels and prevent and treat blood clots.

The cost of acute hospitalisation and the even higher cost of treating patients with long-term disabilities constitutes a significant burden on families and communities in both developing and developed countries (Palmer, Valentine, Roze, Lammert, Spiesser & Gabriel 2005, Andersson, Levin, Oberg & Mansson 2002, Grieve, Dundas, Beech & Wolfe 2001). Stroke is a preventable disease. Most of the risk factors can be modified through lifestyle changes, or controlled using medications, such as anti-hypertensives, anti-arrhythmics, serum lipid lowering drugs, anticoagulants, anti-platelet and anti-thrombotic drugs (Heart and Stroke Foundation 2002a). However, these drugs are expensive. Each year more people are using them and the cost rises. As an example of soaring prices, the cost of serum lipid lowering drugs increased 3.6 times within five years from \$49 million in 1990 to \$178 million in 1995, up to the fourth highest ranking drug in the Pharmaceutical Benefits Scheme (PBS) (Waters, Armstrong & Senes-Ferrari 2001). According to a PBS survey, there were 125 million prescriptions for cardiovascular drugs at a cost of \$2,686 million in 1995–1996. Using the expensive medications may not be the most cost-effective way forward. It may well be that the adoption of lifestyle changes can make a significant difference at a relatively low cost.

Cerebrovascular diseases are expected to rise as our population ages. Figures suggest that the total cost of prescriptions has more than doubled in the past 10 years from 817 million in 1995 up to 1.891 billion in 2004. This accounts for about 38% of

government and patient costs for all prescription drugs (ADHA 2004a, Waters, Armstrong & Senes-Ferrari 2001). This indicates the rapid growth in cost and number of prescriptions from doctors and increasing reliance on pharmacological treatment to control the risk factors for stroke.

Surgical interventions to prevent stroke, such as carotid endarterectomy for carotid stenosis and cerebral angioplasty are costly and carry associated risks and complications. The cost of these procedures continues to be very high due to the acute management and hospitalisation required (Spieler, Lanoe & Amarenco 2004). While these invasive interventions are suitable for use in emergencies and in high-risk cases, for many patients, lifestyle changes, as an early intervention strategy, are the most efficient way to avoid recurrence of stroke.

The cost of an unhealthy lifestyle can be vast if people in the community are not well educated about the potential hazards related unhealthy lifestyle choices and go on to develop acute and chronic diseases such as, diabetes or stroke. Treatment and support services are more costly than prevention and governments will need to continually increase spending to save lives and provide stroke survivors with vital social and health support services for long-term care (National Stroke Foundation 2002).

Patients who have suffered a minor stroke or TIA have an increased risk of stroke; therefore motivating this group of people to make lifestyle changes is of paramount importance (Greenlund, Giles, Keenan, Croft & Mensah 2002). Assessing patients' perceptions and experiences of lifestyle changes may help determine methods to facilitate change (Mosca et al. 2000). Long term, ascertaining their health needs and providing appropriate assistance may be a very cost-effective strategy. Thus, health professionals may be able to apply suitable strategies as a part of health promotion programs to help alleviate the heavy burden on health care services (Mihalopoulos, Cadilhac, Moodie, Dewey, Thrift, Donnan & Carter 2005).

Preventive measures such as lifestyle changes are clearly important factors in reducing the risk of stroke recurrence, however patients with stroke may choose not to make lifestyle changes. It appears that little recent research has been conducted to investigate patients' perceptions of the suggested lifestyle changes. The lack of

current research in this area means this information has not been available in the planning of health promotion strategies and may significantly impact their effectiveness.

In 2003 Smith, Lawrence, Kerr, Langhorne and Lee conducted a study to investigate informal carers' experience of caring for stroke survivors. They found that most carers and families wanted more information about stroke, the physical or emotional effects, risk factors, recurrence, medication, treatment options, aids, services, benefits and respite care (Lilley, Lincoln & Francis 2003). Fear of recurrence of stroke remained a concern for patients and their families (Forsberg-Wärleby, Möller & Blomstrand 2002).

Although medicine is currently searching for the most effective way to cure and prevent stroke and treat its complications, patients can also be encouraged to adopt lifestyle changes, which are relatively safe, have few side effects and are cost-effective (Gencheva, Sloan, Leurgans, Raman, Harris, Gorelick & AAASP S Investigators 2004).

Until now there has been limited research exploring patients' perceptions following stroke or TIA and factors that may influence patients' decisions in making lifestyle changes.

Previous studies have found that patients have a poor understanding of the link between unhealthy lifestyle and stroke. In addition many patients did not know the signs and symptoms of strokes and did not consider themselves to be at risk (Mosca et al. 2000, Yoon & Byles 2002). This is particularly common in the elderly (Gupta & Thomas 2002). Social isolation and a lack of access to information sources such as the Internet, may compound this problem for older people. Health care providers need to enhance education and improve communication in order to increase people's awareness of symptoms and risk factors and plan prevention measures which consider the importance of the adoption of behavioural changes in minimising the risk of recurrence (Yoon & Byles 2002, Smith et al. 2003, King, Shade-Zeldow, Carlson, Feldman & Philip 2002, Mosca et al. 2000, Denby & Harvey 2003, Gupta & Thomas 2002).

One of the reasons there has been limited research about stroke victims' perceptions and lifestyle changes may be due to some of the after effects of stroke. Researchers may have trouble exploring the opinions of patients who have dysphasia, difficulty communicating or depression (Kauhanen, Korpelainen, Hiltunen, Brusin, Mononen, Määttä, Nieminen, Sotaniemi & Myllylä 1999, King et al. 2002). These obstacles have impeded the understanding of the needs of the patients following a stroke.

In 2003 Denby and Harvey studied the influence of education on stroke victims and caregivers on secondary prevention. This education program was called 'Healthy Living After Stroke' and gave essential information about causes, signs, symptoms and risk factors. The program was not specific also including victims of major stroke. They found the individual's readiness to learn, unique learning styles and timing of sessions were significant factors influencing the effectiveness of the lifestyle changes made. The study examined not only the patient's knowledge regarding the risk factors, but also which follow up lifestyle changes they made and the factors, which influenced their decisions. It may be that patients who are not exposed to an education session do not have a good understanding of the causes of CVDs and therefore are not as motivated to make lifestyle changes. In addition, patients who suffer minor stroke or TIA may have more control over their own lives and more urgency to make lifestyle changes than patients who suffer a more severe stroke and are left with serious disabilities.

Thus this study was designed to collect data from patients who have suffered a minor stroke or TIA and explore their perceptions related to making lifestyle changes suggested to prevent or lower the risk of recurrence. The findings may be helpful for health professionals in the development of more effective rehabilitation programs for this group of patients following discharge.

PREVENTION AND TREATMENT

Stroke can be prevented and treated (National Stroke Foundation 2003). There are several different strategies that can prove useful in reducing the incidence of stroke, for example: increasing public awareness about risk factors and encouraging people to

adopt a healthy lifestyle. In addition it is important to make people aware of the signs and symptoms of stroke, so they will seek treatment promptly thus minimising complications and optimising their chance of recovery (Verro 2004, Johnston & Hill 2004).

Adopting a healthy lifestyle is not always easy. This is because people have individual beliefs about themselves, beliefs about health and may also have deeply entrenched habits due to their background and socialisation. Nurses are in a good position to help people make behaviour changes through effective interpersonal communication skills combined with motivational interviewing principles to increase patients and providers' satisfaction, adherence and continuity of treatment (Shinitzky & Kub 2001). The support of families and friends in this process can be significant. Health care professionals can also review patients periodically to assess how they are going with their lifestyle changes, provide appropriate support, maintain awareness of the risks and update information for long-term health strategies (McBride, White, Sourial & Mayo 2003).

Patients with complex health disorders such as heart failure, hypertension, diabetes and obesity, may need to consult their doctor before making changes such as introducing an exercise program or significantly modifying their diet. Age and disability may also influence one's ability to modify lifestyle. In addition, it is important, particularly for people at risk of stroke, that their blood pressure, heart rhythm, blood lipids, cholesterol levels and body weight are checked regularly (Aldana, Greenlaw, Diehl, Salberg, Merrill, Ohmine & Thomas 2006).

Health-related lifestyle and risk factors

In 2001 an Australian National Health Survey (ANHS) collected information on five behavioural risk factors; physical activity, body mass, fruit and vegetable consumption, cigarette smoking and alcohol consumption. Compared with previous surveys conducted in 1989 and 1995, although the percentage of the population smoking and not exercising is declining, it still remains high and the percentage of the population who are overweight continues to increase (ABS 2002, 2003).

Smoking

Cigarette smoking is the second highest cause of death in the world; with about five million premature deaths from smoking each year (WHO 2005c). Due to legal changes affecting advertising and an increased recognition of the health risks associated with smoking in developed nations, the tobacco industry increasingly markets its products to people in developing countries (James 2005, Food and Agriculture Organization of the United Nations 2003, Fonda 2005). Currently, over 600,000 smoking-attributable deaths occur in China every year (American Cancer Society 2003). Smoking increases the risk of stroke four-fold and is recognised as one of the main risk factors for stroke (Bonita, Duncan, Truelsen, Jackson & Beaglehole 1999). Smoking 20 cigarettes a day, increases the chances of suffering a stroke by six times (National Stroke Foundation 2003). In 2001 in Australia about 24% (28% male and 21% female) of adults smoked, with 22% being regular daily smokers. The number of young adult (18–34 years) smokers was even higher with males at 36% and females at 28%. ABS figures indicate there has been little change since 1995, when 25% of Australians were current smokers (ABS 2002).

Alcohol

Alcohol abuse is the third leading preventable cause of death. Binge and heavy drinking may increase the risk of stroke (CDC 2004). In Australia a standard drink is any drink that contains 10 grams (or 12.5 millilitres) of alcohol (ADHA 2003). Some health organizations such as Heart Foundation and the National Health and Medical Research Council (NHMRC) found that males have higher tolerance (four standard drinks a day) than females (two standard drinks a day). Low and moderate amounts of alcohol (one to two drinks per day, three to four days of the week) may reduce the risks of ischaemic stroke (almost one-third less than non-drinkers) (Mukamal, Ascherio, Mittleman, Conigrave, Camargo Jr, Kawachi, Stampfer, Willett & Rimm 2005, NHMRC 2001). However, heavy drinking (three or more drinks per day) may increase the risk of atrial fibrillation, high blood pressure, high blood cholesterol level and or obesity, all of which are important risk factors for stroke (Djousse, Levy, Benjamin, Blease, Russ, Larson, Massaro, D'Agostino, Wolf & Ellison 2004, Heart Foundation 1995, Iso, Baba, Mannami, Sasaki, Okada, Konishi, Tsugane & JPHC Study Group 2004, Mukamal et al. 2005). Thus, there are strong reasons for

moderating alcohol use. Patients on medication, in particular, should be aware of the possibility of interactions and may need to either stop drinking or restrict their alcohol intake. This may significantly lower the risk of stroke and the reduce need for medication (Heart Foundation 1995).

Obesity and lack of exercise

In recent decades the number of people who are overweight or obese has increased dramatically in both developed and developing countries, especially in economically advanced regions of developing countries and in urban populations (American Obesity Association 2002). This epidemic is not limited to adults. The number of young people who are overweight has more than doubled in past decades (Feng 2004, Carmona 2004). The main reasons are an over intake of food, poor diet and lack of physical exercise. People who are overweight or obese, have an increased risk of high blood pressure, diabetes, heart disease and stroke. Although numerous health recommendations and guidelines urge people to eat a healthy diet and exercise regularly, more than half of the populations in both developed and developing countries do not get enough exercise. In Australia the percentage of overweight people has increased from 46% to 58% in males and 32% to 42% in females, about a 29% increase in prevalence from 1990 to 2001 (ABS 2002). The Australian Bureau of Statistics 2002 survey also found that overweight or obese people had an inadequate fruit intake and a higher percentage were physically inactive and added salt to their food. These people are more likely to develop high blood pressure, high blood cholesterol, diabetes mellitus and or heart disease.

In terms of exercise level, the majority of people were classified as sedentary or having a low exercise level; about 65% in males and 74% in females (ABS 2002). As a strategy, governments have sought to provide more education about nutrition and physical activity programs to support people to improve their health status.

Hypertension

Hypertension is a major risk factor for stroke and develops among people who are overweight, obese, physically inactive or have high dietary salt intake (Heart Foundation 2003). Hypertension is a common problem in the Australian population

with 28.6 per 100 people suffering from this condition, but over a half (15.2 per 100) remain untreated (Briganti, Shaw, Chhaban, Zimmet, Welborn, McNeil & Atkins 2003). Of those with untreated hypertension, 78.3% have mild hypertension, 17.4% moderate and 4.3% severe. Many of them are young, male and not diabetic or obese, have normal lipid levels, currently smoke, engage in excessive alcohol intake and are physically inactive. In about 71.7% of patients with untreated hypertension, at least one modifiable lifestyle factor was present (Briganti et al. 2003).

Stress

Stress has been implicated as a risk factor for hypertension and thus stroke (Harmsen, Lappas, Rosengren & Wilhelmsen 2006, Ohlin, Nilsson, Nilsson & Berglund 2004). An individual's coping style may have a significant impact on how they respond to stress. In addition there are many effective ways which stress can be alleviated such as meditation, exercise and positive thinking, social support and counselling.

Each patient has a different background and a unique set of experiences and feelings, so each individual's reactions to stress will be quite different. Living in a competitive society, people often feel pressure from a variety of sources such as a part of daily living; work, family, finances, relationships and emotional suffering; grief from losses and adjustment to new situations. The amount of pressure felt may increase gradually over time and if not addressed properly, directly affects people's behaviour and lifestyle choices. Increased cigarette smoking, binge consumption of alcohol and increased food intake may be part of an individual's response to stress (Nielsen, Truelsen, Barefoot, Johnsen, Overvad, Boysen, Schnohr & Gronbaek 2005).

Therefore stress has an indirect effect on the adoption of an unhealthy lifestyle, significantly increasing the risk of stroke.

Investigations and management

Limited definitive treatments are available for stroke. Currently thrombolytic therapy is the only non-surgical treatment available for ischaemic stroke and must be commenced within three hours of symptom onset to dissolve the thrombus and allow reperfusion. Craniotomy for re-canalisation or decompression to reduce intracranial

pressure (ICP) constitutes major surgery and is a high-risk option (Heart and Stroke Foundation 2002a).

Clearly, where possible, preventative strategies are favoured. These include measures such as anticoagulant and anti-platelet drug therapies, control of hypertension and treatment for abnormal blood cholesterol (e.g. high LDL or low HDL) as well as surgical procedures such as carotid endarterectomy, angioplasty, stenting and coiling of aneurysms. Advanced investigation techniques such as Computed Tomography Scanning (CT scan), Electroencephalogram (EEG), Carotid ultrasound (Doppler), Magnetic Resonance Imaging (MRI) and Magnetic Resonance Angiography (MRA) are widely used to diagnose CVD (Heart and Stroke Foundation 2002a, Hacke, Kaste, Olsen, Bogousslavsky & Orgogozo 2000).

Research has shown that many people are still not well informed about stroke and remain unfamiliar with the signs and symptoms (Mosca et al. 2000) therefore further public health education is warranted. For many patients their only contact with a health professional is with their local GP. In Australia there is currently a shortage of GPs particularly in some of the poorer socio-economic regions and in rural areas (Australian Broadcasting Corporation 2005), which means there are fewer opportunities for health counselling and health promotion services. This may also mean it is easier for doctors and more likely that they will prescribe medications rather than work with patients to help them adopt a healthy lifestyle. This may not be the best option, as drugs are costly and they have side effects. Lifestyle changes and other preventative strategies are more effective long term (CDC 1999, Cook, Drum, Kirchhoff, Jin, Levie, Harrison, Lippold, Schaefer & Chin 2006).

It is generally accepted that health professionals play an important role in advocating a healthy lifestyle, because of their knowledge, experience and communication skills, as well as their contact with the public. GPs are respected professionals and as they are the first point of contact for most people with a health concern, they are in a strategic position to deliver some of the necessary education and coaching to support patients in effecting lifestyle change. Ongoing support from the GP may give patients the confidence and motivation to adopt lifestyle changes and improve their health

status (Ashenden, Silagy & Weller 1997, Reid, Maher, Jennings & Heart Project Steering Committee 2000).

Existing community health programs may be lacking in this area. Health care providers may not yet have in place well-organised, appropriately structured health promotion programs to support people to implement the healthy lifestyle changes. An increased understanding of the needs, concerns and obstacles faced by people who have experienced a minor stroke or TIA as well as an awareness of how their knowledge impacts on their ability to make lifestyle changes will assist health professionals to respond appropriately to patients' health needs. A shared understanding may facilitate and promote shared decision-making between patients, families and health care providers about preventive options (Bader & Prendergast 1997, Berra 2003, Smith et al. 2003).

SUMMARY

While healthy lifestyle changes have been shown to significantly reduce risk factors, minimising the chance of stroke, these have not yet been widely adopted. The reasons for this are complex and include a lack of understanding about the nature of stroke, a perception that stroke is unpredictable, unpreventable and an acceptance of stroke risk as part of the normal problems of ageing.

To make lifestyle decisions people need to be aware of the risks. The support of health professionals is also very important. With the current situation of GP shortages and limited health resources and the fact that priority is being given to emergency, acute and severe patients in hospitals and stroke rehabilitation programs, less resources are available for primary health care initiatives aimed at prevention and minimising recurrence in patients who have suffered only a minor stroke or TIA (Lilley, Lincoln & Francis 2003). The increased survival rate may result in a higher number of disabled patients, consequently increasing the cost of care. If stroke survivors with modifiable risk factors do not take action to eliminate or minimise the risk factors, the chance of recurrence is high (Coull, Lovett & Rothwell 2004).

Therefore, it is important that health professionals learn more about patients' efforts to make lifestyle changes and the knowledge surrounding these, so that they will be in a position to create better long-term strategies to prevent recurrence in this group of patients. These programs need to educate, raising awareness about the risk of severe disability or death if changes are not made and a major stroke is suffered. They need to work generally in the community to improve people's awareness of the importance of preventive measures. On a societal level this may help to reduce the cost of health care services to the community and lessen suffering from stroke. From a global perspective the WHO suggests that cooperation between countries in primary health care strategies is essential in order to control the trend of increasing cardiovascular diseases including stroke (WHO 2003).

Adopting a healthy lifestyle will not only help to reduce the risk factors of stroke but will also reduce the risk of other chronic disorders such as diabetes, hypertension and coronary artery disease.

METHODS

RESEARCH STUDY DESIGN

This descriptive study used a questionnaire as the data collection instrument. This method can provide a large amount of data and detail regarding trends and frequencies. Polit and Beck (2004, p.192) state 'the purpose of descriptive studies is to observe, describe, and document aspects of a situation as it naturally occurs ...'. In this study the researcher wanted to increase understanding of this group of patients' knowledge, behaviours and individual experiences of lifestyle changes following a minor stroke or TIA, thus a descriptive study design was most appropriate model.

STUDY SETTING

The subjects were recruited through a major metropolitan general hospital in South Australia. This hospital provides adult tertiary referral services and has three campuses and about 1000 beds. The researcher was introduced to patients, by a medical doctor they knew. This process enabled the researcher to access contact addresses of patients who had suffered a minor stroke or TIA. This also allowed the researcher to identify those who met the inclusion and exclusion criteria through medical records by reviewing diagnosis, treatment, admission period and destination of discharge.

STUDY POPULATION AND SAMPLE SELECTION

Subjects

The researcher chose to use a sample of patients who have suffered a minor stroke or TIA because they have higher risk of recurrence than healthy people. These subjects may also be more able to answer a questionnaire than those who have suffered a severe stroke. In addition they may have more personal control over changes made than those who have suffered a major stroke. Patients who have already experienced a stroke or TIA may also be more motivated to make lifestyle changes to prevent recurrence. Although most patients who suffer minor stroke or TIA recover rapidly, they can be left with varying degrees of disability, either temporary or permanent, which may affect their daily activities and quality of life. It appears that health care

services and supports for this group of patients are often insufficient (Tyson & Turner 2000).

Potential subjects' were initially identified through the Australian Patient Management System (APMS) database in a major public hospital. The researcher selected those who met the inclusion and exclusion criteria for the research and contacted patients by letter using their recorded addresses. A questionnaire was used due to the limited time frame for the study and the fact that subjects were dispersed throughout South Australia and interstate. A questionnaire that could be posted was an economic and efficient way to collect the information.

The study surveyed a convenience sample of patients who had been admitted to the Stroke Unit and Neurology wards with a minor stroke or TIA and who met the following selection criteria.

Inclusion criteria

Subjects were eligible for the study if they:

- were 18 years or over.
- were admitted for treatment to the hospital at which the research was conducted.
- had a diagnosis of minor stroke or TIA.
- were discharged within ten days of their admission.
- were discharged between three months, to one year prior to the commencement of the study.
- were able to complete the questionnaire or use a friend or relative to record their responses.
- understood English.

Exclusion criteria

Subjects were excluded from the study if they:

- had had a haemorrhagic stroke.
- were seriously sick or had a terminal illness.

- had had a major stroke resulting in prolonged admission for greater than ten days.
- were transferred to rehabilitation hospital or aged care facility which they had not been in prior to admission.
- were discharged less than three months before or more than a year from the commencement of the study.
- had severe receptive and expressive communication problems.

The researcher decided to include patients who had been discharged from hospital three months to one year from the commencement of the study, as previous research has indicated that this time period allowed the patient to stabilise psychologically and to make decisions regarding lifestyle changes (Smith et al. 2003, King et al. 2002). It was also important for this study to recruit subjects who had been discharged for at least 3 months because initially there is a focus on recovery and rehabilitation rather than preventive measures. It may be that in the year following the stroke when the memory of the event is fresh that patients may be most motivated to make lifestyle changes.

It was decided to exclude patients transferred to a rehabilitation hospital or aged care facility which they had not been in prior to admission, because such patients might have comparatively severe complications from their stroke, which warrant the care in such institutions. This would also influence their ability to make decisions regarding lifestyle changes.

It was also necessary to exclude patients who have severe receptive and expressive communication problems because they may not have understood the content of the questionnaire or been able to provide appropriate feedback. Such problems were documented in patients' medical records. Moreover, patients who have had a haemorrhagic stroke were excluded because there may be a genetic cause such as an aneurysm or AVM, that ruptures causing bleeding into the brain. In these cases lifestyle changes may not be so relevant (Englewood 1997).

Recruitment of subjects

Adult patients who had suffered from a minor stroke or TIA and were admitted to the hospital for ten days or less, and were discharged from three months to one year from the commencement of the study were targeted for the research study. They were identified and selected from the APMS at the hospital. This enabled the researcher to categorise patients according to their diagnosis, duration of stay and discharge details.

ETHICAL CONSIDERATIONS

The research proposal was approved by the Discipline of Nursing, the University of Adelaide, Research and Higher Degrees Subcommittee (RAHDS) (Appendix 1) and the Research Ethics Committee (REC) of the hospital at which the research was conducted (Appendix 2). Patients were selected using the hospital database according to diagnosis, duration of stay and discharge details. The patients' data were assessed individually to ensure each patient was appropriate for the study, to ensure they met the inclusion and exclusion criteria. After this process, 56 patients were identified and sent a package, which included a questionnaire and an introduction letter (Appendix 3) from a Staff Specialist in Neurology Unit at the hospital, introducing the study and inviting the patients to participate. An information sheet (Appendix 4) with a clear explanation about the purpose of the study and the questionnaire was also enclosed (Appendix 6).

As this group of patients are generally followed up by their GPs or clinics, it was not feasible to gain written consent. The information sheet explained that consent would be assumed if they returned the questionnaire. If subjects had any queries about the research, they were informed that they could contact the researcher or the chairman of REC and phone numbers were provided. If the researcher had not received a returned questionnaire after two weeks, a reminder letter (Appendix 5) was sent to the subjects, including a copy of introductory information.

Subjects were informed that they were under no obligation to participate in the study and their anonymity would be maintained. Patient details were only used to identify possible subjects to send out the questionnaires and reminder letters. Once this process was completed these details and electronic and paper copies of documents

were destroyed. The names of subjects who returned their questionnaire were replaced by a code. Anonymity and confidentiality was maintained throughout the study and no identifying information was recorded or published. Data will be stored in a locked cupboard for fifteen years as required by the ethics committee.

DATA COLLECTION

A questionnaire (Appendix 6) was selected as the data collection method rather than interviews as it is less resource dependent and data could be collected from all possible subjects simultaneously. A questionnaire would also allow subjects to seek appropriate help from their families or friends if they had disabilities that made it difficult for them to complete the questionnaire. Items within the questionnaire were designed according to the findings from the literature review regarding risk factors relating to CVD and healthy lifestyle changes (Mozaffarian, Fried, Burke, Fitzpatrick & Siscovick 2004, Yoon & Byles 2002, ABS 2004f).

Validity

As the design of a suitable questionnaire was pivotal to the success of the study, the researcher invited experts in questionnaire design to assist in this process. A clinical nurse consultant (CNC) and a Staff Specialist in Neurology were also invited to assess the face and content validity. Face validity relates to whether the questions appeared appropriate to the aims of study and whether each was clear and unambiguous. To assess content validity they were asked to assess if the questionnaire covered the full range of questions relating to the topic and whether each item allowed for the full range of responses. Although this stage was time consuming, it was worthwhile in the interests of developing the best research tool for the study.

Within the questionnaire both open and closed questions were used to explore subjects' demographic data, health background, perceptions of risk factors, any changes to their lifestyle and experiences on processing preventive measures in daily living. For most questions there was a space where subjects could explain reasons for their response and make any other relevant comments. As this study related to subjects' knowledge and reasons for their decision-making regarding lifestyle

changes, open-ended questions were very beneficial in assessing their views and opinions.

It is well recognised that questionnaires may yield the low response rates and this may influence the validity of the results, therefore the following measures were taken to maximise patients' response rate:

- A letter of introduction inviting subjects to participate from a doctor representing the subject's consultant.
- An information sheet was provided with clear explanations about the nature and aims of the study.
- The phone numbers of the researcher and the chairman of ethics committee were provided for subjects to contact if they wanted further explanation or had any queries about the study.
- A stamped return addressed envelope was provided for subjects to return the completed questionnaire.
- After two weeks a reminder letter was sent to the subjects who had not yet returned the questionnaire.

Next a pilot study was performed to assess subjects' understanding and interpretation of the questionnaire. This also augments the validity of the study design. The researcher sent out ten letters to the potential subjects asking for reply. As only four subjects had responded to the pilot in the first week, a further ten questionnaires were posted. The responses from these subjects indicated that they followed the instructions, understood the questions and responded appropriately. Thus, no further changes were made to the questionnaire as a result of the pilot, thus the responses of these subjects were included in the final results.

Reliability

This study is specific to a group of people who had been admitted to the same hospital and have experienced a minor stroke or TIA within the past year. Thus the sample is a relatively homogenous group.

The researcher hopes that, due to the careful design of the study the responses of this group would be a reliable indicator of all patients who have suffered a minor stroke or TIA and have the other inclusion criteria. The instructions requested that subjects fill in their views and experiences, but if they had any difficulty in doing so their relatives or friends were allowed to help. However, it was emphasised that information come from the original ideas of subjects. Such primary source data is important if the findings of this study are to constitute a reliable source of information about patient attitudes and behaviour change.

Questionnaire administration procedure

The questionnaire was mailed to the subjects who met all the inclusion and exclusion criteria. Double-checking of names and addresses was time consuming but important to minimise possible mistakes and wrong delivery. A stamped return addressed envelope was provided for the subjects to return the questionnaire.

The researcher waited two weeks for subjects to respond. All those who had not replied after two weeks were sent reminders renewing the invitation to participate. After a further two weeks, the process of data collection was ceased.

Analysis

Quantitative data were analysed using descriptive statistics such as frequency distributions. Qualitative data from the comments section and answers to the open-ended questions were analysed using content analysis. Content analysis is a method for the objective, systematic and quantitative description of communications and documentary evidence (Burns 1997). The method considers the occurrences of particular words, interpretation of concepts and language that includes the word combinations, grammatical relationships, idiomatic and slang expressions by individuals. For this process the researcher examined the words, phrases, descriptors and terms that subjects had used and summarised the content of the responses (Morse & Field 1996).

This lifestyle study focuses on the subjects' knowledge, behaviour and decision making enabling analysis of their similar and different expressions from individual

subject's words in the questionnaire. It is then possible to compare and contrast the basic statements.

RESULTS

DATA ANALYSIS

Data were analysed using the Statistical Package for the Social Sciences (SPSS) 11.5 version for Windows package. The results of data are presented below supported by a series of graphs and tables. The qualitative data from the open-ended questions was subjected to a content analysis.

RESPONSE RATE

Questionnaires were mailed to fifty-six potential subjects identified on the database who had suffered a minor stroke or TIA during the period from 1st July 2003 to the 30th of June 2004. Thirty-five subjects returned their questionnaire, giving a response rate of 62.5%.

DEMOGRAPHICS

There was an almost equal gender distribution; males 51.4% (n=18) and females 48.6% (n=17). The mean age was 68.1 years and the age range was from 52 years to 93 years. The mean age for males was 63.9 years and for females was 72.5 years, nearly 9 years variation. The subjects in this study were mostly between 60 years to 70 years of age; 60% (n=21) (Figure 3).

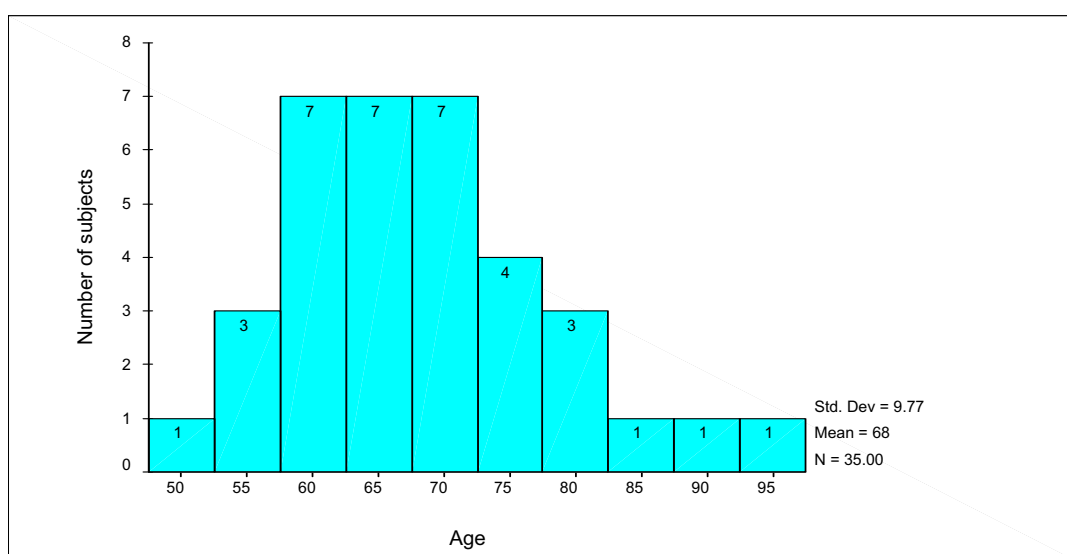


Figure 3: Histogram of subjects' age distribution

Most subjects lived in private residences (88.6%, n=31) with only one living in a retirement village (2.8%), three subjects (8.6%) indicating that they lived in rented or housing trust accommodation. Almost half of the subjects (48.6%, n=17) lived alone, while the same number lived with a spouse or partner and one indicated she lived with friends.

As would be expected from the age of subjects most indicated that they were either retired or on aged or disability pensions (77.2%, n=27). However, seven subjects were employed (8.6% full time and 11.4% part time) and only one subject was receiving sickness benefits, as shown in (Table 1).

Table 1: Subjects' employment status

Employment status	Frequency	Percent
Full time	3	8.6
Part time	4	11.4
Sick benefits	1	2.8
Retired	17	48.6
Aged pension	5	14.3
Disability pension	5	14.3
Total subjects	35	100.0

SUBJECTS' HEALTH STATUS POST-STROKE

Almost two-thirds (62.9%, n=22) of the subjects had recovered completely from their minor stroke or TIA, while 37.1% (n=13) indicated that they had sustained some disability. Four subjects listed more than one disability. The most common of these were weakness and numbness in an upper limb. These disabilities are listed in (Table 2).

Table 2: Subjects with certain disabilities

Disability	Number of subjects
Arm pain	3
Arm weakness	4
Blindness 2	
Chronic back pain	2
Decreased memory	1
Dysphagia 1	
Dysphasia 1	
Incontinence of urine	1
Impairment in movement	1
Tiring quickly	1

Over a quarter (25.7%, n=9) of subjects indicated that they had experienced more than one episode of minor stroke or TIA; two subjects (S1 & S25) indicated that episodes were 5 to 7 years apart. One subject had suffered four episodes of minor stroke or TIA since 1977 requiring admission to hospital (Table 3). One subject did not respond to this question.

Table 3: Number of episodes of minor stroke or TIA

Episodes of stroke or TIA	Frequency	Percent
1	25	71.4
2	6	17.1
3	2	5.7
4	1	2.9
Total	34	97.1
Missing data	1	2.9
Total subjects	35	100.0

Patients' understanding of risk factors

Almost three quarters of the subjects (74.3%, n=26,) stated that they believe they have a good understanding of the risk factors relating to stroke and TIA. Twenty-three percent (n=8) of respondents gave a negative response to this question. One subject (2.9%) did not answer this question.

Although 74.3% of respondents believed they had 'a good understanding' of risk factors for stroke, when they were asked to list them, 37.1% (n= 14) either indicated

that they had no idea or did not complete this section. One subject indicated that he was unsure whether being overweight was a risk factor. Four subjects (11.4%) listed physiological conditions such as blockage of the carotid artery, blood clotting disorders and cardiac abnormalities such as valvular disease. The remaining subjects listed some less specific factors such as shock and non-compliance with medication.

The remainder (60%, n=21) listed between 1 and 6 correct risk factors. They included smoking, excessive alcohol consumption, being overweight, poor diet, lack of exercise, hypertension, diabetes, high cholesterol, genetic factors, stress, and hormone replacement therapy (HRT) as shown in (Figure 4).

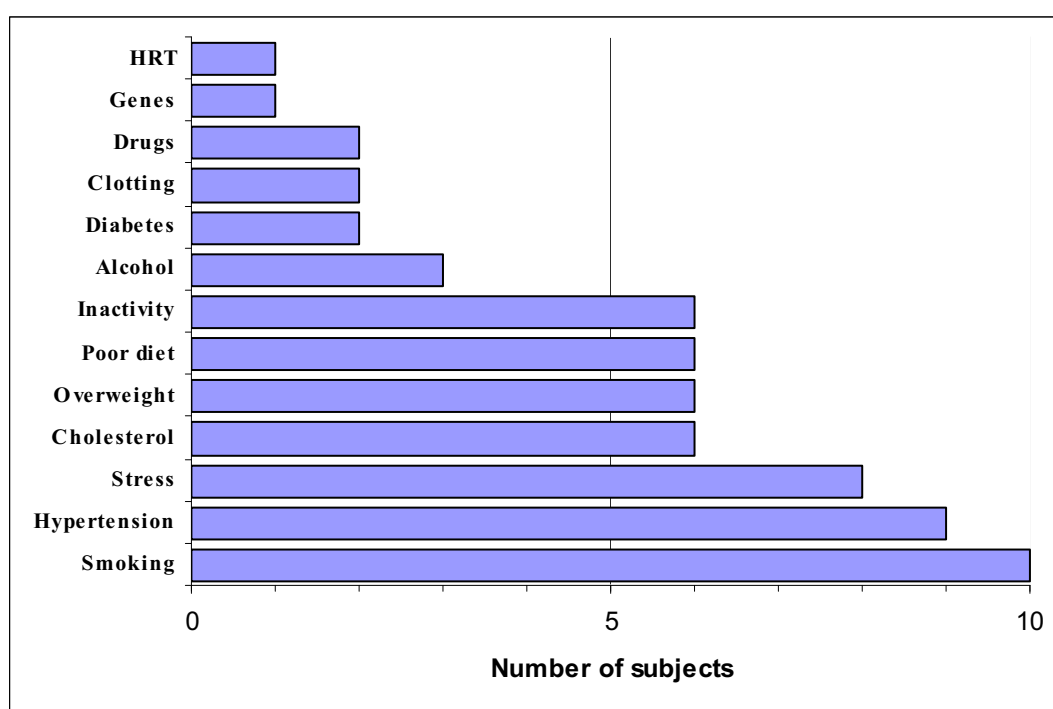


Figure 4: Subjects' perceptions of risk factors for stroke

The most commonly indicated risk factors were smoking (28.6%, n=10), hypertension (25.7%, n=9), stress (22.9%, n=8) and being overweight (17.1%, n=6), lack of exercise (17.1%, n=6), poor diet (17.1%, n=6) and high cholesterol (17.1%, n=6). In contrast few respondents listed excessive alcohol consumption (8.6%, n=3), blood clotting disorder (5.7%, n=2), diabetes (5.7%, n=2), non-compliance with drugs (5.7%, n=2), genetic factors (2.9%, n=1) or hormone replacement therapy (2.9%, n=1).

HEALTH INFORMATION

The main source of health information regarding the risk factors given was doctors, 40% (n=14), indicating they were the sole source of their information. One subject indicated that he had gained information from a friend. Two subjects stated that they gained information from other sources such as a physiotherapist and printed matter. Nine subjects (25.5%) ticked two or more sources for information. Overall 65.7% (n=23) of respondents chose doctors as at least one of their main sources of health information. Only 11.4% (n=4) of respondents considered nurses to be one of their main sources of health information (Table 4). Eleven subjects (31.4%) did not answer this question.

Table 4: Subjects' main source of health information

Source of information	Frequency	Percent
Doctor	14	40.0
Friend	1	2.9
Doctor & nurse	1	2.9
Doctor & relatives	1	2.9
Doctor & other	2	5.7
Doctor, relatives & friends	2	5.7
Doctor, nurse, relatives & friends	2	5.7
Doctor, nurse, friends & others	1	2.9
Total	24	68.6
Missing data	11	31.4
Total subjects	35	100.0

In the next question the researcher asked the subjects if they would like to receive any further information regarding prevention of stroke. Just over half of subjects (51.4%, n=18) indicated they would like further information (Table 5). Three subjects (8.6%) indicated that they wanted details regarding a healthy diet, two subjects stated that they would like more information related to stress, exercise and medications in order to better manage their health after a stroke. One subject stated that she has accessed the Internet and found this to be a useful source of information. Four subjects (11.4%) indicated that they wanted more information because they wanted to lead an active lifestyle and it was important for them and their whole family to stay healthy.

Table 5: Subjects' desire for further information

Further information	Frequency	Percent
Yes 18		51.4
No 16		45.7
Total 34		97.1
Missing data	1	2.9
Total subjects	35	100.0

In terms of the form this additional information would take, it was found that most would like written material, with 45.7% (n =16) with all but two indicating written material as one of their choices. The next most popular choice was video (17.1%, n=6). Only two subjects chose the Internet as their preferred option. Although two respondents had expressed no desire for further information in the previous question, they replied to this question, selecting written material as their sole source of information. They were not included in the following (Table 6).

Table 6: Modes of information desired

Types of information	Frequency	Percent
Written 8		22.9
Internet	1	2.9
Video	1	2.9
Written & verbal	1	2.9
Written & video	2	5.7
Written, verbal & internet	1	2.9
Written, verbal & (TV/ radio)	1	2.9
Written, verbal & video	1	2.9
Written, video, (CD/cassette)	2	5.7
Total 18		51.4
Missing data	1	2.9
Total subjects	35	100.0

HEALTH AND LIFESTYLE

Smoking

Nine subjects (25.7%) smoked at the time of their stroke or TIA. Of these only two continued the habit and both stated that they had reduced to 10 or 15 cigarettes a day. One subject did not answer this question.

Alcohol

Subjects were asked if they considered their alcohol consumption to be less than or equal to standard two drinks per day. Five subjects (14.2%) indicated that they considered that they consumed more than the recommended daily amount, one (S5) explaining that this was for enjoyment and one (S3) indicating that he only drank in excess occasionally. One subject did not answer this question (Table 7).

Table 7: Subjects who consume within two standard drinks of alcohol per day

Limited alcohol intake	Frequency	Percent
Yes 29		82.9
No 5		14.2
Total 34		97.1
Missing data	1	2.9
Total subjects	35	100.0

Body weight

Question 16 asked subjects who considered themselves to be overweight to indicate whether they had commenced a weight reduction program. If they did not consider themselves to be overweight they were asked to miss this question. Twenty-two subjects (62.8%) indicated that they considered themselves to be overweight (Table 8).

Table 8: Subjects who consider themselves overweight

Considered to be overweight	Frequency	Percent
Yes 22		62.8
No 12		34.3
Total 34		97.1
Missing data	1	2.9
Total subjects	35	100.0

One subject missed a whole page of questions, so did not respond to this question and this was counted as missing data.

The percentage of subjects who considered themselves to be overweight according to gender was 28.6% (n=10) male and 34.2% (n=12) female (Figure 5).

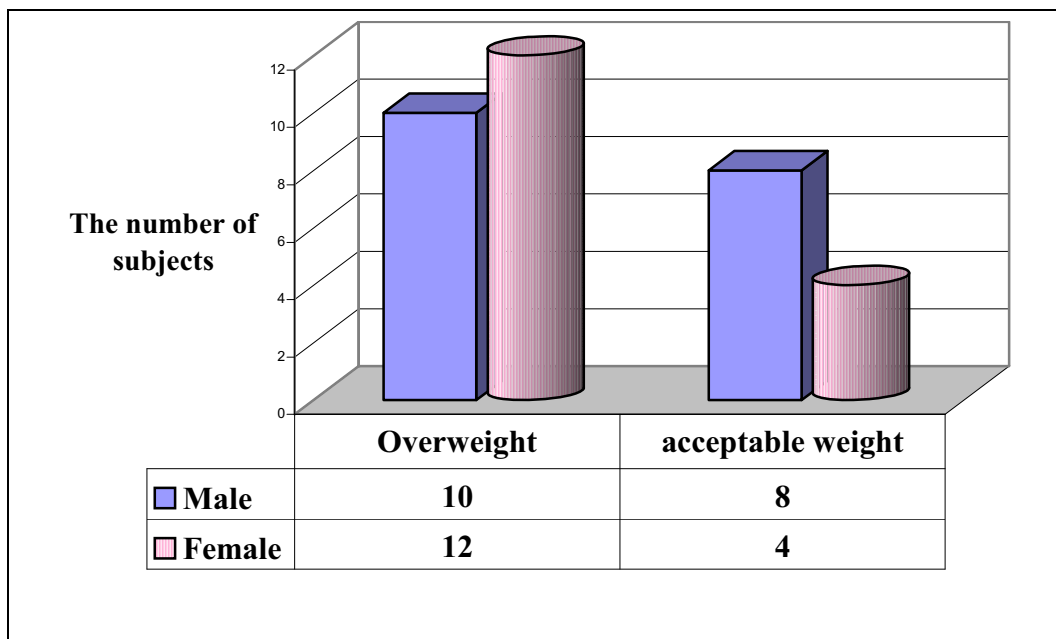


Figure 5: The ratio of subjects by gender who consider themselves to be overweight

Of all the subjects who consider themselves to be overweight, only 18% (4 out of 22) had commenced a weight reduction program (Figure 6). These four subjects indicated that they had modified their eating and drinking habits with the aim of losing weight.

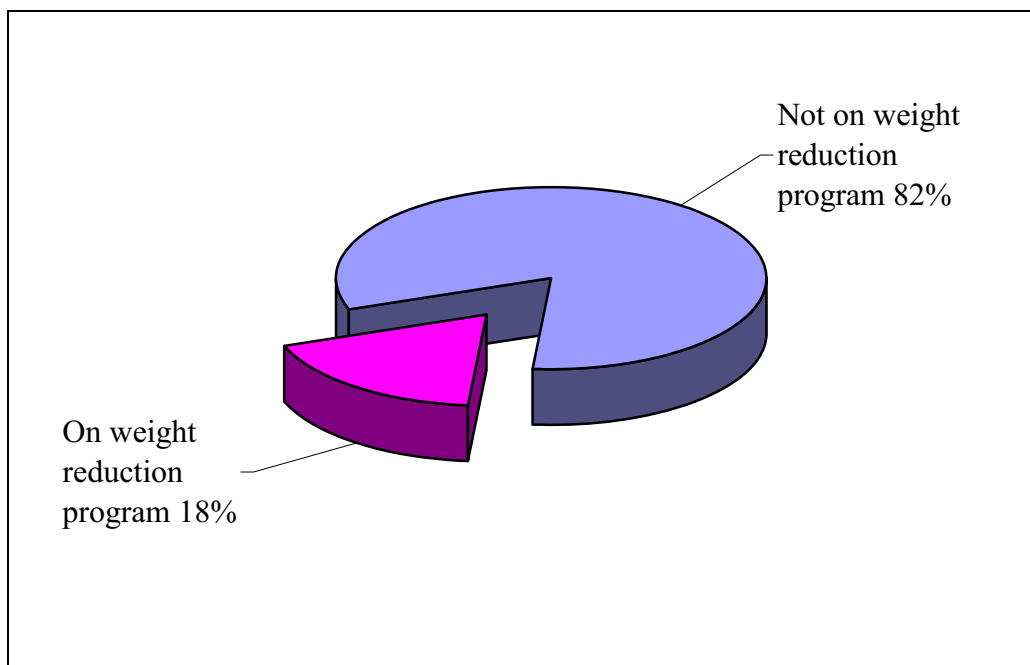


Figure 6: Subjects who consider themselves overweight

Exercise

Question 17 asked subjects whether they exercised regularly. Most subjects (65.7%, n=23) answered 'yes' while 28.6% (n=10) did not exercise regularly. Two subjects did not answer the question. The reasons given for not exercising included age, previous injuries or joint discomfort such as back strain, knee problems; recovery from a back operation, procrastination, too lazy, too tired, lack of motivation and not enough time.

In contrast, there were several comments given regarding regular exercise, these included: 'to keep fit and to keep my weight down', one subject found her body was very stiff if she just sat around without exercise; four subjects indicated that they were going to keep active lives and exercise most days per week; one subject stated that regular exercise made her feel better; and finally one man said 'I stopped driving with my first stroke and now, I walk everywhere'.

Hypertension

Subjects were asked to indicate whether they suffer from hypertension. Twenty-nine subjects (82.8%) indicated that they have hypertension and require medication to control their blood pressure. Within this group, four subjects (11.4%) stated that their blood pressure was normal but they still needed to take anti-hypertensive drugs to control it. Three subjects (8.7%) indicated that hypertension was found after a stroke or TIA. Two subjects stated they had been told they had hypertension three to five years before their stroke or TIA. Four subjects indicated that they have had hypertension for seven to twenty years. Two subjects indicated they had hypertension for 'many years'. One subject had been diagnosed with hypertension since 1977 and another since 1961. Some were diagnosed with hypertension by chance, for example when seeing their GP about another health issue for example when being treated for conditions such as nephropathy, heart disease and first pregnancy. All twenty-nine subjects stated doctors informed them of their hypertension. One subject did not answer this question (Table 9).

Table 9: Subjects with hypertension

Hypertension	Frequency	Percent
Yes	29	82.8
No	5	14.3
Total	34	97.1
Missing data	1	2.9
Total subjects	35	100.0

Of the subjects who indicated that they have hypertension, only 86.2% (n=24) have their blood pressure checked while attending a clinic or by a care provider. Only one subject checks his own blood pressure at home and one has her blood pressure checked regularly by a nurse or carer. Two subjects did not respond to this question because they assumed their blood pressure was 'normal' and they did not intend to undertake monitoring (Table 10).

Table 10: Subjects whose blood pressure is being monitored

Blood pressure monitoring	Frequency	Percent
Attend doctor or clinic & check	24	82.8
Regular self-checking at home	1	3.4
Regular monitoring by nurse or carer	1	3.4
Total	26	89.6
Missing data	3	10.4
Total subjects have hypertension	29	100.0

Actions to control blood pressure

Twenty-nine subjects (82.8%) suffered from hypertension but only 11.4% (n=4) subjects had made lifestyle changes to control their blood pressure. These four subjects indicated that had adopted lifestyle changes that focus on diet and exercise. All of the respondents who suffered from hypertension indicated that they used medication as the main or at least part of a strategy to control their high blood pressure (Table 11). Seven subjects (20%) did not respond to this question, six stating that they have normal blood pressure.

Table 11: Subject's actions to control blood pressure

Control actions	Frequency	Percent
Medication 24		68.6
Medication & lifestyle changes	3	8.5
Medication, lifestyle changes & other	1	2.9
Missing data	1	2.9
Total subjects have hypertension	29	82.9
Normal blood pressure	6	17.1
Total subjects	35	100.0

Diet

Nearly sixty-three percent (n=22) of subjects have made changes to their diet to help reduce the risk of recurrence of stroke or TIA (Table 12).

Table 12: Subjects on diet control

Diet control	Frequency	Percent
Yes 22		62.9
No 9		25.7
Total 31		88.6
Missing data	4	11.4
Total subjects	35	100.0

Subjects said that the reason they made the decision to adjust their diet was because it may lead to a longer and healthier life. Three female subjects explained that since being diagnosed with heart disease and recent stroke, they have changed their diet to ensure it is more healthy and balanced. Two subjects stated that they agreed to their families' suggestion to change their diet. One female subject (S33) stated 'I feel better when I am not overweight'. All subjects who have made changes to their diet selected a low fat, low salt and or a low cholesterol diet to lower the risk of recurrence of stroke.

Four male and one female subjects (14.3%) indicated they had problems making dietary changes due to lack of knowledge. Several indicated that they now avoid using butter, instead using olive oil based products and have ceased adding salt to their meals. One subject also stated that he could not understand the nutrition information on food packaging, so he did not know how to choose healthy products. Two subjects

indicated that they did not need to change their diet as they already had a healthy balanced diet.

Specific lifestyle changes

Question 22 asked subjects whether they had made any other changes to their lifestyle to reduce the risk of stroke or TIA. Fifteen (42.9%) subjects gave more information on specific changes they had made, mostly relating to diet and exercise. These included beginning ballroom dancing, increasing exercise, walking longer distances (3 kilometres) every morning, compliance with doctors' prescriptions, taking multi-vitamins, eating less salt, eating more fruit and uncooked vegetables, getting sufficient sleep and avoiding stress.

Many different reasons were given for these lifestyle changes. One subject expressed that she understood that minor stroke or TIA is a warning. One subject stated she followed recommendations by a physiotherapist and an occupational therapist to undertake regular exercises and found it very beneficial. One subject mentioned that he had changed his occupation to a clerical role because doctors had told him that his stroke was possibly related to the stress in his previous job. One female subject indicated that at the time of her second stroke she was underweight and therefore needed to take dietary supplements such as vitamins. Eighteen (51.4%) subjects indicated they did not make any other changes to their lifestyle. Two subjects (5.7%) did not answer this question.

FACTORS INFLUENCING LIFESTYLE DECISIONS

Question 23 asked subjects whether they had experienced any difficulties in making lifestyle changes. Only four subjects (11.4%) reported difficulties. Two subjects indicated they were frustrated by limb weakness. One subject stated that after thirty years of smoking he had difficulty giving up and although he had ceased smoking a month previously he was still finding this difficult. One male subject indicated it had been hard in the beginning but it was something he had to do.

The remaining subjects (77.2%, n= 27) stated that they have had no difficulties in making lifestyle change. Four subjects (11.4%) did not answer this question.

Subjects were asked if they were interested in participating in a program to assist them in making changes to prevent stroke or TIA. Nearly half of the subjects (45.7%, n=16) would like to participate in such a program. Fourteen subjects (40%) indicated that they were not interested in attending a program. A female subject explained that her son was her carer and she would like information on a lifestyle program so that her son could assist her to make changes according to the guidelines or suggestions. Five subjects (14.3%) did not answer this question.

Question 25 asked subjects if there were any other measures that would assist them in making lifestyle changes. Only seven subjects (20%) answered the question. Measures included strategies to assist in stopping smoking for example, use of Nicabates™ (a patch that when applied to the skin to slowly releases nicotine to reduce craving for cigarettes), motivation to control stress, employing a personal trainer, programming of exercise, becoming more active and enjoying exercise and seeking a doctor's advice.

Question 26 asked subjects to describe any illness that may have had that affected their ability to make lifestyle changes. Nine subjects (25.7%) indicated that they had other illnesses including hereditary hypertension, diabetes, back pain, previous strain injuries from work, agoraphobia. Two subjects indicated loss of vision, and three subjects indicated that they were suffering arthritis. One subject stated that she does not have a physical problem but has lost confidence since her stroke. Fifteen subjects (42.9%) indicated that they had no significant illness that influenced their ability to make lifestyle changes. Eleven subjects (31.4%) did not respond to this question.

In question 27 subjects were asked for any preventive measures that they found useful. Sixteen subjects (45.7%) replied to this question. Five subjects stated activities such as walking, dancing, gardening and fishing were useful for them. One subject stated that focussing on activities helped her reduce the anxiety she had been feeling since her stroke. Three subjects indicated reducing stress was a useful strategy. Three subjects stated that they had found medication such as painkillers helpful. One subject stated that he had a carotid endarterectomy to reduce the risk of stroke. Other

measures were controlling diabetes and monitoring blood pressure. Nineteen subjects (54.3%) did not answer this question.

Finally subjects were asked to give any other comments. Eleven subjects responded. Some subjects gave information about their personal health histories, were pleased with their treatment in hospital and were satisfied with their present health condition. Two subjects indicated that they had suffered from problems relating to medication. One indicated that this had been the cause of his stroke and the other indicated that multiple medications prescribed post stroke had interacted adversely. One subject stated that the stroke had made her 'realise how vulnerable life is', so she took one day at a time and tried to keep her focus on keeping busy. One subject mentioned he thought positively after a stroke and he realised how much people need to help each other. Twenty-three subjects (65.7%) stated that they maintained awareness about lifestyle changes which consisted mainly of diet and exercise recommendations and eleven subjects (31.4%), followed doctors' prescriptions to minimise the risk of recurrence.

SUMMARY

Thirty-five subjects responded to the questionnaire 48.6 were female and 51.4% were male. The age range was 52- 93 years and the mean age was 68. Eighty-eight percent were living in private residences and almost half of the subjects lived alone. Seventy-seven percent were on aged or disability pensions and 20% were employed full time or part-time. Thirty-seven percent had sustained some disability as a result of their stroke.

A quarter of subjects experienced more than one episode of minor stroke or TIA and one of the subjects had four episodes. Although three quarters of subjects believe they have a good understanding of risk factors relating to stroke and TIA, only 14% of subjects were able to list about five different risk factors correctly. Sixty-six percent of subjects indicated their doctor was their main sources of health information and 40% regarded doctors as the sole source. Fifty-one percent of subjects desired further information and written material was preferred.

Some barriers to lifestyle changes include psychological problems such as stress, anxiety, lost confidence, agoraphobia. In addition to individual beliefs and long established habits may inhibit change. For example, cigarette smoking was a well recognised unhealthy lifestyle, 37% of subjects were current or ex smokers. Sixty-nine percent (n=9) of the subjects who smoked at the time of their stroke or TIA ceased; however, some subjects stated that this was hard even a month and that they still have great temptation to restart. Fourteen percent of subjects indicated had excessive consumption of alcohol, but were reluctant to change this habit as they considered it to be enjoyable. Regarding body weight, 63% of subjects considered themselves overweight, but only 18% of them had commenced a weight reduction program with modified eating and drinking habits. Exercise is a common issue within lifestyle modification, 66% of subjects indicated that they exercised regularly to reduce stress, feel more confident, reduce weight and lessen body stiffness. In contrast, reasons were given for not exercising included age, previous injuries or joint discomfort after an operation, procrastination, too lazy, too tired, lack of motivation and time. Sixty-three percent of subjects have made diet changes since being diagnosed with recent stroke, however 14% of subjects stated they lack the appropriate knowledge to make dietary changes and to choose healthy products.

Hypertension is a common problem and may trigger stroke. Eighty-three percent of subjects stated that they were informed by their doctors that they have hypertension and that it was controlled with medication. Nine percent of subjects only found out that they had hypertension after suffering a stroke or TIA. Only 11% of subjects had made lifestyle changes to control their blood pressure. Twenty-six percent of subjects stated that illnesses affected their ability to make lifestyle changes. These included hereditary hypertension, diabetes, back pain, previous strain injuries, agoraphobia, loss of vision and arthritis. One subject indicated that while she does not have a physical problem, she has lost confidence since her stroke.

Suggestions given by subjects to reduce the risk of stroke included avoiding stress, focusing on activities, doing regular exercise, using Nicabates™ to help quit smoking, using medication to reduce pain, eating more roughage and taking dietary supplements, controlling and monitoring diabetes and hypertension and getting

sufficient sleep. Seventy-seven percent of subjects indicated that they have had no difficulties in making lifestyle changes and forty-five percent of subjects were interested in participating in a program to assist them in making changes to prevent stroke or TIA.

DISCUSSION

INTRODUCTION

Stroke is a preventable disease and many risk factors are closely related to an unhealthy lifestyle. An understanding of the risk factors is integral for the prevention of stroke. Increasing health promotion and empowerment through knowledge may motivate people to make behavioural changes by adopting a healthy lifestyle. This is the most important strategy in preventing this devastating condition.

Minor stroke or TIA is one of the important warning signs that a more serious stroke may happen in the near future. The aim of this study was to increase awareness of health professionals about the knowledge and attitudes of patients who are at high risk of suffering a major stroke; encouraging prevention rather than focusing on cure. The results may inform health professionals especially those involved in policy making and planning for both primary and secondary health care, so that they are in a better position to create interventions aimed at motivating people to adopt a healthy lifestyle after stroke. Thus, this study focused on this group of patients understanding regarding the risk factors of CVD, the lifestyle changes they make and the factors that affected their decisions. The researcher adopted a descriptive design using a questionnaire method to explore minor stroke or TIA subjects' knowledge, behaviours and individual experiences around lifestyle changes after being discharged from a hospital within the last year. A more thorough understanding of the subjects' understanding of risk factors and their capacity to make lifestyle changes, can help inform policy makers and health care providers so more effective health strategies can be implemented to meet the needs of this group of people and help reduce the risk of recurrence. Understanding subjects' intentions, motivations and ability to adopt the recommended lifestyle changes may be useful for future planning of prevention strategies. Knowing more about patients and families' levels of knowledge and support can help develop education strategies.

On the other hand, subjects' problems or difficulties that influence their ability to adopt appropriate lifestyle changes may indicate health care services need to be modified to meet patients' health needs. The main problems and difficulties of

patients in implementing lifestyle changes are poor understanding of the risk factors for stroke, lack of motivation, inability to access good quality and appropriate information and lack of encouragement and support from health professionals and families. Subjects reported significant confusion regarding healthy diet and exercise recommendations. Some found exercise difficult due to physical impairments. Most of the subjects depended on doctors as their main source of health information, but the current shortages of GPs and short appointments leave less time for education. There are shortages in many fast growing areas of the city but shortages in the country and remote areas are even more critical (Rowley, Daniel, Skinner, Skinner, White & O'Dea 2000). Many subjects suffered from hypertension, and medication was the predominant method used for control. Few subjects realised the value of lifestyle factors in management of this problem. It should also be recognised that deeply entrenched lifestyle habits are difficult to change. If these complex factors are recognised more effective health care strategies may be developed

CHARACTERISTICS OF THE SUBJECTS

Although stroke is more common in the elderly, it can happen at any age. Patients who adopt effective preventive measures and so avoid stroke, may not become dependent and thus able to maintain a productive role in society. Forty percent of subjects (n=14) in the study were less than 65 years old. Some were still employed in a full time or part time capacity. According to the National Health Survey, ABS in 2001 the number of stroke victims under 65 years was 40%, while 18% were under the age of 55 years (ABS 2002, AIHW 2004). This means within the 217,500 stroke victims in Australia, there were 87,000 victims less than 65 years, while about 40,000 victims were under 55 years. Therefore a large proportion of stroke victims are of the age where it would be expected that they would be employed.

Stroke and the resulting disability is the main burden of the disease and it can be expected that the cost of care and management will increase with the ageing population. This is because around two-thirds of stroke hospitalisations occur among those aged 70 years and over (AIHW 2004).

This study used a convenience sample of subjects recruited through a major metropolitan public hospital. The aim was to gain a sample of subjects who were not significantly disabled by stroke and thus would have had the ability to make lifestyle changes. The characteristics of the sample support the view that this aim was achieved, as 63% of subjects had recovered completely from their minor stroke or TIA with no disability and 20% were employed in a full time or part time capacity. In addition 90% of subjects lived in private dwellings, with over half living with families or friends and the rest lived alone. Forty percent subjects (n=14) were less than 65 years old. These factors are important as they indicate that it is likely that the subjects lead independent lives and had the ability to implement lifestyle changes following their stroke or TIA. Subjects who are confined to a long term care facility or have significant disabilities may not have the degree of independence required to make their own lifestyle decisions.

In addition patients who suffer minor stroke or TIA may be under-represented in hospital-based studies, as they are usually admitted for short periods of time and most resources appear to be directed to those who suffer severe problems. However, they may be good candidates for primary and secondary health prevention management to reduce the risk of recurrence of stroke, as they have a higher chance of complete recovery and can be motivated to improve their overall health status.

Stroke victims have a high risk of recurrence and subsequent disability. This study found a quarter of subjects had experienced more than one episode of stroke or TIA; one subject had four episodes since 1977. Moreover, thirty-seven percent (n=13) of subjects sustained some disability, these ranged from relatively mild to severe such as blindness and dysphasia. It is a crucial that these patients maintain preventative measures for the rest of their lives. The National Stroke Foundation indicated that about one-third of stroke victims may survive with mild to severe permanent disability (National Stroke Foundation 2004b). The possible reasons for a large number of stroke victims having a disability following stroke may be due to patients with milder symptoms not being aware that stroke is a 'brain attack' and should be treated as seriously as heart attack. Consequently, they may lose valuable time in seeking medical treatment.

Moreover some patients and health care providers may have the attitude that stroke is untreatable, leading to a strategy of conservative management or observation instead of taking urgent and active action. Some patients suffering from heart disease and hypertension may not have been warned by their doctor about the risk of stroke and the need to take appropriate preventive strategies. Overlooking important risk factors, lack of sufficient knowledge about the symptoms of stroke and hesitancy in seeking immediate treatment, may increase the severity and thus the rate of disability. For example two subjects who were diagnosed with heart disease and started diet change many years ago, did not know that they also suffered from hypertension until a minor stroke occurred. Furthermore many subjects depended on medication to control their risk factors such as hypertension and high serum cholesterol and did not recognise the need for lifestyle change.

SUBJECTS' UNDERSTANDING OF STROKE

Almost three quarters of subjects (n=26) stated that they had a good understanding about the risk factors of stroke and TIA. However, the subjects' responses to the risk factors of strokes or TIA did not confirm this belief. Four subjects (11.4%) who indicated they had a good understanding the risk factors of stroke failed to list even one factor and 20% (n=7) of subjects only managed to correctly state one or two risk factors. Only 14.3% (n=5) could correctly list up to five different risk factors. The risk factors listed were mostly modifiable. Risk factors that subjects did not recognise included increasing age, gender, race, family history of stroke, previous stroke or TIA and atrial fibrillation. In the context of this study although the overall knowledge level was poor, it is more important that subjects recognise those risk factors that they are able to modify such as smoking or obesity (Fuller, Dudley & Blacktop 2004).

SOURCES OF HEALTH INFORMATION

Sixty-six percent (n=23) of subjects indicated that their doctor was their main source of health information, with 40% (n=14) of subjects indicating that their doctor was the sole source of their health information. Only 11.4% (n=4) of subjects indicated that other health professionals, such as nurses, physiotherapists and occupational therapists were their main source of health information. Eight subjects (22.9%) stated that they would ask health information from friends or relatives who had had similar or related

experiences. Thirty-one percent (n=11) did not answer the question regarding their main source of health information. This may indicate that they are unsure of where they gained information. The large variety of information available and questionable quality of some, may add to the confusion regarding healthy lifestyle.

These results are significant considering the current shortage of GPs in the Australian community, particularly in rural and lower socio-economic areas (Weyden 2004, ADHA 2005b). This shortage means there is less time available for health education. As a result, patients may not be well informed about preventative measures or may not have the opportunity to discuss these with their GP. Limited health resources might result in more people relying on information from friends or relatives, which may be an unreliable source. Clearly there is a need for other health professionals to contribute to primary health care education. If patients do not have a good understanding of the risk factors relating to stroke and are not given the opportunity to discuss healthy lifestyle choices, they will be at significant risk of recurrence. Not only does this have serious implications for individuals and their families, but clearly for society as a whole.

Nurses are well placed to provide health care information and counselling to supplement the education and support offered by GPs and may be able to provide these services more cost-effectively than doctors can. In addition such services would free up the limited GPs to provide services that only they are qualified to perform. In addition health counselling services could be provided at a community level and resourced according to population based data. This strategy would be consistent with recommendations of the Generational Health Review for population based health care (Menadue 2002) (<http://www.dh.sa.gov.au/generational-health-review/reports.asp>). For this strategy to work a change in the current public attitudes would need to occur, as most of the subjects did not consider nurses to be a main source of health information.

DESIRE FOR HEALTH INFORMATION

Health information is an important tool to empower and motivate patients to make lifestyle changes. Thirty-seven percent (n=13) of subjects in this study either stated

that they did not know the risk factors, or did not answer the question regarding risk factors. Regardless of this fact, only eight of these subjects wanted to receive information about stroke or TIA. Is it possible that these subjects believe stroke is an inevitable part of ageing, or believe that making lifestyle changes is just too hard or too late.

Just over half of subjects (51.4%, n=18) indicated they desired further information regarding stroke. This is a positive finding as it indicates that subjects have a desire to understand more about their disease and prevent recurrence. In question 21 subjects were asked what changes they had made to their diet to help reduce the risk of recurrence. Some subjects expressed the view they could not make appropriate dietary choices due to lack of knowledge and confusion regarding information on food labels.

This is in contrast to the findings of Smith et al in 2003 who indicated that following a stroke with disability, most patients and their families wanted to receive information regarding stroke prevention (Smith et al. 2003). The difference in the findings may be due to the fact that the subjects in the Smith et al study had suffered major stroke and severe disability. Perhaps a minor stroke or TIA is not taken as seriously as a major stroke with the possibility of recurrence not being well recognised. It was anticipated that a minor stroke or TIA, might have acted as a warning to patients that they may suffer a more serious stroke motivating them to make lifestyle changes. However, the results do not clearly support this view. Despite the clear lack of understanding of the risk factors demonstrated by many of the participants, they did not desire further information regarding the disorder.

The implications of this finding are that health professionals need to find new ways to assist patients to understand the seriousness of stroke and to educate them about how it may be prevented. There appears to be some degree of complacency with subjects believing they understand stroke. The general public are constantly bombarded with health advice and therefore may begin to disregard information. More personal ways of presenting the information and challenging individuals about the lifestyle choices they are making may be required before patients really understand the health risks (Menadue 2002).

MEANS OF PRESENTING HEALTH INFORMATION

Technological innovations have meant that there are now many new ways to present health information such as the Internet, video player and compact disk or digital video disc (CD/DVD) players. However, only 29% (n=10) of subjects who wanted more information indicated that they would like to receive health information via these technologies. Fifty-one per cent (n=18) of subjects who wanted more information chose written information as the desired method. This may be partly due to the age of the subjects (mean 68 years old) as this part of the population are generally less familiar with and less likely to have access to newer technologies. It appears there is already substantial written health information regarding stroke available in the community, for example in GP rooms, libraries and chemists. However, the relative lack of knowledge the subjects displayed regarding risk factors may indicate that these types of information are not effective tools for educating patients. Health professionals need to consider new ways of presenting information and evaluating the effectiveness of such interventions. For example: recently, a free seminar 'Strokesafe' was conducted at a major hospital to explain the causes, risk factors and symptoms of stroke and participants were invited to ask questions. The seminar was initiated by a Health Promotion Unit (HPU) and was conducted in collaboration with the Department of Neurology and Stroke Unit as a part of health promotion program in 2005. The speaker was a neurology and stroke specialist and he spoke on a healthy lifestyle that can be useful to prevent stroke.

LIFESTYLE OF PARTICIPANTS

The concept of lifestyle changes is easy to understand, and compared to other interventions aimed at preventing stroke, is cost-effective and safe. However, making these changes can be difficult, and even more challenging is maintaining the changes. Individual control and choice is essential in the change process. Some of the barriers to the effective implementation of changes include lack of motivation, inadequate knowledge and inability to access good information, advice and counselling. It is also essential that individuals have the support of their families and health care workers.

Smoking

Smoking is commonly recognised as a modifiable risk factor. Recent advertising campaigns have been introduced to graphically inform the public regarding this risk. Cigarette smoking was among the most common risk factors listed by the subjects in this study. Smoking is associated with a two- to three-fold increase in the risk of stroke. In the current study 37% (n=13) of the subjects were current or ex-smokers. Eleven percent (n=4) of subjects indicated they had ceased smoking prior to suffering a stroke and 20% (n=7) of subjects said that they had ceased smoking after their stroke or TIA. Only 6% of subjects were current smokers, but all stated they had reduced smoking to ten or fifteen cigarettes per day. Thus the results of this study indicate that smoking may be one of the more commonly recognised risk factors relating to stroke and that subjects had taken this seriously.

There are now many organisations that encourage and assist people to cease smoking, for example 'Quitline' – a free hotline support and quit smoking counselling service. In addition there are current marketing campaigns promoting products to assist individuals to cease smoking, such as Nicabates™. Moreover the Australian Government National Tobacco Strategy has been implemented to discourage people from smoking (ADHA 2004b).

Alcohol

The study found 17% of subjects claimed to consume more than two standard drinks per day (Table 7). However, several who were not regular drinkers claimed they occasionally drink in excess, for example for a special celebration. Excessive alcohol consumption was not well recognised by the subjects in this study as a risk factor for stroke. In addition it appears that many continue to drink in excess despite suffering stroke or TIA. There are many possible reasons for these findings. Government campaigns regarding excessive drinking have concentrated on the risk of motor vehicle accidents, rather than long-term effects such as disease. This may be because alcohol consumption is well accepted in the community and compared with occasional drinkers, non-drinkers actually have an increased risk of stroke (Wannamethee & Shaper 1996). This means that the information given to the public can appear contradictory and is less well defined than the information relating to

smoking. Although there is an advantage relating to ingestion of limited amounts of alcohol, studies indicate that binge or excess consumption of alcohol is related to a significant increase in the risk and mortality of stroke, (Hart, Smith, Hole & Hawthorne 1999, CDC 2004, Djousse et al. 2004, Iso et al. 2004, Djousse, Ellison, Beiser, Scaramucci, D'Agostino & Wolf 2002, Hillbom, Numminen & Juvela 1999). In fact people who have high alcohol consumption in association with smoking are more likely to have high blood pressure, increasing the risk of mortality when they do suffer a stroke. (Romelsjö & Leifman 1999, Malinski, Sesso, Lopez-Jimenez, Buring & Gaziano 2004).

Diet and exercise

The results indicated 62.8% (n=22) of subjects considered themselves overweight, but that only 9% (n=2) had commenced a weight reduction program. This is of concern as it reflects a poor motivation to make lifestyle changes relating to such a significant risk factor. This may also reflect a public perception that weight increases are naturally related to ageing and that little can be done about weight gain and obesity. According to the findings from CDC National Center for Health Statistics, National Health and Nutrition Examination Survey in 1988 to 1994 and 1999 to 2002, there is a gradual increase in obesity with age which may reinforce this belief.

An ABS 2001 survey also found that the 45 to 74 year age group had the highest proportion of people who were overweight or obese (ABS 2002). For the ageing population it may be particularly difficult to make dietary changes, when eating habits have been established over many years. In addition it may be more difficult for this group of people to undertake vigorous exercise due to disabilities or chronic illness. However, nearly half (45.7% n=16) of the participants indicated a willingness to participate in a program to assist them in making lifestyle changes. Tailored programs could be designed to assist this group of people to make lifestyle changes that may reduce their risk of future stroke.

Increased body weight and obesity are not confined to the elderly, but are a significant problem for society as a whole. Eating habits have changed, with less people cooking at home and an increased reliance on the fast food industry, which tends to produce

foods high in fat, sugar and salt. It is important that the public are made aware of the long term consequences of poor diet and that healthy options are freely available. There have been some recent changes in the fast food industry with many outlets now providing 'healthy options'. While these are positive moves, more needs to be done to prevent increasing health problems in the future.

Sixty-three percent of subjects had made changes to their diet by adopting low salt, low fat or low cholesterol diets. Comments regarding this question demonstrated some confusion regarding healthy eating options, with some respondents focusing on low fat diets generally while others stated they were eating a low cholesterol diet. None of the subjects demonstrated awareness about 'good and bad fats'. One subject wrote of the difficulty they had in making decisions about what comprised a 'good diet' and in particular understanding labelling and the ingredients listed. This confusion may reflect the volume of information that is available on diet and the many conflicting views on the subject. It is important that this group of patients have access to simple accurate information regarding diet, so that they can make informed decisions.

In this study 68.6% (n=24) of subjects claimed they exercise regularly. Reasons given for not exercising included injuries, lack of time and lack of motivation. Again, individualised programs may assist this group of patients in forming healthier habits. For example low impact exercise programs can allow even those with injuries to increase their daily exercise without impacting on their pain or disability. Exercise programs have also been designed specifically for elderly people, for example 'Heartmoves' a video or DVD produced by the Heart Foundation (Heart Foundation 2006) is a low-to-moderate intensity exercise program designed to be safe for people with heart problems and who have been advised by doctors to only undertake moderate exercise or for those who have simply never exercised before. The video provides accredited training programs on safety skills, guidelines and tools for working with older adults and people with medical conditions. Patients who have suffered stroke or TIA could be referred to rehabilitation programs, secondary prevention programs or a heart health centre. Professionals such as physiotherapists and occupational therapists could be of assistance in assessing patients' needs and abilities in order to refer them to appropriate programs. Patients need to be made

aware of the potential hazards relating to a sedentary lifestyle as well as the advantages of getting enough exercise. As stated by the WHO 'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO 2005a).

Perhaps in the absence of reliable information, some patients may have a fear of undertaking exercise. It is possible that people who have suffered a minor stroke or TIA may be less likely to be referred to a physiotherapist, occupational therapist, dietician or other health professional who will reassure them and actively encourage them to undertake exercise. An interesting area for further research might be to do with the subjects' beliefs about whether they can do exercise or whether it would do damage after an operation or certain disability.

Hypertension

Hypertension is a silent risk factor, and is considered to be the main underlying cause and trigger of most strokes. Eighty-five percent (n= 29) of respondents suffered from hypertension, with three subjects (10%) only realising that they had hypertension after their stroke or TIA. Unless people attend their GP regularly they may not have their blood pressure checked and may remain unaware that they have hypertension. With the current shortage of GPs, it is essential that there be other opportunities for blood pressure screening. For instance: introducing more services which provide blood pressure screening services as monitoring in the workplace, Health Promotion Units and pharmacies. Although simple devices for monitoring of blood pressure are now available, it appears people with hypertension are rarely encouraged to monitor their own blood pressure at home. Conversely it appears that diabetics are encouraged to monitor their blood sugar levels at home and manage their own progress effectively.

Blood pressure is influenced by many factors from emotions, to diet. It is important that people with high blood pressure get it checked regularly so that they can take steps to control it with lifestyle changes and medication if necessary. Although nearly all subjects indicated that they have their blood pressure checked when attending their GP or clinic, only two subjects (7%) of those who suffer from hypertension check their own blood pressure at home or have it monitored by a district nurse or carer.

Considering that hypertension is such an important risk factor for stroke and that the subjects in this study are at increased risk of stroke, it is of concern that the importance of blood pressure monitoring does not appear to be recognised (Hart, Hole & Smith 2001).

Few of the subjects appeared to recognise the role that lifestyle plays in controlling hypertension, with only four subjects (14%) indicating that they had made lifestyle changes to assist in controlling their blood pressure. However, all used medications to control blood pressure. Clearly for this group of patients who have already suffered stroke or TIA, it is imperative that hypertension is controlled. The results indicate a reliance on drugs which may be because lifestyle changes are seen as the harder option. There may also be a lack of understanding of how significantly lifestyle factors affect blood pressure.

OTHER REFLECTIONS ON LIFESTYLE AND STROKE

Many of the subjects commented on stress contributing to their risk of stroke, however, there were no comments given on how subjects were reducing stress. It appears that this could be another major consideration in designing education and support programs to assist this group of patients to manage stress. For example programs such as exercising, meditating, relaxation skills, social support from health care providers, counselling and stress reduction programs may all help to alleviate pressure and control anxiety. Western lifestyle with common habits such as smoking, unhealthy eating habits, drinking and sedentary living increases the risk of stroke.

It is of concern that despite having suffered a minor stroke or TIA several subjects continued to make poor lifestyle choices: continuing to smoke, consume excessive amounts of alcohol and remaining physically inactive. Several subjects expressed the view that long established habits were difficult to change and that enjoyment of life was a major consideration in their decision not to make changes. As two-thirds of subjects had completely recovered after their stroke without sustaining any significant disability, they may not have realised the seriousness of their illness or the high danger of recurrence. Clearly lifestyle changes are a personal choice, but it is

important that this group of patients are made aware of the risks associated with an unhealthy lifestyle.

MISCONCEPTIONS REGARDING STROKE

Statistics indicate that the majority of stroke victims (60%) in Australia are aged 65 years and over (AIHW 2004) and the prevalence of stroke increases with age. There appears to be a public perception that stroke is an age related problem and not preventable. The traditional medical name for stroke is 'cerebrovascular accident' (CVA) and this name itself may reinforce the view that stroke is unavoidable. However, ischaemic strokes are predominantly caused by modifiable risk factors, so there is a high potential for prevention. Even in many haemorrhagic strokes which may be caused by familial vascular defects such as aneurysm or AVM, the trigger for rupture is often associated with hypertension. Therefore adoption of healthy lifestyle is integral to the prevention of stroke.

Health promotion strategies are essential to correct people's misconceptions regarding stroke and to inform them regarding healthy lifestyle choices. Each single risk factor has a different influence on the chance of an individual suffering a stroke and when these are combined the risk is significantly increased. Although stroke is popularly considered to be 'a disease of old age', it is the lifestyle that is adopted during the preceding years that lays the foundations for a stroke. First we need to educate health professionals about lifestyle choices so that they have the knowledge to develop relevant and effective health promotion strategies.

The cost of caring for victims of acute stroke is considerable, with most resources directed to the diagnosis, treatment, rehabilitation and long-term care. Currently there are many sophisticated rehabilitative programs that involve neurologists, nurses, physiotherapists, occupational therapists, psychologists and speech therapists. These are designed to help restore stroke victims to self-sufficiency reducing dependence upon family, friends and society. Unfortunately, about one-third of stroke victims will be left with a degree of residual disability; thus stroke is the most common cause of permanent disability. Stroke prevention strategies do not have immediate visible results, but rather will reduce stroke rate in the population over time. As it stands, few

resources are being put toward stroke prevention, most being directed to acute care and rehabilitation of patients who have suffered a major stroke. It is essential that resources are allocated to preventative strategies. In order to intelligently design these, evidence about patients' and families' experiences needs to be gathered.

STRENGTHS AND LIMITATIONS

The strength of the study was to fill a gap in health care providers' knowledge of the understanding of patients who have suffered a minor stroke or TIA and lifestyle changes they may implement

The support from a specialist and a clinical nurse consultant who care for these subjects in a state hospital was important to identify important issues and to recruit the subjects. This study may also have prompted some subjects to consider making lifestyle changes. One subject came to the Discipline to ask about the study and fill in the questionnaire and the researcher also received enquiries directly from three subjects.

There were some limitations in the ability to assess lifestyle risk factors using a questionnaire, as the accuracy of the data is dependent on the subjects' responses and actual lifestyle and risk factors were not examined. Other limitations of this study related to the small sample size, and the fact that those who did not answer the questionnaire may have responded differently. The results of this study may be applicable to the population that has suffered minor stroke or TIA and not more generally to all those at risk of stroke. In addition, this was not an epidemiological study so no conclusions can be drawn regarding prevalence or incidence. A further limitation is that the questionnaire was not worded to detect changes made in drinking habits and exercise since the subject's stroke or TIA. In retrospect these questions should have been worded to gain this information.

The possible influence of factors such as psychological status and social support in lifestyle choices was not investigated in this study. For example, depression could be a possible barrier to making lifestyle changes, and is a common consequence of stroke. The level of depression experienced is often related to the degree of

neurological and functional deficits and the level of handicap sustained (Kauhanen et al. 1999). These considerations are complex and would require focused studies. Given the short time frame for the study and the lack of research on this particular group of patients, it was important to begin with a more general survey. Although ABS data are available on the prevalence of risk factors there is little information regarding individual lifestyle choices.

Although the researcher, through the inclusion and exclusion criteria, sought to select patients with little or no disability following a minor stroke or TIA, 37.1% (n=13) of the sample had sustained some disability and this may have influenced their ability and/or will to make lifestyle changes.

Since the majority of subjects were 60–70 years old (60% , n=21), their experiences and views may not be representative of those of the younger population.

SUMMARY

Stroke victims have a high risk of recurrence and subsequent disability. If effectively planned and delivered, health promotion initiatives may enhance patients' understanding the risk factors of recurrence of stroke and motivate them to make healthy lifestyle changes. One-third of the subjects in this study were less than 65 years old and 20% were employed full or part time. Therefore, they have the ability to make a positive contribution to the workforce and are good candidates for primary and secondary health prevention because they have autonomy to make their own lifestyle decisions.

This study recruited minor stroke or TIA subjects, the majority of whom had recovered completely and were good candidates for lifestyle change. Subjects' views and experiences may reflect their capability and difficulties adopting healthy lifestyle changes. This study may be useful to increase health care providers' understanding of patients' situation and help in creating effective preventive strategies to reduce the burden of stroke on patients, families, health care services and communities.

Although a large number of subjects stated that they had a good understanding, only a small number could list the risk factors of stroke. Subjects' sources of health information were limited and mainly came from their doctor. Other less common sources were other health professionals and friends or relatives who themselves had suffered a stroke or TIA. The current shortage of GPs especially in rural and remote areas and limited consulting time may impact on doctors' ability to provide patients with adequate education and to allow discussion about important preventative measures. Other health care professionals such as nurses may be able to supplement the service provided by doctors, providing health information and counselling services more cost-effectively.

Subjects' attitudes and beliefs about health generally and stroke in particular need to change. We need to get the message across, loud and clear, that stroke is preventable. If subjects who suffer minor stroke or TIA are not made aware of the high risk of recurrence they may not take the warning signs seriously and be less motivated to make lifestyle changes, than those who suffer a major stroke. Health professionals need to find new ways of ensuring patients understand the seriousness of stroke and the necessity of adopting prevention strategies. Although modern technological advances have produced new ways of presenting health information, the subjects in this study preferred information in hard copy, written format. This may be a generational trend, with older people having less access to and a lack of familiarity with the newer technologies. Although lifestyle changes made to prevent stroke are cheap and safe, subjects felt they were difficult to commence and challenging to maintain. Some other barriers included lack of motivation, inadequate knowledge and inability to access good information advice and counselling. Not receiving adequate support from their families and health care providers was also an issue.

Smoking is a highly publicised modifiable risk factor and many subjects had either reduced or ceased smoking after their minor stroke or TIA. Stop smoking campaigns have had significant support from the government and widespread media coverage in order to get the message to the public successfully.

In contrast, alcohol consumption has not yet been widely recognised as a major risk factor for stroke. Media messages regarding the advantages of consuming small

amounts of alcohol may be understood by the public as mixed messages. Alcohol consumption is high on the scale of social acceptability and together with people's personal enjoyment of alcohol, there are many barriers to a change in attitudes regarding alcohol use and stroke risk. These prevailing attitudes may interfere with subjects' ability to make a decision to reduce their drinking.

Poor diet and physical inactivity are cited as two characteristics of a Western lifestyle which contribute significantly to stroke risk. This is compounded by a public perception that weight increases are natural with ageing and that little can be done about this. Obesity worsens each year in most developed and many developing countries. This is reflected by low participation in weight control programs and low motivation for exercise and diet control. A lack of knowledge about diet; the nutritional dangers and benefits of different kinds of foods and a lack of skills and confidence about how to choose a healthy diet was a problem for some subjects. Other reasons such as lack of time and previous injuries were also given as explanations for subjects not exercising. Low impact exercise programs specially designed to take into account any injury, disability and pain are available.

Hypertension is the most common trigger of strokes and a silent risk factor. Most of the subjects suffered from hypertension and required medication to control it. Some subjects only discovered they had hypertension after a stroke or TIA. Subjects mainly depend on their doctor or attend a clinic for monitoring and very few self-check at home or have regular monitoring by nurse or carer. Only a small number of subjects indicated that they would like to adopt lifestyle changes to control their blood pressure.

Many of the subjects commented that stress contributed to their risk of stroke, but they made no comments about how this might be reduced. Therefore it may be necessary to consider stress reduction programs as part of preventive measures. Certain misconceptions about stroke and ageing interfere with patients' ability and propensity to make lifestyle changes, for example seeing weight gain as unavoidable. Thus health promotion strategies need to work to correct misconceptions, disinformation and myths regarding stroke and send a clear message that healthy

lifestyle choices are vital to lower the risk factors of stroke and related chronic diseases.

The study was limited in that the results were dependent on subjects' responses and could not be further explored, the sample was small and the majority of subjects were aged 60 to 70 years. Thus the results can only provide a generalised view of patients who have already suffered a minor stroke or TIA. Factors such as psychological status, social support and the impact of disability on patients' ability to make lifestyle changes were not investigated.

RECOMMENDATIONS

Up to 60% of subjects had little or no understanding about the risk factors, therefore the first recommendation relates to health education. However, the strategies need to be chosen with care. Most patients who suffer stroke or TIA are in the older age bracket and seek written information so newer mediums such as the Internet and DVDs may not be as effective in reaching this population. The reliance on doctors for health information is of concern given the current shortages and limited consultation times. The recommendations of the Generational Health Review conducted in South Australia by the Department for Families and Communities, include 'family friendly' measures to improve community services, a greater focus on health promotion, illness prevention and early and individuals being active, independent and connected to community (Government of South Australia 2006). Further it was recommended that information be provided regarding healthy lifestyle and reducing overuse and inappropriate use of medicines. It was also suggested that 'one-stop shops' be established for older patients in places such as supermarkets or social clubs to improve the dissemination of health information and facilitate health screening. These initiatives could also assist people in gaining access to health information. Education about stroke prevention needs to target patients' families too so that a shared understanding can be reached, with the aim of providing a more supportive environment in which patients have a better chance of making the recommended lifestyle changes.

Health education must begin early as the deposition of fatty plaques in vessels (atherosclerosis) the underlying contributor to stroke, is a slow and complex process starting in childhood and progressing with age. Healthy lifestyle habits can also contribute to the prevention of many other chronic disorders such as diabetes and heart disease. Many nations such as Britain and Singapore have started healthy lifestyle programs for school children with a view to helping children to adopt healthy habits early in life (Cookson, Heath & Bertrand 2000, Hayman & Reineke 2003, Sahota, Rudolf, Dixey, Hill, Barth & Cade 2001).

There is a trend of CVD developing in the younger population especially in developing countries and lower income groups. Therefore governments should target those populations, which are at particular risk. The ageing population is also becoming a challenge to health care services. This problem is not unique to Australia as most nations around the world predict similar problems. It is imperative that education programs are established promptly. Primary health care requires long-term health strategies. The effects of these cannot be assessed easily in the short term. However, the influence on the health of the population long term is undoubtedly significant. As modifiable lifestyle risk factors have cumulative effect over years, the results of preventative programs would show in the statistics of stroke rates over several years.

Healthy lifestyle can improve people's general health status and eliminate the risk factors of stroke and many major and chronic diseases. Thus preventative strategies can help alleviate the burden on the health care system of chronic illness. Therefore preventive measures should be promoted in a systematic and informed manner. Motivating people to adopt a healthy lifestyle is challenging, a relatively low cost strategy and has the potential to benefit society as a whole. This would enable valuable resources to be directed to other health problems.

Cardiac rehabilitation programs are common, yet the same risk factors are responsible for stroke. Stroke rehabilitation groups could provide mentorship and the professional and peer support necessary to assist victims in making the necessary lifestyle changes. Counselling, accurate information and appropriate support needs to be available to empower individuals and their families. A stroke information and counselling

telephone line could be set up counselling to provide up to date information and support to patients and their families.

Health care professionals need to be able to provide more evidence to patients about the hazards so patients will be making an informed decision about whether to make healthy lifestyle changes or not. Once a patient is motivated to change their behaviour a tailored self-care plan could be made to support them through the process.

Improvement in health resource distribution

The majority of health resources are directed to acute health care. This often results in poor funding of health promotion and primary health care. It is important that this situation is reviewed to prevent health crises in particular when considering the ageing population. It is predicted that by the year 2017, 74,000 people will suffer a stroke in Australia (National Stroke Foundation 2004a), resulting in a huge social burden. Stroke is preventable and resources need to be directed to prevention; specifically the adoption of healthy lifestyle choices. Such interventions are more cost-effective in the long term, having the added benefits of reducing patients' reliance on expensive medications and reducing the risk factors for several other chronic diseases

In order to increase awareness about the risk of stroke and increase the number of patients adopting healthy lifestyle changes, the government and the health department could coordinate and invite other organisations and departments to join a cohesive community stroke prevention campaign. In terms of what forms this could take, involvement in fun and competitive activities may successfully motivate people across different age groups to do more physical activity and engage in other healthy living activities. In the future, research may need to concentrate on how to motivate people to make healthy lifestyle changes, increase health education in schools and educate the lower socio-economic groups about the negative effects of unhealthy lifestyle.

Health motivation programs can be focused on people's interests and provide more rewards for successful achievement to encourage participation in an active healthy life. Moreover, health care providers should assess carefully the use of medication and

minimise over dependence and the neglect of lifestyle changes. Clearly patients understand that drugs cannot achieve the benefits of lifestyle changes and there is no contraindication in adopting a healthy lifestyle while taking medication. In fact previous experience and findings show that when body function has significantly improved, it may be possible to reduce doses or entirely cease drugs (Nelson, Reid, Krum & McNeil 2001).

As hypertension is the most common and main risk factor for stroke, all health care professionals should follow a standard guideline or protocol to monitor and manage hypertension in both the general population and especially in people who have had a minor stroke or TIA. This is the first priority to lower the chance of stroke.

Enhancing health education

Health promotion is a proactive health intervention to prevent and control illness. Knowledge can change our lives and by avoiding preventable diseases with efficient action reduce the risk factors. Health education programs should focus on patients' individual needs in order to prevent disease and enhance well being.

If we are to successfully assist people to change from their norm of inactivity and poor diet, health departments need to be more creative and innovative with their health promotion programs. A recent example of new strategies was the public seminar called 'Strokesafe' an educative event which allowed people to discuss their health directly with professionals. The risk of serious illness was explained to overweight or obese patients and weight reduction programs were recommended. The long-term repercussions of years of being inactive and having a poor diet are the degradation of peoples' health and abilities and the development of chronic disease. It is important that people are empowered to take responsibility for their own health by having a clear understanding of the link between lifestyle and disease.

CONCLUSION

In conclusion the researcher hopes to this study will assist health professionals to understand the lifestyle choices of patients who had suffered a minor stroke or TIA. Carefully tailored preventive strategies may significantly reduce the prevalence and severity of stroke and thus the social burden of this problem.

The incidence of stroke is increasing worldwide every year. This is caused by ageing populations and globalisation which has promoted the adoption of some unhealthy Western lifestyle in many developing and low-income countries. Although there has been a decline in the mortality rate of stroke in many developed countries, this is outweighed by the increase in prevalence. Eighty-three percent of stroke is ischaemic and is preventable.

Misconceptions about the nature of stroke may influence patients' motivation, and attitudes thus limiting the success of health promotion strategies. It appears that the prevalence and recurrence rate of minor stroke or TIA is underestimated and patients presenting with a minor stroke or TIA are not always recognised and treated appropriately.

In Australia the cost of stroke is about \$1.8 billion per year and cardiovascular medications cost over \$2.6 billion. In comparison the cost of lifestyle changes is very low. The benefits of a healthy lifestyle do not only impact on stroke alone but will also influence the incidence and severity of chronic disease generally.

Multiple sources of health information and subsequent confusion may impact on the effectiveness of health promotion strategies. Effective health promotion may help prevent millions of strokes and TIA each year, reducing hospitals, social and economic costs and health care burden in communities and also minimise physical, psychological and emotional suffering to individuals, families and carers.

This study investigated factors influencing patients' decisions about whether or not to adopt lifestyle changes. It also assessed what this group of patients' know about

stroke and the risk factors. The major findings indicated many patients had a poor understanding of risk factors for stroke. Smoking was well recognised as a risk factor among the samples, while patients showed less awareness of other risk factors especially excessive alcohol consumption, obesity and confusion about healthy diet. Patients' over dependence on doctors as their main source of health information poses significant risks in the light of workforce issues. It also appears that there was an assumption that medication was the only way to treat hypertension and many did not monitor their condition. However, results indicated that many were interested in gaining quality information from health professionals that they could trust and were interested in participating in lifestyle-changing programs.

Hence, these findings may assist health professionals to develop effective health promotion program designed to reduce the risk factors relating to stroke. Health professionals and policy makers might use this valuable information to facilitate better health strategies for stroke victims, and to improve the cost-effectiveness and quality of health care services in the long-term to reduce the burden from preventive lifestyle diseases generally and CVDs in particular. In fact the WHO and the Australian Heart and Stroke Foundation consider preventive measures, especially lifestyle changes, to be pivotal strategies in the prevention of stroke. It is hoped that the findings of this study will add to the knowledge necessary to develop effective health promotion strategies for these patients.

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APPENDICES

Appendix 1: Approval letter from Research and Higher Degree Sub-committee (RAHDS)



DEPARTMENT OF CLINICAL NURSING
FACULTY OF HEALTH SCIENCES

Dr. David Evans
LECTURER

LEVEL 3, ELEANOR HARRALD BUILDING
ROYAL ADELAIDE HOSPITAL
ADELAIDE UNIVERSITY SA 5005
AUSTRALIA

TELEPHONE +61 8 8303 6288
FACSIMILE +61 8 8303 3594
d.evans@adelaide.edu.au

3rd June 2004

Mr. Albert Yip
Department of Clinical Nursing
The University of Adelaide

Dear Albert

I write regarding your research proposal titled 'What lifestyle changes for risk factor modification do patients who have suffered a minor stroke or TIA adopt on discharge from the hospital and what factors influence these decisions?'

Two members of the committee have reviewed your proposal. The sub-committee supports the submission of your research proposal to the ethics committee.

Regards

Dr David Evans
Chair: Research and Higher Degree Sub-committee
Department of Clinical Nursing
The University of Adelaide

Appendix 2: Approval letter from Research Ethics Committee



ROYAL ADELAIDE HOSPITAL
North Terrace
Adelaide
South Australia 5000

RESEARCH ETHICS COMMITTEE
Level 3, Hanson Institute
Telephone: (08) 8222 4139
Fax: (08) 8222 3035
email: tpietraf@mail.rah.sa.gov.au

30 August 2004

Mr A Yip
DEPT OF CLINICAL NURSING
LEVEL 3, EHB
ROYAL ADELAIDE HOSPITAL

Dear Mr Yip,

**Re: "A descriptive study of lifestyle changes made by patients who have suffered a minor stroke or transient ischaemic attack (TIA), following discharge from hospital."
RAH Protocol No: 040823.**

I am writing to advise that ethical approval has been given to the above project. Please note that the approval is ethical only, and does not imply an approval for funding of the project.

Research Ethics Committee deliberations are guided by the Declaration of Helsinki and NH&MRC National Statement on Ethical Conduct in Research Involving Humans. Copies of these can be forwarded at your request.

Adequate record-keeping is important and you should retain at least the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them if necessary, in the future. The Committee will seek a progress report on this project at regular intervals and would like a brief report upon its conclusion.

If the results of your project are to be published, an appropriate acknowledgment of the Hospital should be contained in the article.

Yours sincerely,

DR M JAMES
CHAIRMAN
RESEARCH ETHICS COMMITTEE

**Appendix 3: Introduction letter from a Staff Specialist in
Neurology**

Dr Thomas Kimber
Staff Specialist in Neurology
Royal Adelaide Hospital

Dear

You are being contacted because you were recently a patient at the Royal Adelaide Hospital for treatment of a stroke or transient ischaemic attack (TIA). While you were at the RAH, your care was conducted under the management of the Neurology and Stroke Unit.

Mr Albert Yip, who is a Doctor of Nursing student at The University of Adelaide, Department of Clinical Nursing, is conducting research into lifestyle changes made by patients who have suffered a minor stroke or transient ischaemic attack (TIA), following discharge from hospital. You are invited to participate in this research by completing a questionnaire. An information sheet containing more information about the research project is enclosed. Please note that your participation is entirely voluntary.

Yours sincerely

Dr Thomas Kimber
Staff Specialist in Neurology
For Dr

Appendix 4: Information sheet to subjects

A descriptive study of lifestyle changes made by patients following discharge from hospital who have suffered a minor stroke or transient ischaemic attack (TIA).

Investigator: Mr A Yip RN, BHSc, MPHc.

Supervisors: Dr J Magarey RN, CCRN, Dip Nurs, MNurs, DNurs.
Ms Heather Peters RN, RM, CCC, GradDip (Health Counselling)
DipAppSc, Gerontic Cert, MNsc CNC Stroke Unit, Royal Adelaide
Hospital.

Dear sir / madam

I am a student of Doctor of Nursing studying at The University of Adelaide, Department of Clinical Nursing. My research study is investigating patients' perceptions of risk factors of stroke and assessing the problems relating to lifestyle changes following a minor stroke or transient ischaemic attack (TIA). Patients who have had a minor stroke or TIA may have varying degrees of disability, but most recover rapidly. However, it is important to recognise the risks of recurrence is related to certain risk factors.

Although considerable health resources have been directed to the care of patients who have had stroke, health professionals need to understand patients' perceptions of lifestyle changes required following a stroke or TIA. Therefore, it is hoped that this study will assist in the development of programs designed to help patients improve their preventive strategies and minimise their risk of stroke.

Therefore, I am asking you to complete the attached questionnaire regarding your perceptions of risk factors related to a stroke and TIA and the lifestyle changes that can reduce the risk of recurrence. The results of the study will be published but any information that could identify you or any individual will be kept strictly confidential.

You can decline to participate in this research and your present care or future treatment will not be affected in anyway. There is no immediate benefit to you from your participation in this research however, your input is considered extremely valuable and will assist health professionals to provide effective care for patients who suffer a stroke or TIA. If you desire you may ask a relative or a friend to complete the questionnaire for you; provided that it is your perceptions and opinions that are recorded.

If you have any queries about this research, please contact Albert Yip in Discipline of Nursing phone no. 8303 6158. The Royal Adelaide Hospital Research Ethics Committee has approved this study. If you want to discuss aspects of the research with someone who are not directly involved, you can contact the Chairman Research Ethics Committee, Royal Adelaide hospital call 8222 4139.

Thank you for your valuable time. I would greatly appreciate your participation in this research study.

Albert Yip

Appendix 5: Reminder to subjects

Dear sir / madam

This letter is just to remind you about the questionnaire sent to you two weeks ago. If you had already returned the questionnaire, please ignore this letter. However, if you did not receive a questionnaire and would like to participate, please contact me on the number given below.

The questionnaire is designed to investigate:

Patients' perceptions of risk factors relating to stroke or transient ischaemic attack (TIA)

If you still have any queries about the research study, please contact the researcher Albert Yip phone no. **8303 6158** or the Chairman of Research Ethics Committee in Royal Adelaide hospital phone no. 8222 4139.

Thank you for your consideration and the time taken to complete the questionnaire. Please return it as soon as possible. I really appreciate your contribution.

Best regards,

Albert Yip

Appendix 6: Questionnaire: Patients' perceptions of risk factors relating to stroke or transient ischaemic attack

Please ✓ the appropriate boxes.

1. What is your age in years?

2. Please indicate your gender.

Male

Female

3. Please indicate your current living arrangements

Private residence

Retirement Village

Aged care facility (please go to question 6.)

Other (Please describe): _____

4. Do you live alone?

Yes (please go to question 6.)

No

5. Who do you live with?

Spouse or partner

Other family member/s (please state): _____

Other (please state): _____

6. Please indicate your employment status.

Employed full time

Retired

Employed part time

Sick benefits

Disability pension

Other (Please describe): _____

(If this has changed since a stroke, please describe how): _____

7. Do you have any disability as a result of stroke or TIA?

Yes (If yes please describe): _____

No

8. Have you had more than one episode of stroke or TIA?
 No
 Yes (Please comment): _____

9. Do you consider that you have a good understanding of the risk factors relating to a stroke and TIA?
 Yes
 No (if no, please go to question 12.)
Please comment: _____

10. Please list below factors that you think increase the risk of stroke or TIA.

11. If you have good understanding of the risk factors what has been the main source of this information? (Please ✓ all those apply.)
 Doctor/s
 Nurse/s
 Relatives
 Friends
 Others (please describe): _____

12. Would you like to receive any further information regarding prevention of stroke?
 Yes (Please comment): _____

 No (please go to question 14.)

13. How would you prefer to receive information about stroke or TIA?
(Please ✓ all those apply)
 Written
 Verbal
 Internet
 TV / radio
 CD / cassette
 Video
Other (please state): _____

14. Have you changed your cigarette smoking habits since your stroke or TIA?

(If you were not a smoker please go to question 15.)

- Increased smoking Reduced smoking
 No change Ceased smoking

How many cigarettes do you smoking in average per day? (Please describe):

15. Do you consider your alcohol consumption is less than or equal to 2 drinks per day? (A standard drink defined as: 12 fl oz /360mls of either wine cooler or beer **or** 5 fl oz /150mls of wine **or** 1.5 fl oz /45mls 80-proof (80%) spirits.)

- Yes
 No (please give reason/s for this decision): _____

16. Have you commenced a weight reduction program?

(If you are not overweight, please go to question 17.)

- No
 Yes (please comment): _____

17. Do you have exercise regularly?

(Regular exercise is 30 minutes of moderate activity 6 times per week **OR** vigorous activity done at least 3 times per week for 20 minutes each time.)

- Yes
 No

Please give your reason/s for this decision: _____

18. Do you have high blood pressure **OR** require medications to control your blood pressure?

(High blood pressure means the systolic blood pressure =140mmHg or higher and or diastolic blood pressure = 90mmHg or higher.)

- Yes (Please indicate when you found about your BP and who informed you.): _____

No **(please go to question 21.)**

Don't know

19. If you have high blood pressure, what action you will take to monitor it?
- Attend doctor/ clinic and check
 - Attend health services (e.g. Health Promotion Unit)
 - Regular self-checking at home
 - Regular monitoring by nurse / carer
20. If you have high blood pressure what actions do you take to control this?
(Please ✓ all those apply)
- Medication/s
 - Lifestyle changes (please state): _____
- Other (please describe): _____
21. Have you made any changes to your diet to help reduce the risk of recurrence of stroke or TIA? (E.g. low salt, low fat, low cholesterol etc.)
- Yes
 - No
- Please describe the reason you made this decision: _____
- _____
22. Following your stroke or TIA did you made any other changes to your lifestyle to reduce the risk of recurrence?
- Yes (If yes please describe): _____
 - No
- Please describe the reason/s that you made the decision: _____
- _____
- _____
23. Have you experienced any difficulties in making changes to your lifestyle?
- Yes (If yes please describe): _____
- _____
- No
24. Would you participate in a program to as sist you in making lifestyle changes to prevent recurrence of TIA or stroke?
- Yes
 - No

25. Are there any measures that you think would assist you in making lifestyle changes?

Please describe: _____

26. Do you have any illnesses that may affect your ability to make lifestyle changes?

Please describe: _____

27. Can you describe any preventive measures you have found useful?

28. Any other comments: _____

Thank you for your time in completing this questionnaire

Research study

Report two:

**The hospital management of patients
with acute dysphagia following stroke.**

A retrospective review.

(Albert) Man-tat Yip

October 2007

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ABSTRACT

Dysphagia is a common complication following stroke, which can result in significant morbidity and mortality. Multidisciplinary collaboration facilitates management strategies, decision-making and the efficiency of rehabilitation. Nurses are responsible for coordination of management and in particular for continuous monitoring, assessment of swallowing and nutritional state, maintaining safety and preventing complications. An understanding of the issues and strategies relating to management may provide valuable information to enhance the safety, cost-effectiveness and quality of care.

A retrospective review of patients' medical records was used to collect data. A sample of ninety-five adults who were admitted to an Australian public hospital between January 2003 and April 2006, with a diagnosis of dysphagic stroke were recruited. Statistical Package for Social Sciences (SPSS) was used to analyse the quantitative data, while content analysis was used to analyse the qualitative data.

All subjects were assessed by a speech pathologist, the mean age was 75 years and 50.5% were male. Except for critically ill subjects, almost all were assessed within three days. Ninety-six percent of subjects had communication problems and 81% had upper limb motor impairment. During hospitalisation almost 60% of subjects had an improvement in their oral intake including 8% resuming their premorbid diet. Eighteen percent were on enteral tube feeding upon discharge, 4% deteriorated and 16% died. It appears that oral intake of most subjects was unsatisfactory. When recorded the mean body weight lost was 2.3kg. At least 22% had malnutrition or dehydration. Forty-five percent aspirated and 22% had respiratory infection. Almost half of the subjects (48%) were discharged to aged care facilities. Eighty percent had no documented follow-up scheduled for management of their dysphagia.

Early identification of dysphagia, prudent supervising of appropriate oral intake and mouth care may help to maintain safe swallowing, preventing aspiration and chest infection. Regular checks of body weight, serum albumin level, oral intake and early enteral feeding are essential to guide nutritional support, minimise malnutrition and problematic medication administration. Encouraging oral intake and providing

families with support could promote recovery of swallowing skills and help patients to regain the ability to eat independently. Providing helpful information on the care options available may allay patient and family anxiety. A qualified nurse practitioner could assess patients and ensure that a tailored care plan was designed to meet patients' needs and this may improve the outcomes considerably.

INTRODUCTION

CONTEXT OF THE STUDY

Stroke is an acute medical event that contributes significantly to mortality and adult disability. Stroke and its complications are so serious, that almost one-third of victims' die within a year of onset. Patients suffering severe stroke and significant disability require comprehensive care to support their activities of daily living (ADL) and education to empower them through rehabilitation. One of the most serious complications of stroke is dysphagia, which may delay recovery and significantly effect outcomes. Nurses can have a significant role in the care of these patients and may be responsible for assessment, monitoring and maintenance of nutritional status, and assisting rehabilitation. It may be argued that nurses are integral to the care of patients in hospitals and communities. However, each health discipline has an important role to play in care and rehabilitation of stroke patients with dysphagia and good collaboration can enhance management.

Patients who suffer a stroke need to be admitted to an acute care facility without delay for medical treatment. Clearly hospital management is the first step to treat stroke and related problems. However, this management is complex in terms of the administration and organisation of many different health departments, units and members of multidisciplinary teams. Hospital policy and coordination is key to sustaining this process and ensuring efficiency and safety.

Assisting stroke patients to resume normal eating patterns to improve nutritional status is a high priority early rehabilitation. However, this aim may be influenced by the patient's level of consciousness, cognitive ability, the severity of impairment of swallowing, and the presence of airway tubes. Such factors can be a challenge for health professionals. The problem of holistic management of dysphagia has not been addressed in previous studies. However, this information is essential, so that appropriate strategies required to maintain intake safely and effectively can be developed. Current issues in clinical management of patients with a dysphagic stroke include lack of timely support, and limited resources and health professionals'

knowledge and experience. Evaluation of the outcomes of current practices is also important to help improve the quality of management.

Although, evidence relating to the standards of care of patients with acute dysphagia is limited, there is some consensus on the importance of early assessment and intervention (Runions, Rodrigue & White 2004, Scottish Intercollegiate Guidelines Network (SIGN) 2004, Perry & Love 2001). A review of medical records is a convenient and efficient method to examine acute management of stroke patients suffering from dysphagia and to establish if this can be improved.

Patients who suffer stroke resulting in persistent disability experience enormous personal suffering and pose a considerable burden on the health care services. If these patients can be identified early appropriate interventions can be implemented and related complications minimised. Moreover, patients can be referred to therapists and specialists for timely supportive care and rehabilitation.

There are many possible complications of stroke, nevertheless health professional have only recently recognised the serious consequences of dysphagia. Food and fluid intake is vital and problems can have a significant effect on patient rehabilitation and recovery. Studies indicate that the actual and potential risks of dysphagic stroke are significant and can be fatal (Finestone, Fisher, Greene-Finestone, Teasell & Craig 1998). These include choking, aspiration and chest infection, and the impact on the patient's physical, psychological, emotional and social health both in the short and long-term. Assessment of dysphagia, continuous observation, supervision, appropriate interventions and the outcomes of stroke care management are major considerations.

The difficulties relating to performing assessment and interventions, such as workload, inadequate training, insufficient communication and collaboration within a multidisciplinary team, hospital policies, should be considered to look for appropriate solutions as soon as possible. Thus in this study the whole process of hospital management of patients with acute dysphagic stroke was reviewed. The results may be useful to policy makers, nurses and related therapists to gain a clear understanding of the current situation and the outcomes.

PURPOSE OF THE STUDY

The purpose of this research was to evaluate the hospital management of patients admitted with stroke resulting in acute dysphagia. In particular, the focus was on the nurses' role and collaboration of the multidisciplinary team, and to investigate assessment, observation and interventions, with regard to the impact on the decision-making and patient outcomes. The findings of this study may assist decision makers, and other health care professionals to gain a better understanding of current practices and illustrate the actual and potential problems that require modification to improve the outcomes.

STATEMENT OF THE RESEARCH QUESTIONS

The research questions were what:

- processes are used for the assessment of patients admitted to hospital with acute dysphagia following stroke?
- is the role of nurses within the multidisciplinary team in the management of patients with acute dysphagia?
- are the outcomes of multidisciplinary team management?

SIGNIFICANCE OF THE STUDY

The goal of this study was to increase the understanding of the role of nurses in the multidisciplinary team for the management of dysphagic stroke patients. The outcomes of management may illustrate the efficacy of strategies and the appropriateness of hospital policies.

DEFINITIONS OF TERMS

The significant terms that are used in this report are defined as below:

Aphasia

Aphasia is 'impaired or absent comprehension or production of, or communication by, speech, writing, or signs, due to an acquired lesion of or injury to the dominant

cerebral hemisphere, it may be transient if cerebral swelling subsides and ability to speak returns' (Stedman's 2005, p.101).

Apraxia of speech

Apraxia of speech is 'an inability to program the position of speech muscles and the sequence of muscle movements necessary to produce understandable speech, although understanding of speech remains intact' (Harris, Nagy & Vardaxis 2006, p.128).

Aspiration

Entrance of fluids or a foreign substance below the level of the vocal cords into the trachea and beyond, that can cause respiratory discomfort, inflammation or infection (Michalakis, Jackson & Catalano 2005).

Aspiration pneumonia

'An inflammatory condition of the lungs and bronchi caused by inhaling foreign material or acidic vomitus' (Harris, Nagy & Vardaxis 2006, p.144).

Bedside swallowing assessment (BSA)

There are several methods that may be used to assess swallowing at the bedside they include: the case history, physical examination, observation, clinical assessment of swallowing function such as oral motor examination (OME), water swallowing test (WST), palpation and auscultation (at the neck). If aspiration is suspected a pulse oximetry may also be used (to assess desaturation of arterial haemoglobin (SaO₂) – more than 2% after eating or drinking is indicative of aspiration). OME and WST will be used to assess the four phases of swallowing: oral preparatory, oral, pharyngeal and oesophageal phase. The patient's tolerance to different textures of modified food and fluids can be evaluated and advice provided on the appropriate method to administer medications.

Body mass index

An individual's body mass is their weight in kilograms divided by the square of their height in metres. The following ranges of body mass index (BMI)s are used by the Centers for Disease Control and Prevention (CDC) to classify individuals:

underweight, $<18.5\text{kg/m}^2$; acceptable weight, $18.5\text{-}24.9\text{kg/m}^2$; overweight, $25\text{-}29.9\text{kg/m}^2$; obesity $>30\text{kg/m}^2$ (Centers for Disease Control and Prevention 2005).

Dysarthria

Dysarthria is ‘a disturbance of speech due to paralysis, poor coordination, or spasticity of the muscles used for speaking’ (Stedman's 2005, p.441).

Dysphagia

‘Dysphagia’ is difficulty in swallowing. Its severity, mild, moderate or severe is usually designated by a speech pathologist using clinical history, observation, physical examination, bedside or clinical assessment of swallowing function and evaluation of oral feeding function with trials of modified food and fluids.

Dysphasia

Dysphasia is loss of or deficiency in the power to use or understand language as a result of injury or disease of the brain (Merriam-Webster Incorporated 2005).

Laryngeal penetration

‘Abnormal swallowing during the oral and pharyngeal stage can cause misdirection of food and fluids into the airway. This misdirection, known as penetration if it enters the laryngeal vestibule’ (Whitaker, Dunnachie & Hughes 2003, p.347).

Malnutrition

‘Any disorder of nutrition. It may result from an unbalanced, insufficient, or excessive diet or from impaired absorption, assimilation, or use of foods’ (Harris, Nagy & Vardaxis 2006, p.1058).

Mendelsohn manoeuvre

A technique that opens the upper oesophageal sphincter may improve propulsion of bolus into the oesophagus. The patient is instructed to hold the thyroid cartilage up for several seconds to maintain the larynx tilted forward and elevated (Voice and Swallowing Center 2007).

Premorbid disability

Disability is loss, absence, or impairment of physical or mental fitness, premorbid disability occurs before the development of disease (Harris, Nagy & Vardaxis 2006).

Risk of aspiration

Risk of aspiration is ‘a state in which an individual is at risk for entry of gastric secretions, oropharyngeal secretions, or exogenous food or fluids into tracheobronchial passages caused by dysfunction or absence of normal protective mechanisms’ (Harris, Nagy & Vardaxis 2006, p.144).

Serum albumin

‘Albumin is a major protein in blood plasma. It is important in maintaining the osmotic pressure. Normal value is 35-50g/L’ (Harris, Nagy & Vardaxis 2006, p.1569). Levels are also an indication of the patient’s nutritional state.

Severity of stroke

The severity of stroke is categorised into three levels: mild, moderate and severe. Glasgow Coma Scale (GCS) is probably the most commonly used method used to assess the neurological status of a patient following stroke. The scale considers the patient eye opening, verbal and motor responses. The range of total score is 3 (unconscious) to 15 (normal): 3 to 8 is severe brain damage, 9 to 12 is moderate and 13 to 15 is mild to normal (Teasdale & Jennett 1974).

Supraglottic swallowing

A four step manoeuvre: inhaling and holding breath; place bolus in swallow position; swallow while holding breath; and cough after swallowing before inhaling (Voice and Swallowing Center 2007).

Swallowing rehabilitation program

A swallowing rehabilitation program is designed to provide rehabilitation to patients exhibiting significant deficits in swallowing. Services are delivered within an intensive interdisciplinary team approach (Rehabilitation Program Definitions Task

Group of the OHA 1999). The dysphagia team includes doctors, nurses, a speech pathologist, dietician, gastroenterologist and other related specialists.

SUMMARY

Stroke and its complications contribute to significant mortality and disability and consume a significant proportion of health care resources. Hospital care is essential in the management of stroke and if effective can minimise patient suffering and improve outcomes. Each member of the hospital multidisciplinary team has an important role in facilitating recovery and minimising complications (Appendix 6). A review of current practices may help highlight issues suggesting strategies for improvement in management of these patients. It will also allow managers to compare practice with international standards.

LITERATURE REVIEW

INTRODUCTION

Stroke is a leading cause of mortality and of adult disability worldwide. The discipline of nursing plays an important role in minimising the rate of mortality and morbidity caused by this disease. Although there are many studies which focus on the management of stroke, few are concerned with holistic management or the role of the nurse (Mitchell & Moore 2004). Sadly, there are many stroke victims who develop complications, remain in a vegetative state, or die from severe brain injury. Nursing care can impact on the recovery process and contribute to the level of comfort patients' experience. The main nursing goals include: promoting recovery; preventing stroke-related complications; minimising the risk of developing persistent disability; and preventing recurrence of a stroke. These are challenging goals, which require effective coordination of care and close cooperation with other members of the multidisciplinary team.

This literature review aims to discuss the findings of research regarding dysphagic stroke, in order to identify the main problems that may affect management. In addition the main causes of a dysphagic stroke, the physiology of swallowing, the pathophysiology and signs and symptoms of dysphagia, assessment methods, interventions and management will also be discussed. Effective management of patients with this condition is dependent on accurate and timely assessments and the provision of appropriate and effective interventions. Nurses are essential members of a multidisciplinary team and are primarily responsible for ensuring the coordination and cooperation between multidisciplinary team members (Feigin 2005, Rodrigue, Cote, Kirsch, Germain, Couturier & Fraser 2002). Finally, the evaluation of patient outcomes is important in order to assess the gaps in the management of dysphagic stroke and to consider actions, which may enhance care.

THE IMPACT OF STROKE

Stroke contributes greatly to the mortality and disability of the overall population. Annually, 15 million people worldwide suffer a stroke; 5.5 million victims die and 5

million are left permanently disabled, placing a heavy health care burden on communities and families. Mackay and Mensah (2005) estimate that the number of disability-adjusted life years (DALYs) will increase from 38 million in 1990 to 61 million by 2020. Although in developed countries the mortality rate of strokes has decreased slightly in the past few decades, in developing countries and lower socio-economic status areas the mortality rate is increasing rapidly. The countries with the highest mortality include China (1.65 million), India (0.77 million) and the Russian Federation (0.52 million) which together account for over half (53.5%) of the world's stroke deaths (World Health Organization 2002). The prevalence of morbidity, mortality and disability are rising globally (Mackay & Mensah 2005).

Although Australia's international ranking for death rates from stroke has improved markedly, stroke is one of the most common causes of hospitalisation and deaths. However, to a degree stroke may be considered as a preventable disease; a 2003-2004 survey by AIHW found 24% of deaths from stroke and 24% of stroke hospitalisations can be attributed to issues relating to socio-economic inequality (Australian Institute of Health and Welfare (AIHW) 2006).

DYSPHAGIA

Dysphagia – difficulty in swallowing, is a common disability following an acute stroke, affecting 30% to 71% of patients (Barer 1989, Hamdy, Aziz, Rothwell, Power, Singh, Nicholson, Tallis & Thompson 1998). The disparity in the reported incidence may be due to variations in, definitions of swallowing difficulties, inclusion criteria for selection, the methods used to assess dysphagia, and differences in the time of assessment. Patients who suffer dysphagia may require modified food and fluids or tube feeding. Occasionally, they may also require special utensils for eating or feeding. Carers or family members may also require education on the preparation of food, feeding and precautions to be taken against aspiration and asphyxiation. However, many family members may not be able to take on the role of carer due to the severity of stroke and of disabilities, hence, this may greatly increase demand on various community health care services, increasing the cost of health insurance and health care expenditure. This may also influence the budget available for other health care services, such as hospital services and primary health care which may be directed

at lowering the prevalence of strokes (Veazie, Galloway, Matson-Koffman, LaBarthe, Brownstein, Emr, Bolton, Freund, Jr, Fulwood, Guyton-Krishnan, Hong, Lebowitz, Ochiai, Schoeberl & Robertson 2005).

During the rehabilitation period, problems with ingestion are common in patients with upper limb disability, facial weakness, and poor control of lips and tongue. Thus, patients may also suffer malnutrition, due to difficulties in manipulating food on a plate, and transporting and manipulating food by mouth (Westergren, Ohlsson & Hallberg 2002). In addition, problems of positioning for example, patients may not be able to maintain balance while sitting or keep their heads midline when eating. These may further compound problems with eating and swallowing. Health care providers may recognise the risk of malnutrition and dehydration through observation of appetite, eating, and recording intake and output. Clinical indicators such as decreasing body weight and low serum albumin levels may also be seen. Aspiration and respiratory infections may also occur and this may be evidenced by patients choking or coughing after swallowing, (Cairella, Scafi, Berni Canani, Garbagnati, Gentile, Gianni, Marcelli, Molfino, Muscaritoli, Paolucci, Pratesi, Rossi Fanelli, Scognamiglio, Tari, Troiano & Branca 2004).

Poor oral intake or malnutrition may influence the outcome of rehabilitation because when patients begin a therapy program, they require more energy and tire easily. If the problem of dysphagia and associated complications cannot be treated properly, length of hospital stay may be extended, increasing the cost of management. Moreover, there is concern among health care providers that difficulty in swallowing may affect the discharge destination of patients, delay rehabilitation programs and raise increasing mortality (Perry 2001b).

Clearly, dysphagia and its related complications not only affect the patient's recovery during the acute phase and rehabilitation, but also complicate long-term care in aged care facilities or at home. Patients suffering from persistent dysphagia following a stroke may require more medical and nursing care to manage feeding and complications such as malnutrition, aspiration and respiratory infections (Thomas, Kamel & Morley 1998, Smithard, O'Neill, Parks & Morris 1998). Therefore, when patients are discharged from a hospital, health care providers need to provide patients,

carers and related care facilities with detailed information and advice on how to manage the patient's dysphagia safely and appropriately. Hence, persistent dysphagia following a stroke is a significant problem that requires cooperation between the multidisciplinary health care team, and the patient, carer and family. Such cooperation is necessary to minimise the risk of complications, reduce health care costs and to maximise the chance of patient recovery, with restored quality of life.

THE PHYSIOLOGY OF SWALLOWING

Normal swallowing function is dependent on the coordination of six cranial nerves:

- trigeminal (V) – chewing movement,
- facial (VII) – swallowing,
- glosso-pharyngeal (IX) – swallowing and secretion of saliva,
- vagus (X) – contraction of muscles of the pharynx and larynx, taste sensation,
- accessory (XI) – controls neck muscles and head turning, and
- hypoglossal nerve (XII) – tongue movement (Barker & Dean-Baar 2002, Mitchell & Finlayson 2000, Baker 2002).

These cranial nerves control different sensory and motor functions of swallowing in various brain regions, for example, the cerebellum controls output for the motor nuclei with cranial nerves V, VII and XII; the medulla controls the involuntary swallowing reflex and the cerebral cortex controls voluntary swallowing with cranial nerves IX and X (Spieker 2000). Swallowing has a bilateral but asymmetric inter-hemispheric representation within the motor and pre-motor cortex. Thus the capacity for compensatory reorganization in the contralateral motor cortex may be increased in recovery (Hamdy & Rothwell 1998).

The functions of swallowing include the closure of the lips, moisturising of food in the oral cavity, coordination of cheek muscles, tongue movement, taste, swallowing reflex, elevation of the soft palate and epiglottis and the initiation of pharyngeal and oesophageal peristalsis. Food or liquid is transported from the mouth through the pharynx and oesophagus into the stomach. The swallowing reflex is a key reaction to protect the airway from laryngeal penetration or aspiration. The process is complex and requires precise coordination. The soft palate elevates to close the nasopharynx,

the suprahyoid muscles pull the larynx up and forward and the epiglottis is moved downward by contraction of pharyngeal muscles to cover the airway within a second (Spieker 2000). The relaxation of the upper oesophageal sphincter – the cricopharyngeal muscle, means that a food bolus can pass through from the mouth into the proximal oesophagus safely propelled by pharyngeal and oesophageal peristalsis to the stomach.

The larynx and pharynx are also involved in speaking and swallowing. Patients who develop dysphagia may also have accompanying dysarthria due to related cranial nerve and or peripheral motor weakness. This condition may affect the patient's communication (Young & Durant-Jones 1990), which may in turn increase the potential for complications such as choking or inhalation.

The physiology of swallowing may be categorised in four phases:

1. oral preparatory phase – chewing and forming a bolus;
2. oral phase – moving the bolus backwards towards the pharynx;
3. pharyngeal phase – the bolus is pushed to the opening of the pharynx and triggers the swallowing reflex to pass the bolus on towards the oesophagus;
and
4. oesophageal phase – conveying the bolus through the oesophagus into the stomach with peristaltic movement (Beadle, Townsend & Palmer 1995).

THE PATHOPHYSIOLOGY OF SWALLOWING

Patients suffer various degrees of dysphagia depending on which phase of swallowing has been affected:

Oral preparatory phase: impairment is indicated by difficulty in chewing, producing a food bolus and pocketing food on the affected side of the mouth, due to facial weakness and lack of sensation and hemiparesis of the tongue (Beadle, Townsend & Palmer 1995).

Oral phase: problems stem from the inability or delay to trigger the swallow reflex. The tongue cannot form a seal with the hard palate, so the patient cannot get food or fluids to the back of the mouth. Drooling occurs because saliva is

difficult to swallow. Dysphagia of this type is difficult to manage and often leads to aspiration (Warlow, Dennis, Gijn, Hankey, Sandercock, Bamford & Wardlaw 1996).

Pharyngeal phase: problems relating to a delay in the swallowing reflex so food can become stuck in the throat. Coughing and regurgitation of food through the mouth and nose may occur. Clinical indicators of problems with this phase of swallowing are of food and fluids accidentally entering the airway, choking, loss of voice quality, and a wet sounding voice due to fluid leaking below the vocal cords.

Oesophageal phase: problems of delay or complete absence of the reflex action or reduced pharyngeal peristalsis. Aspiration will occur after swallowing, due to food collecting in the pharynx and overflowing past the vocal cords and into the trachea. Silent aspiration may occur and is difficult to identify because no obvious signs are displayed such as coughing and dysphonia. The ability to expectorate may be compromised due to weak respiratory muscles and this promotes chest infection (Beadle, Townsend & Palmer 1995).

Patients who have suffered a brainstem stroke may be prone to oesophageal phase dysphagia. This paralysis is because of unilateral or bilateral destruction of vagus nerve and can result in asphyxiation. One or both vocal cords will be adducted; resulting in blockage of the glottis and obstruction of the airway (Barker & Dean-Baar 2002, Han, Chang, Lu & Wang 2005, Baker 2002). However, recurrent cortical or sub-cortical stroke predisposes to oral preparatory and oral phase dysphagia. Daniels and Foundas (1997) studied four unilateral cortical stroke patients and found three patients who had a lesion that involved the anterior insula developed dysphagia. One patient however, had a lesion restricted to the posterior insula without developing dysphagia. This indicates that anterior insula may be an important cortical structure in swallowing. The reason is the anterior insula has connections to the primary and supplementary motor cortices, the ventroposterior medial nucleus of the thalamus, and to the nucleus tractus solitarius, all of which are important regions in the mediation of oropharyngeal swallowing. Although the site of the stroke, such as brainstem and subcortical regions, will affect swallowing, the size of the stroke lesion, pre-existing

medical problems, medications and complications may trigger or increase the severity of the disorder (Loemann 2005). Daniels, Brailey and Foundas (1999) also found that lesions in anterior and subcortical periventricular white matter result in a higher risk of aspiration than those in the posterior and subcortical grey matter. This is because vocal cord mobility is reduced and voluntary pharyngeal motor activity is impaired. Sensory thresholds are not increased. A delayed onset of epiglottic tilt during swallowing may result in reduced airway protection (Sellars, Campbell, Stott, Stewart & Wilson 1999). Thus it is clear the control of swallowing is extremely complex and appears to be mediated by a widely distributed neural network that involves both cerebral hemispheres with descending input to the medulla. Specific locations of lesion may however put patients at a greater risk of aspiration.

CLINICAL FEATURES OF DYSPHAGIA

Generally, dysphagia may also be classified as oropharyngeal, oesophageal and obstructive dysphagia, or neuromuscular symptom complexes. A patient history, observations, physical examination, barium swallow studies and endoscopy can be used to confirm the diagnosis (Spieker 2000). There are many clinical signs and symptoms of dysphagia (Table 1) that can be identified.

Table 1: Signs and symptoms of dysphagia

<p>NOTE: This table is included on page 14 of the print copy of the thesis held in the University of Adelaide Library.</p>
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NOTE Continued:
This table is included on page 15 of the print copy of
the thesis held in the University of Adelaide Library.

Cited from: Ramritu, Finlayson, Mitchell and Croft (2000, p.44)

Common clinical manifestations of swallowing dysfunction include abnormal lip closure (85%), decreased tongue motility (68%), insufficient opening of the cricopharyngeal muscle (81%), weakness of palate, decreased or absent gag reflex, abnormal lift of larynx, and weakened muscles of the mouth (Zhang, Zhou & Wang 2006). On the other hand, poor coordination of the swallowing movement may appear in patients as prolonged chewing and repetitive swallowing, or as a dry swallow and piecemeal swallowing. These may increase the difficulty of swallowing and risk of choking. Patients may also have decreased appetite and experience extreme anxiety at meal times (Morris 2006). This condition may be aggravated by other disabilities such as facial weakness, speech impairment, upper limb motor weakness. Finally, a patient may not consume enough nutrients for recovery and may deteriorate.

Psychologically, patients suffering dysphagic stroke may experience significant emotional difficulties. They may feel demoralised and experience irritability, fatigue, feelings of social isolation and depression (Morris 2006).

Early identification of dysphagia and appropriate interventions are necessary to optimise outcomes. This is because the likelihood of complete recovery from dysphagia is diminished by about 15% with each week of duration (Barer 1989); so that dysphagia which lasts more than six weeks is indicative of a poor prognosis. This is often classified as persistent dysphagia. Hence, the assessment of dysphagia should be a high priority in the management of stroke, because of its severe complications. Although dysphagic stroke patients may be kept on nil orally, aspiration can still occur from their own oral secretions. However, prolonging 'nil by mouth'

unnecessarily may lead to malnutrition, lack of energy and suppressed immune function subsequently undermining recovery. Therefore, many researchers suggest that the assessment of dysphagia should be carried out within 24 hours and not later than 72 hours (3 days) from the onset of stroke, if the patient's condition has stabilised (Runions 2004, Davies 1999, Westergren, Hallberg & Ohlsson 1999, Trapl, Enderle, Nowotny, Teuschl, Matz, Dachenhausen & Brainin 2007). However, with cerebral thrombosis, oedema may reach its highest level at three to five days. This is after what is generally considered to be the acute phase (48-72 hours) (Fuzy 2000). Thus, health professionals need to be aware of the possibility of delayed onset of dysphagia. Deterioration of the patient's condition during admission may also indicate a second stroke or an extension involving the neural pathway of swallowing. Thus if the patient displays any clinical signs of dysphagia, swallowing ability should be reassessed even if previous assessment excluded this problem. If bedside swallowing assessment is inconclusive, or if aspiration is suspected, a speech pathologist should be consulted or further investigations performed.

Some patients who have an intact gag reflex, may aspirate and present with few significant clinical signs. This is silent aspiration. Using the gag reflex as an indicator of swallowing safety has been shown to be inaccurate and unreliable (Ramsey, Smithard, Donaldson & Kalra 2005, Ding & Logemann 2000). Therefore, the risk factors of dysphagic stroke should be assessed (Table 2). In complicated cases, it is essential that the multidisciplinary team is involved in assessment, investigations and management.

Table 2: Risk factors associated with poor prognosis

Cited from: Ramritu, Finlayson, Mitchell and Croft (2000, p.43).

<p>NOTE: This table is included on page 16 of the print copy of the thesis held in the University of Adelaide Library.</p>
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RECOVERY

Usually, mild dysphagia will improve spontaneously within one to two weeks (Dziewas, Schilling, Konrad, Stögbauer & Ludemann 2003). This is because the functions of the affected hemisphere and the area of the motor cortex that are concerned with swallowing function may be taken over by the unaffected hemisphere.

COMPLICATIONS

Dysphagia may result in fatal, nutritional, and respiratory complications. Asphyxiation and aspiration pneumonia may cause death indirectly following dysphagic stroke and other complications such as, cachexia, malnutrition and dehydration and may extend the patient's length of stay in hospital and delay the process for rehabilitation impacting on the patient's chance of recovery.

Horner, Massey, Riski, Lathrop and Chase (1988) evaluated 47 patients with stroke clinically and videofluoroscopically and found half had aspirated. They found this correlated with combined cerebral-brainstem strokes, with patients with bilateral or unilateral cranial nerve signs being at greatest risk. Horner, Massy and Brazer (1990) performed neurologic and videofluoroscopic barium swallowing studies on 70 patients with bilateral strokes and similarly found 48% of patients had aspirated. Patients who aspirate are also more likely to have posterior circulation strokes and can be identified by the presence of an abnormal voluntary cough and abnormal gag reflex. Dysphonia is also a clinical feature of aspiration (Garon, Engle & Ormiston 1996). Smithard, O'Neill, England, Parker, Wyatt, Martin and Morris (1997), performed a prospective study on 121 acute stroke patients who were assessed by a physician and a speech pathologist with videofluoroscopy and found 51% of the patients were at risk of aspiration on admission and 6% of patients had persistent swallowing problems after 6 months of stroke onset.

Although aspiration is a severe problem, BSA may not easily differentiate between laryngeal penetration and aspiration. Rosenbek, Robbins, Roecker, Coyle and Woods (1996) developed an 8-point scoring system named the Penetration Aspiration Scale (scored from 1-8) (Table 3) which uses the results of videofluoroscopy to quantify penetration, depth of airway aspiration and the presence of foreign bodies to

differentiate the severity of airway invasion and residue. The scale provides health care providers with a clear guide to identify and categorise the level of laryngeal penetration and aspiration.

Table 3: A Penetration – Aspiration Scale

Category Score		Description
No penetration or aspiration	1	Material does not enter the airway.
Penetration (Material falls into laryngeal vestibule)	2	Material remains above true vocal cord (TVC), no residue. Patient senses and expels it.
	3	Material remains above TVC, visible residue remains. Patient does not sense it.
	4	Material falls to TVC, no residue. Patient senses and expels it.
	5	Material falls to TVC, visible residue remains. Patient does not sense it.
Aspiration (Material falls below true vocal cord)	6	Material passes below TVC and residue is ejected into the larynx or out of the airway. Patient spontaneously expectorates material.
	7	Visible residue of material below TVC. Patient tries to expel material but is unsuccessful.
	8	Visible residue of material below TVC. Patient makes no attempt to expel the material. (Silent aspiration)

Source: Rosenbek, Robbins, Roecker, Coyle, and Woods 1996.

Aspiration is common in dysphagic stroke patients. Horner and Massey (1988) and Daniels, Brailey, Priestly, Herrington, Weisberg and Foundas (1998) found that about 38% of patients who suffer stroke also experience aspiration. The Daniels et al (1998) study further identified that 33% of these patients aspirated overtly, and 67% aspirated silently as evidenced via a videofluoroscopic swallow study (VSS). The researchers used chi-square analysis to investigate the relationship of clinical signs to aspiration. The signs included dysphonia, dysarthria, abnormal gag reflex, voice change after swallowing, an abnormal volitional cough and coughing on swallowing. They were all significantly related to aspiration, and the presence of the last two signs were particularly indicative of risk. Loemann (2005) also indicated that silent aspiration occurs in approximately 40% of stroke patients. He found the signs and symptoms associated with silent aspiration were low-grade fever, fatigue, a change in respiratory pattern, weak cough and dysphonia. Thus, VSS should be used to rule out any silent aspiration in patients who suffer stroke with inconclusive clinical signs and symptoms

of dysphagia. The patient's own perceptions are also unreliable, as few patients suffering from dysphagic stroke perceive they have a swallowing problem (Parker, Power, Hamdy, Bowen, Tyrrell & Thompson 2004). Therefore, health care providers have a responsibility to assess the patient's swallowing ability following an acute stroke and take necessary precautions before starting oral food or fluid intake. Patients should have the risk of aspiration explained to them and a nurse should supervise and record the patient's compliance and progress. This is essential because patients with dysphagia may be eating in a manner which places them at significant risk of aspiration, despite a speech pathologist's advice for safe swallowing (Rosenvinge & Starke 2005).

The most common and serious complication of dysphagia is aspiration pneumonia (Bowman & Giddings 2003). This is when a solid or liquid is inhaled into the trachea and lungs. Inhaled materials include food, drink, saliva, stomach acid or vomit. Where the patient cannot expel sputum or foreign bodies effectively aspiration can occur. Once materials are aspirated into lower lobes of the lungs this may cause inflammation and oedema, resulting in blockage and development of pneumonia, that is difficult to reverse and is life threatening. Dziewas, Ritter, Schilling, Konrad, Oelenberg, Nabavi, Stögbauer, Rngelstein and Lüdemann (2004) undertook a prospective study of 100 consecutive dysphagic stroke patients who required nasoenteral tube (NET) and found 44% acquired pneumonia on the second or third day after stroke onset. This occurred more often in patients requiring endotracheal intubation, mechanical ventilation or with a decreased level of consciousness and severe facial palsy. NETs offer limited protection against aspiration pneumonia. Therefore health professionals have to be aware and take precautions to prevent aspiration for stroke patients with acute dysphagia.

Aspiration pneumonia is related to significant dysphagia and ineffective coughing reflex, which allows heavily colonised oropharyngeal contents including food and fluid to enter the larynx and lower respiratory tract. This initiates a humoral and cellular immune response designed to fight infection. Loeb and colleagues (1999) performed a study on 475 residents in 5 nursing homes and found factors such as: difficulty in swallowing; older age; male gender; and inability to take oral medication were significant risk factors for pneumonia and were associated with a deterioration in

functional status (Loeb, McGeer, McArthur, Walter & Simor 1999). In addition, poor oral hygiene may facilitate heavy growth of pathogens such as *Haemophilus influenzae* and *Streptococcus pneumoniae* in the oropharyngeal cavity increasing the risk of pneumonia.

Angiotensin-converting enzyme (ACE) inhibitor is a cardiovascular drug mainly for treating hypertension and cardiac failure and also used for reserving a salivary substance P – a neurotransmitter which is believed to play a significant role in cough and swallowing sensory pathways. Ohkubo and his colleagues (2004) conducted a study on 6,105 subjects in Australasia, Europe and Asia who had suffered stroke or TIA. Subjects were randomly assigned ACE inhibitors or placebo. They found ACE inhibitors reduced the risk of pneumonia in the Asian subjects by 2.8% when compared to patients on placebo or other antihypertensive drugs (Ohkubo, Chapman, Neal, Woodward, Omae, Chalmers & the Perindopril Protection Against Recurrent Stroke Study Collaborative Group 2004). This indicates possible usefulness in the management of patients with aspiration pneumonia following stroke.

Coughing is an important protective mechanism to prevent aspiration by way of a forced cough expelling fluids or foreign bodies from the airway. Choking is an obvious sign of aspiration or dysphagia, especially during or after swallowing. If the choking reflex is impaired, silent aspiration may result and aspiration pneumonia may follow. This especially relates to physically disabled and bedridden patients who, may be inactive for periods of time and have an increased risk of developing pneumonia. Therefore, a physiotherapist can be consulted to assess the patient's lung function and perform chest physiotherapy if necessary (Hough 2001).

Asphyxiation is an acute blockage of airway by food, or a foreign body. This is the most dangerous and serious complication of dysphagia and may cause death suddenly at home or in hospital (Finestone et al. 1998, Schapel 2005). Although the incidence of asphyxiation appears low compared with other complications, it can happen easily and suddenly in patients with moderate or severe dysphagia. The common causes are the airway being accidentally obstructed by inappropriate size or texture of food. However, such incidents can be avoided by carefully following guidelines. A dysphagia protocol or guideline can be used in hospital and sent home or to residential

care with a patient. Guidelines are available for safe eating and management of choking and aspiration (Department of Ageing Disability & Home Care (DADHC) 2003, DADHC 2006, Perry & McLaren 2003). Nurses should be well prepared for the use of suction and oxygen for emergency resuscitation in hospital. These strategies may help to minimise the risk of death (Mitchell et al. 2004, Cummins, Chamberlain, Hazinski, Nadkarni, Kloeck, Kramer, Becker, Robertson, Koster & Zaritsky 1997).

Malnutrition is a common complication in hospitalised dysphagic stroke patients and it influences the outcome of stroke. Finestone, Greene-Finestone, Wilson and Teasell (1996) found that malnutrition was the most potentially modifiable variable relating to length of stay and functional outcome in stroke patients. Martineau, Bauer, Isenring and Cohen (2005) performed a retrospective study on 73 acute stroke patients regarding outcomes and found nearly one fifth (19.2%) of patients were malnourished on admission and their nutritional status further deteriorated during hospitalisation. Poor outcomes were found when comparing malnourished acute stroke patients with well-nourished patients including the length of stay (13 versus 8 days); prevalence of dysphagia (71% versus 32%); enteral feeding (93% versus 59%) and complications (50% versus 14%) respectively. However, malnutrition is not well recognised as a problem in hospitals that may increase cost (McWhirter & Pennington 1994). On the other hand, Gariballa and Sinclair (1998) stated that some clinical nutrition screening instruments lack sensitivity and specificity. They indicate use of muscle strength, upper-arm skin-fold thickness (triceps and biceps), mid-arm circumference, BMI and serum albumin level should be the main nutritional status screening instruments.

One factor that directly impacts on the nutritional state, is that patients may be ordered 'nil by mouth' until their condition is stabilised or assessment by a speech pathologist or a professional skilled in the management of dysphagia. According to dysphagia guidelines, all stroke patients should be screened for swallowing ability before eating and drinking (SIGN 2004). This means that sometimes for several days patients may only be supported by intravenous therapy. In addition to this, other factors may impact on oral intake, such as altered consciousness level, fatigue, poor appetite, pain, and gastrointestinal upset. Therefore, nutritional status needs to be appropriately assessed by a dietician who can provide oral or enteral nutritional support if necessary.

RESEARCH FINDINGS REGARDING STROKE MANAGEMENT

Although many recent studies have reported on the validity and reliability of methods used to assess dysphagia, evidence of the effectiveness of treatment and management is limited. Rudd, Irwin, Rutledge, Lowe, Wade, Morris and Pearson (1999) performed a national sentinel audit of 6894 stroke patients and involving 197 trusts in Britain. The audit found suboptimal stroke care and a wide variation in standards across the country. It was also found that only 64% of the trusts had a physician with responsibility for stroke management and only 50% had a stroke team. Assessment of swallowing was only performed in 55% of stroke patients; whereas only 18% spent at least 50% of their time in a specialised stroke unit. Multidisciplinary team participation in patient management varied from 37% to 61% and the team agreed on rehabilitation goals in only 55% of eligible cases. Consequently, improvement is required to enhance the quality of stroke patient care and safety. However, this study was conducted some eight years ago, so management practices may have improved.

The risk of dysphagia and aspiration was emphasised in Ramritu, Finlayson, Mitchell and Croft (2000) who undertook a systematic review on the identification and nursing management of dysphagia in individuals with neurological impairment. They state ‘...individuals suffering from dysphagia have been found to be at risk of increased morbidity and mortality’ (Ramritu et al. 2000, p.41). Mitchell and Finlayson (2000, p.2) in the ‘Best Practice Sheet’ based on the above systematic review also state ‘there is limited nursing research that identifies effective nursing interventions related to the recognition and management of dysphagia...’.

PRINCIPLES OF MANAGEMENT

The goals of dysphagia management are early assessment, effective screening, provision of adequate nutrition and hydration, minimization of the risk of choking, and aspiration, and prevention of other complications. Improving stroke management is crucial in order to minimise the severity of permanent disability associated with stroke. If disabilities following acute stroke can be identified early and accurately and

are managed properly, the recovery can be enhanced. A multidisciplinary team approach may therefore be effective in management of this problem.

The introduction of dysphagia guidelines or protocols provide clear information on management, including maintaining oral hygiene, swallow screening, assessment methods, nutritional screening and interventions, diet modification and information on how to make decisions for long-term feeding strategies and the evaluation of complications (SIGN 2004). It is also vital to increase staff and carers' understanding of the policies relating to management of dysphagia so effective measures may be taken to minimise potential risks. It is also important that these patients are observed closely and their intake is recorded accurately. They should also be reviewed regularly by health professionals skilled in the management of dysphagia (SIGN 2004).

The initiation of oral feeding for stroke patients in a timely manner enhances the recovery of swallowing function and preserves the quality of life (Chang, Rosendall & Finlayson 1998). Beadle, Townsend and Palmer (1995) also indicated one of the important issues of dysphagia management is the needs and desires of patients and their families. Therefore, it is suggested that health professionals explain the current situation to the patients and their families and formulate individualised care plans and support. The success of management depends significantly on the level of understanding of patients and their families about the condition, and also the strength of cooperation and communication between patients, families, carers and the multidisciplinary team.

Assessment

Before the development of dysphagia management policies, it appears there was less recognition of this problem by health professionals. This is evidenced by the higher incidence of aspiration and chest infection and limited records regarding assessment of swallowing during admission (Ellul, Gibson, Barer & the Merseyside and North West Stroke Dysphagia Collaboration 1998). It appears many acute dysphagic stroke patients were not assessed for swallowing ability before starting oral intake. Ellul et al in 1991-93 performed a preliminary evaluation of a dysphagia management policy

with a multidisciplinary team approach, which compared a pre- and post-intervention clinical practice and evaluated 379 patients admitted with acute stroke. During the pre-intervention phase, they found there was no documentation about swallowing assessment in medical records. In addition only 44% of subjects had their gag reflex assessed. Although it was suspected that 127 patients initially had unsafe swallowing, only 54% had their oral intake restricted and only 29% had this clearly documented. The study also found nearly 40% of patients with unsafe swallowing were not seen by a speech pathologist during admission and of the patients who had dysphagia assessment; only 30% were swallowing safely. In the post-intervention phase, although the percentage of subjects who had the potential to aspirate fell to 22% from 47% the numbers of patients with unnecessary oral restrictions rose to 24% from 16%. Thus, dysphagia management with a multidisciplinary team approach is necessary to reduce the risk of unsafe swallowing.

Initially the assessment of dysphagia mainly depends on the patient's history and complaints of swallowing difficulties. Studies by both Barer (1989) and Spieker (2000) state that up to 80 to 85% of the causes of dysphagia could be identified by a doctor through conducting a careful patient history. Common patient complaints are coughing, choking, nasal regurgitation or poor nasal tone in oropharyngeal dysphagia. Nevertheless, Chang, Rosendall and Finlayson (1998) state that clinical assessments of dysphagia are limited in providing adequate guidelines for oral feeding. Following the introduction of a multidisciplinary team approach and guidelines and protocols for stroke management, patients who are suspected of having dysphagia may be referred to a speech pathologist for detailed assessment. Speech pathologists or dysphasia specialists can provide a systematic and detailed assessment to find out the causes and severity of swallowing disability and estimate the risk of aspiration, so that an appropriate diet and fluids or maintaining 'nil by mouth' can be individually prescribed. In those patients who have a high risk of aspiration or unclear clinical signs, a speech pathologist may further consult an ear, nose and throat (ENT) specialist. In addition, further investigations such as endoscopy and radiology may be performed to explore the underlying problems.

The benefits of early identification of dysphagia following stroke are recognised in a number of studies. Nursing observation and BSA are very important to ensure the

patient's safety with oral intake. Any abnormalities may be discovered early and appropriate actions taken. Westergren (2006) performed a systematic review for bedside detection of eating difficulties following stroke. The review covering seven screening methods and almost 2000 adult patients found BSA was the first step for 'best nursing practice' for detecting dysphagia. If a pulse oximetry is used with BSA, it may increase the accuracy of detection of aspiration particularly when this is silent. Another step was observing the swallowing and ingestion continuously until recovery during hospitalisation. The review demonstrated that nurses can take an important role in the screening and monitoring of the progress of stroke patients with dysphagia. BSA is a special assessment skill and but training may only be available for nurses working in a stroke unit or wards where these patients are commonly admitted. It is essential that nurses have basic BSA skills for screening all stroke patients and understand the correct treatment for any abnormalities found. This also minimises unnecessary speech pathologist consultations and improves the quality of dysphagia management.

Clearly with severe stroke a patient may be unconscious and critically ill during the acute phase, so it may not be possible to assess their swallowing ability. However, the patient's neurological conditions should be monitored using a tool such as the GCS to evaluate any significant changes. The nutritional and hydration status of critically ill patients should be monitored from the first day of admission, and intravenous therapy or enteral tube feeding can be provided. When the patient's condition has stabilised, swallowing ability may be assessed, and diet and fluids can be provided as appropriate.

There are many methods, which can be used to assess the cause of swallowing impairments including clinical, physiological and imaging evaluations. These include:

- Inspection of oral cavity – lip, teeth, dentures, tongue movement and control of secretions.
- Bedside Swallow Assessment (BSA) – including Oral Motor Examination (OME) and general observation of any signs and symptoms of dysphagia (Table 1). OME is a series of systematic oral examinations that requires training and experience to identify any abnormalities. However, using a BSA alone to assess the risk of

aspiration may be unreliable, because the assessment is not indicative of the depth impairment of pharyngeal and oesophageal phases. Therefore, endoscopic, radiologic or other investigations may be required for further identification, especially in patients who have unclear signs and symptoms and a high risk of aspiration or silent aspiration is suspected (Khoo, Buller & Wong 1996).

- The Water Swallowing Test (WST) is one of the commonly used methods and it can be combined with the use of pulse oximetry to increase its accuracy. The amount of water used is flexible and can vary in different settings. It can start from one teaspoon (about 5 millilitres) up to 60mls of plain water to test a patient's tolerance of swallowing. The test is suitable for patients with various degrees of dysphagia. The speech pathologist may also try various thickened fluids and carefully observe how the patient manages these. Commencing with a small amount of clear water can minimise the risk of aspiration pneumonia, in case of aspiration, water can be coughed out or rapidly reabsorbed by tissues. If the patients can tolerate a larger amount of water, continuous drinking and timing the speed of drinking may be used to evaluate swallowing. Another type of WST is called Repetitive Oral Suction Swallow test (ROSS test) was introduced by Nilsson, Ekberg, Olsson and Hindfelt (1998). They studied 100 patients suffering from stroke. The patient is seated and is asked to ingest water through a straw for the evaluation of oral and pharyngeal function. Nilsson et al found all dysphagic stroke patients were abnormal in the ROSS test. Patients with swallowing dysfunction can be identified during forced, repetitive swallowing and this method is also commonly used by speech pathologists to assess patient tolerance of fluids and prescribing the appropriate consistency of thickened fluids. It has also been proposed that facial paresis is associated with dysphagia because the processes of chewing, swallowing and tongue movement require sensation and good control of facial muscles.
- Pulse oximetry is generally used for the clinical assessment of the saturation of arterial haemoglobin with oxygen (SaO_2) – a desaturation of more than 2% after eating or drinking is indicative of aspiration. It is proposed that this method may be reliable to screen for aspiration in most dysphagic stroke patients. Indeed, Collins and Bakheit (1997) studied 44 consecutive dysphagic stroke patients and found that in most patients aspiration could be identified by desaturation. The

exceptions were smokers with chronic lung disease. In these patients desaturation may reflect their chronic disease rather than aspiration. Although this method is not very accurate in identifying the risk for aspiration, it is generally used to assess episodes in patients with known dysphagia. This is because it is simple, quick, non-invasive, portable and used routinely in clinical assessment. Thus, it is good for monitoring dysphagic stroke patients regularly for any early signs of inadequate oxygenation resulting from aspiration.

If a patient requires further investigation or identification of dysphagia or aspiration, the following types of investigations can be used:

Endoscopic investigations such as:

- Direct or indirect laryngoscopy;
- Nasopharyngoscopy;
- Fiberoptic Endoscopic Examination of Swallowing (FEES) – to evaluate laryngeal or pharyngeal sensory and motor functions and risk of aspiration. The use of this method has increased substantially in the clinical setting because this equipment is portable, and it is comparatively safe with no airway compromise and related complications such as epistaxis (0.07%), are relatively rare (Aviv, Murry, Zschommler, Cohen & Gartner, 2005). In addition the patient requires less preparation and there is less risk of aspiration pneumonia of FEES (12%) than MBS (18.4%) or VSS (Aviv, 2000) and no exposure to radiation. It is, however, more costly and complex than bedside assessment.
- Laryngopharyngeal Sensory Discrimination Testing (LPSDT) is beneficial to detect any laryngopharynx sensory deficits, using an air pulse or electricity stimulation of the mucosa of the pyriform sinus and aryepiglottic fold that is innervated by the superior laryngeal nerve. Patients who have no subjective or objective clinical evidence of dysphagia, but have silent laryngopharynx sensory deficits which may cause aspiration can benefit from this test (Aviv, Sacco, Thomas, Tandon, Diamond, Martin & Close 1997).

Radiologic investigations including:

- Modified Barium Swallow (MBS) is a therapeutic diagnostic test to examine the oropharyngeal swallowing function, quantify the risk of aspiration and silent aspiration and assess which textures of diet can increase the safety of swallowing. The patient fasts for 12 hours and then liquid contrast barium is given slowly per oral via nasoenteral tube. The patient is positioned sitting upright and a fluoroscopic video is recorded to detail the physiology and function of the oral, pharyngeal and oesophageal musculature during the swallow;
- Videofluoroscopy Swallowing Study (VSS) is considered the ‘gold standard’ test and also is used to detect risk for aspiration with the different features of swallowing and compensatory strategies used by the patient. Timed VSS measures any delay of swallow initiation of epiglottic tilt. However, this method has some limitations and disadvantages including its lack of practicality in acute stroke, there is no evidence to indicate that aspiration detected by this method is clinically important, limited generalisability of the results for patients tested under artificial conditions, patient exposure to radiation and the risk of patient inhalation of radiological contrast which may cause lung damage (McCullough, Wertz, Rosenbek, Mills, Webb & Ross 2001, Warlow et al. 1996).
- Videomanofluorometry (VMF) – measures the upper oesophageal pressure and pharyngeal swallowing function;
- Computed Tomography (CT); and Magnetic Resonance Imaging (MRI) may also yield more detailed information.

Other tests which are rarely used include:

- Cervical auscultation, which is dependent on the swallow sounds heard through a stethoscope being interpreted by an experienced clinician or specialist to diagnose swallowing impairment. This is a controversial technique because of variations in clinician experience, analysis and descriptive terminology used for the voice quality such as stridor, bubbles, gurgling and wet voice. Although the reliability of individual judgements vary widely, research has shown group consensus for correct identification is high including the rate of identification of aspiration or penetration which was higher than VSS (Leslie, Drinnan, Finn, Ford & Wilson 2004).

- Ultrasound is an imaging, radiation-free technique used to scan the oral cavity and hypopharynx. This is considered the safest method of assessment. A transducer is placed below the chin to assess oral function including any continuous swallowing and the duration to complete swallows;
- Electro-glottography (EGG) tests the frequency of vocal fold vibration in speech and laryngeal elevation during swallowing with electrodes which produce a visual record (Barker & Dean-Baar 2002, Baker 2002, Spieker 2000, Higo, Tayama & Watanabe 2002, Merriam-Webster Incorporated 2005, Sellars et al. 1999).

These investigations each have different advantages in assessing the structure and functions of muscles and sphincters, laryngeal sensitivity and motility of pharynx and oesophagus.

Early identification of long-term dysphagia in stroke patients may help physicians make better decisions for long-term management. Broadley, Croser, Cottrell, Creevy, Teo, Yiu, Pathi, Taylor and Thompson (2003) found that patients who fail the WST and have a Parramatta hospitals dysphagia score of less than 70 (Table 4), modified Barthel Index score of less than 20 (Table 5 and Table 6) and radiological brain imaging showing a stroke involvement of frontal or insular cortex were more likely to develop prolonged dysphagia following acute stroke. Early identification also benefits patients who have co-morbidities with other chronic diseases such as diabetic patients who need a special diet to control their blood glucose level (Kerr, Hamilton & Cavan 2002).

Table 4: Parramatta hospitals dysphagia score

NOTE:
This table is included on page 30 of the print copy of
the thesis held in the University of Adelaide Library.

*Cited from: Broadley, Croser, Cottrell, Creevy, Teo, Yiu, Pathi, Taylor & Thompson
2003, p.303.*

Table 5: Modified Barthel Index (MBI)

NOTE:
This table is included on page 30 of the print copy of
the thesis held in the University of Adelaide Library.

Cited from: Western Australia Functional Impairment Groups (WAFIG) 2000.

Table 6: Detailed description of feeding in MBI

NOTE:
This table is included on page 31 of the print copy of
the thesis held in the University of Adelaide Library.

Cited from: Western Australia Functional Impairment Groups (WAFIG) 2000 – Part of Modified Barthel Index (Shah version): Self care assessment of feeding.

Because the sensitivity and specificity of individual methods is not high, health care providers may need to use at least two methods to evaluate dysphagia. This increases the rate of accuracy and reduces the danger of false positive or false negative results (Lim, Lieu, Seshadri, Venketasubramanian, Lee & Choo 2001, Smith, Lee, O'Neill & Connolly 2000, Ramsey, Smithard & Kalra 2003, Mann, Hankey & Campbell 1999). In comparison the safest and easiest methods of assessment are the BSA and WST (50ml) with pulse oximetry to measure changes in the oxygen saturation. Research indicates that the combined sensitivity of these tests was 100% with a specificity of 70.8% (Lim et al. 2001, Smith et al. 2000, Ramsey, Smithard & Kalra 2003).

Interventions

Currently, patients who are suspected of having dysphagia and of being at risk of aspiration may be ordered 'nil by mouth' and observation. This is a preventive strategy to minimise the risk of aspiration until the patient has a detailed swallowing assessment by a speech pathologist. Many studies suggest swallowing ability should be assessed within 48 hours of admission because nutritional status may be affected if kept on 'nil by mouth' for more than two days (Tudor 2006, Stroud, Duncan,

Nightingale & British Society of Gastroenterology 2003, SIGN 2004). If dysphagic stroke patients who have upper limb or swallowing disabilities are unable to feed themselves properly, an assistant may be required to set up a meal or feeding temporarily and allow time for the patient to adapt to eating gradually, especially in the first weeks post-stroke. However, for patients who cannot tolerate a modified diet and fluids or have altered level of consciousness, health professionals may consider enteral tube feeding or other interventions to minimise the complications.

The selection of interventions is mainly dependant on the patient's diagnosis and results of swallowing assessment, which determines the level of dysphagia. Through ongoing assessments, the patient's swallowing problems can be monitored with greater accuracy and effective interventions can be initiated. The main interventions for dysphagia include: different types of modified diet and fluids; enteral tube feeding; intravenous therapy (IVT); swallowing rehabilitation programs; medications and surgery. These interventions can be ordered individually or combined if timely. The use of medications, surgery and alternative treatments are developing and are only used for specialised cases of dysphagia. Doctors may consider alternative treatments if the usual methods are not effective for the patients. The current interventions are described as follows:

Modified diet and fluids

The oral route is the preferred method of providing nutritional intake. Mann, Hankey and Cameron (2000) found 87% of dysphagic patients had returned to their pre-stroke diet 6 months after stroke. There are several types of modified diet and thickened fluids that can be prescribed at different stages. The main types include: vitamised (pureed), minced, soft and normal diet. The main types of fluids include: fully, semi, and slightly thickened and thin fluids. Speech pathologists can prescribe the type of diet and fluids according to the results of assessment and a trial of various types of diet and fluids. During admission, a speech pathologist will usually assess dysphagic patients multiple times to evaluate their progress. Once a patient can start a modified diet and thickened fluids, health care professionals need to make sure they are getting sufficient nutrition. If the patient's condition improves, diet and fluids will be upgraded after successful trial. In contrast, meals will be downgraded or withheld if

aspiration is suspected. This is very important in ensuring the dysphagic patients are ingesting diet and fluids of a suitable texture of safely and to prevent the risk of aspiration or asphyxiation.

Goulding and Bakheit (2000) performed a study regarding the provision of thickened fluids to dysphagic patients and found that overly thickened fluid may reduce the patients' fluid intake without increasing the safety of swallowing. A viscometer can be used to ensure the viscosity of fluids is as prescribed. Moreover, health care providers' attendance during a mealtime is important for observing and supervising, especially for those patients who are suffering severe dysphagia or initially starting a diet. Food should also not be too dry or wet and people serving meats should be careful regarding the size of chunks because of the danger of airway blockage. Fluids should be provided if not contraindicated. Placing food and fluids within patient's reach and sight is useful, as is providing appropriate utensils and crockery so that the patient can maintain their independence in eating as much as possible. However, the patient should still be observed and assistance provided if required. Observing the patient's food and fluid preferences is also wise and this may help improve intake. If the patient has frequent coughing following eating or drinking, oral intake may be withheld in favour of seeking a doctor's advice or consulting a speech pathologist for further swallowing assessment (Mitchell & Finlayson 2000).

Enteral tube feeding

Enteral tube feedings including nasoenteral tube (NET), jejunostomy and percutaneous endoscopic gastrostomy (PEG) are commonly used to replace nourishment if the patient is unable to swallow or oral intake is persistently inadequate (Beadle, Townsend & Palmer 1995). The aims of enteral tube feeding are to bypass the mouth and deliver food or fluid directly into the stomach, minimising the risk of aspiration, ensuring sufficient food and fluid intake, and providing a period of time for the upper gastro-intestinal tract to rest and the swallow reflex to return. NET is often suggested for temporary or short-term use. Disadvantages include limitations relating to the diameter of the feeding tube, only thin and normal fluids are allowed. In addition they are usually inserted via the nose, pharynx, larynx and oesophagus to the stomach (possibly causing some discomfort), and they may also

lower the patient's morale or self-esteem, and reduce the quality of life by loss of the enjoyment of eating. However, the advantage of NET is its easy implementation and removal; no traumatic surgery is required. Moreover, the size of a fine bore feeding tube is usually only Fr 8 and it can be used up to six weeks in comparison with a Ryles tube (wide bore feeding tube) for which the usual size is Fr 12 to 16 meaning it only can be used up to 10 days. Fine bore feeding tubes can minimise patient discomfort, and are less likely to cause irritation of the oesophagus (Mallett & Dougherty 2000).

The disadvantages of NET are dislodgement, blockage, incorrect placement in the trachea, leakage and multiple tube placement which may be required due to impaired cooperation, reduced state of consciousness, aphasia, lingual unco-ordination, or buccofacial apraxia (Dziewas et al. 2003). Dziewas et al (2003) studied 104 dysphagic stroke patients who required NET insertion. Up to 98% of subjects had successful placement of NET in average of two attempts, if the method of reflex placement was used. It was found that this method could also minimise sympathetic stimulation of systolic arterial blood pressure (mean 176mmHg), and heart rate (mean 14 beats/min) by about 14 to 16.5% during insertion. The main reason for failure to successfully insert a NET was that the swallowing reflex could not be provoked. In many hospitals nurses are responsible for insertion of a NET this means that patients do not have to wait for insertion by a doctor and nutritional supplements can be commenced quickly (Meyer, Harrison, Cooper & Habibi 2007, Wekch 1996).

In 2005 Dennis, Lewis and Warlow performed a study on 859 patients in 83 hospitals in 15 countries, comparing early tube insertion versus avoidance and found early tube feeding was useful in reducing the absolute risk of death by 5.8% with a reduction in death or poor outcome of 1.2%. The study also assessed 321 patients in the PEG versus NET feeding trial. The result demonstrated that PEG feeding was associated with an increased risk of death of 1% and poor outcome of 7.8%. Thus, early initiation of PEG feeding in dysphagic stroke patients was not supported. In addition, this study also found routine oral protein energy supplementation of the usual hospital diet did not improve outcomes in patients admitted with recent stroke, but had a potential benefit for patients who were undernourished on admission and where dysphagia had not been excluded.

However, the benefit of PEG feeding in improving the nutritional status was supported by Hamidon, Abdullah, Zawawi, Sukumar, Aminuddin and Raymond in a 2006 study. This research compared NET and PEG on the outcomes for 22 acute dysphagic stroke patients and found that PEG is more effective than NET in improving the nutritional status. It found that almost half of the NET involved treatment failure. This was due to the high rate of NET tube blockage or dislodgement. The different results of two above studies may be due to different inclusion criteria of patients and stages following stroke and the difference in the outcomes evaluated. Nutritional support may be more effective in the early stage following stroke. In addition NET may be more uncomfortable than PEG and more difficult to maintain. Therefore, health professionals should consider the severity of stroke and dysphagia, the patient's quality of life following stroke and the family's view on the care plan before making any decision on types of tube feeding. In addition it should be recognised that because tube feeding is a type of supplementary intervention it may not save but prolong the lives of very ill patients.

If repeated NET insertions are required delicate mucous membranes along the nasoenteral tract may be damaged resulting in ulceration or bleeding. In addition, if a fine bore feeding tube is inserted by a doctor X-ray screening is required to confirm its position, so each insertion may increase the exposure of radiation and may delay nutritional support. Fine bore tubes have a higher risk of blockage than the wide bore one, and the tube needs to be flushed with water regularly. Training the patients to adapt to bolus feeding is an important strategy for long-term tube feeding. A 'Kangaroo'TM feeding pump – an automated electronic machine pump – is used to gradually accelerate the rate and amount of feeding at regular intervals in order to meet daily caloric requirements, so that patients and carers can more easily control the feeding times (Serpa, Kimura, Faintuch & Ceconello 2003).

For patients who have severe impairment of swallowing, health professionals may consider PEG or jejunostomy tube feeding to replace NET for long-term alternative nutritional support. James, Kapur and Hawthorne (1998) did a retrospective study of four years in 126 dysphagic stroke patients on the long-term outcome of PEG. They

found the median duration of PEG use was 127 days (range 1-1372); however, for patients with a PEG inserted within two weeks the median duration was greatly reduced by almost 60% to 52 days (range 2-1478). Twenty-nine percent of patients had PEG removed at follow up and 4% had PEG in use when their swallowing recovered. Although up to 57% of patients with a PEG died while it was still in use, including 28% patients who died in hospital because of suffering severe stroke, for those in whom there was early PEG placement (within two weeks) the median survival rate with PEG was up to 305 days. Hence, health professionals may consider early placement of PEG, if persistent dysphagia is expected, so long-term nutritional status and the survival rate may be timely supported and improved respectively.

However, NET and PEG tube feeding are also associated with the risk of aspiration. Patients who suffer from severe dysphagia should be continually evaluated for swallowing ability to minimise the risk of aspiration. The dysphagia may become worse or improve due to the development of stroke and the progress of rehabilitation. Regular assessment may assist with decisions regarding appropriate diet and interventions. Moreover, tube feeding and oral intake can be combined as the patient gradually progresses. This can provide well-balanced nutrition and encourage resumption of oral intake.

Although only 8.5% to 29%, of acute stroke patients require tube feeding the decisions of when to commence and discontinue this, are major concerns for health professionals (Blackmer 2001, Rodrigue et al. 2002, Ha & Hauge 2003). A systematic review done by Bath, Bath-Hextall and Smithard (2000) on interventions for dysphagia in acute stroke found that PEG feeding may improve outcome and nutrition as compared with NET feeding. However, few studies had been performed and sample sizes were small. Hence interventions were limited and it remains unclear on what should be done to achieve the best result. Wilkinson, Thomas, MacGregor, Tillard, Wyles & Sainsbury (2002) suggest that doctors should consider PEG insertion for patients who are unable to tolerate full thickened fluid (honey-like thickened) or a vitamised (pureed) diet 14 days after the onset of stroke. Although PEG insertion is considered to be minor surgery and the complications are limited, this foreign body may be considered an intrusion which reduces dignity for patients who are in the final days of their life. Akpunonu, Mutgi, Roberts, Khuder, Federman and Lee in a 1997

study of 302 stroke patients, found that of the 25 (8.3%) who were determined as requiring a PEG, only 9 (3%) had barium studies and were found to have abnormal of swallowing; 16 patients (5.3%) had significant neurological deficits and an increased prevalence of aspiration pneumonitis. Therefore, the decision to insert a PEG is generally made on clinical grounds rather than on the results of a barium swallow. Therefore, health professionals need have a detailed discussion with patients and their families about their condition, the progress of dysphagic stroke explaining the available interventions or strategies that can be chosen to meet their needs.

It has been reported that peristomal wound infection is a common side effect of PEG occurring in up to 30% of patients but prophylactic antibiotics are now administered which given reduces this risk significantly (Gossner, Keymling, Hahn & Ell 1999). Gossner, Ludwig, Hahn and Ell (1995) performed a retrospective study in 1182 patients in whom a PEG had been inserted; the mortality rate in general patients was as low as 0.5%, peristomal wound infection about 8.7%, abdominal pain (4.8%) and gastrointestinal symptoms with nutrition such as constipation, diarrhoea, meteorism, vomiting was 39.3% (Gossner et al. 1995, James, Kapur & Hawthorne 1998). Other severe complications that are less common accounting for around 1% of cases include stomal leakage, peritonitis, perforation, traumatised tissue of the abdominal wall, tubal movement or migration and gastric haemorrhage. Fever occurred in 8% of the patients.

Intravenous therapy

During the critical stage of very severe dysphagia, patients may not be allowed to start oral or tube feeding until further assessment occurs. Close monitoring of patients in the intensive care unit (ICU) or the high dependence unit (HDU) may be needed during this stage. However, due to prolonged fasting or interrupted nutrition, dependence on intravenous fluids alone may impede recovery. Physicians may consider total parenteral nutrition (TPN) during the critical stage. TPN is a sterile solution which contains a high level of essential nutrients for the body including glucose, lipids, amino acids, multi-electrolytes and soluble vitamins and it must be administered via central vascular access. However, TPN and insertion of central venous access may be associated with many side effects, such as sepsis,

pneumothorax, bleeding, catheter site infection, electrolyte imbalance, and fluid overload (Cheung, Napier, Zaccaria & Fletcher 2005, Naylor, Griffiths & Fernandez 2004). Since TPN is a costly method and has more complications than other interventions, it is often the last option. In contrast, a peripheral IVT is generally used for rehydration and providing glucose, other essential nutrients and an access for medications during the critical stage, when dehydration is suspected or the patient is ordered 'nil by mouth' or. The main complications of peripheral IVT are phlebitis and fluid overload, although these can be prevented or treated.

Swallowing rehabilitation program

A swallowing rehabilitation program requires the collaboration of the whole a multidisciplinary team including nurses, a speech pathologist, dietician, occupational therapist and physiotherapist. The aims are to assist the recovery of swallowing and to minimise the risk of aspiration. The program may include teaching the patient oral motor exercises; compensatory swallowing techniques such as rotating the head towards the weakened side while swallowing to help food being funnel around the larynx on the stronger side of the pharynx (Logemann & Kahrilas 1990); positioning or postural adjustment; supraglottic swallowing; the Mendelsohn maneuver; effortful swallowing; chin tuck skills. Patients require proficient cognitive function to perform these techniques and continued supervision by nurses or trained family to ensure safety. Regular swallowing assessment is necessary to evaluate the patient for any aspiration and to measure the progress of rehabilitation.

Other strategies that facilitate safe eating include encouraging patients to eat slowly and small mouthfuls, allowing time for each to be cleared before giving another, a pattern of single consistency foods or drinks and clearing pocketed food with fingers or flushing with water. Correct positioning of the patient for eating is essential; they should be sitting upright with their head and neck flexed slightly forward to facilitate intake and minimise the risk of aspiration. Heimlich (1983) found a swallowing rehabilitation program could help 70% of dysphagic patients resume a regular diet from tube feeding within 5 months to 3.9 years. Elmstahl, Bulow, Ekberg, Petersson and Tegner (1999) also found that nearly 60% of dysphagic stroke patients had improved swallowing function, nutritional parameters and plasma protein levels with

rehabilitation. Their program included oral motor exercises, different swallowing techniques, positioning, and dietary modification.

Jacobsson, Axelsson, Norberg, Asplund and Wenngren (1997) undertook a study of 15 dysphagic stroke or brain tumour patients with individualised interventions, which included training functions needed for eating, activities in eating and discussions with the patients. They found 40% who were previously unable to eat resumed a regular diet, while for 27% of patients the feeding tube could be removed. Moreover, these patients expressed satisfaction that eating was easier and safer. They also found that although a swallowing rehabilitation program may not often alleviate all impairments, it may offer some improvement and teach patients ways to cope with their swallowing difficulties. When discharged, the patients and their families were advised on how to prevent aspiration and of the importance of keeping to a modified diet plan. Encouraging a sufficient intake of food and fluids is important to minimise the risk of complications.

Medications

Although some medications may have side effects that influence the swallowing or cause gastrointestinal (GI) upset, their reactions usually are mild, with the exception of drugs such as, haloperidol and phenothiazines and antipsychotics (Dziewas, Warnecke, Schnabel, Ritter, Nabavi, Schilling, Ringelstein & Reker 2006). Health care providers should be aware of any potential side effects which may affect the oral intake of patients.

Several drugs have been used to treat aspects of dysphagia for example, botulinum may be administered into the bilateral cricopharyngeal muscles to treat cricopharyngeal spasm, which can restore the normal swallowing function in five days, and last for five years. This treatment is controversial and may have serious side effects and appears to be rarely undertaken. Perez, Smithard, Davies and Kalra (1998) found that slow-release nifedipine (30mg) resulted in a significant improvement for relatively simple persistent dysphagia. The drug mainly improves the initiation of pharyngeal contractions and reduces the time taken for the bolus to transverse the pharynx. The mean time was reduced by -1.34 seconds and -1.91 seconds

respectively. However, Bath, Bath-Hextall & Smithard (2000) who performed a systematic review on interventions for dysphagia found nifedipine did not alter end-of-trial case fatality or the frequency of dysphagia. The advantages of using medication are non-invasiveness, the dosage can be adjusted and it may replace the need for surgical intervention for cricopharyngeal spasm (Kamitsukasa, Kojima, Nakajima, Nagumo & Hirayama 1999).

Surgery

Surgery known as ‘cricopharyngeal myotomy’ has occasionally been used to treat upper oesophageal dysphagia and aspiration caused by unilateral combined laryngeal and pharyngeal paralysis. Woodson (1997) in a study involving 13 patients including one suffering from tenth cranial nerve injury from stroke found aspiration was eliminated and weight gained in all cases. However, Campbell, Tuominen and Toohill (1997) had less convincing findings in their study of in 23 patients, each with a different cause of cervical dysphagia. Two patients who suffered from a dysphagic stroke, had no significant improvement with cricopharyngeal myotomy and both had complications such as self-limiting pharyngeal leaks. Pneumonia and postoperative ipsilateral recurrent laryngeal nerve injury occurred in 5 patients. Therefore, it seems there is limited application for this procedure for patients suffering dysphagic following stroke. Nevertheless, Aviv, Mohr, Blitzer, Thomson and Close (1997) combined cricopharyngeal myotomy and unilateral micro-neurotomy (a microsurgery that involves suturing of a divided nerve) between the greater auricular nerve for two dysphagic stroke patients who had aspiration pneumonia, intolerance of oral intake and severe bilateral laryngopharyngeal sensory deficits. They found within one year both were able tolerate an oral diet without the development of aspiration pneumonia and postoperative laryngopharyngeal sensory capacity. However, it appears that due to possible complications and the complexity of these procedures surgery is rarely performed.

Other interventions

Freed, Freed, Chatburn & Christian (2001) compared the effectiveness of thermal-tactile stimulation (TS) with transcutaneous electrical stimulation (ES) therapy in the treatment of dysphagia. TS uses a cold metal probe to stimulate the base of the

anterior faucial arch while for ES a hand held battery – powered electrical stimulator is connected to electrodes on the neck. Most subjects had some improvement of swallowing, but ES subjects had higher swallowing scores. Ninety-eight percent of ES patients had some improvement while 27% of TS subjects remained at their initial score and 11% got worse. Thus it appears that ES may have the potential to be a safe and effective treatment for dysphagia due to stroke.

Neuromuscular Electrical Stimulation (NMES) therapy-VitalStim® is a new method in which small electrical currents are used to stimulate the muscles responsible for swallowing. A trained specialist helps patients ‘re-educate’ their muscles through rehabilitation therapy. This method was approved by Food and Drug Administration (FDA) in 2001 and it is claimed improved swallow function can be achieved in 98% of patients with severe dysphagia and 38% can regain normal function. At three years follow up, over 76% had retained swallowing function and only 3% reported aspiration from a total of 892 patients. However, it has some limitations for and cannot be used in patients who have pacemakers, are severely demented and exhibit non-stop verbalization, who have significant reflux due to use of a feeding tube, or are prone to repeated aspiration pneumonia or dysphagia due to drug toxicity. This method has been provided mainly by a private company and has not yet been used, to a great extent, in hospitals (Chetney & Waro 2004).

THE NURSE'S ROLE

Nurses are essential members of a multidisciplinary team and should have sound knowledge of the management of dysphagia (Davies 1999). They are the only members of the team who are in attendance 24-hours a day for the observation and management of stroke patients. Thus, nurses provide the link between other members of the team and patients. They are responsible for observation of airway, and swallowing, monitoring the nutritional status, and supervising feeding techniques including positioning (Langhorne & Dennis 1998). Nurses are also required to respond to emergencies such as choking with such as emergency suction and resuscitation if necessary. The nurse’s role may also include:

- The early detection of dysphagia;
- Monitoring for patient appetite changes, difficulties experienced with eating;

- Ensuring patients receive appropriate food and fluids;
- Administration of medications;
- Maintenance of oral hygiene;
- Observation of patient for any sign of chest infection;
- Supervision of swallowing exercises;
- Provision of up-to-date information to multidisciplinary team;
- Liaison between team members; and
- Providing emotional support and education to patients and their family (Long, Kneafsey, Ryan & Berry 2002, Mitchell & Finlayson 2000, Travers 1999).

Nurses have an important role in tube feeding and these include: insertion (in some facilities) and checking the position of NET; measuring the residual amount of content in the stomach; giving appropriate amount and types feed; and accurately recording intake and output. Nurses must also report and document any signs of abnormality such as fever, weight loss, and intolerance of feeds, regurgitation of any fluid and abnormal output. If patients are discharged from hospital whilst still requiring tube feeding, health care providers can give clear instructions about the schedule of feeding and teach the patients and carers how to manage tube feeding appropriately (Sanders, Carter, D'Silva, McAlindon, Willemse & Bardham 2001, Guenter & Silkroski 2001).

MULTIDISCIPLINARY TEAM ROLE

The multidisciplinary team members who are responsible for care of the patient who has suffered a stroke includes, physicians, nurses, speech pathologists, dieticians, physiotherapists, occupational therapists and social workers (Nair & Taly 2002). Depending on the complexity of each patient's condition, specialists such as a radiologist, clinical pharmacist, ear, nose and throat (ENT) specialists, gastroenterologists, psychiatrists, neuro-psychologists, dentists, dysphagia specialists, patient educators and recreational therapists may also be consulted. Team meetings or case conferences may be used once or twice a week to discuss the progress of each patient; review care plans and decide upon further management and discharge. Patients and their families may be encouraged to participate with their own care plan and rehabilitation. Patients who have persistent of dysphagia may be referred to a

rehabilitation centre for a swallowing program after discharge or be provided with a dysphagia referral to a follow up speech pathologist for further advice and therapy as an outpatient. Collins and O'Neill (1998) studied 100 over 65-year-old stroke patients and reported that 61% were referred for physiotherapy, occupational and speech therapy for various treatments. Knowledge of the nature and timing of complications is important in planning stroke services, as early assessment by a medical specialist has been shown to influence patient rehabilitation and mortality.

Currently, nearly half of the acute stroke patients in developed countries are cared for in a stroke unit jointly managed by a multidisciplinary team. Anecdotally, this approach is reported to improve care. This is because it is easier to coordinate available health resources to meet the different needs of individual patient conditions. Although many studies have recommended a multidisciplinary approach to improve the management of dysphagic patients, studies related to the efficiency and effectiveness of such approaches are limited (Bhalla, K, Kolominskyu-Rabas, Heuschmann, Megherbi, Czlonkowska, Kobayashi, Mendel, Giroud, Rudd & Wolfe 2003, Beadle, Townsend & Palmer 1995).

Patients who suffer from a stroke may have a variety of disabilities. Patients and their families may have complex needs and goals which may include physical, emotional, psychological and financial support when discharged. As Reddy, M and Reddy, V (1997) stated that the multidisciplinary team approach can maximise the available health resources which may restore patient's functional loss, improve their quality of life and decrease long-term economic costs. Clearly, providing patient and family education, management of stroke-related complications and prevention of recurrent stroke are important strategies. However, Sulch, Perez, Melbourn, Kalra (2000) performed a study comparison between integrated care pathway based management and conventional multidisciplinary care on 152 stroke patients who suffered persistent impairment and required specialist rehabilitation. They found that patients managed by integrated care had lower quality of life scores than conventional care and it did not reduce mean length of hospital stay and mortality rate. There was also not much difference among the outcomes of ADL, disability, anxiety and depression and mean duration of physiotherapy and occupational therapy and only slightly lower

institutional admission rates. This negative result indicates the complexity of stroke care and the existence of large variations in patient conditions and needs.

Health care providers may solve the patient's issues more efficiently through multidisciplinary team meetings and case conferences to share and discuss their concern and decide upon further settings or interventions. This may reduce time in waiting for consultation as professional advice can be clarified directly or be implemented in an individual care plan at the same time. Thus, assessing the outcomes of the multidisciplinary team approach on dysphagic stroke assessments, interventions, and preventing complications assists in identifying the advantages and disadvantages of stroke care and may also help health care providers and policy makers to explore any existing problems (National Health and Medical Research Council (NHMRC) 2005). Organising seamless collaboration and good communication among the team members are vital for the success of dysphagic stroke rehabilitation program (Botell 2005, LaBresh 2006).

Speech pathologists have an important role in assessing a patient's swallowing ability and function including identifying the severity of dysphagia and recommending timely intake routes including the type of modified diet and fluid and tube feeding if required. They also coordinate and liaise with all members of the multidisciplinary team for a dysphagia management plan and discharge planning process. They teach the patients, staff and carers to use compensatory techniques or strategies to feed and swallow correctly and safely; and provide chilled foods or ice chips to help stimulate appropriate swallowing reflex. If the patients have aphasia problems, speech pathologists can assist them to improve their speech and communication impairments (Martin & Corlew 1990, Appleton, Bagnall, McRae & Stevens 1996).

A dietician may assess the patient's dietary needs including nutritional status, cultural needs, any preferences or restrictions of food and drinks, manage tube feeding regimes, and advise on the nutrition, suitability and consistency of the diet. Dieticians will liaise with nurses, a speech pathologist and catering staff to offer an appropriate diet to the patients. Some modified diets and thickened fluids may not achieve an adequate nutritional intake for the patients. Extra nutritional supplements or enteral tube feeding may be ordered to fortify nutrition for the body (Beadle, Townsend &

Palmer 1995). Moreover, the dietician can teach the patients, their families or carers how to choose and prepare food, healthy cooking techniques and making thickened drinks, so that the patients may continue to receive a suitable modified diet and fluids when discharged. Discussion about the patient's eating problems, such as decreased taste sensation and may be helpful. If a patient still cannot tolerate a modified diet, physicians may consider providing tube feeding or gastrostomy to improve the patient's nutritional status. If a problem is related to teeth or dentures, a dentist may be consulted (Light, Edelman & Alba 2001).

Physiotherapists can provide early ambulation, deep breathing and coughing exercises, turning and positioning to prevent aspiration pneumonia and enhance the lung function. Moreover, improving balance and improving the range of motion of upper limbs are useful exercises to train patients to help themselves by maintaining appropriate posture and enhancing the strength for self feeding.

An occupational therapist (OT) can assess a patient's feeding problems and provide assistance if the patient has impairment of vision and teach patients to use feeding aids to manage food and fluids. If the patient has with limited arm and wrist movement, this includes providing special utensils and cutlery such as a non-slip mat, plate guard, rocker knife, angled-fork and spoon and feeding cup to help them handle their food and drinks much easier. Teaching patients to use one-handed operating skills and some compensatory strategies may help them manage foods and drinks safely. The patient's family can be taught how to help and to be aware dangers such as hot food and drinks and sharp or potentially dangerous implements (Avery-Smith & Dellarosa 1994).

Social workers may assess the patient and his or her family's living and financial conditions, and may provide support with psychological, financial and social needs. Although social workers may not directly participate in the management of, they provide an efficient supportive role for the rehabilitation and after-care including looking for appropriate high-level aged care facilities, approval of financial support and minimising the problems of discharge. These may be very important as the patient may be the sole breadwinner and family income may be lost (Rizzo 2006).

EVALUATION OF OUTCOME

Although many studies have investigated the methods of screening and interventions, there is very limited research regarding the holistic care of dysphagic stroke patients especially through multidisciplinary approach. Therefore, a review of patient's medical records may be useful to evaluate the outcomes of current dysphagic stroke management.

SUMMARY

Stroke is a leading cause of mortality and of adult disability worldwide. Although dysphagia is common it is a potentially manageable disability, the complications are serious and the patients may die as a result of delays in assessment and inadequate interventions. Early and regular assessment of dysphagia may enhance the safety of dysphagia-affected patients. Nurses have an important role in ensuring the efficiency of management, in providing communication between multidisciplinary team members and coordinating care. This study provides an opportunity to evaluate this process in order to inform strategies that may improve care to better meet patient needs, prevent or reduce complications and facilitate recovery.

METHODS

STUDY DESIGN

This study used a descriptive design with collection of retrospective data from medical records. The advantage of descriptive research is that it provides a fairly accurate illustration of the subject's characteristics and situations as well as information on the frequency of certain incidents occurring (Polit & Beck 2004). The retrospective design is about linking a phenomenon that exists in the present with events that occurred in the past, before the study was started (Polit & Beck 2004). In this case, the aim was to investigate the assessment of patients admitted to an acute hospital with acute dysphagia following stroke, the role of nurses within the multidisciplinary team and the outcomes of management. The main reason the retrospective method was adopted was that it would have been too labour intensive, time consuming, and costly to collect data prospectively. It was believed that the research question could be answered through a review of medical records. A retrospective study may have some disadvantages such as recall bias, and over or under reporting of events. Therefore, causation cannot be inferred as associations between data will not automatically indicate that one event caused the other (Talbot, 1995).

The information recorded included: demographic data; the process of dysphagia assessment; investigations; monitoring of nutritional status; interventions; complications; and any significant findings during the subject's admission. Multidisciplinary team assessments, advice given and interventions provided were investigated. To allow all relevant information to be recorded a data collection form was designed and applied to the current study (Appendix 3).

STUDY SETTING

A major metropolitan general hospital in South Australia was selected. The hospital has a linkage with tertiary education and three campuses provide over 1000 adult beds including emergency, acute and rehabilitation care services. This hospital has a wide range of units including a neurology unit with 12-bed stroke unit, two neurosurgical

wards with a total of 30 beds and other general and high acuity units. Over 1100 adult patients were admitted for neurology services in 2003–2004 (Walsh 2004). The hospital has adopted a multidisciplinary team approach to the care of patients with complex disorders. In addition, clinical practitioners in the hospital are concerned about the impact of dysphagia and have conducted studies regarding the risk factors for persistent dysphagia following stroke (Broadley et al. 2003, Broadley, Cheek, Salonikis, Whitham, Chong, Cardone, Alexander, Taylor & Thompson 2005). This made this hospital an ideal place to collect data.

STUDY POPULATION AND SAMPLE SELECTION

Subjects

Subjects who met the inclusion and exclusion criteria of this study were identified and selected from the Australian Patient Management System (APMS) database at the research hospital.

The researcher selected the patients who were admitted to the hospital for management of stroke and developed acute dysphagia (first episode not pre-existing). The reason that patients with chronic or recurrent dysphagia were excluded was to focus on the management of acute dysphagia.

Inclusion criteria

Subjects were included in the study if they:

- were adults (18 years old or over);
- had a diagnosis of stroke or cerebral vascular accident (CVA);
- had a diagnosis of acute dysphagia following acute stroke;
- were admitted for treatment in a state hospital between 1st January 2004 and 30th April 2006 (28 months).

Exclusion criteria

Subjects were excluded from the study if they had:

- no assessment of their dysphagia by a speech pathologist;

- no record of the management of their dysphagia;
- previously suffered acute dysphagia following a stroke;
- dysphagia not related to stroke;
- severe upper gastrointestinal tract disease before a stroke;
- severe respiratory tract disease before a stroke;
- major surgery or radiotherapy on the upper gastrointestinal tract including mouth, larynx or pharynx before their stroke;
- required continuous tube feeding before their stroke;
- any prior disorder that impacted on their nutritional state such as severe cancer, neurological disease;
- dysphagia due to the severe side-effects of medications including haloperidol, phenothiazines and cytotoxic agents.

It was decided to include all adult subjects who had been diagnosed with acute dysphagia and all types of stroke or cerebral vascular accident, because it is important to maintain the generalisability for this group of patients. Data were collected on subjects admitted to hospital in the two most recent years prior to investigation. This period of time was selected because it was considered that this would generate sufficient numbers of subjects as well as obtain up to date information about current hospital policies and strategies for dysphagic stroke management.

The exclusion criteria provided a restriction to minimise major extraneous variables that might interfere with the results of interventions and outcomes for the different causes and effects of the diseases. Screening out inappropriate cases, such as those with no records about the management of dysphagia and where dysphagia did not occur following stroke was important to enhance the validity of the findings. Significant diseases such as upper gastrointestinal tract disease, respiratory tract infections, neurologic problems, carcinoma and side-effects of medications might have an impact on management and outcomes. Therefore the investigator had to exclude all the known causes that might influence or bias results. To allow the results to be analysed it was essential that there was some uniformity on the method used to assess the severity of dysphagia. The assessment by the speech pathologist was used

for this purpose, thus those subjects who did not have an assessment were excluded from the study.

MEDICAL RECORDS

The medical record is a formal and legal document, which is commonly used as a source of data in retrospective studies examining possible causes and effects.

Advantages

Using medical records has a series of advantages, these include:

- All the patients admitted in a hospital that were eligible to be included in the study, could be identified quickly and easily using the APMS.
- The medical records have data relating to the assessment, investigation, intervention and general management of dysphagia. Many incidents and multidisciplinary team member comments relating to the dysphagia were also documented allowing the investigator to collect and identify crucial factors that might have affected the outcomes of management.
- The staff in the department of Medical Record Service (MRS) provided support by preparing all the records for the investigator to review within a short period. The investigator was able to control the process of data collection because all the records that were available for data collection were placed on the shelves of the MRS department and the investigator could collect data during office opening hours. This meant the data could be collected in the time frame available to the investigator.
- All related medical records except those which were currently in use could be assessed by the investigator after receiving approval from the ethics committee and hospital administration.
- Assessing medical records meant the investigator did not need to contact the staff or patients involved in the study, thus consent was not required. Data was pooled so that no individual would be identified.

Disadvantages

This source of information also had some limitations including:

- As the medical records are used by all staff to document care, the investigator could not control the quality of information.
- The quality of the data was impacted by varied writing skills, jargon and handwriting, only the discharge summary and some discharge letters were typed, thus unclear handwriting, or errors influenced the quality of the data.
- It was also likely that there would be some incomplete records, however, it was hoped that recruiting a large number of subjects might compensate for this limitation.
- The information regarding the management of dysphagia was dispersed widely in the records making data collection difficult and time consuming.
- The investigator could not contact staff to ask questions or to verify data.

ETHICAL CONSIDERATIONS

This research involved access to medical records and the investigator commenced the research following approval from the Research Ethics Committee (REC) of the hospital where the research was conducted (Appendix 1). As there was no need for direct or indirect contact with the subjects and related health care providers, consent was not required. According to the requirements of REC for the use of medical records, all information collected was de-identified by the investigator to protect the subject's identity and preserve confidentiality. No information that could identify an individual was or will be reported or published. The subject's name was replaced by a code on the data collection sheet and database. Moreover, the investigator and his supervisor agreed to keep confidential all information from the medical records which was viewed during the conduct of the study (Appendix 2) and only to record that information that was indicated in the REC approved data collection tool. All data came from patients' medical records and there was no manipulation of study variables. All data were stored on a password protected file and locked in a confidential file in the Discipline of Nursing, University of Adelaide, and will be kept for fifteen years, as required by the REC, and then be destroyed.

DATA COLLECTION METHOD

Recruitment of subjects

The subjects were identified and selected from the Australian Patient Management System (APMS) at a public hospital. The aim was to obtain subjects meeting the selection criteria and admitted within recent years. The reasons for choosing the last two years and four months, between the beginning of January 2004 and the end of April 2006, were that subjects were more likely to receive similar strategies, in terms of treatment response, etc. from hospital to manage their dysphagic stroke. The investigator also had a limited time frame in which to undertake this work. The APMS system could categorise the subjects according to their diagnosis, condition, admission and discharge date and procedures. The investigator then assessed the subjects selected by the APMS and ensured they satisfied all the inclusion and exclusion criteria.

Request for preparing medical record

After the potential subjects had been identified, the investigator notified staff in the Department of Medical Record Service (MRS) to prepare the medical records of the selected subjects for data retrieval. The investigator then assessed all the records one by one, in a room provided in the department until the data collection was finished.

A hard copy of the data was collected using the tool is shown in (Appendix 3), and its related references or descriptions were listed in (Appendix 4). Patient hospital record numbers were recorded on a separate sheet and an identification code used on the file for data entry. This ensured there was no direct link with any identifying information to the data collected.

Design of the data collection form

A specifically designed data collection form was used to record data. The form was categorised into eleven areas and each contains several questions designed to collect information that might influence the outcomes of dysphagic stroke management.

The organisation of the form is divided into two phases:

The first phase of data analysis on the subject of frequency distribution was described under the following headings:

- Demographics.
- Past history.
- General health condition.
- Assessment of dysphagia.
- Assessment of nutritional status.
- Interventions.
- Eating and drinking management.
- Outcomes.

The second phase of data analysis was to review documentation from multidisciplinary team members and summarise these into four main areas are listed as below. The last extra question 'remarks' provided a final space for any significant statements that were not covered in any of the questions, so as to minimise missing any important data. The four main areas for the other questions are in the following categories:

- Any significant issues about the assessment or investigation of the dysphagia?
- Any significant issues about intake or nutritional problems?
- Any significant strategies used to improve patient's intake or nutritional issues?
- Any significant strategies to prevent complications and improve outcomes?
- Remarks?

The form contains 105 questions including 53 questions which had a choice of 'Yes or No or Not available'; 44 questions with an option list for selecting appropriate answers; 23 questions requiring calculations; 14 questions requiring detailed answers and 12 open-ended questions.

A pilot study was performed with five subjects to test the form and check the appropriateness of the questions. The form was then modified to increase the section on patient nutrition.

VALIDITY AND RELIABILITY

Validity is concerned with convincing, accurate and complete collecting and interpretation of data. The research question was derived from clinical practice and increasing concern expressed by health care professionals about dysphagia following stroke. Many questions in the data collection form were drawn from the literature review, the findings of related articles, knowledge gaps, significant problems and areas of interest to the investigator. A broad literature review using the related terms was undertaken to identify the issues relating to the management of dysphagia and stroke. The form was then designed using this information and was organised in a logical sequence from patient admission until discharge. Moreover, the proposal for the study and the data tool were reviewed by health professionals including the clinical nurse consultant (CNC) of the stroke unit, neurology, and the Research and Higher Degree Studies Sub-committee (RAHDS) for further assessment of the content and face validity.

Reliability is concerned with the consistency and accuracy of approaching and using a dependable tool to measure the outcomes. The investigator had over four years of work experience in a neurosurgical unit including caring for patients who had suffered from stroke. In order to ensure that the investigator had an understanding of the basic structure, care practices and management in Australia, specialists and senior staff in the state hospital were consulted regarding the current dysphagia protocol used. To ensure the tool was valid and therefore reliable the design was checked by health professionals including the CNC of the stroke unit and neurology.

DATA ANALYSIS

Quantitative data were analysed using SPSS (Statistical Package for Social Sciences) software version 13.0 for Windows. Descriptive statistics such as frequencies and measures of central tendency were used to analyse data and non-parametric tests such as Chi-square were used to consider relationships between data such as assessments, interventions and outcomes. One way analysis of variance was also used to investigate the relationship between variable such as the severity of dysphagia and the length of time subjects were ordered nil by mouth. The level of statistical significance was set at $p < 0.05$.

Nutritional status is a state of the body in relation to the consumption and utilisation of nutrients (Biology-Online.org 2006). This is a global term comprising a number of comprehensive nutritional assessments which determine the extent to which an individual's nutritional needs have been or are being met. There is however no single way of assessing nutritional status. Monitoring using repeated measures overtime is required (Harris, Nagy & Vardaxis 2006). For this study, the methods adopted to assess the nutritional status were BMI, serum albumin level and health professionals' assessment and comments in records.

Variations in the complexity and the severity of stroke might necessitate different interventions. The investigator analysed the data separately in relevant areas. The severity of stroke was categorised into three groups—mild, moderate and severe stroke according to the GCS score at admission. The severity of dysphagia was also classified into three levels—mild, moderate and severe using the speech pathologist's assessment. The levels took into account neurological observations of the patient, the results of swallowing assessment, the tolerance to diet and fluid and the duration of significant dysphagia. The reason for classifying dysphagia into three groups was to differentiate the treatments and to compare the outcomes for subjects with similar severity in condition.

Qualitative data included the views of the multidisciplinary team. Content analysis was used to analyse this data. Content analysis allows for the identification of common issues (Burns 1997). For example; significant issues about the assessment of nutritional status, and strategies used to improve the patient's nutritional state.

SUMMARY

This was a descriptive study for which retrospective data was collected from medical records in order to examine general and specific dysphagic stroke management by the multidisciplinary team, especially nursing team members. Subjects who met inclusion and exclusion criteria were selected through APMS in a state hospital and screened by the investigator. All medical records were prepared by MRS staff and assessed by the investigator in the department. A data collection form was developed and used as an instrument for data collection. All data were collected in the Medical Records Service

(MRS) Department and there was no manipulation of variables. Quantitative data were analysed using SPSS for statistical analysis and qualitative data were analysed using content analysis.

RESULTS

INTRODUCTION

This chapter describes the results of the analysis of data collected from medical records of patients suffering from acute dysphagic stroke. The focus of the study was the management of dysphagic stroke by the multidisciplinary team. The large amounts of data were analysed in two phases, first quantitative and then qualitative.

Frequency distributions and descriptive statistics including a mean, mode, median, minimum, maximum, range and the sum of available data were generated.

For the second phase, data from the open questions was analysed using content analysis. The questions concerned significant issues and strategies, which influence the assessment and interventions for the condition of dysphagia. The major issues, conditions and strategies are illustrated to demonstrate their impact on current dysphagic stroke management. In the interests of rigour, each subject's medical record was assessed against questions in the data collection form (Appendix 3). As each case involved different conditions and different planning for interventions, the answers only applied to relevant questions with the best choice or description. Details of the statistical analysis and results have been illuminated with the use of tables and figures.

Following approval from the Ethics Committee at the state hospital which agreed to participate, the investigator contacted the department of medical record services, who provided a list of 132 potential subjects diagnosed with dysphagic stroke between the years 2004 and 2006. Twenty-one medical records were not available during a two-month period of data collection; which was applied due to the limited time frame for the study. After the investigator screened 111 available medical records, 16 medical records were excluded for not satisfying all the inclusion and exclusion criteria. The main problems were: seven subjects had a previous history of dysphagic stroke and two subjects had a previous history of dysphagia following dementia before the period of admission. Four additional subjects had no description of dysphagia management following a stroke in their medical records. This was because the subjects transferred

in or out of other health care facilities within a short period or were discharged against medical advice. Two subjects were excluded because they had not been assessed by a speech pathologist and their classification of severity of dysphagia was not available. One subject was excluded due to a previous history of oral and upper gastric problems. Finally, ninety-five subjects (85.6%) met all the inclusion and exclusion criteria for data collection.

PHASE ONE

Demographics

Age

The results indicate that subjects were aged between 30 and 92 years, with a range of 62 years. The median age of subjects was 78 years. The mode was 80 years (n=6). The histogram below (Figure 1) indicates the greatest proportion of subjects were between the ages 75 and 89 (60%, n=57).

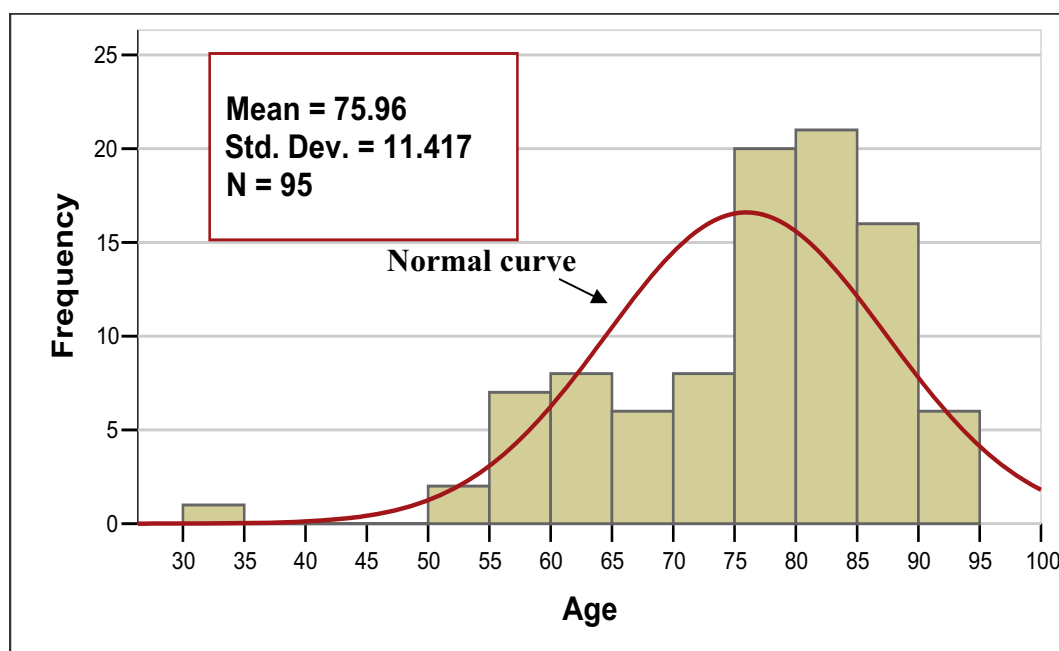


Figure 1: Histogram of age distribution

Gender

There was an almost equal distribution of gender between female (n=47, 49.5%) and male subjects (n=48, 50.5%). The mean age of females was 78.9 years and males 73.1

years. In the older age groups (75 years and over), the gender balance of females comprised 57.1% (36 out of 63) and males comprised 42.9% (27 out of 63).

Diagnosis

Type and severity of stroke on admission

The diagnoses for the study were stroke and dysphagia. Subjects were categorised according to two types of stroke: ischaemic and haemorrhagic. Most subjects suffered from ischaemic stroke 73.7% (n=70) compared to 26.3% (n=25) who sustained haemorrhagic stroke. The subject's GCS on admission was used to classify the severity of stroke. There were three subjects (3.2%) who were intubated or had a tracheostomy tube during admission. This their verbal scores could not be assessed, a score of 1 was allocated. All three had total scores below 8, so they were classified as having severe stroke. As can be seen in the table below the majority of subjects were admitted with mild stroke.

Table 7: Severity of stroke

Severity of stroke by GCS	Frequency	Percent
Mild	54	56.8
Moderate	32	33.7
Severe	9	9.5
Total	95	100

More subjects with mild and moderate severity suffered from ischaemic stroke (69%), while a similar number (four verses five) of subjects suffered severe ischaemic or haemorrhagic stroke (Figure 2).

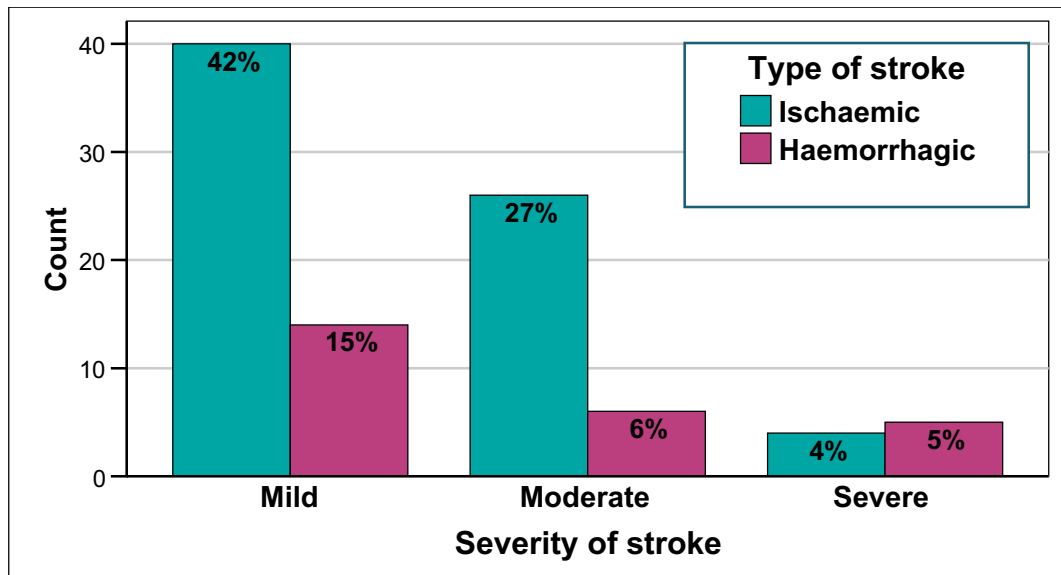


Figure 2: Distribution of different type of stroke

Stroke was also categorised according to the site of lesion. The percentage of subjects with a left hemisphere lesion was 49.5% (n=47); 47.4% (n=45) right hemisphere and for 3.1% (n=3) both hemispheres were involved. The relationship between type of stroke and severity was not statistically significant; chi-square: 4.9 (df 2, n=95) p=0.086.

Episode

Sixty-eight subjects had not previously suffered a stroke, however, 27 (28.4%) had suffered two or three (Figure 3).

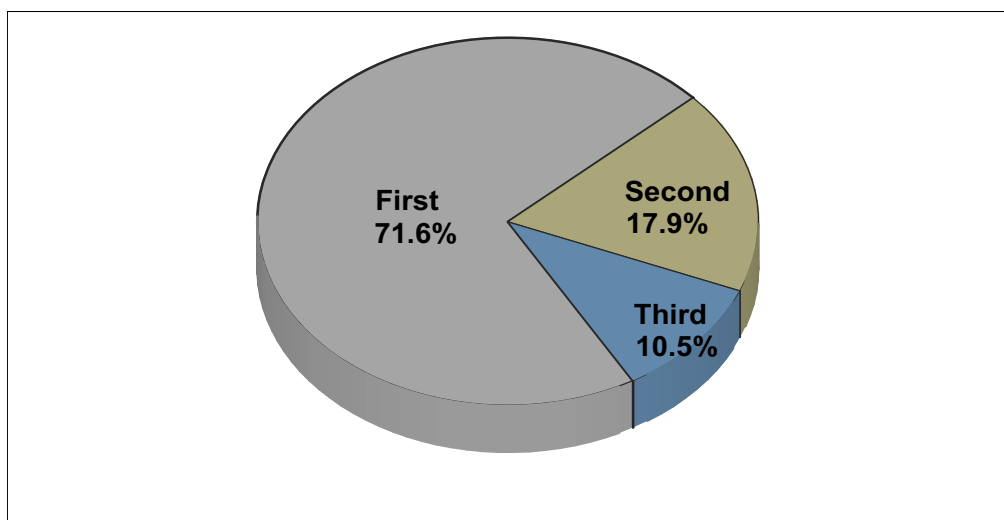


Figure 3: Episode of stroke

Hospitalisation

The minimum length of stay in hospital was one day and the maximum was 115 days, with a range of 114 days. Although there was a large range, the median was 21 days and the mode was 14 days (n=7). The distribution of days the subjects were admitted into hospital is shown in Figure 4.

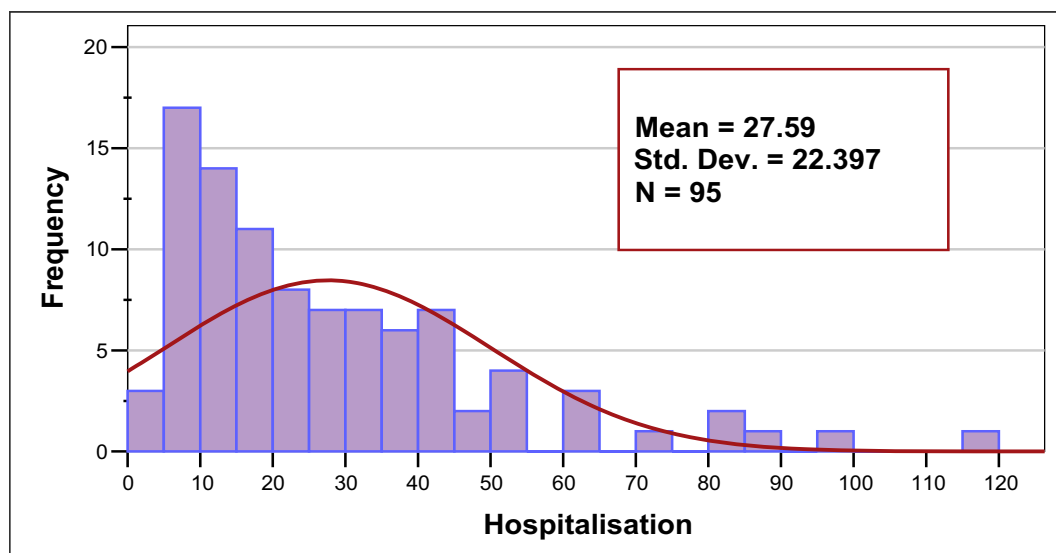


Figure 4: Duration of hospitalisation

Critical Illness

Twenty-three subjects (24.2%) were classified as critically ill during their hospitalisation. This included one who was unconscious, and one who suffered a cardiac arrest.

Airway management

There were 10 subjects (10.5%) who required airway management with placement of respiratory tubes. These included endotracheal intubation (4.2%, n=4), a tracheostomy tube (4.2%, n=4) and nasal pharyngeal tube (1.1%, n=1). One subject (1.1%) required endotracheal intubation and then a tracheostomy tube.

Admission to high acuity units

Thirteen subjects (14%) were admitted to high acuity units, these included the intensive care unit (ICU), the high dependency unit (HDU) and the step down unit (SDU). Some were admitted to more than one of these. The percentages of subjects

admitted to individual high acuity units were: ICU 9.5% (n=9); HDU 8.4% (n=8) and SDU 2.1% (n=2). Five of the 13 subjects (38.5%) required transfer between the high acuity units. The minimum number of days a subject was admitted to high acuity units was one, and a maximum number was 29. The mean was 7.5 days. Of the 13 subjects were admitted to high acuity units, the number of subjects who suffered mild, moderate or severe stroke were three (23%), six (46.2%) and four (30.8%) respectively.

Admission to general wards

Subjects were admitted directly or transferred from high acuity units to five different units or wards (Figure 5). Nine subjects (9.5%) were transferred between two different units.

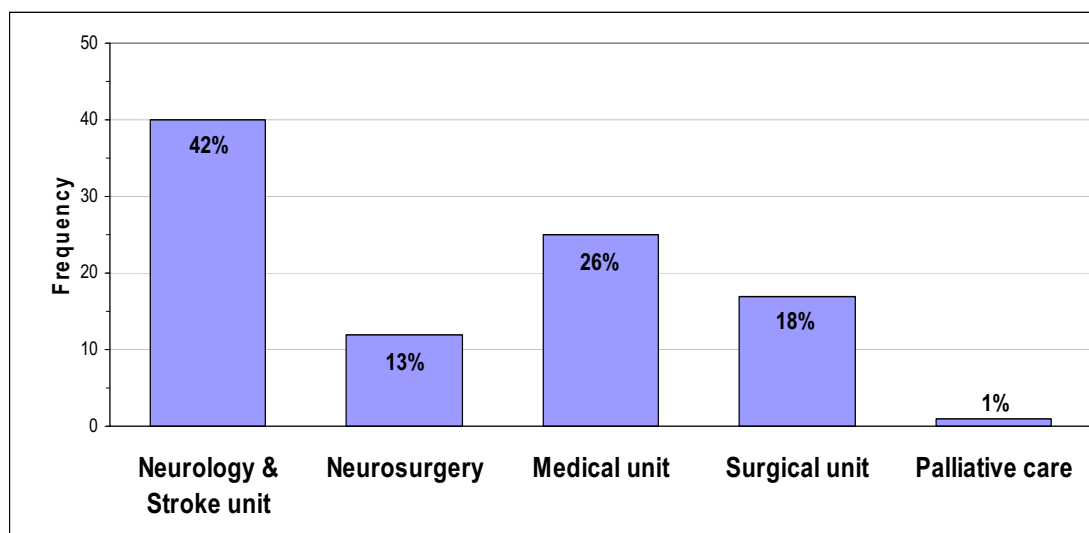


Figure 5: Admission to general wards

Seventeen subjects (18%) were admitted to the surgical unit, of these eleven (64.7%) had suffered a mild, four (23.5%) a moderate and two (11.8%) a severe stroke. Three (17.6%) had mild, 11 (64.7%) had moderate and three (17.6%) had severe dysphagia.

Severity of dysphagia on assessment by speech pathologist

The severity of dysphagia was categorised using the speech pathologist's subjective and clinical assessment of the subject's swallowing and tolerance of diet and fluids. The classification is made by the speech pathologist using their professional judgment. There were three classifications: mild, moderate and severe and the

numbers of subjects involved were 27, 42 and 26 respectively. The percentages are shown in Figure 6.

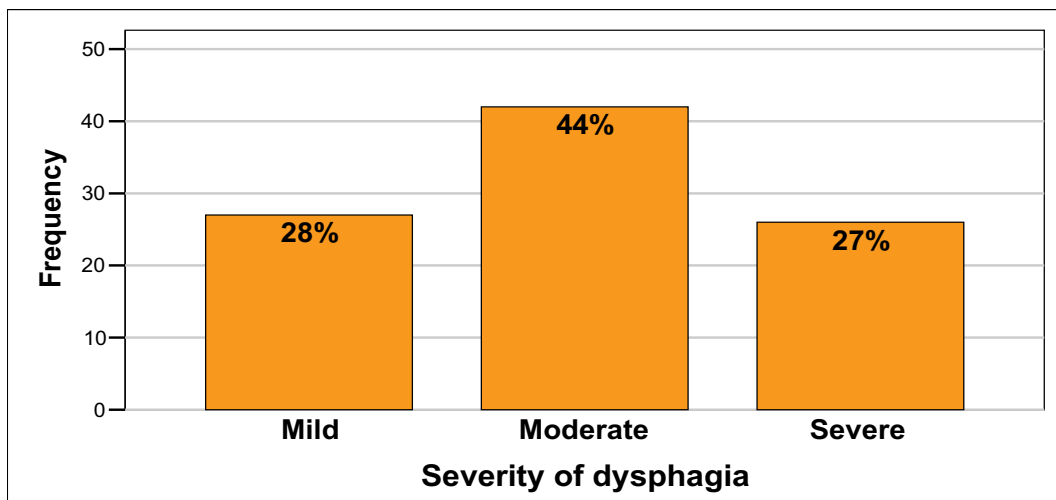


Figure 6: Severity of dysphagia

The relationship between the type of stroke and the severity of dysphagia was not statistically significant; chi square: 2.7 (df 2, n=95) p=0.253. Relatively more subjects with ischaemic stroke suffered moderate and severe dysphagia (Figure 7).

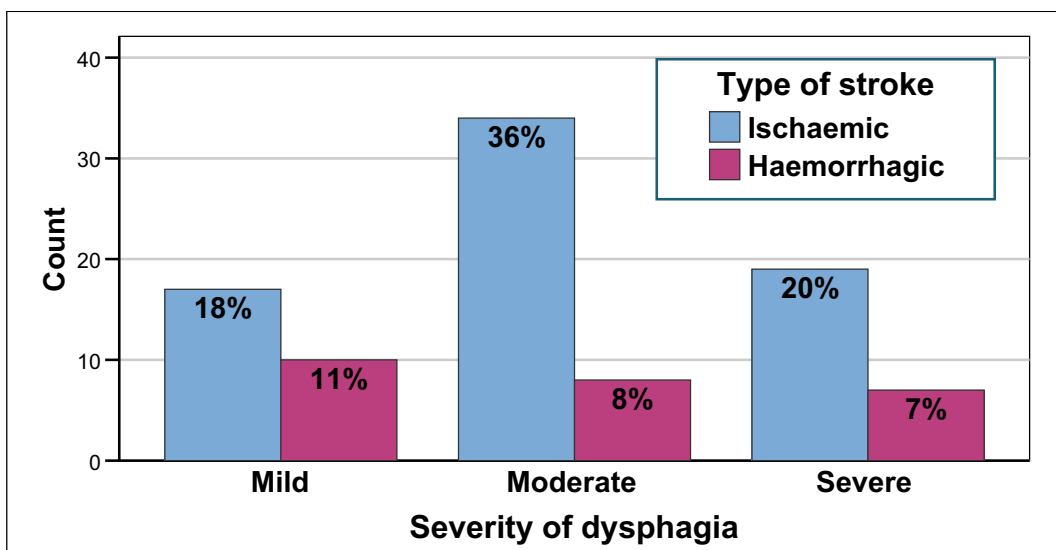


Figure 7: Severity of dysphagia and type of stroke

Twenty eight percent of subjects had suffered more than one stroke, however, the severity of dysphagia was not related to the episode of stroke, chi-square result not statistically significant: 1.6 (df 4, n=95) p=0.805.

The relationship between severity of stroke and dysphagia

Chi-square demonstrated a statistically significant relationship between the severity of stroke and severity of dysphagia; chi-square: 12.4 (df 4, n=95) p=0.015. Severe dysphagia was more common in the subjects who sustained moderate stroke (50% of all cases within this group). However, as can be seen in the figure below (Figure 8) a high proportion of subjects (85%) with mild stroke suffered from mild or moderate dysphagia. Additionally, a relatively higher ratio of severe dysphagia occurs in severe stroke (56% of those with severe stroke).

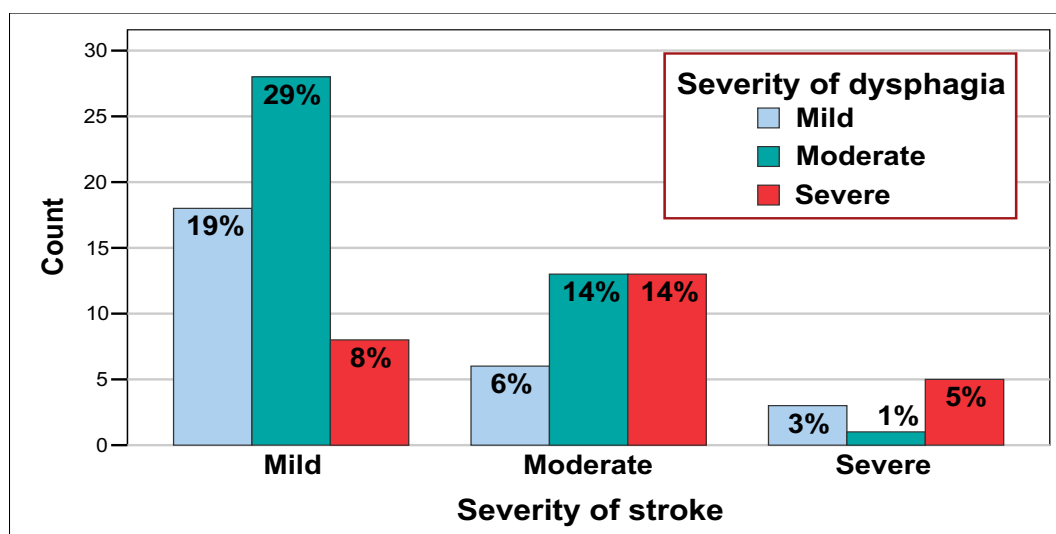


Figure 8: Severity of dysphagia and severity of stroke

Risk Factors

Data were collected on three main risk factors for stroke. These include hypertension, diabetes and atrial fibrillation (Figure 9). Twenty-seven percent (n=26) had a combination of two risk factors. This included 15.8% (n=15) with hypertension and diabetes, 8.4% (n=8) with hypertension and atrial fibrillation, and 3.2% (n=3) with diabetes and atrial fibrillation. In addition 5.3% (n=5) of subjects had all three risk factors.

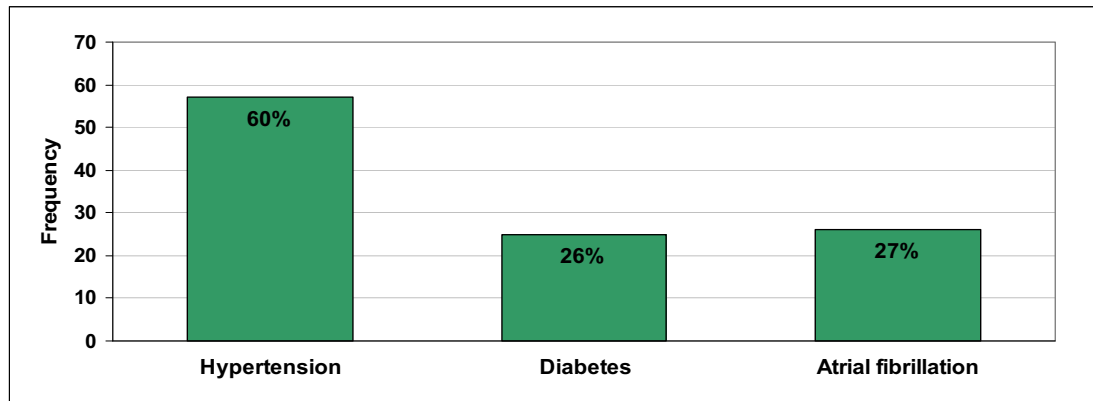


Figure 9: Risk factors

Premorbid disabilities

Data were collected on premorbid disabilities. These were classified into visual, speaking, upper limb motor impairments and facial weakness. Visual impairment included blindness, hemianopia, diplopia, blurred vision, visual field deficits and any other disabilities of eyesight. Speaking impairments included aphasia, dysphasia and dysarthria; and ‘upper limb’ motor impairments included hemiplegia, upper limb weakness and sensory impairments.

Forty-one subjects (43.2%) had premorbid disabilities. Thirty-one subjects (32.6%) had premorbid disabilities with the potential to influence oral intake. There were five subjects (5.3%) who had two types of premorbid disability and one subject (1.1%) who had three types of premorbid disability (Figure 10). Those classified as ‘disabilities not related to eating’ included lower limb impairment and incontinence.

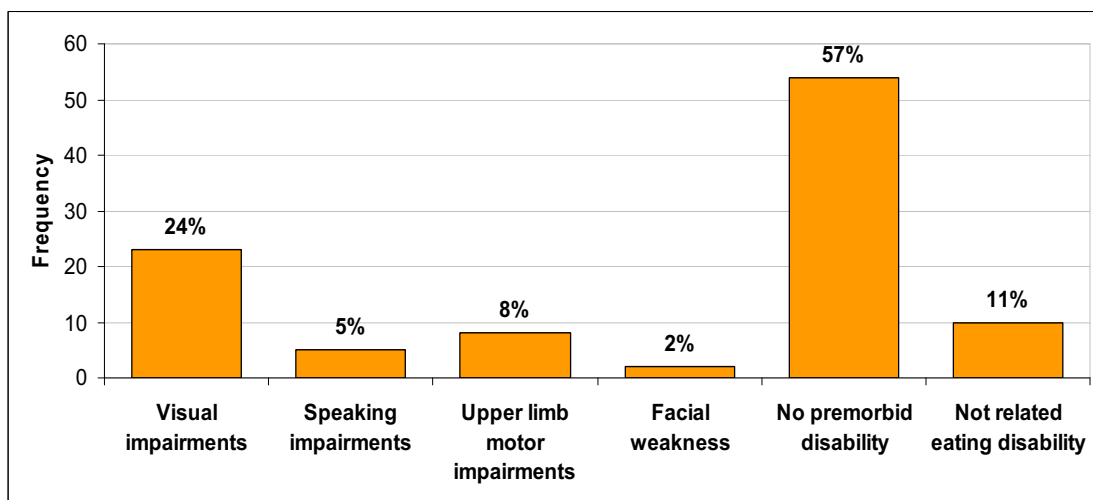


Figure 10: Premorbid conditions of subjects

Disabilities

Data were also collected regarding any disabilities noted on admission with stroke. These included premorbid disabilities. Those relating to dysphagia or eating were categorised into four main types in the same way as the premorbid disabilities. The distribution of these is shown in Figure 11. As can be seen from the figure below the majority of patients had major impairments. The total percentage of subjects suffering from one, two, three and four types of disabilities were 13.7% (n=13), 32.6% (n=31), 41.1% (n=39) and 12.6% (n=12) respectively. Eighty-six percent of subjects (n=82) suffered from one or more of these.

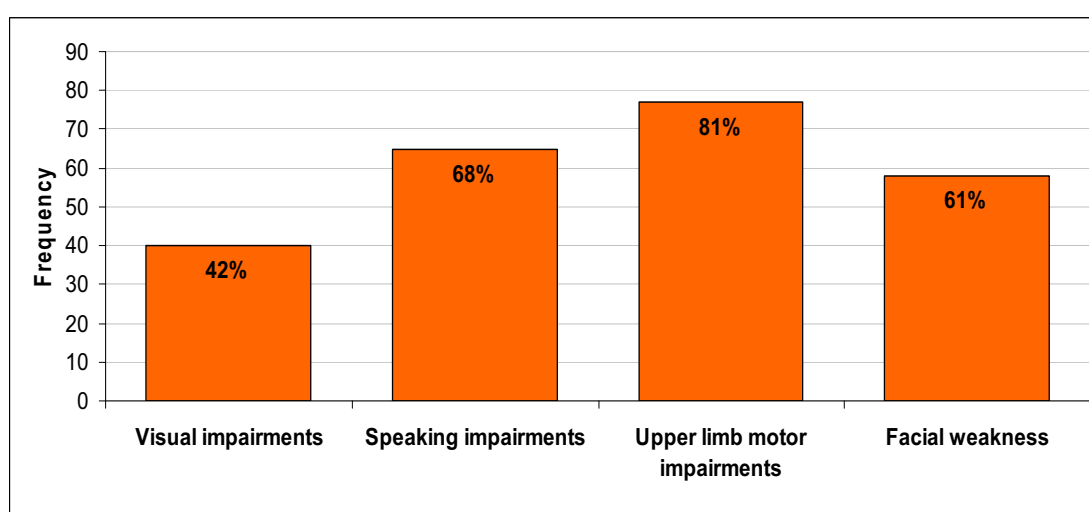


Figure 11: Impairments following stroke

Neurological condition following admission

GCS scores during hospitalisation

Glasgow Coma Scale (GCS) (Appendix 4) scores were recorded for each subject at three stages during their hospitalisation: on admission, following initial swallowing assessment by a speech pathologist and before discharge (Figure 12). Data were missing from 3 to 5% (n=11). The proportion of subjects who suffered from moderate injury (scores 12-9) decreased from admission to discharge and the number with severe brain injury (scores 8-3) did not change, but 16% (n=15) died.

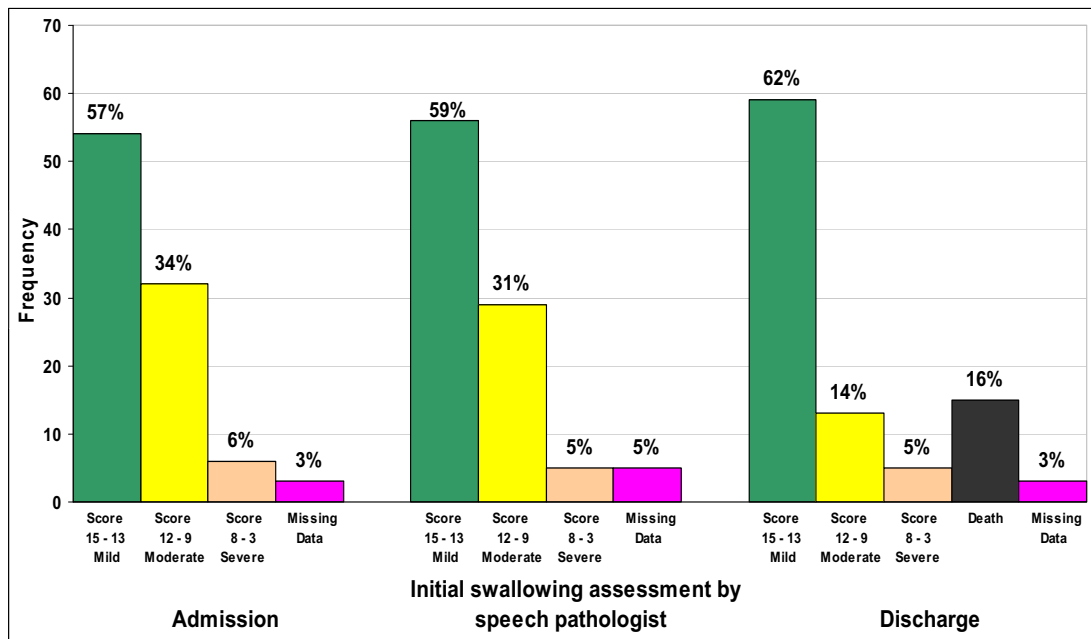


Figure 12: GCS scores during hospitalisation

GCS verbal scores

On all three assessments less than half of the subjects (41%-48%) were orientated and a significant proportion (6%-15%) was unable to respond verbally (none). As stated above 16% (n=15) died (Figure 13).

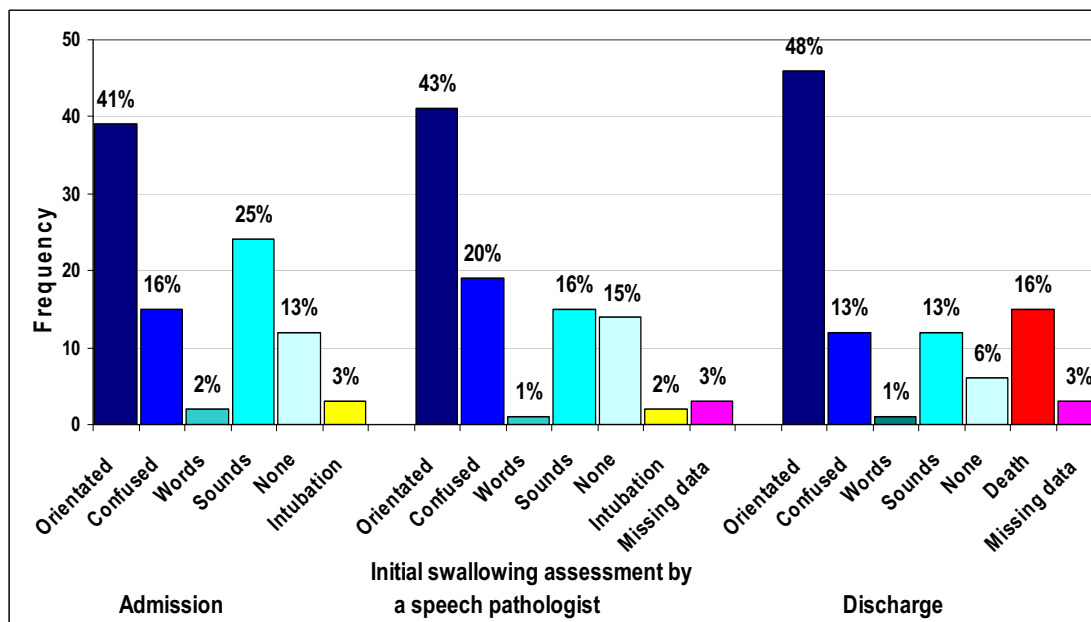


Figure 13 Verbal GCS scores

GCS motor scores

However, motors scores indicated that the majority (73%-77%) could respond appropriately to command (Figure 14).

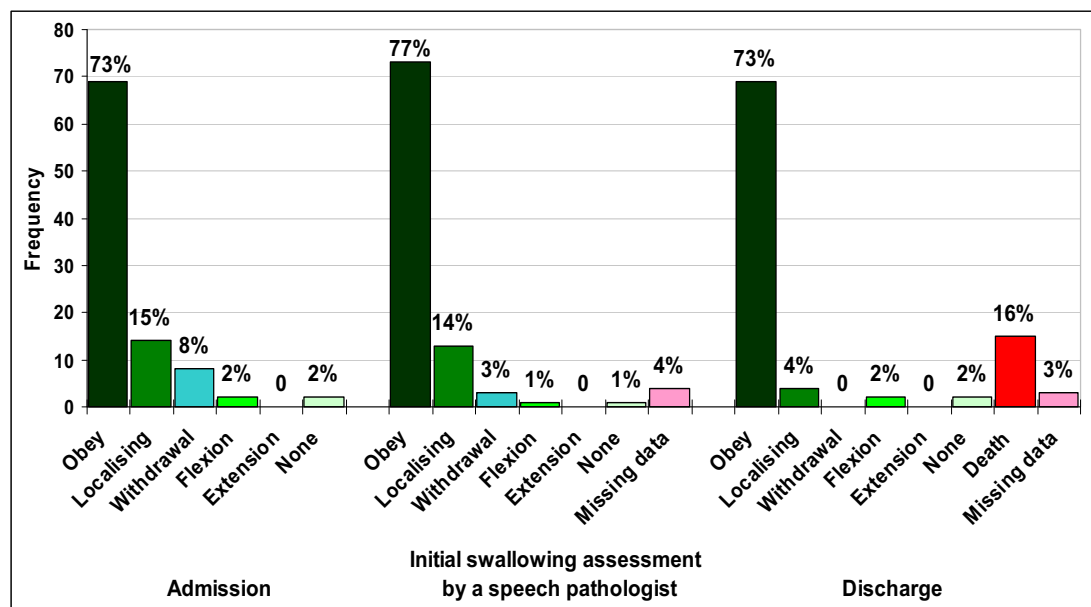


Figure 14: Motor GCS scores

Communication problems

Swallowing and speaking require functioning of similar structures including the pharynx, tongue and larynx. Thus patients with dysphagia commonly have problems with speaking; however, central damage may also result in communication difficulties and voice control, such as expressive or receptive dysphasia.

The subjects' severity of communication problems was classified as mild, moderate or severe by the speech pathologist. The classification was made by the speech pathologist using their professional judgment. The percentage of subjects in each category was mild 37% (n=35), moderate 3% (n=3) and severe 56% (n=53). The percentage of subjects with no communication problems was 4% (n=4).

Major communication problems

Data were also collected by the researcher on documented communication problems. Aphasia, dysarthria and dysphasia were combined in one category; others were decreased conscious level and cognitive impairments such as dementia. Most of the

subjects (93.7%, n=89) has some form of communication problem (Figure 15). twenty-five subjects (26.3%) had a combination of two types of problems.

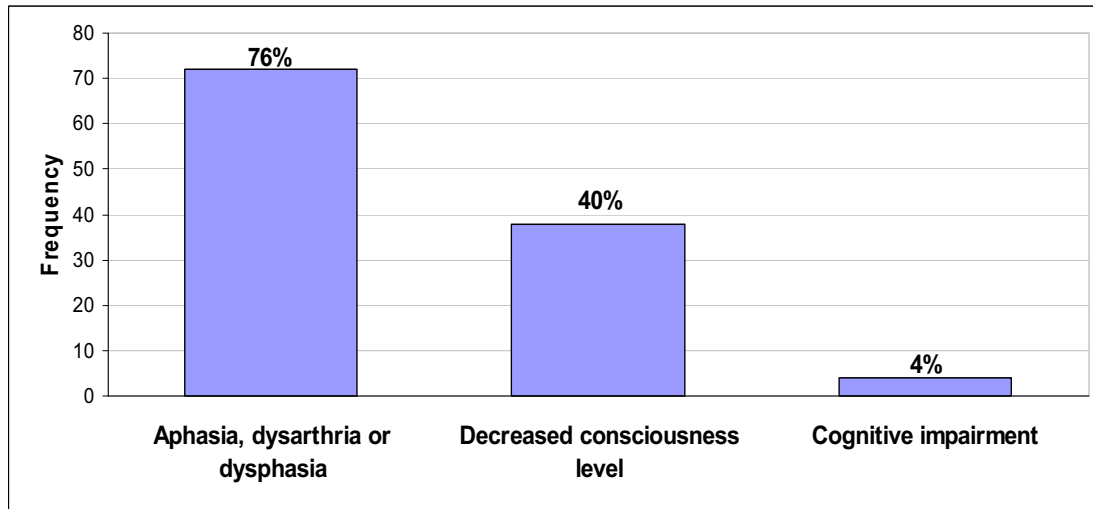


Figure 15: Major communication problems

The relationship between severity of communication problems and severity of dysphagia was also investigated (Figure 16). A chi-square was statistically significant: 13.4 (df 6, n=95) $p=0.037$. Subjects with severe communication problems were also more likely to have severe dysphagia.

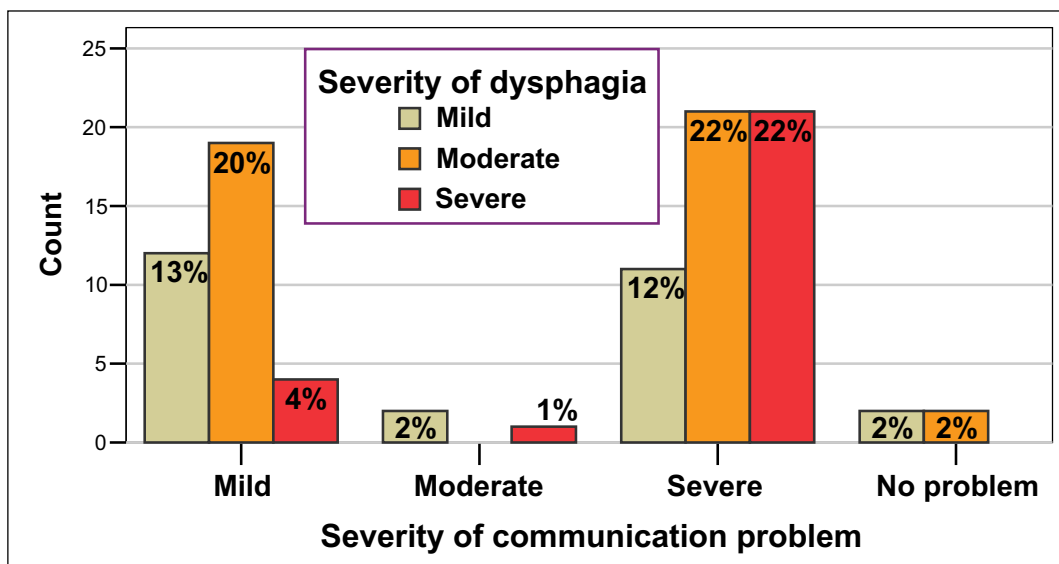


Figure 16: Severity of dysphagia and severity of communication problems

Recognition and assessment of dysphagia

Recognition of dysphagia

In most cases the dysphagia was recognised by a doctor, and as can be seen in the Figure 17 below, few (5%) were identified by nurses.

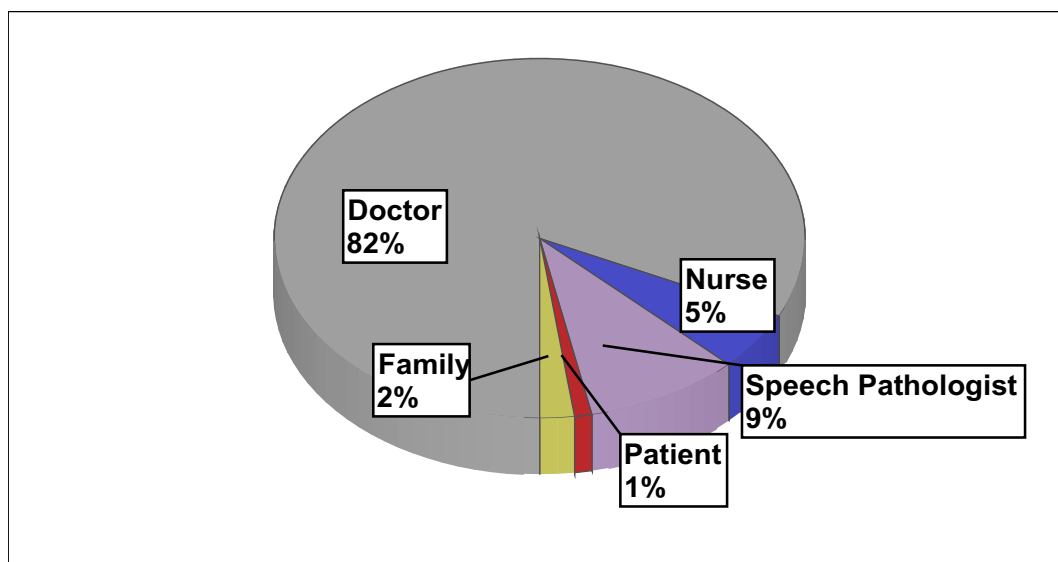


Figure 17: Recognition of dysphagia

Timing of assessment

The timing of the first swallowing assessment by speech pathologist was from a minimum of first day of admission to a maximum of the 26th day. The median was 3 and the mode was 2 days. Thirty-nine subjects (41%) were assessed within 24 hours (including day 1 and day 2), eighteen (19%) were assessed between 24 and 48 hours (day 2 to day 3) and sixteen (17%) were assessed between 48 and 72 hours (day 3 to day 4). Twenty-two (23%) subjects were assessed after day 4.

Reasons for delayed swallowing assessment

There were 23% (n=22) subjects who had delayed assessment of their swallowing ability by a speech pathologist (more than 4 days). The main reasons included the subjects being too ill to be assessed (41%, n=9), a delayed onset of dysphagia following stroke (27%, n=6), confusion or drowsiness (14%, n=3) and 'other reasons' included: 18% (n=4) being post-operative, a second stroke occurring during hospitalisation, and an oral diet or NET feeding had already started. Each of these

reasons occurred for about 5% to 9% (n=1 to 2) of the subjects. Three subjects (14%) waited for three days for an assessment because they were admitted just before or during a weekend or holiday.

Swallowing ability assessed before oral intake

Eighty-five percent (n=81) of subjects had their swallowing ability assessed before starting oral intake. Seven subjects (7.4%) were too ill to start oral intake and could not be assessed. Seven subjects (7.4%) were not assessed before oral intake was commenced.

Subsequent assessment

Following the initial swallowing assessment by a speech pathologist, subjects then had their swallowing ability assessed by various team members (Figure 18).

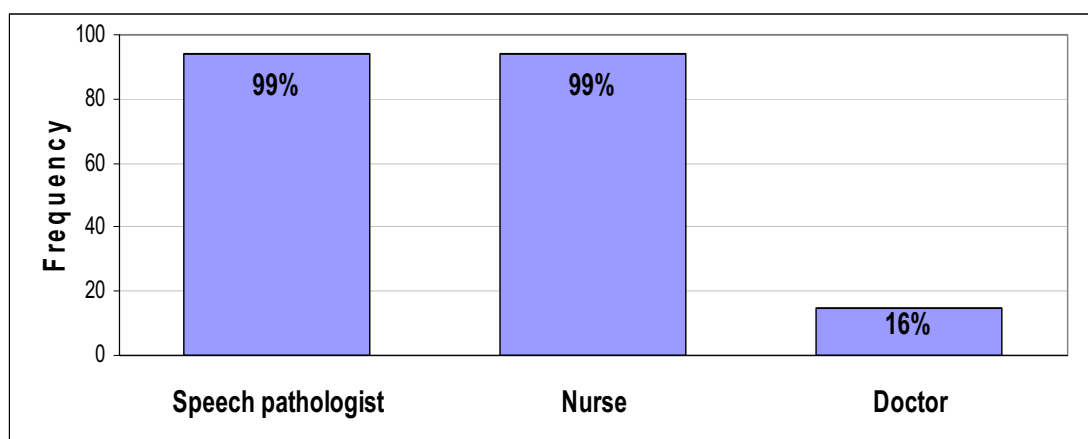


Figure 18: Staff who subsequently assessed subjects' swallowing ability

Consultations related to dysphagia

Data regarding consultation by the multidisciplinary team were also collected. As can be seen in the diagram below (Figure 19) all subjects were referred to a speech pathologist (SP), a significant number were also referred to a dietician (DT), or occupational therapist (OT) and gastroenterologist (GE). Few were referred to an ENT specialist.

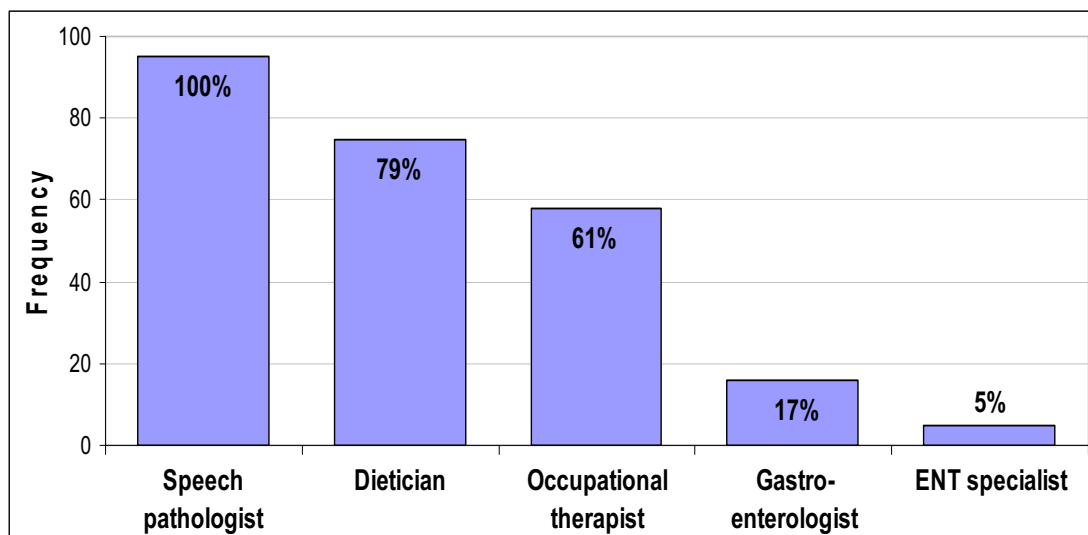


Figure 19: Consultations for dysphagia

Methods used to assess swallowing

The most common methods used by health care providers to assess subjects' swallowing ability were bedside swallowing assessment (BSA), a water swallowing test (WST) and pulse oximetry. Less common were, laryngoscopy and a fiberoptic endoscopic examination of swallowing (FEES) (Figure 20).

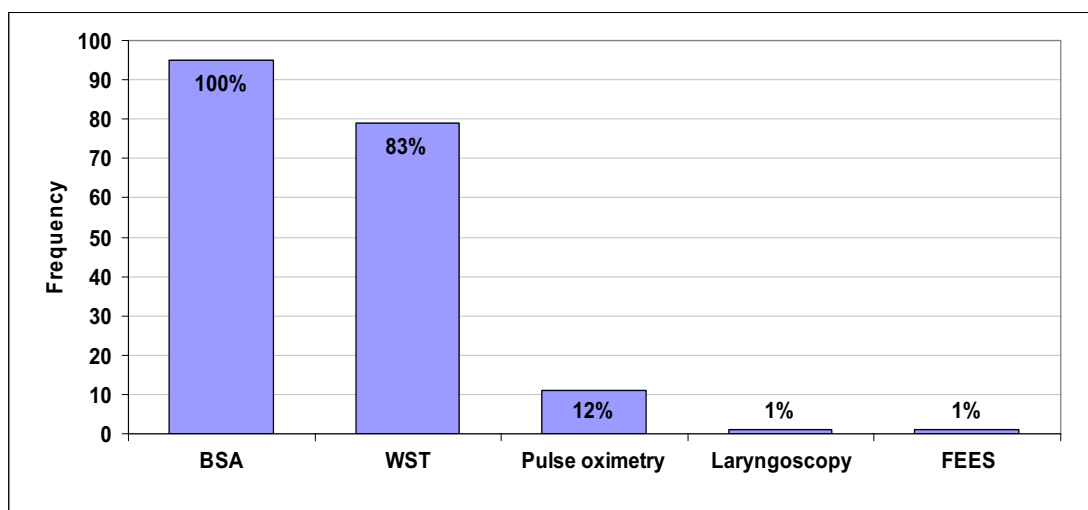


Figure 20: Method for swallowing assessment

Types of dysphagia

On assessment by a speech pathologist 92 subjects (97%) were found to have different types of dysphagia. There were four main categories: facial weakness, poor

manipulation of a bolus in the mouth, problems with initiation of swallowing reflex and problems with substances passing through the pharynx or the oesophagus (Figure 21). Most subjects had more than one type. Nine subjects (9%) had one type, 35% (n=33) two, 37% (n=35) three and 16% (n=15) all four types. Three subjects (3%) were too ill and could not be assessed during admission.

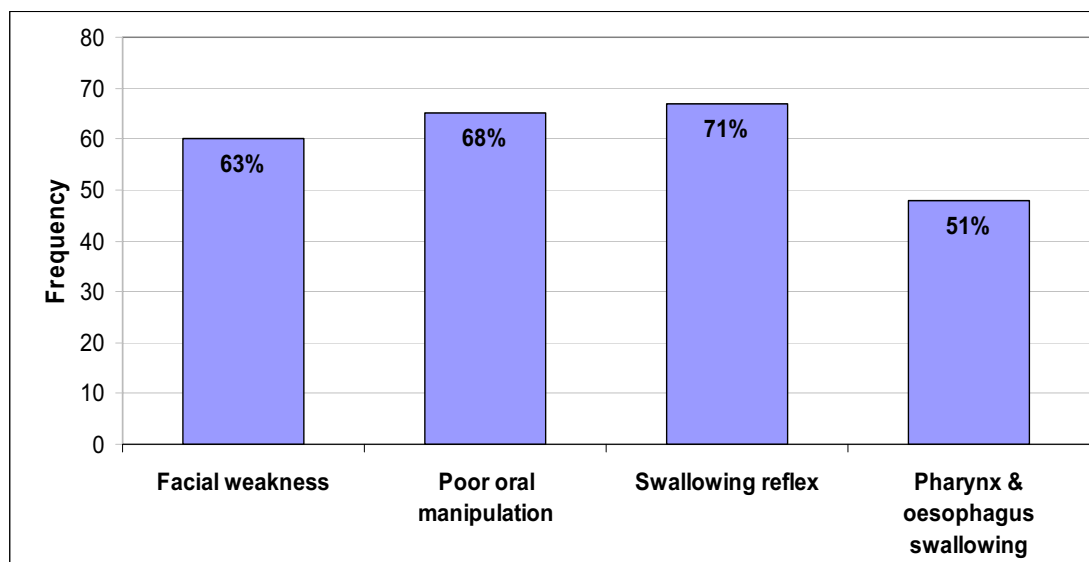


Figure 21: Types of dysphagia

Frequency of assessment of dysphagia by a speech pathologist or doctors

All subjects had their swallowing assessed throughout their hospitalisation by either a speech pathologist or doctor. The minimum number of assessments was one and the maximum of 19. The number of dysphagia assessments according to the severity of dysphagia is shown in Table 8.

Table 8: Number of dysphagia assessments

Severity of dysphagia	Number of Subjects	Range	Minimum	Maximum	Mean	Standard deviation	Variance
Mild	27	9	1	10	3.4	2.7	7.3
Moderate	42	16	1	17	6.2	3.5	12.4
Severe	26	18	1	19	6.6	4.7	21.9
Total	n=95						

For the eighty-four subjects (88.4%) who had multiple swallowing assessments the time in days between assessments according to the severity is shown in Table 9.

Table 9: Time in days between dysphagia assessments

Severity of dysphagia	Number of subjects	Range	Minimum	Maximum	Mean	Standard deviation	Variance
Mild	20	13	1	14	4.9	3.7	13.5
Moderate	41	21	1	22	6.7	4.3	18.4
Severe	23	30	3	33	9.2	6.3	40.0
Total	n=84						

Clinical indicators of risk of aspiration

Following initial assessment by a speech pathologist, sixty subjects (63.2%) had one or more clinical indicator for risk of aspiration. These were coughing after swallowing, an abnormal gag reflex, an abnormal volitional cough, voice change after swallowing, decreased consciousness, dysarthria, and absent swallow reflex (Figure 22). Fourteen subjects (23%) had two types and six (10%) had three.

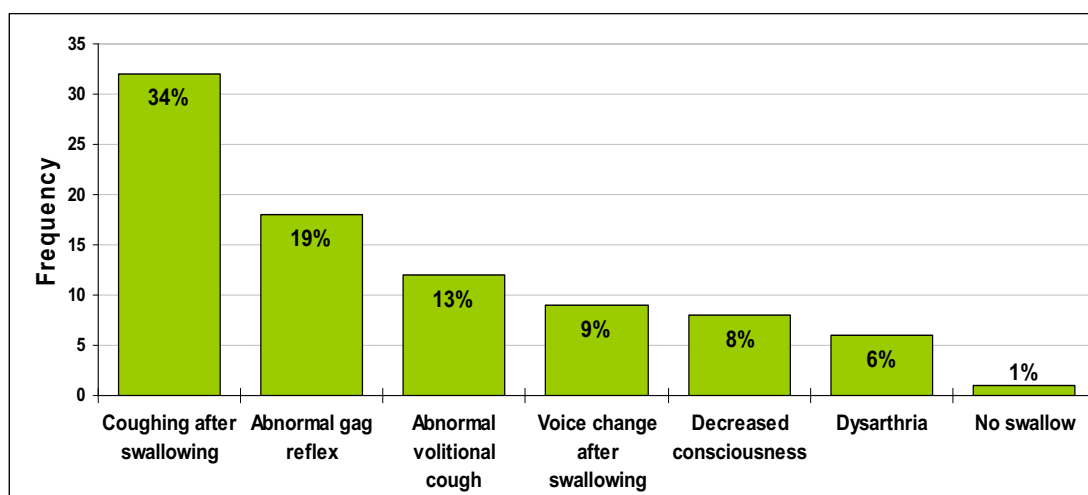


Figure 22: Indicators of risk of aspiration

Assessment of nutritional status

Body mass index

Only 42.1% (n=40) of subjects were weighed during hospitalisation and the height was recorded for 28 subjects (29.5%). Thus BMI could not be calculated for 70.5% (n=67) of subjects. The 28 subjects who had their BMI calculated were categorised into four groups: normal, underweight, overweight and obese (Figure 23). Around 8% (n=8) were overweight or obese.

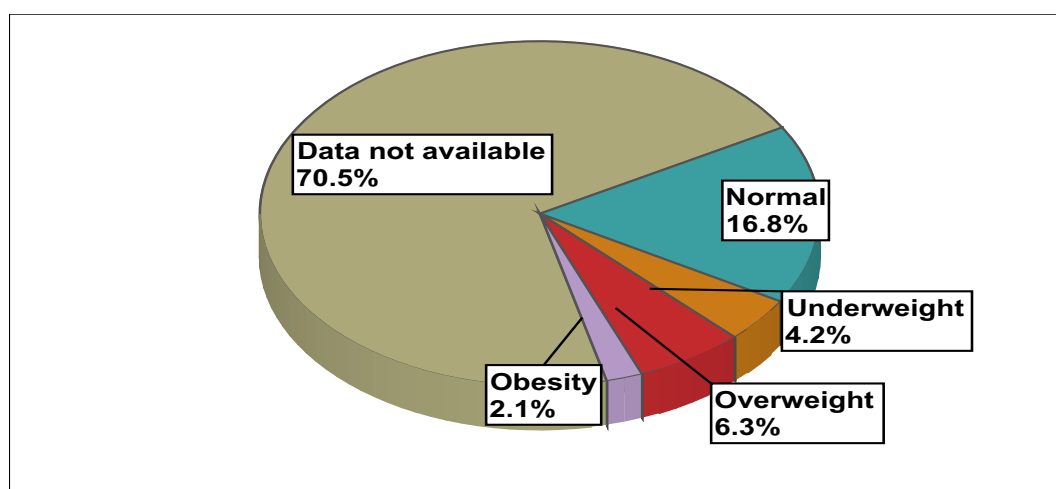


Figure 23: Body mass index

Food and fluid restriction

Five subjects (5.3%) required fluid restriction and only one subject required restricted diet due to the presence of renal disease.

Accurate recording of food and fluid intake

Most subjects (n=90, 94.7%) required their intake to be recorded. This was indicated when they were on intravenous (IV) fluids or when ordered. Of these records those for 24 subjects (25.3%) were found to be incomplete. This was caused by factors such as urinary incontinence, visits to the toilet or relatives giving patients food or fluids.

Nil by mouth

Eighty-three subjects (87.4%) were ordered 'nil by mouth' at some time during their hospitalisation. While patients were ordered 'nil by mouth', they may have been

receiving enteral tube feeds. The minimum for these subjects was 1 day and the maximum 84. The median was 6 and the mode was 1 day (n=14) (Figure 24).

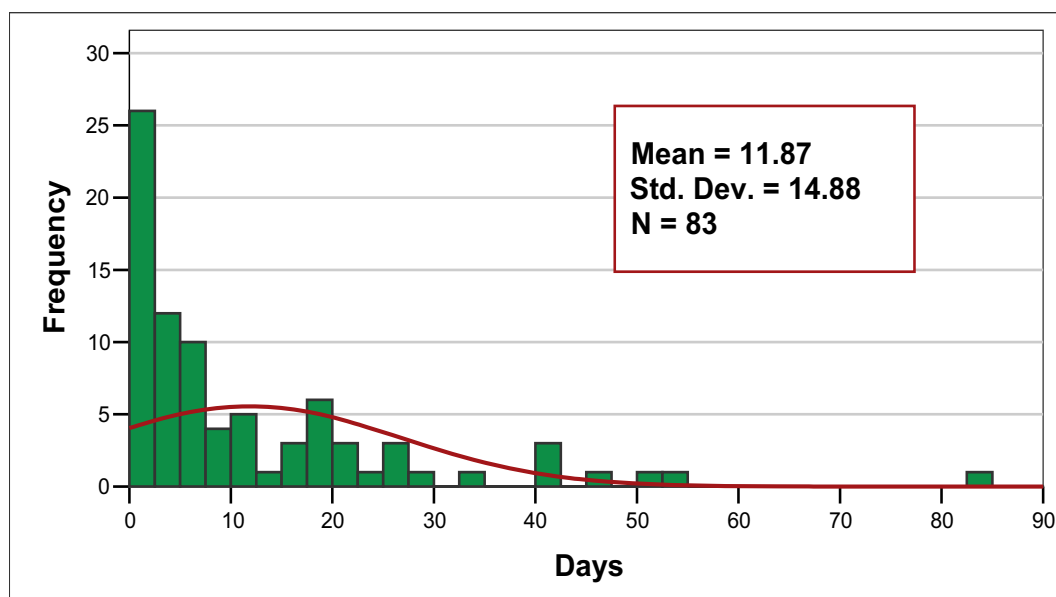


Figure 24: Number of days ‘nil by mouth’

The relationship of severity of dysphagia and the length of time subjects were ordered ‘nil by mouth’ was analysed using one-way between groups analysis of variance. Subjects were divided into three groups according to their severity of dysphagia. Levene’s test was significant indicating that the data violated the assumption of homogeneity of variance. Therefore ‘robust tests for equality of means’ were used (Table 10). As can be seen below the results were significant. Post Hoc comparisons using the Tukey HSD indicated that the mean days of ‘nil by mouth’ for severe (\bar{x} =24.5, σ =19.7) was significantly different from the mild (\bar{x} =3.1, σ =5) and the moderate (\bar{x} =6.3, σ =6.9). But that the mean day of ‘nil by mouth’ for those subjects with mild dysphagia was not significantly different from those with moderate dysphagia.

Table 10: Robust tests of equality of means - days of ‘nil by mouth’

	Statistic	df1	df2	Significant
Welch	15.1	2	49.7	.000
Brown-Forsythe	22.4	2	33.6	.000

Reasons for ‘nil by mouth’

The reasons for ‘nil by mouth’ were categorised into four groups and illustrated in Figure 25. These were suspicion of a swallowing problem, an unstable condition, preoperative fasting and fasting for an investigation. Fifteen subjects (15.8%) were fasted for two reasons and four subjects (4.2%) were fasted for three reasons.

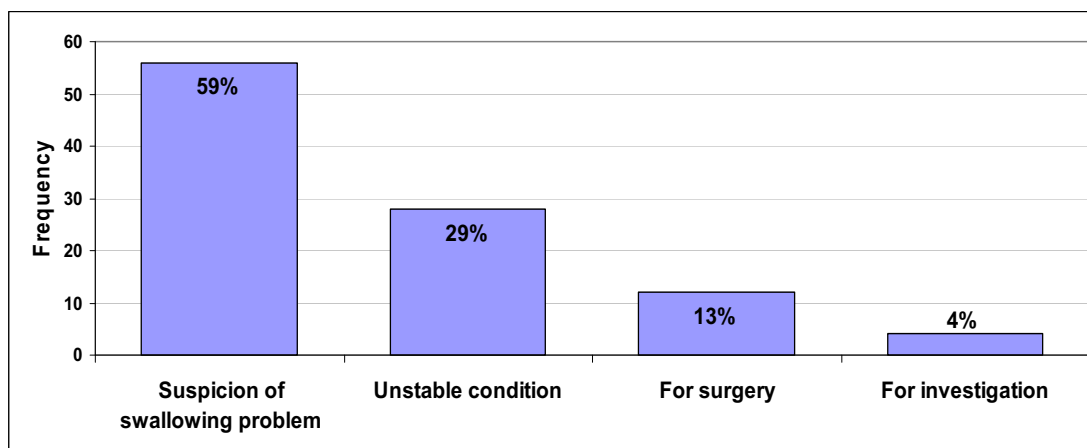


Figure 25: Reasons for ‘nil by mouth’

Number of days ‘without any enteral intake’

Eighty-three subjects (87.4%) were ‘without any enteral intake’ (oral or feeding) at some time during their hospitalisation. The minimum duration of ‘no enteral intake’ was 1 day and the maximum 36 (IV fluids were given). The median was 4. There were two modes: 1 and 2 (n=15) (Figure 26). None of the subjects received total parenteral nutrition (TPN).

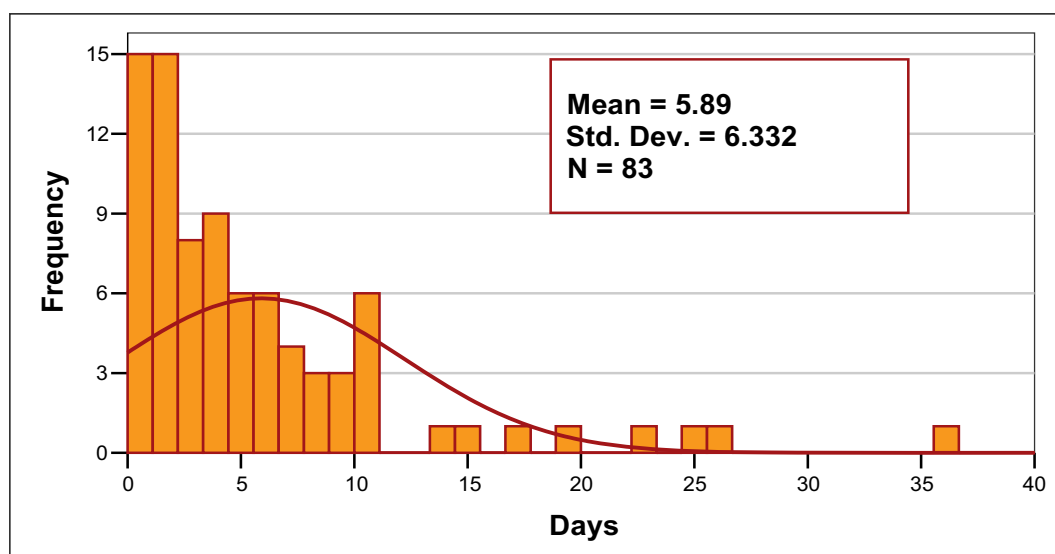


Figure 26: Number of days ‘without any enteral intake’

The relationship between the severity of dysphagia and the length of time subjects were ‘without any enteral intake’ was analysed using one-way between groups analysis of variance. Levene’s test was significant indicating that the data violated the assumption of homogeneity of variance. Therefore ‘robust tests for equality of means’ were used (Table 11). Post Hoc comparisons using the Tukey HSD indicated that the mean days of ‘without any enteral intake’ for severe (\bar{x} =8.7, σ =8.2) was significantly different from the mild (\bar{x} =2.4, σ =3.5) and the moderate (\bar{x} =4.7, σ =5.2). However, the mean days ‘without any enteral intake’ for those subjects with mild dysphagia was not significantly different from those with moderate dysphagia.

Table 11: Robust tests of equality of means - days of ‘without any enteral intake’

	Statistic	df1	df2	Significant
Welch	7.1	2	52.4	.002
Brown-Forsythe	7.2	2	50.6	.002

Interventions

Intravenous therapy

Ninety subjects (94.7%) required intravenous therapy (IVT) during hospitalisation. The median was eight days, the minimum duration of IVT was 1 day and the maximum was 58. The distribution of days on IVT is shown in Figure 27.

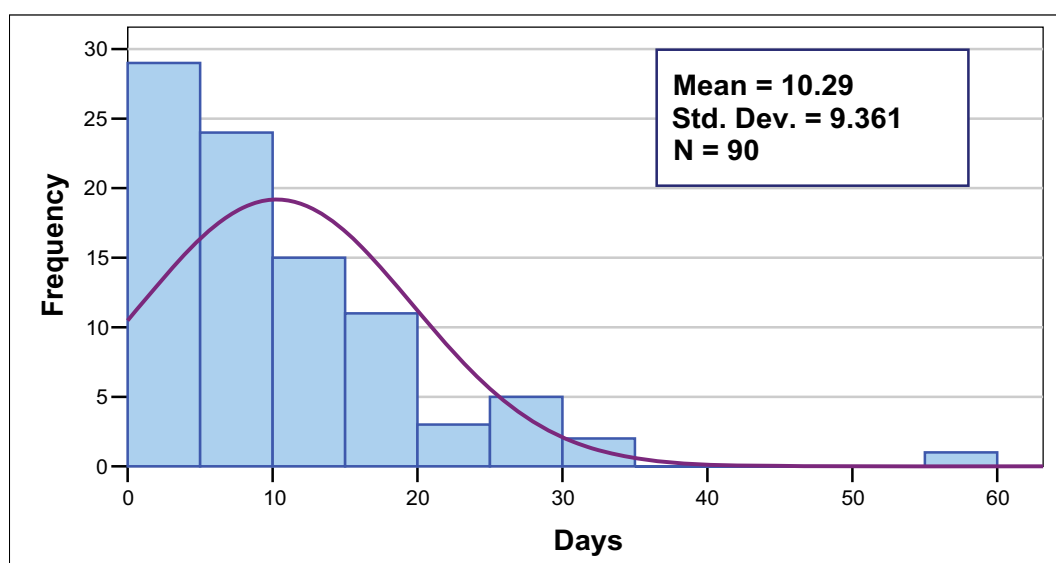


Figure 27: Number of days on intravenous therapy

The relationship of severity of dysphagia to the length of time subjects were ordered 'IVT' was analysed using one-way between groups analysis of variance. Subjects were divided into three groups according to their severity of dysphagia. Levene's test was significant indicating that the data violated the assumption of homogeneity of variance. Therefore 'robust tests for equality of means' were used (Table 12). The results were significant. Post Hoc comparisons using the Tukey HSD indicated that the mean days of 'IVT' for the mild ($\bar{x}=4.3$, $\sigma=3.5$) was significantly different from the moderate ($\bar{x}=10.6$, $\sigma=10.1$) and the severe ($\bar{x}=15.5$, $\sigma=8.9$). But the mean day of 'IVT' for those subjects with severe dysphagia was not significantly different from those with moderate dysphagia.

Table 12: Robust tests of equality of means - days on IVT

	Statistic	df1	df2	Significant
Welch	21.1	2	50.6	.000
Brown-Forsythe	12.9	2	69.7	.000

Special diets prior to admission

Twenty-six subjects (27.3%) required a special diet before admission. These included diabetic diet (13.7%, n=13), minced / soft diet, (7.4%, n=7), renal and diabetic diet (3.2%, n=3), a diabetic minced / soft diet (2.1%, n=2). One subject was a vegetarian (1.1%).

Modified diet or fluids following assessment

Seventy-three (76.8%) subjects were commenced on a modified diet or fluids after assessment. Three subjects (3.2%) were tolerating a normal (2.1%, n=2) or soft ward diet (1%, n=1) before assessment. Nineteen subjects (20%) were on 'nil by mouth' and they were supported by IVT or tube feeding.

Time from admission to commencing modified diet or fluids

Excluding two subjects (2%) who remained on a normal diet and fluids on admission, eighty-five subjects (89.5%) were able to commence a modified diet and or fluids during their hospitalisation. The time taken for these subjects to commence diet or

fluids from admission was from a minimum of 1 day to a maximum of 44 days; the range was 43. The median was 3 and the mode was 1 (n=23). Forty-nine subjects (51.6%) started a modified diet and or fluids within three days (Figure 28). Eight subjects (8.4%) remained on 'nil by mouth' throughout their hospitalisation, seven of these suffered from either severe stroke or severe dysphagia and one subject suffered moderate stroke and moderate dysphagia. Although this subject had been classified as only having moderate dysphagia, it was severe enough to warrant an order of nil orally and the subject died after 16 days of hospitalisation.

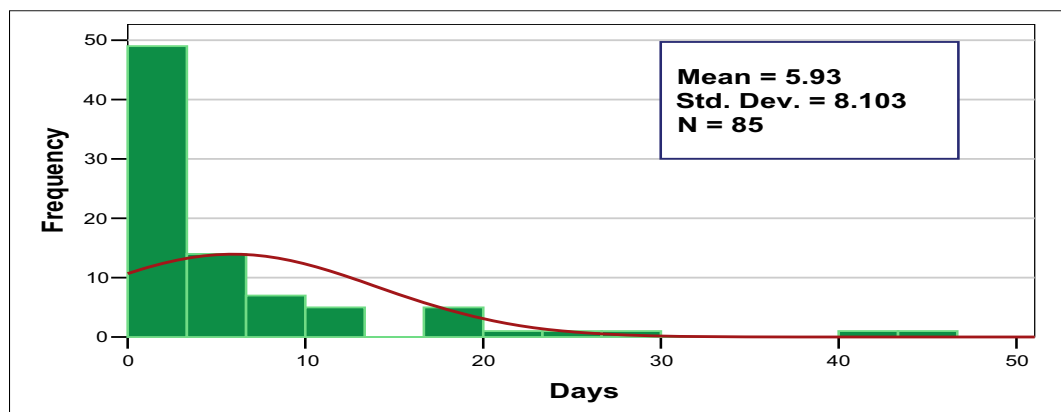


Figure 28: Days to commence a modified diet and or fluids

The number of day subjects stayed on a modified diet

Excluding those who were able to tolerate a normal diet on admission, for the 85 subjects (89.5%) able to commence a modified diet and or fluids during their hospitalisation, the minimum number of days on a modified diet was 1 and a maximum was 72 days. The median was 15 and the mode was 5 days (n=6). The distribution of days on a modified diet or fluids is shown in Figure 29.

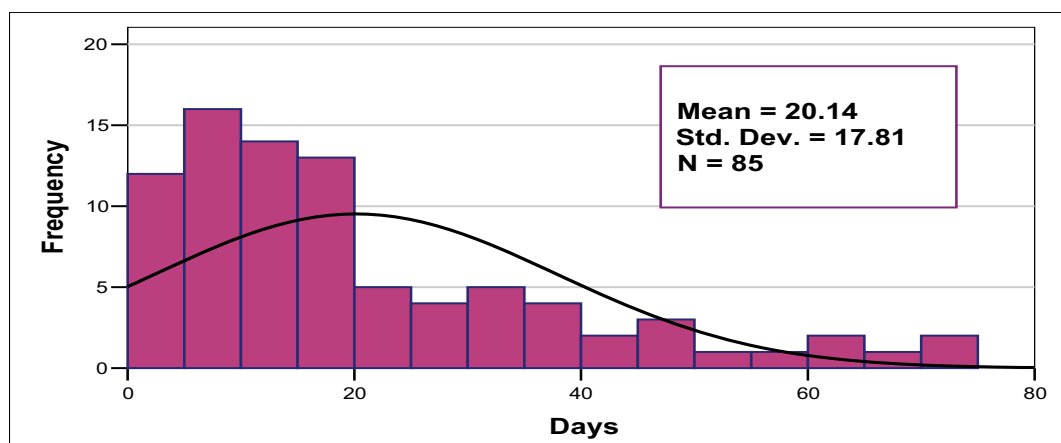


Figure 29: Number of days on modified diet and or fluids

Intake following initial swallowing assessment by a speech pathologist and on discharge

A comparison of the type of diet subjects were ordered following the initial swallowing assessment by a speech pathologist and on discharge is shown below (Figure 30).

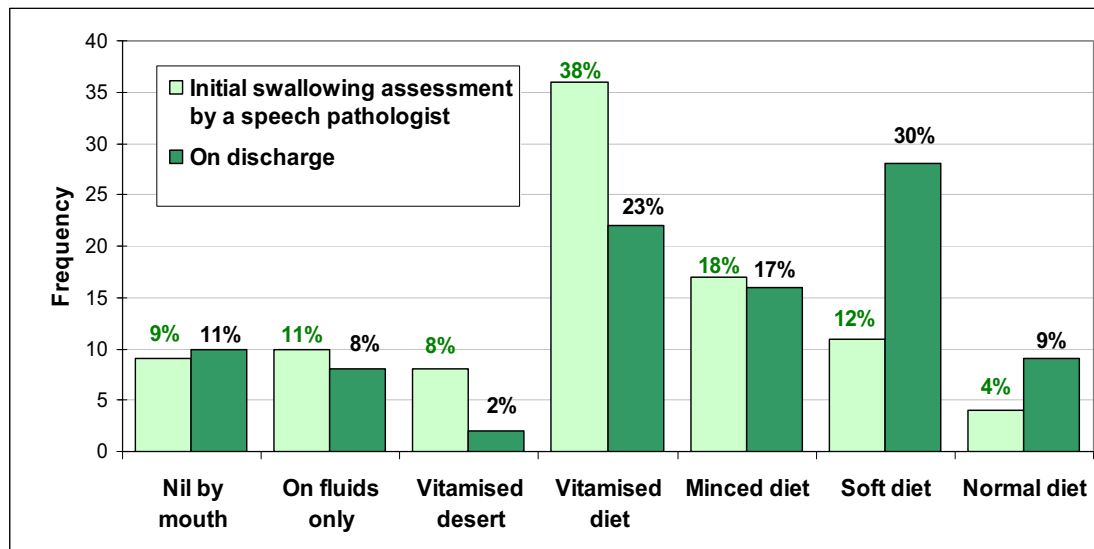


Figure 30: Intake of subjects

Intake following initial swallowing assessment by a speech pathologist according to severity of dysphagia

Following initial assessment of swallowing by a speech pathologist 20% (n=19) were on 'nil by mouth' or only allowed fluids. Seventy-four subjects (78%) were ordered some type of a modified diet (two subjects were excluded on a normal diet since admission) (Figure 31). As would be expected more subjects with severe dysphagia were on 'nil by mouth' and only subjects with mild dysphagia were on normal diets.

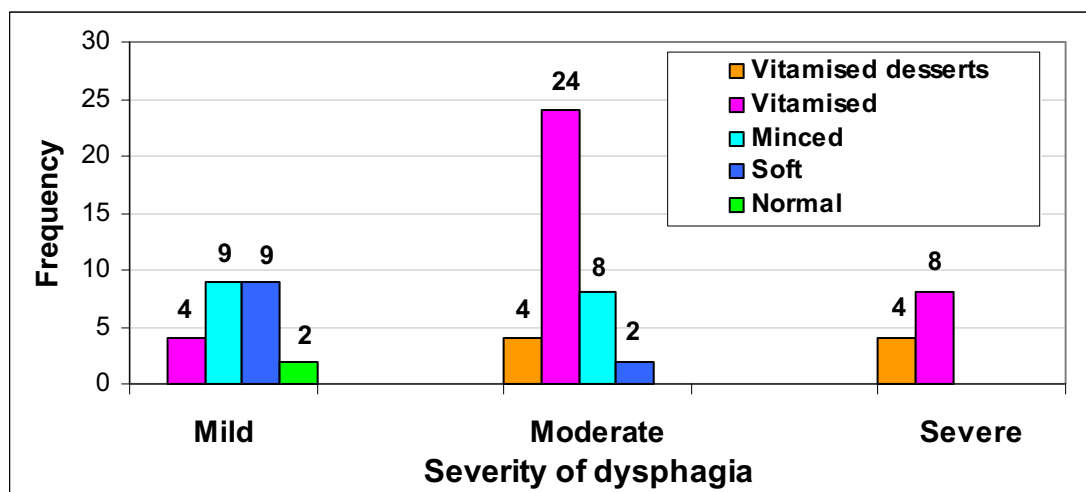


Figure 31: Diet following swallowing assessment by a speech pathologist according to severity of dysphagia

Diet on discharge according to severity of dysphagia

On discharge 10.5% (n=10) were on 'nil by mouth' and 8.4% (n=8) were only allowed fluids. Figure 32 shows the diet of subjects on discharge. The percentage of subjects who could tolerate a soft or normal diet were for those with mild dysphagia 75% (18 out of 24), moderate 36% (14 out of 39) and severe 25% (3 out of 12).

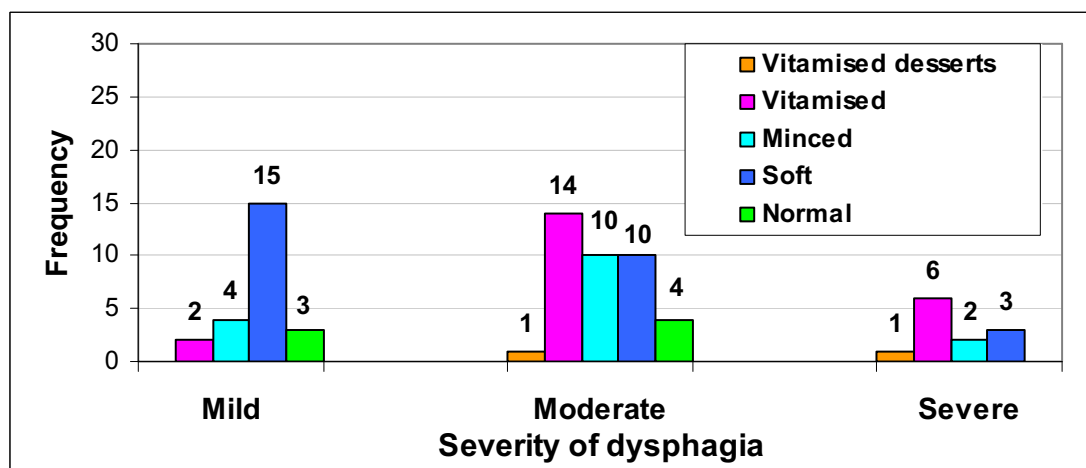


Figure 32: Diet on discharge according to severity of dysphagia

Fluids following initial swallowing assessment by a speech pathologist and on discharge

There were seven different types of orders regarding fluids. These included 'nil by mouth', 'ice chips', 'fully-thickened', 'semi-thickened', 'slightly-thickened', 'thin

fluids' and 'normal fluids'. Comparison of the numbers and percentages of subjects in each category following initial swallowing assessment by a speech pathologist and on discharge is shown in Figure 33.

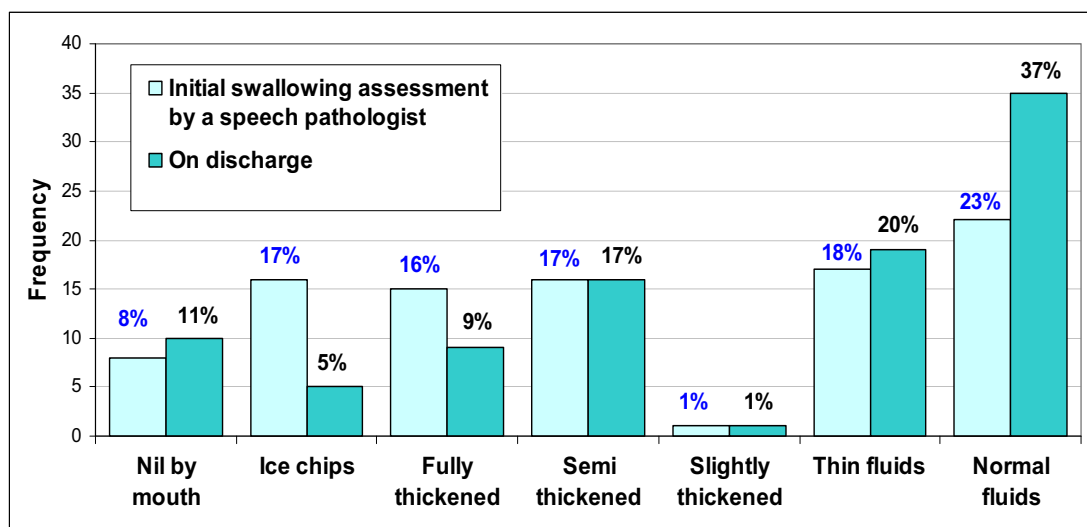


Figure 33: Fluid orders

Changes to fluid and diet orders during hospitalisation

Sixty-six percent (n=63) of those who required and could tolerate a modified diet or fluids, had their diet or fluid orders changed during hospitalisation (excluding those on a normal diet on admission or those who remained on nil orally). Of these, the percentages of mild, moderate and severe dysphagia were 24% (n=15), 57% (n=36) and 19% (n=12) respectively (Figure 34). There was a statistically significant relationship between the severity of dysphagia and the requirement to further modify diet and or fluids. Chi square: 18.7 (df 4, n=95) p=0.001.

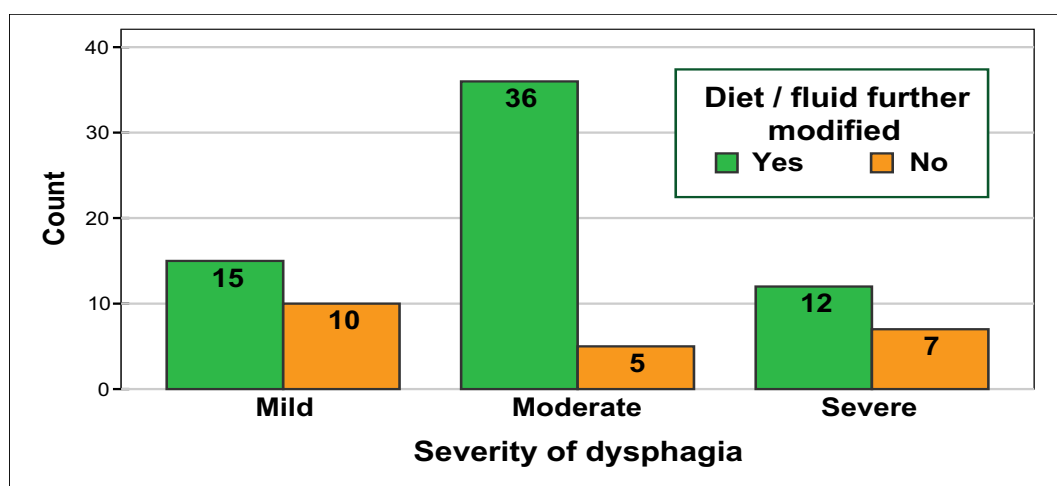


Figure 34: Diet or fluid further modified during hospitalisation

Tube feeding

There were two types of enteral feeding tubes used for subjects – nasoenteral tube (NET) and a percutaneous endoscopic gastrostomy (PEG). Forty-four subjects (46%) had tubes inserted for feeding during hospitalisation. Initially 43 subjects (45%) had a NET and one subject (1%) had a PEG tube. Subsequently, 39% of subjects (17 out of 44) who initially had a NET had a PEG tube inserted. Thus the total percentage of subjects who had a PEG was 19% (n=18). In addition two subjects (2%) had tubes inserted solely for aspiration of gastric contents or for receiving medication.

When categorised according to mild, moderate and severe dysphagia, the percentages of 44 subjects who had NET and or PEG tube insertion for feeding were 11% (n=5), 41% (n=18) and 48% (n=21) respectively. In addition, of the 18 subjects who had PEG tube feeding the percentage with moderate dysphagia was 22% (4 out of 18) and severe 78% (14 out of 18) (Figure 35).

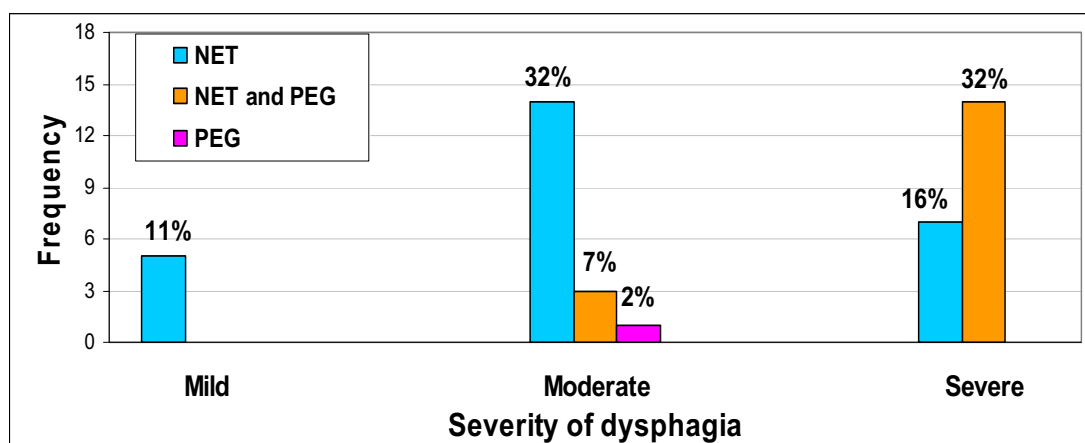


Figure 35: Feeding tubes according to severity of dysphagia

Number of NET insertions

For each of the 45 subjects (47%) who had a NET inserted during hospitalisation either for feeding or aspiration, the number of insertions was recorded. The minimum was 1 and the maximum was 11. The median and mode of times of NET insertion were both 3. The number of times subjects had a NET insertion is shown in Figure 36.

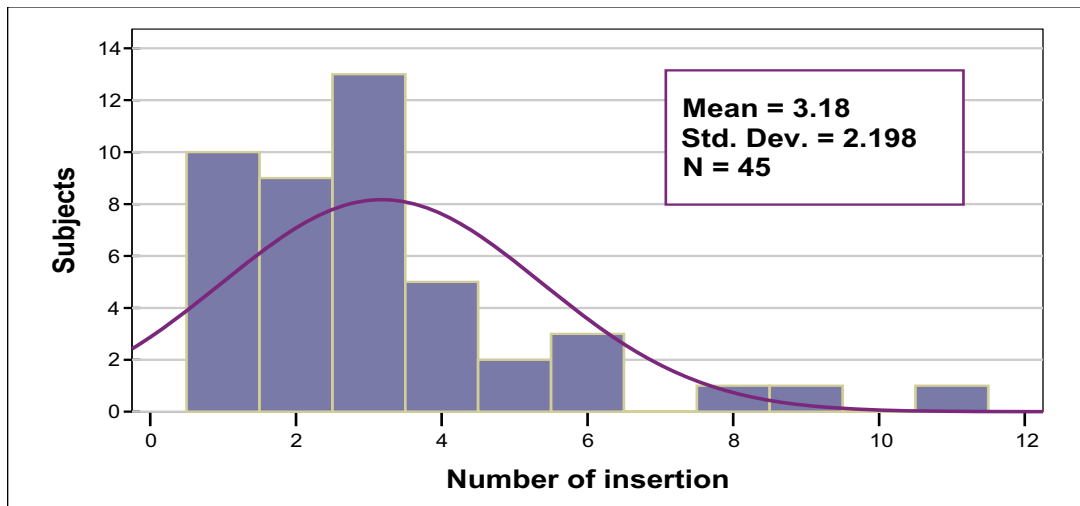


Figure 36: Number of times NET inserted

Enteral tube feeding commencement following assessment by a speech pathologist

Forty-four subjects (46%) had enteral tube feeding via either a NET or PEG. Fifteen out of 44 subjects (34%) started enteral tube feeding prior to assessment by a speech pathologist. For the remaining 29 subjects (66%) the time until commencement was from a minimum 1 day to a maximum 28 days, the median was 2 days and the mode was 1 (n=11). The distribution is illustrated in Figure 37.

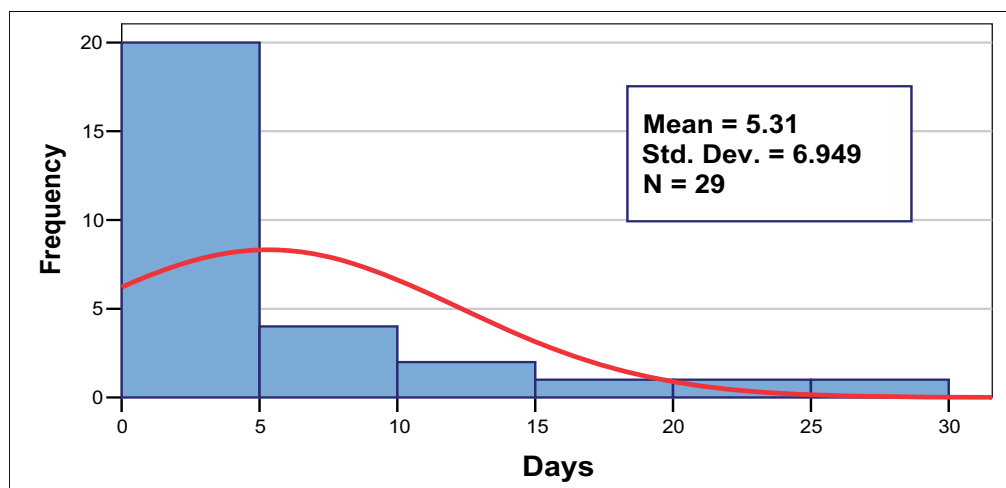


Figure 37: Days until enteral tube feeding commenced

Although 29 subjects had the tubes inserted for feeding, only 55% (16 out of 29) of subjects were started on tube feeding immediately (within 24 hours) following the assessment by a speech pathologist.

PEG insertion

Eighteen subjects (19%) required PEG tube feeding as a long-term feeding strategy. These included 17 subjects (18%) who had their NET changed to a PEG and one subject (1%) who had a PEG insertion directly (no prior NET insertion) during hospitalisation. These 18 subjects comprised 41% of all enteral feeding subjects (n=44).

Except for one subject who had a PEG tube inserted eight days prior to their initial swallowing assessment by a speech pathologist, the minimum number of days before a PEG tube was inserted following the initial assessment was 12 days and a maximum was 38 days; the range was 26 days (this included those who initially had a NET). The median was 21 days and the mode was 15 (n=4). The distribution of days of PEG insertion following the initial swallowing assessment is shown in Figure 38.

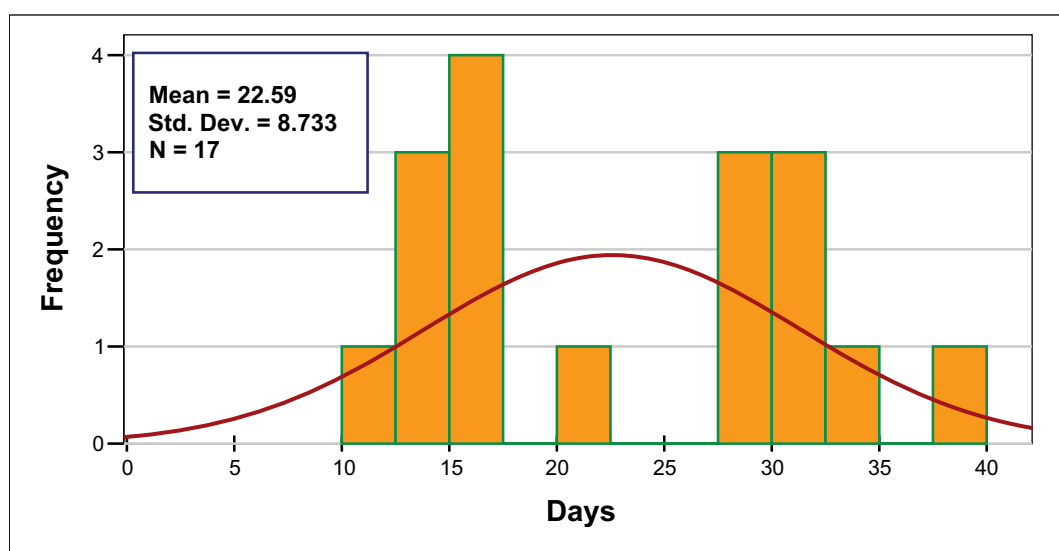


Figure 38: Number of the days until PEG insertion

Complications of PEG

Five of 18 subjects (28%) who had a PEG insertion suffered complications. These were wound infection (11%, n=2), gastrointestinal (GI) upset (11%, n=2) which included gastric reflux and nausea, wound pain (6%, n=1) and tube displacement (6%, n=1). One subject suffered two types of complications at the same time, which were GI upset and pain.

Duration of enteral feeding

One of the subjects with an NET tube and all the 18 subjects who had a PEG inserted were discharged on enteral feeds. Of the 25 remaining subjects who required enteral feeds the duration was recorded. The minimum was 2 day and a maximum was 35 days. The median was 12 days and two modes were 10 and 12 days (n=3). The distribution of days that subjects were fed by enteral tube is illustrated in Figure 39.

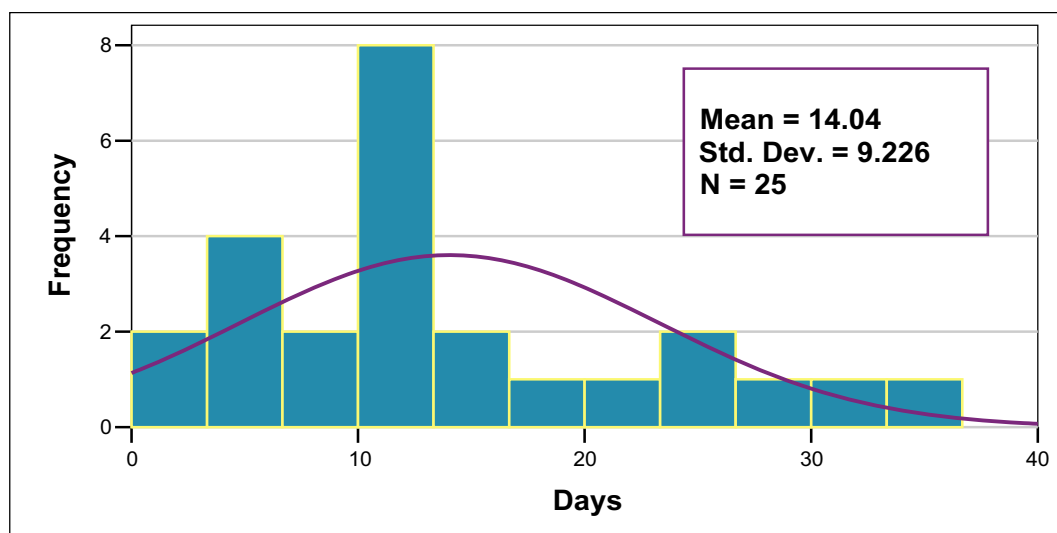


Figure 39: Duration of enteral feeding

Swallowing rehabilitation program

Thirty-eight subjects (40%) had a swallowing rehabilitation program or liaison with multidisciplinary team members to manage their dysphagia. The percentages of subjects who were referred to particular multidisciplinary team members were: speech pathologists 100% (n=38), dieticians 95% (n=36), physiotherapists 32% (n=12) and occupational therapists 18% (n=7). The combination of multidisciplinary teams in the program is shown in (Table 13).

Table 13: Multidisciplinary team liaison in swallowing rehabilitation

Team liaison	Frequency	Percent
Speech pathologist & dietician	21	58
Speech pathologist, dietician & physiotherapist	8	22
Speech pathologist, dietician, physiotherapist & occupational therapist	4	12
Speech pathologist, dietician & occupational therapist	3	8
Total 36		100

Management of oral intake

Food allergies

Only two subjects (2%) had any documentation of food allergies. This was seen in the surgery records. However, there was no documentation regarding the assessment during admission or modification of diets according to these allergies.

Factors affecting choice of diet or fluids on admission

There were 33 subjects (35%) who were found to have some factors that might affect their choice of diet and fluids. These factors included dentures (55%, n=18), teeth problems (3%, n=1), chronic illnesses (18%, n=6) (which included diabetes and or renal diseases); religious beliefs (3%, n=1), vegetarianism (3%, n=1) and requiring soft food (3%, n=1) due to decrease ability to chewing solid food. Four subjects (12%) had a combination of diabetes and denture problems and one subject (3%) had a combination of diabetes, renal and denture problems.

Monitoring intake and output

Of the subjects who had orders for monitoring of intake and output 85% (n=81) had complete documentation. Eleven subjects (12%) had incomplete documentation and

there were three subjects (3%) with no documentation about the status of intake and output.

Special utensils required

Twenty-six subjects (27%) required a nurse or occupational therapist to provide special utensils to assist in feeding. The utensils include: a teaspoon (46%, n=12), a spouted cup (38%, n=10), a straw (27%, n=7), a non-slip mat (8%, n=2) and a rimmed plate (4%, n=1).

Medications

Seventy subjects (74%) had problems taking tablets and required alternative routes or medications to be withheld. Fifty-three subjects (76%) were able to swallow crushed tablets or syrup, and 39 subjects (56%) had to have their medications administered via an enteral tube. One subject (1%) required injection or infusion and another had her medications withheld. Chi-square test indicated the relationship between severity of dysphagia and medication required alternative route was statistically significant; chi-square: 58.3 (df 10, n=95) $p < 0.000$.

Assistance with eating or drinking

Only seventeen subjects (18%) could eat and drink entirely independently. Sixty-three subjects (66%) required some degree of assistance, of these 30% (n=19) only required assistance with setting up a meal tray; and 70% (n=44) subjects required staff or family members to feed them and help them with eating or drinking. Twelve subjects (13%) were kept on long-term tube feeding and three subjects (3%) were on IVT only during hospitalisation.

According to the severity of dysphagia the 44 subjects who required full assistance with feeding were the category of, mild 16% (n=7), moderate 52% (n=23) and severe 32% (n=14) respectively. This excludes those who could not eat or drink at all and depended on IVT or tube feeding (Figure 40). The relationship between severity of dysphagia and requirement of eating or drinking assistance was statistically significant; chi square: 43.1 (df 8, n=95) $p < 0.000$.

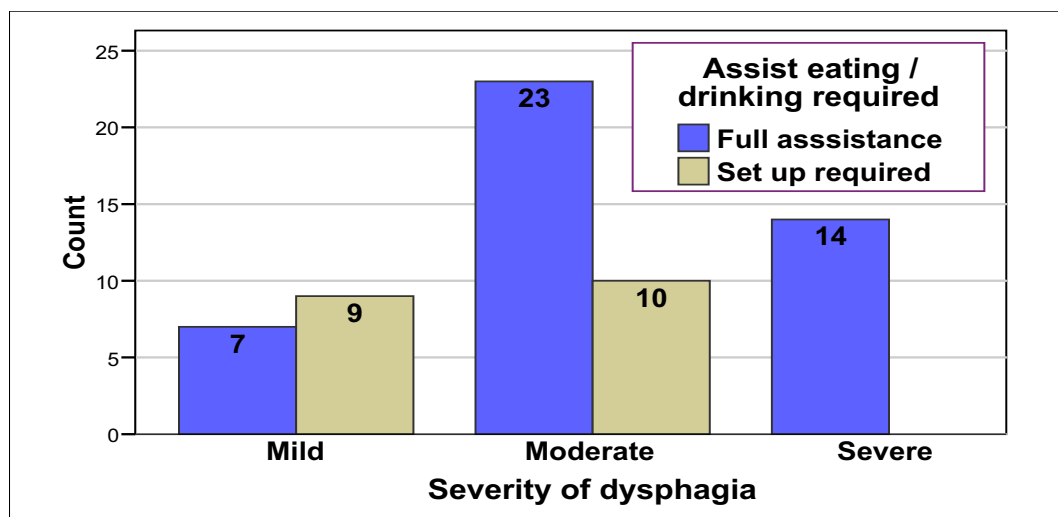


Figure 40: Subjects require different assistance for various severity of dysphagia

Extra nutritional support

Excluding the 13 subjects (14%) who depended on enteral tube feeding for all their nutrition, 52 subjects (63%) required extra nutritional support. This included 18 subjects (35%) who required enteral nutrition (for example: Ensure™) and 24 (46%) who required extra oral nutritional support (for example: snacks, milkshakes, yoghurt). Ten subjects (19%) required additional oral and enteral nutritional support. Of the fifty-two subjects who required extra nutritional supplements and the percentage for mild, moderate and severe dysphagia groups were 19% (n=10), 60% (n=31) and 21% (n=11) respectively (Figure 41).

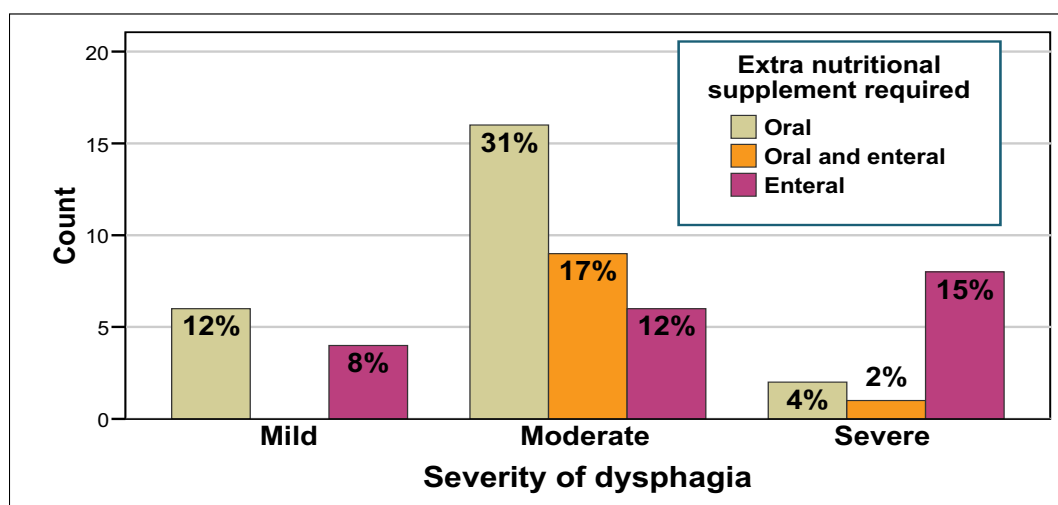


Figure 41: Subjects requiring extra nutritional supplementation according to severity of dysphagia

Other factors influencing oral intake

Excluding the seventeen subjects (18%) with severe dysphagia who were ordered nil orally, sixty-seven subjects (71%) had factors other than their dysphagia that impacted on their oral intake. The reasons for were categorised into eight main factors. Appetite could be affected by more than one factor, 26 subjects (39%) had one factor, 25 (37%) had two, 14 (21%) had three and 2 (3%) had four. Factors included poor appetite (58%, n=39), drowsiness and decreased conscious level (46%, n=31), fatigue (27%, n=18), behaviour or cognitive impairment (19%, n=13) and gastrointestinal problems (16%, n=11).

Outcomes

Body weight

The study found few subjects were weighed on admission or discharge. The documented weight came from several sources. These included the subjects' medical records from age care facilities, reports from the subjects themselves or their family, an estimation of dietician, or being weighed by a nurse. Consequently, forty subjects (42%) had their weight recorded on admission. Subsequently thirty-one subjects (33%) had a weight recorded during their hospitalisation. The difference in body weight between admission and during hospitalisation could only be calculated for the 31 subjects. The percentage of subjects who gained weight was 26% (n=8), and those who lost weight comprised 74% (n=23). For those who lost weight during hospitalisation the distribution is shown below (Figure 42).

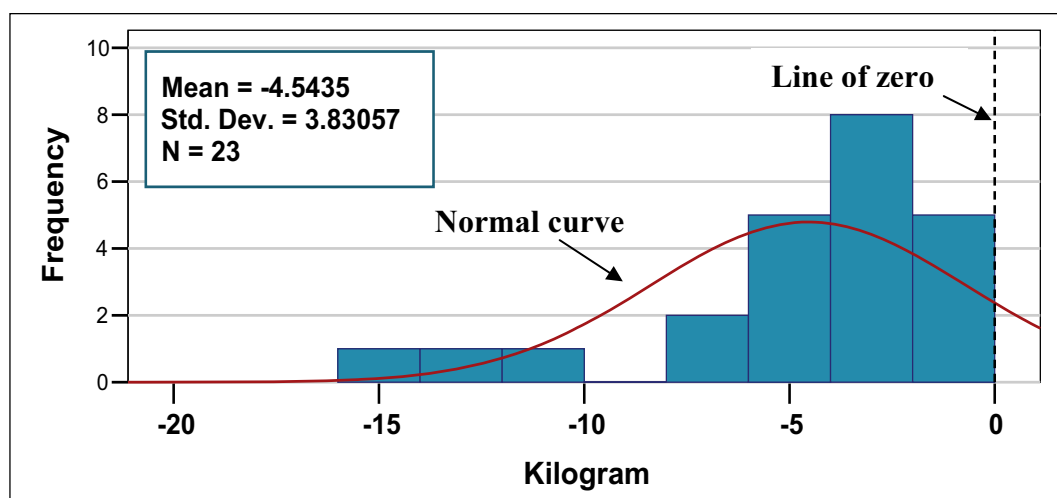


Figure 42: Difference of body weight during hospitalisation

Subject' BMI on discharge

Nineteen subjects (20%) had the data on body weight and height recorded on admission and during hospitalisation. Of the group of 19 subjects, the percentage of subjects who were of normal weight was 47% (n=9), underweight 21% (n=4), overweight 21% (n=4) and obese 11% (n=2). Of the four subjects who were underweight before discharge, two were underweight on admission.

Low serum albumin level before discharge

Seventy-seven subjects (81%) had their serum albumin level checked at least once during their hospitalisation. Results from the final reading prior to discharge were analysed. Of these, 43 subjects' levels (56%) were below 35g/L and 34 subjects (44%) had serum albumin levels within a normal range: 35-50g/L before discharge.

Malnutrition and dehydration

Twenty-one subjects (22%) had malnutrition documented by a doctor or dietician. Forty-three subjects (45%) had low serum albumin levels and twenty-three (24%) lost weight before discharge. Fifty-nine subjects (62%) had one or more of these factors. Subjects who either lost weight, had low albumin before discharge or were documented as having malnutrition were classified as being malnourished (Figure 43). The relationship between nourishment (malnourished or not) and the occurrence of chest infection was analysed statistically using a chi square test. Excluding those who were not assessed, the result was found to be statistically significant: 8.1 (df 2, n=87) p=0.017.

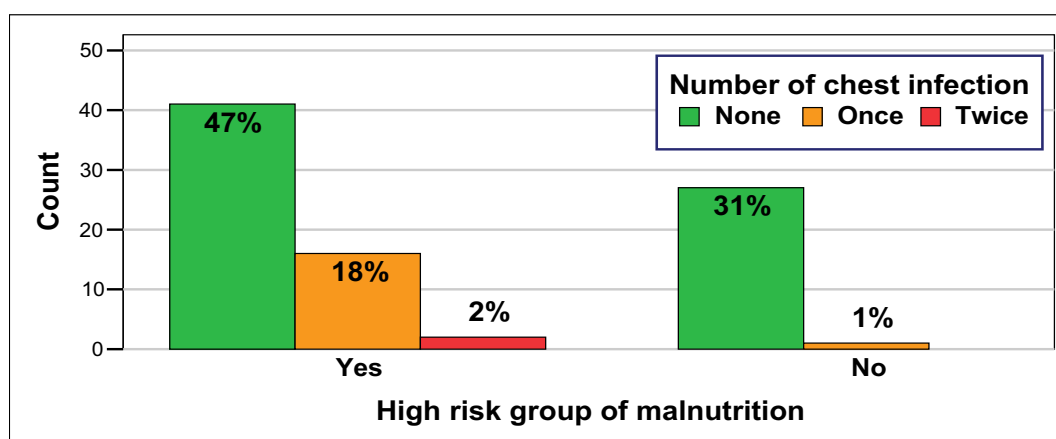


Figure 43: Subjects risk of malnutrition and the number of chest infections

Laryngeal penetration and aspiration

When material (including food, fluids, oropharyngeal or gastric secretions) enters the laryngeal vestibule it is known as laryngeal penetration. If the material passes through the vocal cords into the trachea and beyond it is known as aspiration and can cause varying degrees of inflammation or infection (aspiration pneumonia). These conditions were observed by a speech pathologist or health care providers with signs such as dysphonia, dysarthria, abnormal volitional cough and or prolonged coughing post swallow.

Incidents or aspiration were recorded from the case notes. Episodes of laryngeal penetration and aspiration were recorded in patient notes by, nurses, speech pathologists and doctors. In the study, 43 subjects (45%) had documented incidents of laryngeal penetration or aspiration during hospitalisation. Seventy-two percent (n=31) had one episode, 21% (n=9) two episodes and 7% (n=3) three episodes. The distribution of the number of laryngeal penetration or aspiration according to the mild, moderate and severe dysphagia groups is showed in Figure 44.

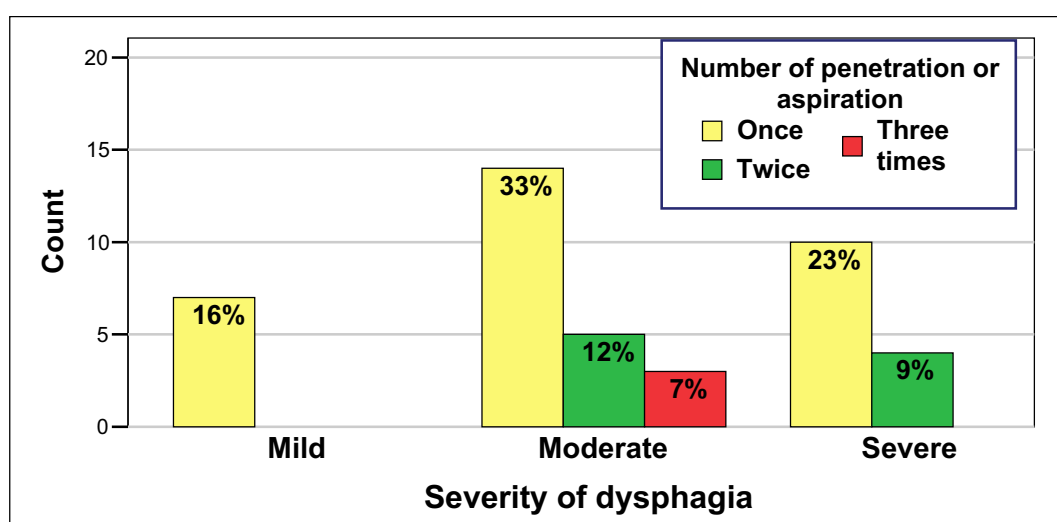


Figure 44: Number of penetration or aspiration occur of the different severity of dysphagia

However, 14% (6 out of 43) of these subjects had no clinical indicators of risk of aspiration identified following initial swallowing assessment by a speech pathologist. The relationship between the occurrence of penetration or aspiration and the severity of dysphagia was not statistically significant; chi-square: 5.7 (df 2, n=95) p=0.058.

Pneumonia

In addition, 21 subjects (22%) had documented aspiration pneumonia or chest infection during hospitalisation. Nineteen subjects (90%) had one episode and two subjects (10%) had two episodes. According to the category of mild, moderate and severe dysphagia groups, the percentages of subjects who had chest infection were 5% (n=1), 33% (n=7) and 62% (n=13) respectively (Figure 45).

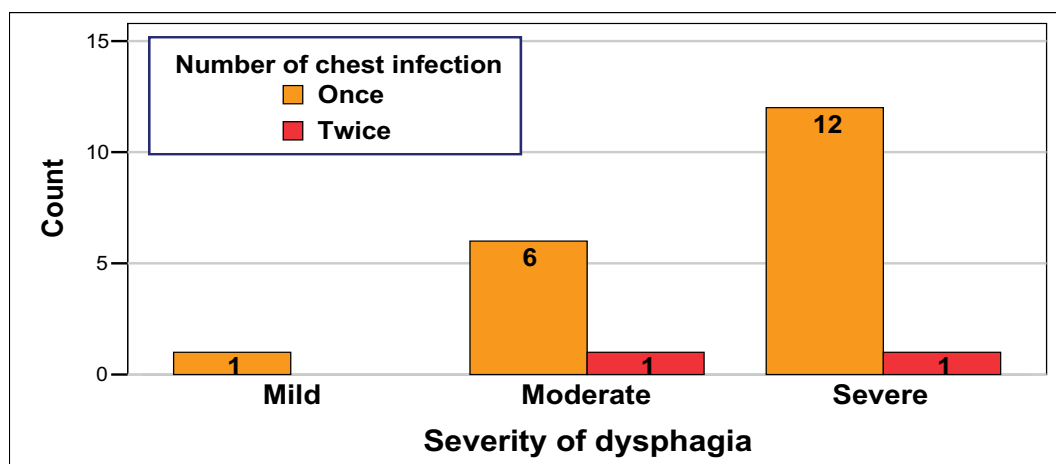


Figure 45: Occurrence of chest infection in various severities of dysphagia

The relationship between the number of chest infections that occurred and the severity of dysphagia was statistically significant; chi-square: 18.1 (df 4, n=95) $p < 0.001$.

Intake on discharge

The types of intake for subjects when discharged was categorised into five groups. These were normal diet and fluids or premorbid diet (8%, n=8), modified diet and fluids (61%, n=58), modified diet/fluid supplemented with enteral tube feeding (7%, n=7), enteral tube feeding (11%, n=10), and IVT (13%, n=12). A combination of methods is shown in Figure 46.

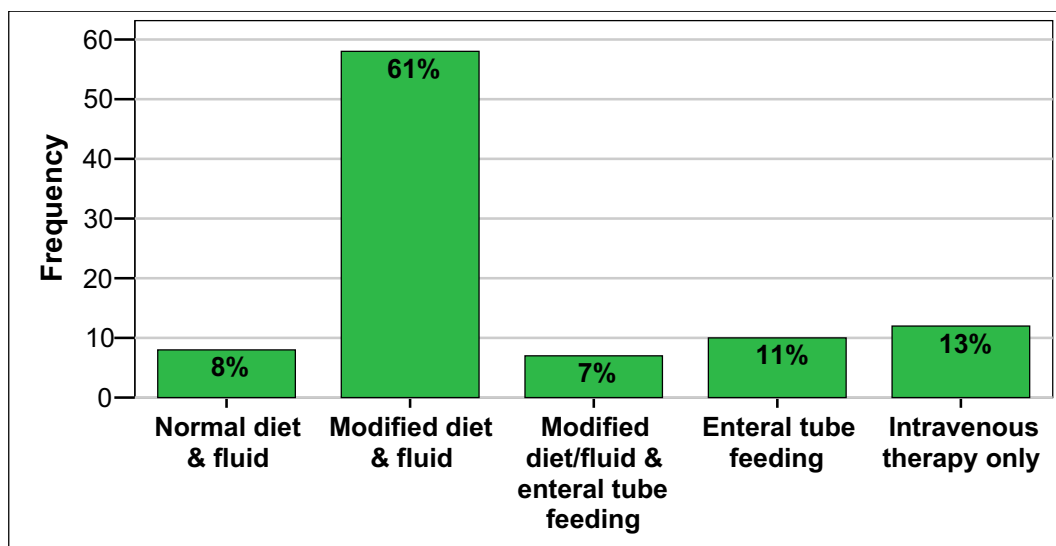


Figure 46: Types of dietary intake on discharge

According to the category of mild, moderate and severe dysphagia groups, the distribution of various types of intake on discharge is shown in Figure 47. Although one subject (1%) suffered mild dysphagia, she was provided IVT only, this is because she suffered from severe stroke and her condition was unstable. There was a statistically significant relationship between severity of dysphagia and type of intake on discharge, chi square test: 45.2 (df 8, n=95) $p < 0.000$.

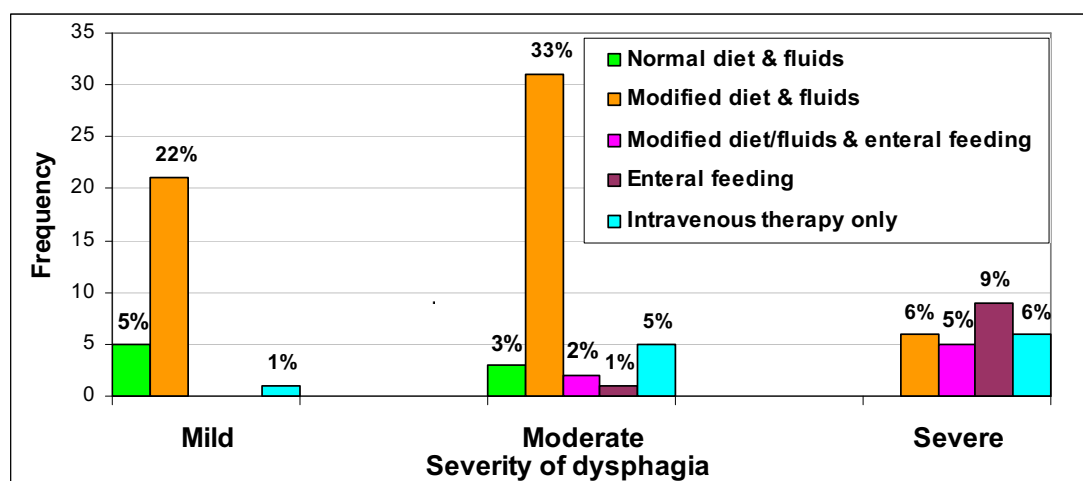


Figure 47: Distribution of various types of intake according to severity of dysphagia

Significant problems with intake on discharge

Thirty-nine subjects (41%) had significant problems with intake on discharge this was defined as inability to tolerate pre-morbid (minced or soft diet) or normal diet.

Change in intake during hospitalisation

Change in intake during hospitalisation was recorded as improved (59%, n=56), unchanged (21%, n=20) or deteriorated (20%, n=19). As can be seen in the graph below, most subjects with mild or moderate dysphagia improved their intake, but in the severe group this was not the case. A chi-square test was statistically significant 13.2 (df 4, n=95) p=0.01.

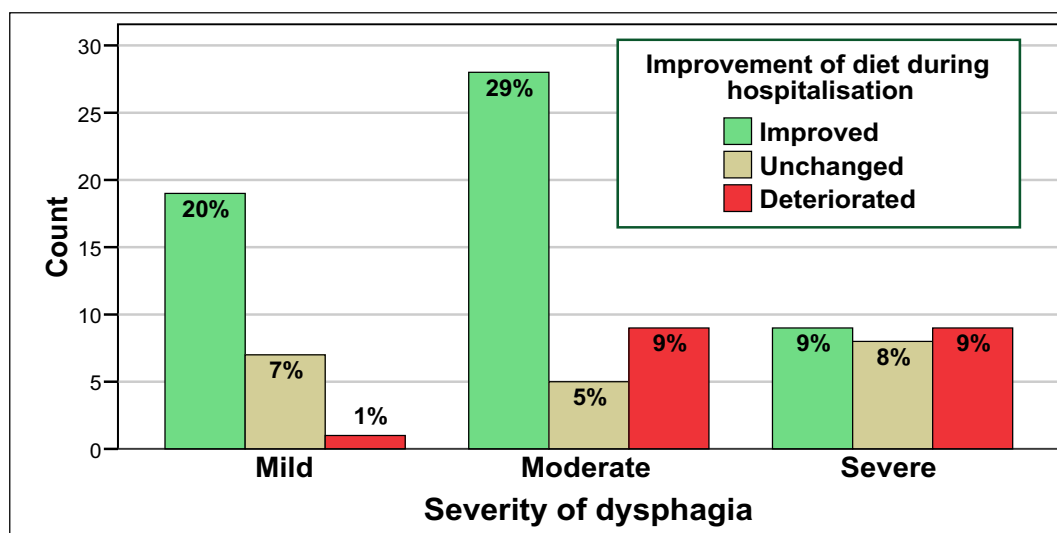


Figure 48: Improvement of intake during hospitalisation

Swallowing rehabilitation program after discharge

Only seven subjects (7%) were referred to a swallowing rehabilitation program after discharge, 15 subjects (16%) died.

Discharge education

Of the 80 subjects (84%) who were alive at discharge from hospital, for 91% (73 out of 80) dysphagia management was explained to subjects, their families and carers. Seven subjects (7%) had no documentation of their management, of these one subject (14%) had resumed a normal or premorbid diet, five subjects (72%) were on a modified diet and one subject (14%) was on PEG feeding.

Follow up

Notes were examined for any documentation of any follow up appointment with either a doctor, dietician, speech pathologist, physiotherapist or occupational therapist.

Only 20% (16 out of 80) subjects alive on discharge were scheduled for a follow up appointment. When subjects were categorised according to mild, moderate and severe dysphagia, the percentages of subjects who were scheduled for follow up dysphagia management were 27% (7 out of 26), 17% (6 out of 35) and 16% (3 out of 19) respectively (Figure 49).

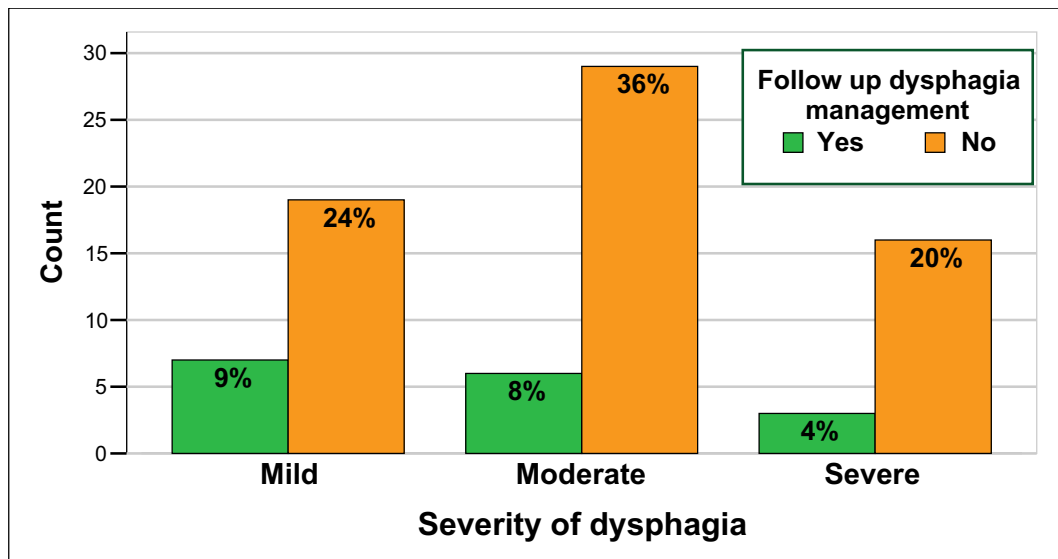


Figure 49: Subjects required follow up dysphagia management

Death and Destination

As can be seen in the (Figure 50) below only a small percentage (9%) of subjects were discharged home. Most (48%) were discharged to an aged care facility.

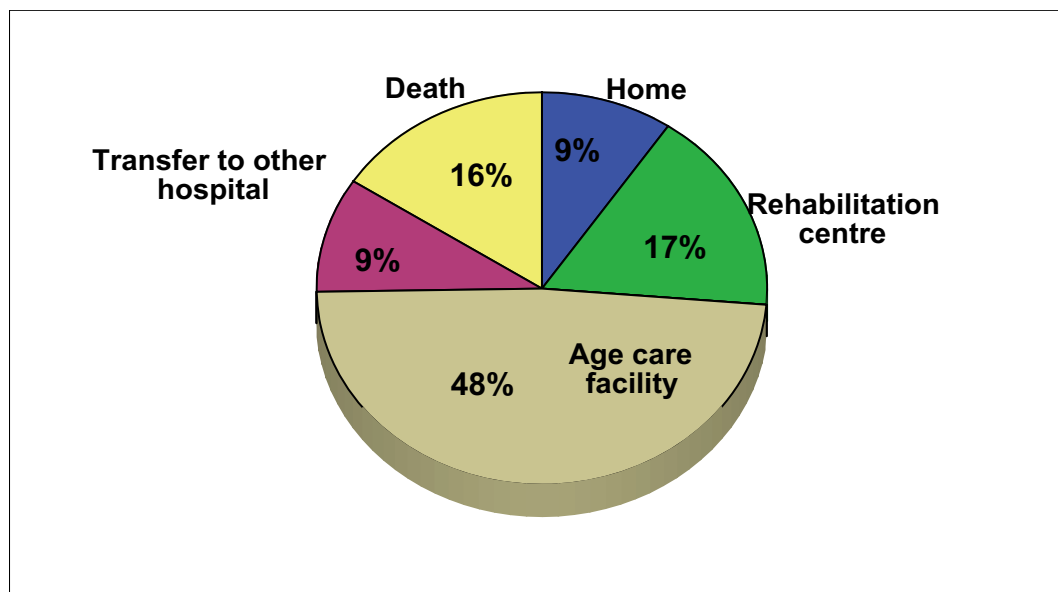


Figure 50: Outcomes at subject's discharge

The results were also analysed according to the severity of dysphagia and shown in Figure 51. A higher percentage of subjects with severe dysphagia died and also higher percentage of subjects with mild dysphagia went home. Of the 46 subjects (48%) discharged to age care facilities, 14 (30%) had suffered severe dysphagia and 22 (48%) moderate dysphagia. Four (9%) had suffered a severe stroke, 16 (35%) a moderate stroke. A chi-square test showed there was a statistically significant relationship between destination and severity of dysphagia 15.9 (df 8, n=95) p=0.043.

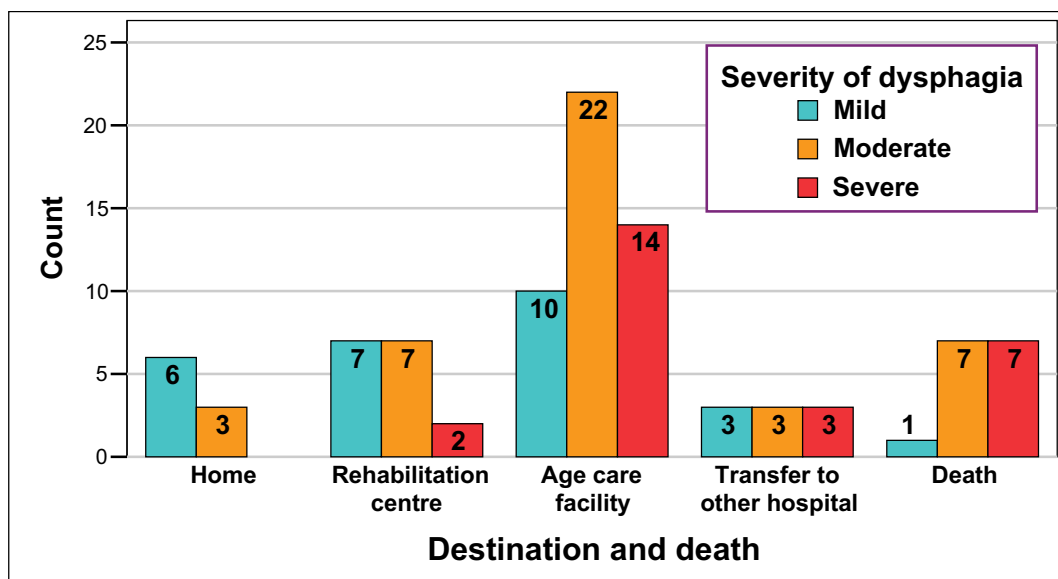


Figure 51: Outcomes of subjects with different severity of dysphagia

PHASE TWO

This phase involved collecting data from the statements of the multidisciplinary team in the medical records. In the interests of interpreting, organising and integrating significant qualitative data and information, a content analysis was used. In this study, the main aims were: to evaluate the strategies that were used for the assessment of acute dysphagia following stroke; to assess the role of nurses within the multidisciplinary team management; and to assess the outcomes of the team approach. These aims shed light on the four essential domains to facilitate the findings and outcomes within management. These four domains are listed below:

- significant issues regarding the assessment or investigation of dysphagia;
- significant issues regarding oral intake;
- significant strategies used to improve patient's oral intake;
- significant strategies used to prevent complications and improve outcomes;
- other issues.

Significant issues regarding the assessment or investigation of dysphagia

The main issues found in medical records regarding the assessment or investigation of dysphagia were:

Physical and mental conditions

A common reason for given for difficulty in assessing dysphagia was the condition of the subject. This included critical illness, reduced consciousness, confusion and lack of cooperation. Some had been diagnosed with dementia.

For example: 'Patient was not cooperative for a long assessment or review of swallowing' (Subject: S46); 'Too fatigued to assess...' (S64); 'Unable to assess with diet or fluids as patient not allowing spoon near her mouth...spitting if touched her lips – quite aggressive...' (S59); 'Patient cannot open mouth well, difficult to assess....' (S77).

Staff issues

Several subjects had their swallowing assessment delayed over a weekend or holiday because a speech pathologist was not available and subjects also had a consultation missed or delayed due to poor staff communication.

For example: 'Unable to get speech pathologist (weekend)' (S25); 'Delayed response of consultation due to verbal referral (phone contact) missed' (S1, 33).

Significant issues regarding problems with oral intake

Significant issues regarding oral intake identified in the notes were:

Physiological problems

One of the issues identified as impacting on intake was patient positioning. Poor positioning resulted in the kinking of the neck which interfered with swallowing.

For example: 'Delayed swallow initiation and reduced hyolaryngeal excursion; further compromised by head position blocking off the stronger side of the throat.'(S11); 'Managing small amount water and minced diet with head turned to right side. Continuing to aspirate thin fluid with head in midline position' (S122).

Patient positioning was also impeded by surgery or diagnostic procedures.

For example: after lumbar puncture, and maximum upright 30 degree sitting position.

Gastrointestinal upsets such as nausea, vomiting, reflux, stomach pain, abdominal cramps or diarrhoea, were documented as reasons for diet being withheld (S60, 113).

For example: 'feeds ceased due to patient vomiting, feed to recommence at midnight' (S104).

Behavioural issues

Un-cooperative behaviour was also reported such as mouth clenching, spitting out medications and subjects pulling out enteral tubes.

For example:

‘Patient clenched mouth shut for refused more oral intake’ (S37);

‘Patient reports not wanting to eat anymore, suggests he just wants to die, not cooperative spat out semi-thick fluids. Generally flat and depressed. Easily agitated....’ (S80);

‘Tried to give medications orally, but unsuccessful as patient was uncooperative’ (S37).

Problems with enteral tubes

Problems with enteral tubes included blockage by sediment of feeds, a guide wire which could not be removed following insertion, dislodgement. These all impacted on intake, prolonged the time before feeding could be resumed.

For example:

‘NET guide wire removed with a little difficulty. Unable to flush with water, doctor advised removal and for review or replacement morning’ (S55);

‘Unable to remove guide wire of NET, unable to give medications.’ (S38)

Dentition and oral hygiene

Some subjects had ill fitting or absent dentures or poor dentition which increased the difficulty of chewing and impeded diet.

Problems relating to the condition of the oral mucosa were very common and these also impacted on appetite and diet. These included thrush, abrasions, dried mucosa and coating on the tongue.

Subject reactions

Several subjects did not understand the reason for 'nil by mouth' order (waiting for a speech pathologist review) and complained of being hungry and thirsty (S1, 50).

Medication problems

The ability to administer medications was reduced not only by the dysphagia but also by patient refusal and enteral tube blockage (S37).

It was also found that there were occasions when medication able to be delivered by the enteral route or syrup form was not available (S23).

Food issues

Some subjects complained about the food itself. Subjects disliked the type, consistency and appearance of food and fluids. Abnormal taste, smell and hypersensitive sensations were also reported (8.2%, n=8). One subject complained about using a plastic cup (S113).

One subject who was unable to eat pork due to their religion could not eat jelly made with porcine gelatine (S53).

Strategies used to improve subjects' intake or nutritional status

Strategies used to improve subject intake or nutritional status included:

Physical support

Nurses reminded subjects who had pocketed food or prolonged mastication with oral residue to remove the bolus with their tongue, clear with fingers, mouth swabs or a fluid chaser (S17, 18, 40).

Aids such as a straw, spouted cup or syringe or a teaspoon were used to assist patients to eat or drink.

Positioning involved sitting the patient up or leaning them onto their unaffected side, doing a chin tuck manoeuvre or positioning the head in a way which facilitated swallowing (S27, 90, 99).

Keeping subjects in sitting upright for half to one hour post-meal to minimise reflux due to position and only feeding the patient if alert (S23, 48, 93).

Documented methods of preventing re-feeding syndrome (gastrointestinal upset caused by commencing diet following a long period of 'nil by mouth' included commencing or tube feeding gradually and slowly increasing increments to allow adaptation (S59).

Psychological support

Documented strategies used to increase intake included frequent encouragement for subjects eat or drink.

Nurses also recorded ordering patient preferred food and drinks from the kitchen to improve appetite (S71, 93). Subjects' likes and dislikes regarding food and drinks were also recorded for examples: soy based milk beverage, milkshakes, tea and coffee.

Family support

Families also provided support by bringing in 'nice food' and feeding their loved ones.

Nutritional support and control

For several subjects tube feeds were ordered overnight to increase intake.

Strategies used to prevent complications and improve outcomes

Strategies that could prevent complications and enhance the outcomes were follows:

Coordination of care

Family members were asked to encourage the patient to perform oro-motor exercises (S23, 38, 85, 93).

Dieticians were involved in educating staff in age care facilities, family and patients on how to cook and prepare a modified diet and fluids when discharged. This was done either by discussion or detailed written instructions.

Family meetings were commonly used to aid communication between multidisciplinary team members, the patient and family members. Issues discussed included the nature of stroke and dysphagia, management, progress, plans for future care and cessation of treatment and comfort only care.

The feeding regimes of subjects discharged with PEG feeding were adapted for bolus feeding before discharge. Equipment was sometimes loaned to the subject or care providers to maintain appropriate care, for example: a 'Kangaroo' feeding pump (S113).

Monitoring the safety of intake

When high risk subjects were commenced on modified diet or fluids the speech pathologist would inform nurses to monitor the patient closely to detect complications and prevent aspiration.

Patients and family members were educated on risks such as feeding or drinking while lying flat (S48, 53).

Preventing infection and aspiration

Measurements of the NET tube were recorded six hourly to ensure the tube remained in-situ.

The correct position of NET was confirmed with X-ray screening following each insertion to prevent displacement.

One test used to check for silent aspiration for patients with a tracheostomy was the methylene blue test. The subject drinks milk with dye added and the tracheal aspirate is checked for discolouration from the dye (S43).

NET aspiration was performed regularly (five to six hours) to check the residue of stomach contents to ascertain the subject's tolerance of intake; if the amount was more than 100mls or gastrointestinal bleeding (haematemesis) was suspected, the feeding regimen was adjusted or withheld (S37, 78).

Food and fluids were commonly withheld due to severe choking, vomiting or signs of aspiration and the subject was reassessed by a speech pathologist as necessary to provide proper management (S9, 55, 106). Staff monitored subjects for the possibility of aspiration with pulse oximetry, observation of respiration rate, temperature, chest X-ray screening and oral pharyngeal suction.

Other issues

Other issues that related to the dysphagia management were:

Decision making

A subject had nausea after insertion of PEG and requested removal of the tube and further stated that she did not wish to be kept alive by any artificial means. Finally, the subject agreed to keep the tube for medications, but not for feeding (S71).

Fluid balance chart (FBC) was initially maintained but then ceased because nurses were unable to check output due to incontinence or voiding in toilet (S53).

Communication issues

Severe communication problems were common including receptive and expressive dysphasia. Language problems were also common requiring an interpreter or families to translate.

DISCUSSION

INTRODUCTION

The purpose of this research was to evaluate the hospital management of patients admitted with stroke resulting in acute dysphagic. In particular, the focus was on the nurses' role and collaboration of the multidisciplinary team, and to investigate assessment, observation and interventions, with regard to the impact on the decision-making and patient outcomes. This study has important implications for the management of patients with acute dysphagia following stroke, in regards to the quality of care provided, cost effectiveness, efficiency and patient safety and recovery.

This chapter discusses the significance of the findings and implications in relation to evidence found in the literature. The discussion encompasses demographics, the impact of functional impairments, assessment, management of nutritional status, interventions, complications, multidisciplinary team collaboration, communication, discharge planning and support, and the strengths and limitations of the study.

DEMOGRAPHIC FEATURES

Cerebrovascular disease is serious with a high mortality and disability rate. Adults of both genders and all ages are affected. The results demonstrated a wide range of ages with subjects between 30 and 92 years, however, the greatest proportion of subjects (60%) were between the ages 75 and 89, and the number of victims was double that of any other age group. This may result in the perception that stroke with dysphagia is exclusively related to ageing. Nevertheless this disease is complicated for aged victims because of the presence of co-morbidities and prior disabilities.

The management of dysphagia is also complicated by the fact that it appears the condition is more commonly severe in those who suffer a severe or moderate stroke (the severity of dysphagia was related to the severity of stroke ($p=0.015$)). However, in this study severity was not related to the type of stroke (ischaemic and

haemorrhagic) ($p=0.253$) or the episode of stroke ($p=0.805$). Thus it should be recognised that dysphagia related to stroke may occur with the first presentation.

Although 24% of subjects were classified as critically ill during admission and 14% were admitted to high acuity unit (such as ICU or HDU), the median of hospitalisation was only 21 days (the \bar{x} was 27.6 days, $\sigma=22.4$). This may be due to the work of medical social workers provide support with appropriate information, arrangement of placements and related community care services for patient and family. However, the range of length of stay was broad, up to 114 days. This indicated several cases still had significant problems and prolonged the length of stay. This could also relate to problems with placement of patients in care facilities.

The results indicated that patients who suffered mild dysphagia following stroke were usually be discharged within two weeks, indicating a more rapid recovery. Thirty-two percent ($n=30$) were discharged within 14 days, 62% of these subjects had mild dysphagia and 35% had moderate dysphagia. In contrast, 78% (42 out of 54) of subjects who suffered significant dysphagia or stroke required prolonged hospitalisation of over two weeks. This result confirms findings from previous studies. However, the comparisons were made using admission GCS and it is possible some subjects deteriorated during hospitalisation for example suffered a second stroke (S57, 109).

Multiple benefits have been reported associated with admission of acute stroke patients to a dedicated unit, these include reduced mortality and length of stay, improved functional status and enhancement of the rehabilitation process (Indredavik, Bakke, Slordahl, Rokseth & Haheim 1999). However, the results of this study indicated that only 55% of patients who suffered dysphagic stroke were admitted to a specialist unit, with 26% admitted to general medical wards and 18% were admitted to surgical wards. This may be less than optimal as nursing staff may be less experienced or have limited training in the management of stroke and dysphagia.

NEUROLOGICAL STATUS IMPACT

On admission the verbal GCS scores demonstrated that more than half subjects (52%) had a problem with their verbal response. This figure improved by discharge, but up to 6% of subjects were unable to respond verbally at this time. Motor GCS indicated that on admission, on initial swallowing assessment by speech pathologists and on discharge from 23 to 27% could not obey commands. Thus more subjects had a problem with their verbal response than motor. The data indicates that dysphagia and ability to respond verbally are linked. This complicates both the assessment and management of these patients. Thus interventions need to be tailored to help manage these problems. Family members who are familiar with the patient may assist in this issue. They may be more easily able to interpret the patient's attempts at communication and can provide information about like and dislikes regarding diet and other matters. All subjects were seen by speech therapists and these professionals can provide valuable interventions to assist in the management of this problem. However, nurses care for the patient 24 hours a day, so they need to be able to assist with communication. Aids such as picture boards and writing pad can be used.

As expected the relationship between communication problems and severity of dysphagia was statistically significant ($p=0.037$). This is explained in part by the pathophysiology of stroke and dysphagia, with the same structures responsible for eating and speaking. Thus, the verbal GCS score could be used as a marker for possible dysphagia.

By discharge overall the number of subjects with GCS scores indicating mild brain injury slightly increased, but the number with moderate decreased. The number with severe injury was unchanged, but this number did not include those who died. Thus in real terms it is likely that there was slight increase in those with severe injury. Up to 5% of subjects had incomplete GCS data; this may indicate the subject's neurological status was not assessed adequately. GCS is an essential observation for assessing cerebral function and changes may indicate deterioration thus it is important that this simple observation should be done regularly during hospitalisation.

Many (43%) of subjects had premorbid disabilities that may have impacted on oral intake. However, this number included minor visual impairments (24%). The majority of subjects did not have a serious disability on admission. Thus these subjects may have previously experienced relatively good quality of life. A significant factor to be considered is the issue of dentition, 24% of subjects had unfitted and missing dentures this compounds problems with dysphagia. Therefore, a dental consult should be considered, to gain expert advice on managing this problem.

DYSPHAGIA ASSESSMENT

Nurses have the most contact with patients and have the greatest opportunity to recognise dysphagia associated with stroke. Although, the documentation indicated that dysphagia was rarely recognised by a nurse, this may not actually be the case as documentation about any assessment by nurses was generally poor. It may also be that the nurses notified doctors of the condition, but did not document this. However, it needs to be considered that this may also indicate a lack of awareness of the problem. It appears that few nurses have formal training on the assessment of swallowing or that they do not recognise this as a part of their role. Also they may be influenced in their decision not to perform a swallowing assessment by whether a speech pathologist is available and may have insufficient confidence or experience perform a comprehensive assessment. A significant number, 28% of subjects suffered only mild dysphagia, 37% of these subjects (10 out of 27) were ordered 'nil by mouth' by a doctor and waited up to three days for assessment by a speech pathologist.

In addition it is essential that severe dysphagia be recognised as early as possible to prevent serious complications such as aspiration. If nurses in the Emergency Department or on admission can identify these patients, risks can be minimised. A dysphagia protocol (Appendix 5) is used in the hospital that authorises only the CNC and senior nursing staff (as delegated) to 'FURTHER' modify diet or fluids for a dysphagic stroke patient when a speech pathologist is unavailable. The nurse is then required to inform a speech pathologist of this situation as soon as possible. This means that nurse have limited opportunities to practice assessment and management of patients with swallowing problems (Magnus 2001). In some institutions a certified nurse will perform the initial assessment of swallowing to screen patients for

dysphagia. This allows patients to be assessed within one day of admission and before any oral intake is commenced (Odderson, Keaton & McKenna 1995, Perry 2001a, 2001b).

Most subjects had a comprehensive swallowing assessment performed by a speech pathologist, excluding 23% of subjects who were critically ill or were too neurologically unstable for assessment. But only 53% of subjects (39 of 73) were assessed within 24 hours although 77% subjects were assessed within three days of admission. According to National Clinical Guidelines for Stroke (NCGS) developed by the Royal College of Physicians in Britain, assessment should be performed within 24 hours of the onset of stroke. A hospital protocol indicates that all stroke patients should be kept on nil orally until their swallowing is assessed. The delay in assessment has implications for the nutrition of patients, particularly for those who in retrospect did not require 'nil by mouth'. Due to limited resources it is very difficult to have prompt swallowing assessment undertaken by a speech pathologist. Screening of acute stroke patients for dysphagia by an appropriately educated nurse prior to assessment by a speech pathologist could possibly reduce the incidence of inappropriate orders for nil orally. This may prove to be a cost effective strategy for improving management.

Some subjects waited for assessment of their swallowing for more than three days. This was sometimes due to the unavailability of a speech pathologist, who does not work on public holidays or weekends. Other possible reasons for delayed assessments are subjects who had late presentation of dysphagia and some who had surgical procedures performed. However, these were uncommon.

Patients who are admitted to the Neurology or Stroke Unit are routinely assessed by a speech pathologist; however, when they are admitted to other units a doctor's referral is required for a consultation. Thus, there may be a risk that the assessment may be either missed or delayed.

On average subjects were assessed by a speech pathologist 5.5 times during hospitalisation. Guidelines (SIGN 2004) suggest swallowing assessment should be

done daily to allow interventions to be adjusted to meet the needs of the individual. Appropriately educated nurses could easily perform such assessments.

Seven percent of subjects were permitted oral intake before a documented swallowing assessment. These patients could have been placed at risk of complications, such as aspiration and respiratory infection. Anecdotal evidence suggests that the general perception of health professionals in the hospital where the research was conducted, is that silent aspiration is rare. However, in this study 43 subjects (45%) had documented incidents of laryngeal penetration or aspiration and 14% (6 out of 43) of these subjects had no clinical indicators of risk of aspiration. This demonstrates the need for frequent assessments and the implementation of precautions to protect patients. Only 2% of subjects had further investigations such as laryngoscopy and FEES to assess their dysphagia. It appears that more subjects may have benefited from these investigations, given the high rate of aspiration and laryngeal penetration. If these investigations were performed protective measures and interventions such as tube feeding could possibly be implemented earlier.

IMPACT ON NUTRITIONAL STATUS

The results indicated that documentation of assessment of nutritional status was inadequate. This may indicate either assessments were not performed or that documentation was poor. In this study data on body weight and height was collected from multiple sources, this included recall from the patient or family, estimation from dietician, and measurement by nurses. It is important that patients with dysphagia are weighed regularly and BMI calculated, so appropriate nutritional support can be provided. However, 70% of subjects had incomplete records of BMI (missing body weight or height) and 58% had no record of their weight during hospitalisation. This indicates that most of the subjects' nutritional status was not fully evaluated and were not adequately monitored. Only 33% subjects were weighed at least twice during hospitalisation, of these 74% lost weight with the mean loss being 4.5kg; 21% were underweight but half of these were underweight on admission. Weighing stroke patients can be problematic, some are seriously ill, many have mobility problems and communication and behavioural problems are also an issue. Multiple staff is usually required. Weigh beds and sitting scales can be used, but with staff shortages this may

not be recognised as a high priority. The importance of weight in assessing nutritional status needs to be recognised.

Although 95% of subjects required their intake to be recorded, charting indicated some difficulties (25% incomplete). This also has an impact on the ability to assess hydration and nutrition.

Furthermore, 19% of subjects did not have their serum albumin measured during their hospitalisation and 56% of subjects were found to have an albumin level below the normal range (35g/L). In addition, 22% had documentation indicating they were at risk of malnutrition or dehydration by doctor or dietician. This finding further indicates a large number of subjects suffer malnutrition probably compounded by or related to their dysphagia. This would significantly impact on their recovery.

Nearly all the subjects (87%) had a period of time on nil orally, the median was six days (\bar{x} =11.9, σ =14.9); with one case was prolonged 84 days. The major reason for this order was suspicion of a swallowing problem (61%). Other reasons for this include severe stroke associated with deterioration in mental status, cognitive disability and behavioural changes including confusion, uncooperativeness, aggression, restlessness or depression. These factors also present barriers to assessment and implementation of interventions. In addition, airway impairment requiring placement of an endotracheal, tracheostomy or nasal pharyngeal tube, also impeded the commencement of oral intake.

Some patients (46%) on nil orally were provided enteral intake. When this was considered the median time 'without any enteral or oral intake', was four days (Figure 26). This creates a risk of malnutrition, thus monitoring of nutritional status is essential. It also needs to be considered that many subjects were elderly and had multiple co-morbidities such as diabetes or renal disease, this increases the risks from malnutrition.

Malnutrition has been demonstrated to impact on the recovery of patients from dysphagic stroke (Martineau et al); a 2005 study found subjects who were

malnourished on admission suffered greater deterioration during their hospitalisation. The results of this study also indicated that malnourished subjects or those identified to be at high risk of this, were at greater risk of chest infection. However, in this study many patients did not have their albumin, weight or nutritional status documented so the results must be cannot be considered to be reliable.

NUTRITIONAL SUPPORT

The data indicated no subjects were provided TPN during hospitalisation, although TPN is an effective way to replace nutrition. However, enteral nutrition is preferred as gut integrity is maintained and there are less complications (Jeejeebhoy 2002). Ninety-five percent of subjects were ordered IVT for some time and the median was eight days (\bar{x} =10.3, σ =9.4). This is an important intervention to provide hydration while the patient is on nil orally and may also be used for administration of medication if required.

Thirty-nine subjects (41%) had significant problems with intake on discharge. This was defined as inability to tolerate pre-morbid (minced or soft diet) or normal diet. This indicates on discharge many patients were possibly at risk of aspiration or malnutrition. Thus the education of the patients, families or care providers is vital to rehabilitation and the quality of life.

Of the 46% of subjects who required enteral feeding during hospitalisation for nutrition, 33% were able to consume a modified diet. Enteral nutrition is beneficial to compensate for patients' inadequate oral intake. Of the subjects who had NET feeding, 39% subsequently had a PEG inserted and this remained in situ on discharge. This indicates the high percentage of subjects require long-term tube feeding, thus early PEG tube feeding should be considered minimising trauma from multiple NET insertion (mean of NET insertion was 3.2, maximum was 11) and the related complications. Only successful insertions of NET were recorded so the actual number of attempted insertions could be much higher (conventional approach was successful only after an average of 2.2 trials) (Dziewas et al. 2003). The complications of PEG appear to be low.

PREVENTING COMPLICATIONS

Laryngeal penetration and aspiration are common complications of dysphagic stroke, 44% of subjects had documented episodes from one to three times. There was no statistically relationship between severity of dysphagia and these complications. This indicates that professionals caring for these patients should recognise the risk of aspiration and laryngeal penetration and observe patients closely for these complications even if they do not have severe dysphagia. Nevertheless, it is possible more precautions could have been taken with those patients with severe dysphagia which may have accounted for the result. There was a statistically significant relationship between aspiration pneumonia and severity of dysphagia. This indicates that silent aspiration may have been a factor and all incidents may not have been recorded.

Nurses can take active measures to prevent aspiration such as taking care to position patients 45°-90° head up particularly following meals or fluids (half to one hour is recommended). In addition most patients should have their head tilted toward the unaffected (stronger) side with their neck slightly flexed (Davies 1999, Mitchell & Finlayson 2000).

OTHER MANAGEMENT ISSUES

Medication

Medication administration to dysphagic stroke patients may be a problematic issue. The results demonstrated that many subjects had trouble taking tablets. In addition many patients have co-morbidities that require treatment such as hypertension and diabetes. Additionally, most medications are prepared for the oral route which is relatively cheaper. Subjects may also be non compliant or medications can be pocketed in the mouth or under dentures. Nurses need to be aware of these problems and solutions such as syrup forms, administration via enteral tubes may be applied. However, this is not without problems such as tube blockage if flushing is not adequate. Mouth care is also highly important for these patients, there is a high incidence of oral infections such as thrush which reduces appetite and is highly

unpleasant for the patient. There is also some evidence that chest infection may be related to poor oral hygiene (Millns, Gosney, Jack, Martin & Wright 2003). Patients suffering stroke may be unable to perform self care or be too weak to bother. Therefore, this is an important nursing intervention. Suction can be useful during mouth care, so the oral cavity can be cleaned and flushed properly.

Feeding

Sixty-five percent of subjects required assistance with eating. This includes 20% of subjects who required assistance with setting up a meal tray and 45% with feeding on food or drinks. Only seventeen subjects (18%) could eat and drink entirely independently, this is indicative of a huge nursing workload. These tasks are important but time consuming. If a ward has a large number of patients requiring this assistance it presents difficulties. Some wards have changed the scheduling of staff meal times to make them available at patient mealtimes. Patients' relatives and friends can also be encouraged to provide support.

Multidisciplinary team collaboration

Holistic care involves meeting all aspects of patients' needs, in including physical, psychological, emotional and social needs and this requires a lot of resources. The multidisciplinary team approach can enhance care by accessing those professionals best able to provide a particular service. Communication between team members is vital to ensure patients' needs are met. Breakdown in communication may result in delays in interventions such as changes in diet or enteral feeding, as well as delayed response to complications such as aspiration. Poor documentation of factors such as nutritional state e.g. weight, may also impact on patient progress. Additionally, it appears that the multidisciplinary team approach can provide enhanced management as the combined experience and knowledge can be used to develop interventions to prevent complications such as oral infections, aspiration and pneumonia.

Communication with family and carers

Family meetings are also integral to management. These provide the opportunity to discuss concerns and care options, so that mutual goals can be created. Family members often provide vital support and inform team members so that care can be tailored to the individual. Dysphagia from stroke is a serious concern and has a high rate of mortality and morbidity, therefore it is important to involve family members in decision making process and keep them informed of progress. If the patient is able to go home in either the short or long-term, education of family carers is also important to reduce risks and optimise recovery. If the multidisciplinary team does not communicate well and care is duplicated or fragmented this may frustrate patients and families. Clearly, nurses play an important role in the coordination of health care and provide an important link between patients, their families and members of the multidisciplinary team. Examples of problems with communication included a patient who complained of swallowing difficulty on admission which was documented by the nurse, but who was not assessed for over a week. The notes also described an incident where assessment by a speech pathologist was delayed by a week due to a missed message (S1, 33).

OUTCOMES AND DISCHARGE PLANNING

As would be expected a higher percentage of subjects in mild dysphagia group than those with severe dysphagia were able to tolerate a soft or normal diet on discharge (75% versus 25%). There was a 24% increase in the percentage of subjects who could tolerate a diet by discharge (n=13 to n=35). The data indicates that those who suffered mild or moderate dysphagia have greater improvement than those with severe dysphagia. Thus a more proactive response to nutrition for this group, such as early placement of PEG may be warranted.

Almost half of the subjects (47%) were transferred to aged care facilities; nearly 80% of these suffered moderate to severe dysphagia; and high-level care was required. It can be anticipated that with the ageing population the number of people who will suffer dysphagic stroke will increase. This will result in an increasing demand for high-level care facilities and may result in a significant strain on the health care workforce and resources if related problems cannot be identified early and solved.

The care required for patients with severe dysphagia is complex as they require assistance with feeding, administration of medications and maintaining oral hygiene to prevent complications. Early intervention and management may optimise recovery and reduce the strain on the health system.

Some hospitals provide support to patients, families and carers with multidisciplinary early supported discharge (ESD) services (Langhorne, Taylor, Murray, Dennis, Anderson, Bautz-Holter, Dey, Indredavik, Mayo, Power, Rodgers, Ronning, Rudd, Suwanwela, Widen-Holmqvist & Wolfe 2005). Langhorne et al describe early discharge services based in a British hospital. This service provides rehabilitation and support in the community and is associated with reduced risk of death or long-term dependency. The hospital stay was eight days shorter for patients assigned to ESD services than for those given conventional care. There was also a significant improvement in scores on the extended activities of daily living scale and in the odds of living at home and reported satisfaction with services. The greatest benefits were seen in stroke patients with mild to moderate disability. It appears that appropriately resourced ESD services can reduce long-term dependency and admission to institutional care and shortening hospital stays around eight days than those assigned conventional care.

It appears that most patients who had follow-up appointments with a speech pathologist were referred for their communication problems, rather than dysphagia. Despite the severity of dysphagia and the long-term problems few patients were referred for a swallowing rehabilitation program. Perhaps this is because for many subjects further recovery was not expected or maybe there is a need to direct limited services to those who would benefit most. In addition some subjects were discharged to a rehabilitation centre which provides such a program and some aged care facilities may have access to the services of a speech pathologist.

SUMMARY

Dysphagic stroke affects adults of all ages and commonly occurs with a first stroke, but in the elderly with co-morbidities it may be more serious. The severity of dysphagia was statistically related to the severity of stroke and likelihood of aspiration

pneumonia. Nearly a quarter of subjects were classified as being critically ill during their hospitalisation. Only half were admitted to a dedicated stroke unit when their condition allowed. This may have implications for the effective management of these patients. As would be expected most subjects had communication problems, as the same structures involved in speaking are responsible for swallowing. This problem complicates the assessment and management of these patients. Some patients waited up to three days for assessment by a speech pathologist and many had extended periods of nil orally, this may result in complications and delay recovery. According to new guidelines, early and frequent assessment of swallowing is required to prevent complications (SIGN 2004). Minimising periods of nil orally, providing extra nutritional support, enteral tube feeding if required and assistance with feeding may minimise the risk of malnutrition.

Although a dysphagia protocol provides clear descriptions of the roles of the multidisciplinary team members and the recommended interventions, compliance with the protocol was variable. For example, some patients were commenced on oral intake prior to assessment by a speech pathologist. The role of nurses in the assessment of dysphagia and documentation appeared to be limited. Other issues identified in relation to nursing care include, documentation of progress, recognition of complications, monitoring of nutritional status and ensuring oral hygiene. Caring for these patients is time consuming as most require assistance with eating, communication problems are common and many have severe disabilities such as hemiplegia. The results indicate that aspiration is a common complication and is often 'silent'. These issues indicate the importance of ensuring nurses are educated in the assessment and management of these patients to optimise outcomes.

The majority of subjects did not suffer a severe disability on admission, so the dysphagic stroke would have been catastrophic and would significantly effect their quality of life. Almost 40% of subjects could not tolerate a soft or normal diet by discharge and several still had enteral tubes; this may indicate that their dysphagia remained significant and that they may continue to be at risk of aspiration or malnutrition. Therefore, holistic management needs to involve family and carers meeting with multidisciplinary team members to ensure patients' needs are met and to discuss mutual goals. Empowering patients and care providers with education and

information; maintaining communication and supporting the rehabilitation process are vital to optimise recovery. Almost half of the subjects were transferred to aged care facilities and 80% of these suffered severe dysphagia and high-level care was required. There was little evidence of the provision of swallowing rehabilitation programs.

Dysphagia as a result of stroke is relatively common and with the aging population numbers of patients with this problem can be expected to rise. The care of these patients is problematic, costly and demands many resources. The results indicate there is a need to coordinate the care of these patients to ensure best practice guidelines are met and recovery is optimised.

RECOMMENDATIONS FOR PRACTICE

Patients should be assessed for dysphagia within 24 hours of admission, if their condition allows. Periods of 'nil orally' should be minimised. The progress of their condition should be closely monitored and documented and interventions such as changes of diet implemented promptly. The patient's nutritional status should be closely observed and interventions introduced to prevent malnutrition as this can have a negative effect on outcomes. Silent aspiration is common so all patients with dysphagia should be observed closely for this complication. Communication between the multidisciplinary team needs to be maintained to reduce delays in assessment and implementation of care strategies.

One of the main recommendations for practice is that a nurse practitioner be introduced to manage the care of this group of patients and to provide education for nurses, patients and families (Davies, Taylor, MacDonald & Barer 2001). This is already done in some institutions and research has demonstrated increased satisfaction for both patient and staff relates to increased quality of care and accessibility services from admission to post discharge follow up. The nurse practitioner can aid in the expedient delivery of complex, comprehensive stroke care (Green & Newcommon 2006, Minchin & Wensley 2003). This nurse could be trained to assess the dysphagia and to implement care according to the set protocols. They could also ensure that the progress of the dysphagia and the patient's nutritional state is monitored. They could

also have a role, preventing and detecting complications, in the insertion of NET tubes and the implementation of strategies to assist feeding and communication. Currently the speech pathologist is the assigned coordinator, however there are limited numbers of these professionals and they cannot provide 24 hour care and coordination. The nurse practitioner would not replace the speech pathologist, but would supplement the role in ensuring communication between health professionals was maintained and care was optimised. Patients with severe dysphagia may be able to be seen more quickly by a speech pathologist if they were identified by a nurse early and milder cases were managed according to protocols.

At the time of the study the hospital planned to introduce a ‘swallowing assessment training program’ for nurses who care for stroke patients. This may help ensure timely assessment and help prevent complications. Hopefully, this will help reduce the number of patients who wait for assessment of swallowing and are ordered ‘nil by mouth’ unnecessarily. In addition a dysphagia protocol should be distributed and to all staff who are required to care for dysphagic stroke patients to increase understanding and adherence to guidelines.

STRENGTHS AND LIMITATIONS

The strength of this study is that it provides an overview of the management of stroke patients with dysphagia in an Australian public hospital. The role of the nurse in the multidisciplinary team was highlighted. This study may increase the understanding of health professionals, patients and health policy and decision makers regarding the management of patients with dysphagia. It will also allow health care providers to assess their care and outcomes in relation to current recommendations and guidelines.

The main limitation of this study was that it documented the care in only one hospital and the results may not be generalisable to other settings. In addition data were collected retrospectively, so may not have been totally reliable. The reliability of data could not be checked with care givers. It was assumed that the documentation represented what actually happened. But it is possible that this was not always the case.

Although most patients did not suffer severe disabilities prior to admission, the researcher did not record data regarding their previous quality of life or whether they were independent prior to the event. Thus outcomes such as discharge cannot be fully evaluated.

RECOMMENDATIONS FOR FURTHER INVESTIGATION

The effectiveness of a nurse practitioner in coordinating care and managing patients who suffered dysphagic stroke should be evaluated.

The outcomes of involving nurses in the assessment of these patients could also be studied.

In addition data on the long-term outcomes should be collected. There is little information available on progress once patients are discharged from hospital. Many patients are ultimately discharged to aged care facilities, but the subsequent care and outcomes have not been investigated.

Future studies could investigate the psychosocial impact of this condition. A phenomenological study could provide information the 'lived experience' of these patients and their families.

CONCLUSION

Acute dysphagia following stroke is a common and significant problem with many associated complications. The management and care of these patients is complex and costly. To maximise the subject's chances of recovery quality care must be provided. This includes timely and accurate assessment, maintenance of nutrition, observation for complications and monitoring of progress. Each member of the multidisciplinary team has their role in this process. However, nurses care for these patients 24 hours and increased education and extending their role in managing these patients may enhance outcomes.

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APPENDICES

Appendix 1: Approval letter from Research Ethics Committee



Government of South Australia
Central Northern Adelaide
Health Service

**ROYAL ADELAIDE
HOSPITAL**

North Terrace,
Adelaide, SA 5000
Tel: +61 8 8222 4000
Fax: +61 8 8222 5939
ABN 80 230 154 545
www.rah.sa.gov.au

Research Ethics Committee

Level 3, Hanson Institute
Tel: (08) 8222 4139
Fax: (08) 8222 3035

2 May 2006

Mr A Yip
Dept of Clinical Nursing
University of Adelaide
Level 3, Eleanor Harrald Building
ROYAL ADELAIDE HOSPITAL

Dear Mr Yip,

**Re: "The hospital management for patients with acute dysphagia following stroke.
A retrospective review." Data Collection Form.**
RAH PROTOCOL NO: 060502.

I am writing to advise that Research Ethics Committee approval has been given to the above project. Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Research Involving Humans.

The general conditions of approval follow:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
 - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
 - (b) changes to the protocol,
 - (c) premature termination of the study.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is ongoing, subject to satisfactory annual review. An annual review form will be forwarded to you at the appropriate time.

If University of Adelaide personnel are involved in this project, you, as chief investigator, must submit a Human Research Approval Notification form (available at: <http://www.adelaide.edu.au/research/ethics/human/guidelines/>) within 14 days of receiving this ethical clearance to ensure compliance with University requirements and appropriate indemnification.

Yours sincerely,

Dr M James
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Appendix 2: Medical records statement

Title: The hospital management of patients with acute dysphagia following stroke.
A retrospective review.

The name of investigator: Mr Albert Yip.

The name of supervisor: Dr Judy Magarey.

We agree to keep confidential all information in the Medical Records which is viewed during the conduct of this study, and to record only that information which is indicated in the Research Ethics Committee approved data record.

The signature of investigator: _____

The signature of supervisor: _____

Date: 1st May 2006.

Appendix 3: Data collection form

1. Code number:

Version 1 (1st May 2006.)

2. Demographic data:

- Age: _____.
- Gender: Male / Female.
- Hospitalisation: _____ days. (_____)
- Admitted to ICU / HDU/ SDU **Yes**/ **No**/ **N/A**
- If yes, number of days _____.
- Admitted/ transferred to: Stroke unit / Neurology / Neurosurgery / Medical / Surgical/ Palliative care. **Yes**/ **No**/ **N/A**
- Destination: Home / Rehabilitation centre / Aged care facility / Transfer to other hospital / Death.

3. Past history:

- Diagnosis (type of stroke): _____.
(other than stroke & dysphagia): _____.
- Number of episodes of stroke: _____ **Nod** (No documentation).
- Premorbid disabilities: _____.
- Disability: Facial weakness / Visual impairments (blindness, hemianopia, diplopia) / Speaking impairments (dysphasia, dysarthria, aphasia) / Upper limb impairments (hemiplegia, weakness, motor or sensory) / Other _____.

4. General health condition since admission:

■ GCS score at admission:	Eye (1-4) / N/A	Verbal (1-5) / N/A	Motor (1-6) / N/A	Total (3-15)/ Incomplete
■ GCS score following initial swallowing assessment by a speech pathologist:	Eye (1-4) / N/A	Verbal (1-5) / N/A	Motor (1-6) / N/A	Total (3-15)/ Incomplete
■ GCS score before discharge:	Eye (1-4) / N/A	Verbal (1-5) / N/A	Motor (1-6) / N/A	Total (3-15)/ Incomplete

- Patient was Critically ill / Unconscious / Arrested during admission. **Yes**/ **No**/ **N/A**

- Patient required Endotracheal intubation / Tracheostomy tube / Nasal pharyngeal tube to maintain patent airway for ventilation. Yes/ No/ N/A
- The category of stroke was Mild / Moderate / Severe.
- Difficulties with communication: Yes/ No/ N/A
- If yes, the problem was Mild / Moderate / Severe and caused by Dysarthria / Dysphasia / Language barrier / Confusion / Cognitive deficit / Other: _____.

5. Assessment of dysphagia:

- The state of the patient's mouth was assessed. Yes/ No/ Nod
- Assessed swallowing ability before started oral intake. Yes/ No/ Nod
- If patient's swallowing ability was assessed more than 3 days from admission, the possible reason(s) was / were: Too ill to be assessed / Confusion / Delayed onset dysphagia / Other _____.
- Dysphagia was initially recognised by Doctor / Nurse / SP / Dietician / PT / OT / Patient / Report by family at admission / Other _____.
- Consultation / referral(s) to: SP / PT / OT / Dietician / Social worker / Radiologist / Clinical pharmacist / ENT / Gastroenterologist / Dentist / Other _____.
_____ Yes/ No/ N/A
- Swallowing assessment was done by: Speech pathologist / Nurse / Doctor / _____.
_____ Yes/ No/ Nod
- Major clinical predictor(s) of dysphagia on presentation: Drooling / Palatal weakness / Wet sounding voice / Incomplete oral clearance / Oral or nasal regurgitation of food or fluid / Impaired pharyngeal response (cough / gurgle) / Severe facial palsy / Abnormal tongue movement / Abnormal lip function / Other _____.
_____ Yes/ No/ Nod
- Clinical indicator(s) of risk of aspiration if relevant: Dysphonia / Dysarthria / Abnormal gag reflex / Abnormal volitional cough / Cough after swallow / Voice change after swallow / Other _____.
_____ Yes/ No/ Nod
- What kind of swallowing assessment method was / were used: Bedside swallowing assessment (BSA) / Water swallowing test / Pulse oximetry (oxygen desaturation >2% after eating or drinking). Yes/ No/ Nod
- Patient required further swallowing investigation. Yes/ No/ N/A

- If yes, investigation(s) was / were Laryngoscopy / Modified barium swallow (MBS) / Fiberoptic endoscopic examination of swallowing (FEES) / Other _____.
- The category of dysphagia was: Mild / Moderate / Severe.
- Number of times assessed swallowing ability: _____ N/A
- If multiple assessments occurred: minimum time between assessment _____ day(s); maximum _____ days. (_____) N/A

6. Assessment of nutritional status:

- Height: _____ cms. Yes/ No/ N/A
- Body weight at admission: _____ kgs. Yes/ No/ N/A
- BMI was _____. (Low / Normal / Overweight / Obese) N/A
- Underweight on admission: Yes/ No/ N/A
- Was the patient weighed during admission: Yes/ No/ N/A
- Restriction of food. Yes/ No/ N/A
- Restriction of fluid. Yes/ No/ N/A
- Accurate recording of food / fluid intake when relevant. Yes/ No/ N/A
- Patient had _____ day(s) on intravenous line. Yes / No
- Patient had _____ day(s) was / were 'nil by mouth'. Yes / No
- If yes, the reason(s) for fasting was / were: Suspected swallowing problem / Unstable condition / For investigation / For surgery / Other _____.
- If yes, patient had _____ day(s) was / were 'without any enteral intake', oral or feeding.
- Patient on total parenteral nutrition (TPN). Yes / No

7. Interventions:

Modified diet / fluid:

- Special diet before admission: _____ Yes/ No/ N/A
- Diet / fluid modified following assessment. Yes/ No/ N/A
- Number of days since admission modified diet/fluids started: _____ days.
- If not, the possible reason(s): Intolerance of oral intake / Required tube feeding / Condition deteriorated / Other _____.

- Patient's swallowing ability reassessed while on modified diet / fluid. Yes/No
 - The initial type of modified diet / fluids prescribed Nil / Vitamised / Minced / Soft / Normal diet and Nil / Ice chips / Fully- /Semi- / Slightly-thickened / Thin / Normal fluids.
 - The final type of modified diet / fluids prescribed when discharged Nil / Vitamised / Minced / Soft / Normal diet and Nil / Ice chips / Fully- / Semi- / Slightly-thickened / Thin / Normal fluids.
 - Diet or fluid modified further during admission. Yes/No
 - Number of days on modified diet / fluids during admission _____ days.
- Tube feeding:***
- Required NET / PEG tube feeding after initial swallowing assessment by a speech pathologist. Yes/No
 - Enteral tube feeding was commenced following initial swallowing assessment by a speech pathologist. Yes/No
 - Number of days following initial swallowing assessment by a speech pathologist NET feeding commenced: _____ days.
 - The length of time on NET tube feeding: _____ days. (_____)
 - Number of times of NET tube inserted: _____ times. (_____)
 - Patient needs to change enteral tube feeding from NET to PEG. Yes/No/N/A
 - Number of days following initial swallowing assessment by a speech pathologist Jejunostomy / PEG tube feeding commenced _____ days.
 - Complications of jejunostomy / PEG tube feeding Yes/No/N/A
 - If yes, the complication(s) was / were: Wound infection / GI upset / Wound pain / Tube displacement / Other _____.
- Swallowing rehabilitation program:***
- Swallowing rehabilitation program was ordered. Yes/No
- If yes, the program was performed by: Speech pathologist / Dietician / Nurse / Occupational therapist / Physiotherapist / Doctor / No doc. / _____

8. Eating and drinking management:

- Food allergies. Yes/ No/ N/A
- Any factors that affected choice of diet / fluid. Yes/ No/ N/A
- If yes, factor(s) is / are Religious / Cultural beliefs / Vegetarian / Denture / teeth problem / Chronic illnesses / Other.
- Accurate monitoring of food / fluid intake in chart. Yes/ No/ N/A
- Patient was assisted with eating / drinking. Yes/ No/ N/A
- Patient was provided with special utensils to help eat & drink by himself / herself. Yes/ No/ N/A
- Medications required alternative routes & preparations. Yes/ No/ N/A
- Oral / enteral nutritional support was required. Yes/ No/ N/A
- Any factors that affected patient's intake: Yes/ No/ N/A
- If yes: Refused diet / Poor appetite / GI upset / Depression / Decreased conscious level / cultural / taste / too tired / ill / Other.

9. Outcomes:

- Body weight before discharge: _____ kgs. Yes/ No/ N/A
- Gained /Lost /Same /Unknown of body weight before discharge: +/- _____ kgs.
- Patient's body weight before discharge: Normal / Underweight / Overweight / Obesity / N/A
- Low serum albumin level before discharged Yes/ No/ N/A
- Malnutrition or dehydration: Yes/ No/ N/A
- Occurred laryngeal penetration / aspiration Yes/ No/ N/A
- If yes, number of times _____.
- Chest infection / pneumonia: Yes/ No/ N/A
- If yes, number of times _____.
- Patient on modified diet / fluid at discharge: Yes/ No/ N/A
- Patient dependent on NET /PEG tube feeding when discharge. Yes/ No
- Number of days during admission with significant dysphagia: _____ days.
- Clinical progression of dysphagia during hospitalisation: Improved / Unchanged / Deteriorated.

- Patient was ordered swallow rehabilitation programme after discharge. Yes/ No/ N/A
- Patient/ families/ carer was explained the potential risks and management of dysphagia. Yes/ No/ N/A
- Follow up arranged for management of dysphagia was needed. Yes/ No

10. Review by multidisciplinary team:

Significant documentation related to dysphagia:

- Nurses: Assessment/ Observation / Assistance of feeding / Monitoring Encouragement /_____.
- Speech pathologists: Assessment / Investigation / Prescribed modified diet / Teaching patient swallow skills / Position /_____.
- Dietician: Assessment / Prescribed modified diet / Required nutrition /_____.
- Physiotherapists: Assessment / Chest physiotherapy / Muscle training / Sitting balance /_____.
- Occupational therapists: Assessment / Provide special utensil / Provide special cutlery / Teaching feeding skills /_____.
- Doctors: Assessment / Investigation/ Treatment /_____.
- Other multidisciplinary team: Assessment / Investigation / Interventions_____.

11. Comments:

- Any significant issues about the assessment / investigation of the dysphagia: _____.
- Any significant issues about intake / nutritional problems: _____.
- Any significant strategies used to improve patient's intake / nutritional issues: _____.
- Any significant strategies to prevent complications and improve outcomes: _____.
- Remarks _____.

Appendix 4: Reference of data collection form

1. The different types of modified diets and fluid:

NOTE:
This table is included on page 144 of the print copy of
the thesis held in the University of Adelaide Library.

Adapted from: Department of Ageing Disability & Home Care (DADHC) 2003.

2. The formula of BMI:

$$\text{BMI} = \left(\frac{\text{Weight in Kgs}}{(\text{Height in metres})^2} \right)$$

(Underweight: <18.5kg/m²; Normal: 18.5 – 24.9kg/m²;
Overweight: 25 – 29.9kg/m²; Obesity: >30 kg/m²)

Adapted from: Centers for Disease Control and Prevention 2005.

3. Glasgow Coma Scale:

Score	Eye opening (E)	Verbal response (V)	Motor response (M)
6	-----	-----	Obeys commands
5	-----	Orientated	Localising pain
4	Spontaneous	Confused	Withdrawal from pain
3	To speech	Inappropriate words	Flexion to pain
2	To pain	Incomprehensible sounds	Extension to pain
1	None	None	None
Remarks: Total = E+V+M = (3-15) 15 – 13 (Mild brain injury) 12 – 9 (Moderate brain injury) 8 – 3 (Severe brain injury)			

Adapted from: Teasdale & Jennett 1974.

Appendix 5: RAH dysphagia protocol

NOTE:

This protocol is included on page 145 of the print copy of the thesis held in the University of Adelaide Library.

***Appendix 6: Roles and responsibilities of the
multidisciplinary team***

NOTE:

This protocol is included on page 146 of the print copy of the thesis held in the University of Adelaide Library.

Appendix 7: Abbreviations

ABS	–	Australian Bureau of Statistics
ACE	–	Angiotensin-converting enzyme
ADL	–	Activity of daily living
ADHA	–	Australian government: Department of Health and Ageing
AIHW	–	Australian Institute of Health Welfare
ANHS	–	Australian National Health Survey
APMS	–	Australian Patient Management System
AVM	–	Arteriovenous malformation
BMI	–	Body mass index
BSA	–	Bedside swallowing assessment
CD	–	Compact disc/disk
CDC	–	Centers for Diseases Control and prevention
CNC	–	Clinical nurse consultant
CNS	–	Central nervous system
CSF	–	Cerebrospinal fluid
CT	–	Computerised tomography (scanning)
CVA	–	Cerebrovascular accident
CVD	–	Cerebrovascular disease
DADHC	–	Department of Ageing Disability & Home Care
DALYs	–	Disability-adjusted life years
DBP	–	Diastolic blood pressure
df	–	degrees of freedom
DT	–	Dietician
DNA	–	Deoxyribonucleic acid
DVD	–	Digital video disc
EEG	–	Electroencephalogram
EGG	–	Electroglottography
EMG	–	Electromyography
ENT	–	Ear, nose and throat
ES	–	Electrical stimulation (therapy)
ESD	–	Early support discharge (service)
FDA	–	Food and Drug Administration

FBC	–	Fluid balance chart
FEES	–	Fiberoptic endoscopic examination of swallowing
GCS	–	Glasgow Coma Scale
GE	–	Gastroenterologist
GI	–	Gastrointestinal
GP	–	General practitioner
HDL	–	High-density lipoprotein (cholesterol)
HDU	–	High dependence unit
HPU	–	Health Promotion Unit
ICD-10	–	International statistical classification of diseases - 10 th revision
ICP	–	Intracranial pressure
ICU	–	Intensive care unit
IVT	–	Intravenous therapy
LDL	–	Low-density lipoprotein (cholesterol)
LPSDT	–	Laryngopharyngeal sensory discrimination testing
MBI	–	Modified Barthel Index
MBS	–	Modified barium swallow
MFMER	–	Mayo foundation for medical education and research
MMWR	–	Morbidity and mortality weekly report
MRA	–	Magnetic resonance angiography
MRI	–	Magnetic resonance imaging
MRS	–	Medical record service
N/A	–	Not applicable
NBM	–	Nil by mouth
NCGS	–	National Clinical Guidelines for Stroke
NET	–	Nasoenteral tube
NHMRC	–	National Health and Medical Research Council
NMES	–	Neuromuscular electrical stimulation
Nod	–	No documentation
HSD	–	(Tukey-) Honestly significantly different (test)
OECD	–	Organization for Economic Co-operation and Development
OME	–	Oral motor examination
OT	–	Occupational therapist
PBS	–	Pharmaceutical Benefits Scheme

PEG	–	Percutaneous endoscopic gastrostomy
PET	–	Positron-emission tomography (scanning)
PT	–	Physiotherapist
RAH	–	Royal Adelaide Hospital
RAHDS	–	Research and Higher Degrees Subcommittee
REC	–	Research Ethics Committee
ROSS	–	Repetitive oral suction swallow (test)
SaO ₂	–	Oxygen saturation of arterial haemoglobin
SBP	–	Systolic blood pressure
SDU	–	Step down unit
SES	–	Socio-economic status
SIGN	–	Scottish Intercollegiate Guidelines Network
SP	–	Speech pathologist
SPSS	–	Statistical package for social sciences
SW	–	Social worker
TCCP	–	Tobacco control country profiles
TIA	–	Transient ischaemic attack
tPA	–	tissue plasminogen activator
TPN	–	Total parenteral nutrition
TS	–	Thermal-tactile stimulation (therapy)
TVC	–	True vocal cord
VMF	–	Videomanofluorometry
VSS	–	Videofluoroscopy swallowing study
WAFIG	–	Western Australia functional impairment groups
WHO	–	World Health Organization
WST	–	Water swallowing test.

Symbols:

\bar{x}	–	Mean
n	–	Number
<i>p</i>	–	probability (level of significance)
®	–	Federal registration trademark symbol
S	–	Subject

- σ – Standard deviation
- ™ – Trade mark

Portfolio conclusion

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CONCLUSION OF PORTFOLIO

INTRODUCTION

The researcher was previously employed as a registered nurse in a neurosurgical ward for four years and had cared for many patients suffering from stroke in both their acute and recovery stages. In addition he had personally experienced the impact of stroke on his own family. For this reason it was decided to focus on the issues relating to stroke. Literature reviews demonstrated two topics that required further research, thus it was decided to study 'behaviour modification' following TIA or minor stroke and 'care of the patient suffering from acute dysphagia due to stroke'. The findings of the two studies may help health care providers and policy makers improve strategies for prevention and to provide quality care.

THE DEVELOPMENT OF THE FIRST STUDY

Although stroke is more prevalent in the elderly it can occur at any age and in both genders. Unhealthy lifestyles increase the risk of stroke and it is also associated with aging meaning the incidence is rising rapidly. This increases the cost of health care and social burden. Minor stroke and TIA are important warning signs of major stroke; however, it appears that patients do not recognise this by changing their lifestyle, but tend to depend on pharmacological treatment such as anti-hypertensives to reduce risk. However, stroke is a preventable disease and many modifiable risk factors can be altered with lifestyle changes. Nevertheless, it appears that limited research has been done regarding the barriers to lifestyle changes or health promotion strategies targeted at these individuals.

THE SIGNIFICANCE OF THE FINDINGS OF THE FIRST STUDY

The most significant findings of the first study: 'a descriptive study of lifestyle changes made following discharge from hospital by patients who have suffered a minor stroke or TIA' was that many subjects had a poor understanding of risk factors for stroke. Although cigarette smoking was well recognised and changes

made, there was less awareness of the contribution of excessive alcohol consumption and obesity. In addition subjects reported significant confusion regarding the implications of diet and some requested more information. It appears that the importance of exercise is recognised, as although 37% of subjects had a disability of some kind, most (66%) stated that they exercised regularly. The main sources of subjects' health information were doctors' instructions and written matter; few wanted access to newer technologies such as Internet, video, compact disks. This may be a reflection of the ages of the subjects.

Subjects indicated lack of motivation, physical impairment, age, inability to access good health information and inadequate knowledge, guidance and support on stroke prevention were the main barriers to lifestyle change. Although most subjects (83%) were on medication to control hypertension, they relied on follow up clinics to check their blood pressure; few realised the significance of lifestyle factors and self monitoring of blood pressure. A quarter of subjects had recurrent mild stroke or TIA and for some their hypertension was only diagnosed after their stroke. This demonstrates the need for health screening including of blood pressure and promotion of stroke prevention strategies in the community.

Health promotion and education are very important in the prevention of stroke. Early detection of hypertension and other risk factors makes effective treatment possible and helps prevent stroke. Prevention is also less costly than acute hospital care and rehabilitation. Changing behaviour long-term is difficult and requires support from health professionals and the community. Family and friends may provide invaluable support in this matter.

An important finding is that over half of subjects indicated that they were interested in obtaining more information about recommended lifestyle changes. It appears that they rely on medical practitioners to provide information. In the current health care climate the demand on medical services is high and General Practitioners have limited time available for education. It is clear that this group of patients would benefit from a targeted program to provide education and support them in making changes to their lifestyle. Existing rehabilitation services for patients with angina or post heart surgery could be extended to this group.

THE DEVELOPMENT OF THE SECOND STUDY

Dysphagia is commonly associated with acute stroke and indeed this is the most frequent cause of the disability (The Merck manual of geriatrics 2007). The rehabilitation of patients who have suffered stroke is greatly complicated by dysphagia and morbidity and mortality is increased. This presents a huge challenge for patients, their loved ones and to the multidisciplinary team providing care. Thus, it is important to assess current practices regarding dysphagic stroke management and evaluate outcomes in relation to promoting recovery.

Although stroke prevention is paramount as a long-term strategy, stroke remains common and many patients require acute hospital care. Holistic management is important to enhance the cost-effectiveness and quality of care. Dysphagia associated with stroke increases the risk of complications; prolongs the length of stay in hospital and increases mortality. In turn this increases the cost of health care and the burden on community. Stroke alone is highly distressing for the patient themselves and their loved ones, but dysphagia and the commonly associated communication difficulties compound the problems. It appears that the implications of dysphagia on outcomes have only recently been recognised by health professionals and that there are still limited resources available to support the assessment and care of these patients. In 1999 audits in Britain indicated screening of stroke patients for dysphagia and assessment of swallowing was poor and interventions were ineffective (Rudd, Irwin, Rutledge, Lowe, Wade, Morris & Pearson 1999). In the light of this finding the intention was to evaluate the care of patients in the Australian context by researching practice in a large acute adult hospital. It was also hoped to explicate the role of nurses, as they alone are responsible for patient care 24 hours a day and are vital in communication with patients, their family and other members of multidisciplinary team.

For these reasons the second study was designed to investigate the hospital management of patients with acute dysphagia following stroke.

THE SIGNIFICANCE OF THE FINDINGS OF THE SECOND STUDY

The second study: 'the hospital management of patients with acute dysphagia following stroke – a retrospective review' demonstrated that dysphagic stroke may occur in subjects in a wide range of ages and both genders with over 70% presenting following their first episode of stroke. Statistical analysis indicated a relationship between the severity of dysphagia, and the severity of stroke and communication problems. Complications such as chest infections were also more common in patients with severe dysphagia and they were more likely to be discharged to an aged care facility or die, while those with mild dysphagia were more likely to be discharged home. Therefore, dysphagia appears to have a profound influence on outcomes. Thus quality hospital care and rehabilitation is vital.

There are numerous factors that appear to impact on the quality of care received by these patients. Many patients are not admitted to a specialist unit for the coordination and implementation of care. Despite best practice guidelines, only 41% of subjects had their swallow assessed within 24 hours; and few had further investigation of their swallowing such as FEES. In addition less than half had their body weight monitored and a quarter had incomplete records of food and fluids intake. However, 74% of the weighed subjects lost weight and 56% of those who had their serum albumin checked had levels below the normal range. Therefore the potential for malnutrition is significant. It appears that the commencement of oral intake (median 6 days) or enteral feeding (median 4 days) was often delayed. Thus there is the opportunity to improving the quality of care and perhaps improve outcomes.

Other issues that commonly impact on nutrition of these patients are fatigue, appetite, behaviour and emotion, dentition, and oral hygiene. These problems not only have the potential to delay recovery but may increase the likelihood of complications such as malnutrition and dehydration, aspiration and chest infection. Therefore, early assessment, monitoring and targeted interventions are strategies that should be applied to minimise complications and enhance outcomes.

Several important strategies could be implemented and evaluated for their impact on outcomes. These are the further development of stroke units and the implementation of a nurse practitioner role to provide specialised care and coordinate services.

CONCLUSION

Stroke is a significant and increasing problem, the complications are serious and the cost on the health care system and society is considerable. The two studies have provided health care professionals and policy makers with information about these two important aspects of stroke management. It is hoped that the information gained will improve the quality of care received by these patients.

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