Assessment of Dysphagia in People with Parkinson's Disease, Multiple Sclerosis and Muscular Dystrophy

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Abstract

Introduction

Previous research has shown that patients with Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy (MD) are known to be at risk of dysphagia and could benefit from dysphagia screening. The aim of this study was to describe the use of dysphagia screening and assessment procedures amongst patients with neurological conditions when they have an unplanned admission to hospital.

Methods

Two methods of data collection were used in this study. The first method was a prospective observational study to determine the use of dysphagia screening and assessment procedures amongst patients with Parkinson's disease, multiple sclerosis and muscular dystrophy. The second, qualitative study examined clinicians' perceptions of the factors that influenced the decision to screen for dysphagia in people with neurological conditions and the difficulties experienced. Data were collected from clinicians using semi-structured in-depth interviews. Potential interventions to improve the management of dysphagia in these conditions were identified.

Results

Two hundred patients were recruited to the observational study. Thirty four percent (n=68) of this group underwent a swallow screening assessment (SSA) during the first week of admission and 93% (n=63) of these were judged to have dysphagia. Amongst those who were not assessed initially (n=132), a further 77% (n=101) were found to have dysphagia.

Twenty people took part in the interview study including doctors, health care assistants, nurses and therapists. Clinicians reported that the factors which underpinned their decision to screen for dysphagia included pre-existing swallowing difficulties, recognition of symptoms, staff/relative anxiety, communication difficulties and the presenting complaint and diagnosis. However, clinicians reported that their limited knowledge, clinical competencies in swallow screening, a lack of confidence and resources, affected their practice and use of dysphagia screening and assessments. Clinicians noted a number of interventions that could improve the management of dysphagia when patients are admitted to hospital and these included: training in dysphagia screening; development of dysphagia pathways or guidelines; provision of an alert system, introduction of on-call speech and language therapy services; and research funding.

Discussions and Conclusions

The findings of this study suggest that screening for dysphagia does not occur routinely when patients with neurological conditions are admitted to hospital for an acute condition. This means that opportunities to detect treatable causes of potentially life-threatening complications are being missed.

Many inter-related factors were reported to account for this practice and these related primarily to limited knowledge and confidence and the limited accessibility of speech and language therapists outside usual working hours. Interventions to improve routine dysphagia screening should help to reduce the incidence of avoidable complications and perhaps shorten length of stay. Dysphagia pathways or guidelines are needed to support effective management in acute hospital settings.

Publications and conference presentations arising from this study

Anuri Joy Molokwu, Margaret Phillips, Lorraine Lea Pinnington: Dysphagia assessment in people with Parkinson's disease, multiple sclerosis and muscular dystrophy: Archives of Physical Medicine and Rehabilitation, Volume: 93, Issue: 10, 2012

Anuri Joy Molokwu: How easily can people with Parkinson's disease, multiple sclerosis and muscular dystrophy eat?: Postgraduate Research Show Case University of Nottingham, 2012

Anuri Joy Molokwu, Margaret Phillips, Lorraine Lea Pinnington**:** Assessment of dysphagia in patients with Parkinson's disease, multiple sclerosis and muscular dystrophy: Should all patients be screened for dysphagia when admitted to hospital? - In preparation.

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List of Abbreviations

ADL	Activity of Daily Living
A&E	Accident & Emergency
AHA	America Heart Association
AHCPR	Agency for Health Care Policy and Research
AHRQ	Agency for Healthcare Research and Quality
AMED	Allied and complementary Medicine Database
ASA	American Stroke Association
ASHA	American Speech and Hearing Association
BDA	British Dietetic Association
BDST	Burke Dysphagia Screening Test
BMI	Body Mass Index
BSA	Bedside Swallowing Assessment
CAG	Canadian Association of Gastroenterology
CAQDAS	Computer Assisted Qualitative Data Analysis Software
CF	Confounding Factors
CI	Confidence Interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CVA	Cerebrovascular Accident
DALY	Disability Adjusted Life Years
DDFT	Dysphagia Diet Food Texture
DST	Dysphagia Screening Tool
DYMUS	Dysphagia Multiple Sclerosis questionnaire
EBP	Evidence Based Practice
EDAT	Exeter Dysphagia Assessment Technique
EDIS	Electronic Data Information System
EDSS	Expanded Disability Scale Status

FEES	Fibreoptic Endoscopic Evaluation of Swallowing
FISCA	Financial Service Centres of America
FOIS	Functional Oral Intake Scale
GBD	Global Burden of Disease
HAI	Hospital Acquired Infection
HAP	Hospital Acquired Pneumonia
ICF	International Classification and Functioning
LOS	Length of Hospital Stay
LSVT	Lee Silverman Voice Treatment
MASA	Mann Assessment of Swallowing Ability
MAC	Mid Arm Circumference
MAU	Medical Assessment Unit
MD	Muscular Dystrophy
MDRS	Modified Dysphagia Rating Scale
MFS	Manofluoroscopy Study
MS	Multiple sclerosis
MUST	Malnutrition Universal Screening Tool
NBM	Nil By Mouth
NCCCC	National Collaborating Centre for Chronic Conditions
NDD	National Dysphagia Diet
NGT	Nasogastric Tube
NH	Nursing Home
NHS	National Health Service
NICE	National Institute of Clinical Excellence
NPSA	National Patient Safety Agency
NREC	Nottingham 1 Research Ethics Committee
NUH	Nottingham University Hospital
OME	Oromotor Exercise

OPM	Oesophageal Pharyngeal Manometry
OPMD	Ocularpharyngeal Muscular Dystrophy
PD	Parkinson's Disease
QMC	Queens Medical Centre
QOL	Quality Of Life
RCP	Royal College of Physicians
RCSLT	Royal College of Speech and Language Therapist
RCT	Randomised Controlled Trial
R&D	Research & Development
RDH	Royal Derby Hospital
REC	Research Ethics Committee
RH	Residential Home
RIC	Rehabilitation Institute of Chicago
ROSS	Repetitive Oral Suction test
RRR	Relative Risk Reduction
RS	Radionuclide Scintigraphy
SDQ	Swallowing Dysphagia Questionnaire
SEMG	Surface Electromyography
SIGN	Scottish Intercollegiate Guideline Network
SLT	Speech and Language Therapist
SSA	Swallow Screening Assessment
STAND	Screening Tool for Acute Neurological Dysphagia
TORBEST	Toronto Bedside Swallowing Screening Test
UES	Upper Oesophageal Sphincter
VFSS	Video Fluoroscopy Swallowing Study
VSE	Voice Strengthening Exercise
WGO	World Gastroenterology Organisation
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

CHAPTER 1: INTRODUCTION

1.1 Study Background

People with neurological conditions such as Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy (MD), often have weak or poorly controlled movements. If these difficulties affect the swallowing mechanisms, eating can become slow and inefficient. These impairments can vary in severity, but are referred to collectively as 'dysphagia' and culminate with poor control of food in the mouth. If particles of food enter the trachea (airway) during or following a swallow, it can cause a potentially life-threatening infection, known as aspiration pneumonia. Other complications of dysphagia include weight loss, dehydration, delayed wound healing and poor recovery from ill health [1-5]. Early detection of dysphagia through effective screening procedures could avoid or reduce in severity many of the above complications. The first part of the study presented in this thesis was designed to determine if patients with PD, MS and MD are screened for dysphagia when they have an unplanned on admission to hospital. These conditions were chosen because of their progressive nature and they are all neurodegenerative conditions. It also seeks to establish whether patients who are screened, are managed differently to those who are not and if they have comparable outcomes. The second part of the study was designed to determine clinicians' perceptions of the factors that influenced the decision to screen for dysphagia in people with neurological conditions and the difficulties they experienced.

The aim of this chapter is to provide an introduction to the topic of study. An overview of dysphagia in neurological conditions is also discussed and the rationale for conducting the present study is explained. This chapter highlights

the prevalence, complications and management of dysphagia in neurological conditions. Following this, the theoretical background to the study is introduced and previous research concerning the assessment of dysphagia when admitted to hospital is reviewed. The chapter culminates with a thesis plan and a summary of the study aims and objectives.

1.2 Dysphagia

Dysphagia is a common disorder which can occur in the oral, pharyngeal or oesophageal phase of swallowing [1]. The aetiology of dysphagia is multi-factorial and can arise from a wide variety of neurological, muscular, mechanical congenital and respiratory conditions [2,3]. A summary of these causes is given in [Appendix 1]. It occurs with increasing frequency in older people and is recognised to be a symptom of a wide range of neurological conditions [4]. People with conditions such as PD, MS and MD may have reduced sensation and range or control of movement of the tongue, lips or jaws can impair efficiency of mastication and prolong oral and pharyngeal transit times. [5] Initiation of the swallow reflex can also be impaired, and in some cases food residue will fall into the valleculae, the pyriform sinuses or the trachea and trigger aspiration pneumonia [5]. Dysphagia can become more severe in acutely ill patients resulting in malnutrition or dehydration and an increased length of hospital stay due to the reduced rate of recovery [6]. In people with neurological conditions aspiration pneumonia is associated with poor outcomes. Aspiration pneumonia can result in dehydration, re-admission to hospital, poor quality of life, increased costs, morbidity and mortality [7].

Dysphagia can present in a number of ways and many of these signs are observable [8]. Whilst familiarity with such signs and symptoms can help to

ensure that the problem is diagnosed, in some conditions progression is slow and therefore dysphagia can remain undetected. A summary of the key symptoms and clinical signs of oropharyngeal dysphagia are listed in Table 1.1

Table 1.1 Symptoms and clinical signs of oropharyngeal dysphagia [8]

Symptoms	Clinical signs
Complaining of swallowing difficulties Difficulty initiating a swallow Recurrent chest infections Unexplained weight loss Coughing with food and drink Choking on food and drink Food sticking behind the throat Taking a long time to finish a meal Avoiding certain foods	Delayed laryngeal movement on swallowing Cough during or after swallowing Choking /stridor during swallowing Loss of food from the lips Pouching of food Wet/ gurgling voice after swallowing Dribbling of water Abnormal lip closure Double swallow and delayed swallow

1.2.1 Dysphagia at Different Phases of Swallowing

Swallowing disorders can occur at different stages of the swallowing process, including the oral, pharyngeal and oesophageal phases; these are outlined below.

a) Dysphagia in the Oral Phase

The duration of the oral phase of swallowing increases with age, especially in the older population and in those with progressive neurological conditions such as PD, MS and MD [9]. This type of dysphagia is characterized by difficulty in moving food from the mouth to the oro-pharynx. The process of chewing, mixing and transfer of food to the back of the mouth is also impaired. The tongue is a vital organ in the mouth and involved in the process of mastication and swallowing. If the strength of the tongue is weak as a result of a disease process, it causes food retention in the valleculae [10]. Often, food and liquid may be seen dripping from the side of the mouth or held at the back of the mouth in people with dysphagia.

The following signs and symptoms are common in this phase: facial, lip and tongue weakness, loss of sensation of food and water, abnormal lip closure and pouching of food [5]. In acute medical conditions where a person's level of consciousness or mental ability may be impaired, it may result in worsening of this type of dysphagia.

b) Dysphagia in the Pharyngeal Phase

Dysphagia in the pharyngeal phase of swallowing occurs when there is a problem with progression of food from the pharynx to the oesophagus and it arises due to weakening of the pharyngeal muscles. The cause of pharyngeal dysphagia is multi-factorial and is common in people with neurological conditions such as PD, MS and MD [11, 12]. The tongue plays a major role in the transfer of food from the mouth to the pharynx [13] and weakness in the tongue musculature may result in inefficient food progression [14]. The propulsion of food is delayed in

time and response during this phase. There is also an increased risk of aspiration, during and after swallowing, due to delayed swallowing, reduced laryngeal closure and dysfunctional pharyngeal contraction [15-16].

The most common symptom is "coughing" with food or drink. The following abnormalities are associated with pharyngeal phase dysphagia: delayed pharyngeal swallowing, pharyngeal wall weakness, bilateral reduction in pharyngeal contraction, impaired posterior tongue movement, incomplete laryngeal closure, cricopharyngeal malfunction, pharyngeal pouch and vocal cord disorders [17].

c) Dysphagia in the Oesophageal Phase

When the swallowing reflex is triggered, food moves from the oral cavity to the pharynx and is assisted by a peristaltic wave. It causes relaxation of the upper part of the oesophageal sphincter, to allow food to enter into the oesophagus. A secondary peristaltic movement is also triggered which then causes food to move into the stomach [17]. Normal oesophageal transit times ranges from 8 to 20 seconds. [15] This is measured from the time of bolus entery into the cricopharyngeal juncture to the oesophagus until it passes the gastro-oesophageal juncture into the stomach. Dysphagia in this phase occurs during the passage of food into the oesophagus. Any delay between the pharyngeal and upper oesophageal sphincter may be a feature of dysphagia in this phase [18]. A common complaint is a 'feeling of food sticking at the back of the throat or chest' after swallowing. Other aspects, such as recurrent chest infections and drooling can also occur in this phase [19]. Reduced opening of the upper oesophageal sphincter may cause retention of the food [20] which may lead to overflow aspiration after swallowing [21]. A careful history is

needed to differentiate the pharyngeal from oesophageal phase dysphagia, as the latter is mainly due to mechanical obstruction or problems with motility [22]. Difficulties associated with swallowing or motility at the oesophageal phase can only be diagnosed by videofluoroscopy. [15]

1.2.2 Prevalence/Complications

The prevalence of dysphagia in PD, MS and MD is estimated to be greater than 80%, 31% and 35% respectively [23-26]. However, prevalence depends on a number of factors such as age, gender, setting and type of neurological condition. In hospitals, the prevalence of dysphagia is between 42% and 46% compared with 6% in the general population [27-28]. It has been suggested that the background prevalence in acutely unwell patients (community dwelling mental health and older patients) is approximately 30% [29-30] but it is estimated that between 30% and 70% of institutionalized residents have dysphagia [31-32]. For the older population, between 6% and 7% present with dysphagic symptoms [33]. The prevalence of dysphagia increases with advancing age, seeing 70% to 80% of elderly patients with neurological diseases presenting with some form of swallowing dysfunction [34]. Finally, an estimated 94% of elderly hospitalized patients experience a diagnosis of aspiration following dysphagia [35]. These statistics vary probably due to the methods, competency of the person conducting the swallowing assessment and operational definition of dysphagia used in various studies. Overall, dysphagia is common amongst older adults and in those with neurological conditions [34-35]. However, the prevalence of dysphagia amongst people with neurological conditions in acute medical units is unknown.

1.2.3 Complications of Dysphagia

a) Aspiration and Aspiration Pneumonia

Aspiration occurs when food, drink, saliva or gastric contents enter into the larynx and lower respiratory airway, which then become colonized by bacteria and cause aspiration pneumonia. These bacteria are aerobic (Streptoccocus pneumonia, Pseudomonas aeruginosa) and anaerobic, (Peptostreptococcus, Bacteroides, Fusobacterium and Prevotella) and they usually colonise in the oropharynx [36]. Many factors, including dysphagia and community or hospital-acquired pneumonias are associated with aspiration pneumonia which is a leading cause of death amongst older people [37-38]. In the United States of America, for example it is the fifth major cause of mortality in people above sixty-five years [39].

The clinical signs and symptoms of aspiration are: coughing with food or drink, regurgitation, gurgly or wet voice after swallowing, and aspiration pneumonia are: shortness of breath, rapid respiratory rate, fever, chest pain, confusion and lack of appetite and weight loss [40]. Aspiration pneumonia can be mild, moderate or severe in presentation. Severity of aspiration can be determined by using the Eight-Point Penetration - Aspiration Scale [41]. This tool estimates the percentage of the bolus aspirated or depth of bolus entry into the airway [41].

Butler et al. [42] have shown that people without swallowing problems can sometimes aspirate minute quantities of food and drink. However the evidence provided was limited, due to the positioning of participants (it was unclear whether they were supine or reclined). The procedures used were not fully

described [42]. Other studies by Robins et al. [43] and Logemann et al. [44-45] have shown that the incidence of aspiration in healthy individuals does not differ with age. It is also known that increased age in a healthy individual does not necessarily increase the risk of aspiration (Marik et al. [46]). Some studies by Robins et al. [43] and Allen et al. [47] have argued that any form of aspiration in healthy people may lead to respiratory complications and if aspiration pneumonia occurs, this can also impaire swallowing if respiratory rate is high. If aspiration is associated with a neurological disease, this debate will have less significance as the focus of attension will be on the management of immediate complications which may result in untimely death. Studies by Pikus et al. [48] and Martin-Harris [49], reveal that people with oropharyngeal dysphagia are known aspirators and are more prone to develop aspiration pneumonia. The frequency of development of aspiration pneumonia has been shown to be about seven times more common in patients with dysphagia during VFSS [49].

Prevention of aspiration is important in people with neurological conditions. Several ways of avoiding the occurrence of aspiration include early identification of dysphagia and routine swallow screening and chin-down or chin-tuck manoeuvres [50-52]. It is unclear whether these methods are suitable for patients with PD, MS and MD, they include sitting in an upright position when eating, thickening of fluids and avoiding medications that dry up secretions [53-54]. This makes swallowing more difficult, requiring application of the mechanism of cueing and environmental adjustment to avoid distractions during meals [55]. However, not all of these mechanisms may apply to all patients.

Silent aspiration is a term used to describe aspiration which occurs with no obvious clinical signs and symptoms [56]. Pathological mechanisms linked with silent aspiration mirror those with other types of aspiration and can include weakness or lack of coordination of the pharyngeal musculature and impaired ability to produce a reflexive cough. [56-57].

b) Malnutrition

One of the complications associated with dysphagia in people with PD, MS and MD is malnutrition. The World Health Organization (WHO) defines malnutrition as "the cellular imbalance between supply of nutrients and energy and the body's demand for them to ensure growth, maintenance, and specific functions. "Its incidence in hospitalized patients on admission is approximately 40% [58] to 70% [59] of in patients and 45% to 100% of outpatients" [60]. [Table 1.2] Research has shown that under-nutrition is often not identified or treated in patients who are admitted to hospital [61]. Malnutrition is associated with increased rate of infection (particularly chest infection), aspiration pneumonia, delayed wound healing, prolonged hospital stay and increased mortality [62-65].

Dysphagic patients have been shown to have a 6% increase in GP consultation rates, 9% increase in prescriptions, 25% increase in hospital admission rates and increased health maintenance costs of about £7.3 million pounds per 100,000 patients [66]. The NICE guidelines (No. 32 Feb., 2006) stipulate that all patients admitted to hospital should have a nutritional assessment [67]. Evidence from randomized controlled trials suggest that nutritional interventions reduce the risk of mortality, complications and length of stay in addition to

reducing the cost of hospitalisation and health care [68-69]. There is therefore a need to detect patients who might be at risk of malnutrition, in order to prevent deterioration and to improve their nutritional status whilst in hospital. Below is a table showing the incidence of malnutrition in hospital. As these figures indicate, malnutrition appears to arise in all settings and is often undetected.

Table 1.2 Incidence of malnutrition in hospitals

In hospital	**Incidence of malnutrition**	**Authors**
On admission	40% of patients are malnourished.	(McWhirter and Pennington, 1994)[58]
In-patients	70% of patients have undetected malnutrition.	(Kelly et al., 2000) [59] (Mowe and Bohmer, 1991) [70]
	2/3 lost weight during hospital stay.	(McWhirter and Pennington, 1994)[58]
Out-patients	45 – 100% have undetected malnutrition.	(Miller et al., 1990) [60]

A full history and clinical examination can identify signs and symptoms of malnutrition. Nutritional assessment involves taking a dietary history, anthropometry (for example, weight, height and body mass index (BMI)) and biochemical indices (such as full blood count, urea and electrolytes, total protein, C-reactive protein) [71-72]. The clinical condition of the patient can also affect nutritional intake. Patients who have an acute illness or fever, for example, will often have a reduced appetite.

It is important to highlight the limitations of BMI measurements, as these do not account for certain conditions such as reduced muscle mass, ascites and peripheral oedema. There is currently no gold standard for determining nutritional status; [73] before a full nutritional assessment, a nutritional screening process is carried out, often undertaken by a nurse, to detect those patients at risk of malnutrition.

c) Dehydration

Dysphagia can lead to dehydration in people with neurological conditions. Several factors are known to contribute to dehydration, such as vomiting and diarrhoea, diabetes. Dehydration is a condition that occurs when the water or fluids levels in a body are insufficient for the body's requirements. Studies have shown for example, that impairment of the part of the brain known as substantia niagra may be responsible for a decreased appetite for water. Similarly, some medications, such as anticholinergics are known to cause dysphagia and reduce the flow of saliva [74-75]. A dry mouth and reduced salivation may make it more difficult for patients to chew their food. Reduced mobility, increased tremors and rigidity, can also make it harder to reach and hold a glass of water.

People with MS may also become dehydrated as the condition progresses. Many may develop swallowing difficulties leading to dehydration [76]. Mobility problems can also lead people with MS, (PD and MD) to limit their fluid intake and also cervical inversion, causing alterations in head position. Bladder problems such as urinary symptoms often lead people to restrict their fluid intake, in order to control urinary frequency, especially in situations where toilet facilities are limited or not easily accessible.

People with muscular dystrophy can also become dehydrated due to swallowing problems. Dehydration decreases salivary flow, which in turn enhances altered colonization of the oropharynx [74]. Dehydration may also cause lethargy, confusion, aspiration and poor wound healing and make patients more susceptible to infection by depressing their immune system [74].

Dehydration can be life-threatening and consequently it is necessary to identify and treat immediately. The signs and symptoms of dehydration are: muscle weakness, light-headedness, dry skin, urinary symptoms, polyphagia, and dry mouth. Other symptoms such as excessive thirst, low blood pressure, sunken eyes, fever, increased heart rate and unconsciousness occur in severe cases of dehydration [77].

The pathophysiological mechanism of dehydration involves depletion of the cellular fluid in the early stages, followed by depletion of extracellular fluid. Water is pulled out of the bloodstream in severe conditions [77] and, if this process continues, the body compensates by retaining water (known as oedema). Complications of chronic, severe dehydration include migraine headaches and impaired sexual function [77]. The skin will also lose its elasticity and the individual is unable to generate tears after crying, due to chronic water loss.

Dehydration can be treated in several ways, depending on the severity of the condition. Drinking adequate amounts of water daily and electrolytes can prevent minor dehydration but in severe cases where the electrolyte imbalance is impaired, intravenous fluid are administered to the individual in hospital [77].

In neurological conditions where dysphagia is a major cause of reduced consumption of liquids, thickened fluids are usually recommended. Though some studies have argued that this approach poses a greater risk of dehydration and it should only be used when other methods of rehydration do not lead to improvement [78-80]. Some individuals may not like the taste of thickened fluids and as such, are not likely to drink them regularly [81]. Also some patients 'risk' drinking fluids which are not thickened.

d) Infections

The three most common types of hospital-acquired infections (HAIs) are pneumonia, urinary tract infection and sepsis [82-84]. The most common organisms responsible include Coagulase-negative staphylococci (39.4%), Escherichia coli (18%), Staphylococcus aureus (10.2%) and Klebsiella spp. (9.9%) [85]. These aerobic, gram-negative organisms may also colonize the lungs of patients who have aspirated.

The Office for National Statistics (2008) has stated that in 2007, approximately 9,000 people died as a result of infections acquired in hospital [86]. Medical personnel must be able to recognize patients who are vulnerable to these infections, such as neurological patients with dysphagia, through early diagnosis and management of the complications associated with their illness, to avoid increased LOS and HAI. In the USA, the cost of complications due to untreated and/or poorly managed dysphagia is estimated by the Financial Service Centre of America (FISCA) in 2002 to have been approximately $15 billion nationally for complications in hospital in-patients [87]. These USA data provides an example of the cost and burden of dysphagia in another region of the world and they

illustrate it is not unique to the UK. The table below summarises some of the costs associated with managing dysphagia.

Table 1.3 Cost of managing dysphagia related consequences and co morbidities in the USA [87]

Dysphagia Co-Morbidities and Secondary Consequences	**Days**	**Hospital Discharge**	**Mean Hospital LOS Cost** (2002 USD)	**Mortality National Bill** (2002 USD)
Pneumonia	5.8	5.56	$18,379	$2,345,241,969
Dehydration	4.11	2.87	$11,267	$6,672,747,130
Aspiration Pneumonitis	8.75	18.3	$30,355	$5,737,998,273
Nutritional Deficiencies	8.45	6.26	$21,823	$2, 958, 85,312

e) Length of Hospital Stay (LOS)

This term refers to the length of time that a patient remains in hospital or other health care facility during an admission. The determinants of LOS are multi-factorial and include: management of the patient, medical complications, co-morbidities, nature of illness and severity [88]. Studies on LOS in patients admitted to hospital with severe illness have shown the stay to extend from 5.7 to 12.6 days [89-91]. Previous studies have reported that patients with dysphagia have poor outcomes in terms of in-patient mortality and LOS [92].

People with neurological conditions, such as - PD, MS and MD, are likely to have dysphagia and poor nutritional status. Both of these factors can result in a longer LOS particularly if dysphagia is not identified [93]. Other possible effects of lengthened LOS include hospital-acquired pneumonia, urinary tract infection and pressure sores [92-93]. To the neurological patient, being in hospital for a long time becomes an additional stressor to their condition and to their carers. Length of hospital stay also has a major impact on health costs, which increases the burden on healthcare providers [93]. The present economic situation leaves health care providers with no option other than to use differences in LOS as one indicator of care quality and clinical outcome.

G) Mortality

Neurological disorders contribute to about one per cent of deaths and approximately 11 per cent of disease burden worldwide according to WHO [94]. As discussed previously, dysphagia in people with long term neurological conditions is associated with higher mortality rates because of its complications and, studies have also shown that the presence of dysphagia is associated with an increased risk of death [95-97].

Disease progression in MS results in various complications such as respiratory infections (dysphagia related–aspiration pneumonia), which is a frequent cause of death in a population with a high mortality rate [95-100]. In MD, respiratory complications are responsible for 30–40% of deaths [101], whereas the mortality rate in PD is about three times that of the general population [102-103].

The commonest cause of death in this population, when compared to those without PD, is aspiration pneumonia [104]. It would be difficult to show that consistent dysphagia assessment would result in a reduction in mortality, because patients often have other diseases which are life limiting. In summary, dysphagia affects people with long term neurological conditions, therefore, it is important that all patients are screened. A review of the methods of dysphagia screening and assessment used for people with these conditions is discussed in the next section of this chapter.

1.3 Dysphagia Screening and Assessment

1.4 Introduction

This section begins by outlining the purpose for the literature review, and is followed by a description of the methods used (see section 1.4). The results of the review are discussed in sections 1.5 to 1.11. The search strategy was not limited to studies which examined people with PD, MS or MD because relatively few studies were uncovered initially. Therefore, studies which considered the assessment of dysphagia amongst people with neurological conditions are discussed in section 1.6 and 1.7. Radiological and non-radiological diagnosis of dysphagia in neurological conditions is discussed in sections 1.8. Furthermore, dysphagia management and outcomes following assessment are discussed in section 1.10 and 1.11. Also, the theoretical underpinnings of the study are discussed in section 1.12. Following this, a discussion of the findings from the literature review, limitations of the review, relevant gaps in the literature and ethical issues are highlighted (see section 1.14). Finally, the conclusion of the review, the study aims and objectives and a plan of the thesis are given in the last section. (see section 1.15)

For many years studies have shown dysphagia in PD, MS and MD populations and this raises the potential importance of screening for dysphagia. [105-107] An effective screening tool is expected to meet the following criteria. It should be: i) valid, ii) reliable, iii) easy to use, iv) economical v) sensitive and vi) specific. A dysphagia screening tool should also incorporate components specified in the NICE guidelines, namely level of consciousness, oral hygiene, water test, signs of aspiration risk and feeding [67]. Their validity, reliability, positive predictive and negative predictive values have been evaluated but the use of these dysphagia screening assessments may differ when applied to people who have PD, MS or MD.

1.4.1 Aim of the Literature Review

The overall aim of the literature review was to summarise and review the literature critically on the use of dysphagia screening assessments amongst people with PD, MS and MD when they have an unplanned admission to hospital.

1.4.2 Objectives

1. To determine if patients are screened for dysphagia during the first seven days following an unplanned admission to hospital.
2. To determine whether patients who are assessed for dysphagia during the first seven days following admission to hospital are managed differently to those who are not assessed.
3. To determine if the clinical outcomes of patients who are assessed during the first seven days following admission to hospital differ from those who are not assessed.

4 To evaluate dysphagia screening tests and methods of assessment adopted when patients are admitted to hospital.

1.5 Literature Search Methods

1.5.1 Search Strategy

A literature search was undertaken to identify all relevant articles on dysphagia assessment in people with PD, MS, and MD. As the volume of literature in this area was known to be sparse no limitations were imposed on the type of study designs included. The databases searched were: Ovid Medline 1950-February 2010, Embase 1980- February 2010, AMED (Allied and Complementary Medicine) 1985- February 2010, British Nursing and Archive 1985- February 2010, CINAHL 1982- February 2010 and the Cochrane Database of Systematic Reviews.

Several search terms were used, in an effort to avoid missing any potentially relevant articles. A total of 41 search terms were applied and combined using the Boolean operation 'AND'/'OR'. The literature has been derived from the electronic search strategy adopted and also through separate means and is presented in Appendix 2. Bibliographies of abstracted references, unpublished studies, conference reports, Google scholar and hand searching of relevant journals not found on databases were also included. Lastly, expert opinions in this field were sought.

1.5.2 Study Population

The studies in this review were limited to adults with PD, MS and MD. As a result of limited research evidence, studies which had 50% or above of the study

population with these conditions, alongside other conditions such as dementia, were included. It is important to mention that studies involving stroke patients primarily were excluded from the review, as there is ample evidence in this field. Studies on assessment of dysphagia of non-neurological origin (dysphagia due to mechanical cause) and non-English language studies were also excluded.

1.5.3 Type of Intervention/Assessment

The various methods of assessing dysphagia in the three groups were explored. They include the following screening and assessment tests: interviews, questionnaires, bedside swallowing assessment (water test), dysphagia rating scales, Repetitive Oral Suction Test (ROSS test), quantitative swallowing tests, tactile monitoring and the Exeter Dysphagia Assessment Technique (EDAT) [26,108-116]. The diagnostic tests consisted of various radiological assessments, such as Video Fluoroscopy Swallowing Study (VFSS), Pharyngeal Oesophageal Manometry, Manofluoroscopy Study (MFS), Fibre optic Endoscopic Evaluation of Swallowing (FEES) and Radionuclide Scintigraphy (RS). The review is centred largely on swallow screening assessments.

1.5.4 Outcome Measures

This part of the literature review will compare the following outcomes for patients screened and not screened for dysphagia: Detection of unrecognised dysphagia, malnutrition, hydration, infection, length of hospital stays and mortality.

1.5.5 Data Extraction/Appraisal

The inclusion criteria and methodological quality of articles were screened by two academic supervisors using a proforma for titles and abstracts (Appendix 3). They were examined based on the following criteria: Article title and Author (AA), Study Design (SD), Study Methodology (SM), Study Population (SP), Study Setting (SS), Study Intervention (SI), Study Outcomes (SO), Confounding Factors (CF) and Author's Conclusion (AC). These articles were appraised using an appropriate evidence-based appraisal tool for each type of study design and graded accordingly [117]. Issues that arose during the course of the review were handled by further discussions with the reviewer until a unanimous agreement was reached.

1.5.6 Results

The search yielded a total of 62 articles from six databases for the three neurological conditions namely PD, MS and MD. The search of papers pertaining to each condition was carried out independently, using the same 41 search terms. Similarly, each database was searched separately. A total of 32 titles and 26 abstracts were retrieved for PD, 22 titles and 19 abstracts for MS and 20 titles and 17 abstracts for MD. For those articles that had only titles, full texts were sought and reviewed, but 12 of these titles could not be retrieved. Of the articles located, 29 were excluded because they were not research that described dysphagia assessment and its management. Fifty-three articles were retrieved in total for the review. Appendix A3 shows the total number of titles and abstracts retrieved for each of these conditions. Below is a diagrammatic summary of the results of the search.

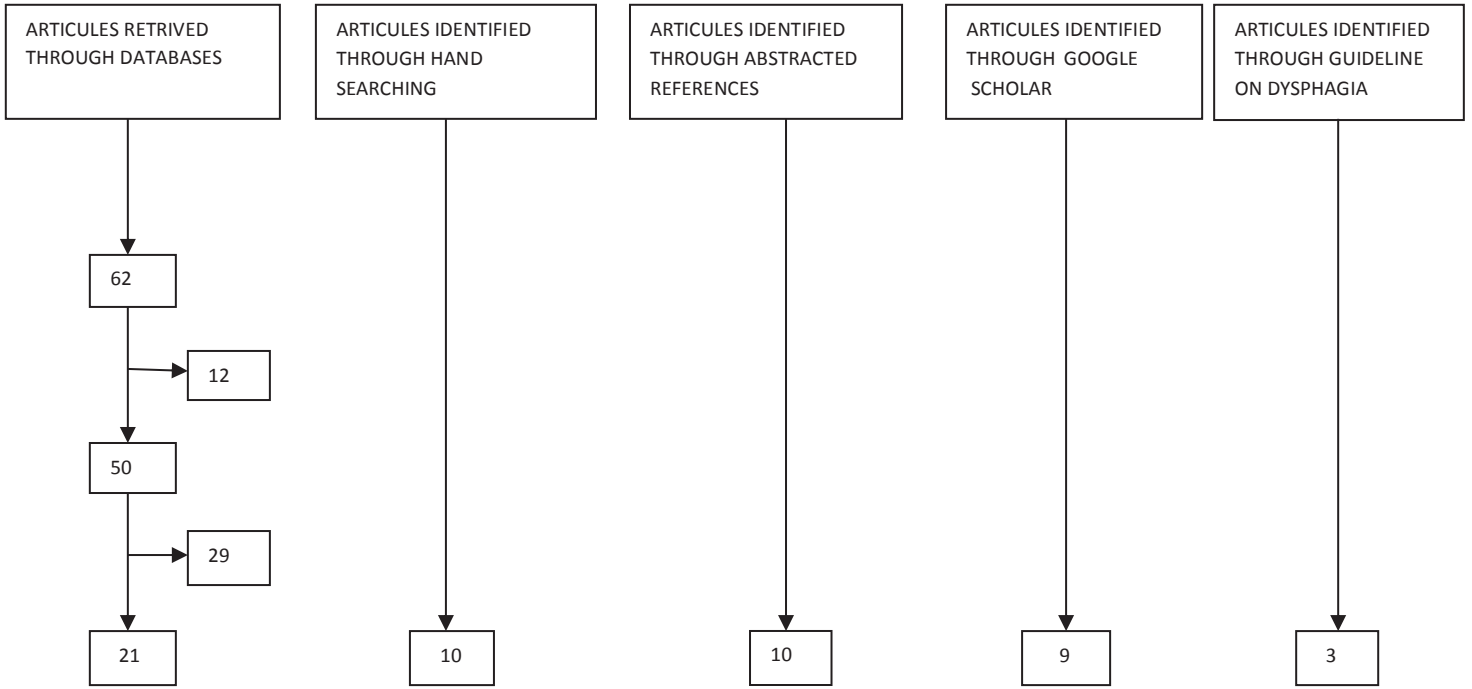

Figure 1.1: Results of the literature search

KEY:

62 articles retrived from six databases
12 articles which could not be retrieved
50 articles retrieved and reviewed
29 excluded; because studies were not research that described dysphagia in PD, MS and MD
21 articles included in the review from the databases
32 articles included in the review from hand searching, abstracted reference, Google scholar and guidelines,
53 articles used in total used for the review

1.6 Dysphagia Assessment

Assessment of dysphagia in people with PD, MS and MD has been investigated using different screening and diagnostic tools. Nineteen studies described an assessment and diagnosis of dysphagia and the effect that screening had on patient outcomes. These used pulse oximetry, respiratory inductance, plethysmography, nasal air flow, measurement by thermistors, EDAT [55], dysphagia questionnaires (swallowing dysphagia questionnaire (SDQ) [115], Dysphagia Multiple Sclerosis Questionnaire (DYMUS)[119], John Hopkins swallowing centre questionnaire [120], clinical itemized questions), dysphagia rating scales [108,113-114], the water swallow test [109,122], the ROSS test[110], radiological tests-videoflouroscopy studies, Solid Phase Radionuclide Scintigraphy [130], FEES and MFS [55,108-110,114-116,118-130]. Ten dysphagia assessment tools and ten bedside screening tools were reviewed. An additional review of five radiological and one non-radiological assessment tools were also included. The studies indicated that a variety of methods are used to assess dysphagia in hospital settings (Appendix 4).

Fabiola et al. [109], in their assessment of dysphagia used a combination of two dysphagia screening methods and concluded that the water test and pre-screening questions can be used to direct individual swallowing rehabilitation when radiological evaluation is not assessable . This study provided both important preliminary information regarding the use of screening methods and suggestions for future research. The authors included a heterogeneous group of people with various neurological conditions such as PD, MS, MD, amyotrophic lateral sclerosis (AML), cerebrovascular accident (CVA) and traumatic brain injury (TBN). They used two dysphagia screening methods; the 3oz water swallow test and Pre-screening questions (25 item clinical assessment forms) and found

supportive evidence for the screening tests to detect patients at risk of aspiration accurately. The authors stated that in the pre-screening questions, the sensitivity was 74% with a positive predictive value of 71% and negative predictive value of 77%. The 3oz water swallow test showed a positive predictive value of 84% and negative predictive value of 78% but a low sensitivity. The authors used VFSS as the gold standard for comparison purposes. Though the 3oz water test is simple and quick to administer as a bedside screening assessment, it may not be suitable for all populations.

The study by Nathadwarawala et al. [122] also demonstrated the use of both methods (water swallow screening tests and pre-screening questions) to assess for the presence of dysphagia in neurological patients. However, the water swallow test used in this study was timed (unlike Fabiola et al. [109]) and produced 96% sensitivity, 69% specificity and 60% positive predictive value of swallowing speed and a negative predictive value of 40%. The gold standard used in this study was also the VFSS. The study provided reliable and valid data. Their study demonstrated that test administration is fast and can be included as part of regular neurological assessments for people with neurological conditions. However, this method may not be suitable for elderly people and for those with severe swallowing problems (because they may be unable to drink 150ml of water from a glass as fast as possible with the assessor recording time taken and speed of swallows). The authors highlighted that it cannot be used as a replacement for SLT or radiological assessment, but that swallowing speed could be a useful tool for observation of progress of dysphagia management.

Some studies have also investigated the use of a dysphagia rating scale for assessment of dysphagia in PD patients. Clarke C.E et al. [108], Kennedy

et al. [113] and Volonte et al. [114] have shown the effectiveness of dysphagia rating scales to detect asymptomatic dysphagia and broadened them to accommodate the methods that are used for bedside swallowing tests. The Clarke study produced a global dysphagia rating scale which was able to categorize patients into different treatment groups, recognize dysphagia, determine the prevalence of dysphagia and could be used as a tool for direct referral to SLT [108]. In addition, the authors reported a high sensitivity of 100% and high specificity of 75%, for questions on swallowing difficulty with food. A positive predictive value of 32% was shown with problems of dysphagia for food. However, Kennedy and colleagues acknowledged that interpretation of these scales may prove difficult at times if using the rehabilitation institute of Chicago (RIC) clinical evaluation of dysphagia, a type of dysphagia rating scale which is limited to patients with cognitive problems [113]. This result is similar to the study by Volonte et al. [114] which found that even when the dysphagia rating scale based on the previous study was modified; it was not suitable for patients who cannot understand verbal commands.

The authors suggested routine dysphagia screening for patients with idiopathic PD, development of better assessment methods which will serve where radiological tests cannot be carried out, SLT referrals to be made for further management of those with dysphagia and yearly assessments.

Bergamaschi et al. [119] conducted a study on 226 MS patients using the dysphagia multiple sclerosis (DYMUS) questionnaire. Their findings revealed that it was possible to identify dysphagia in MS patients, but an inability to account for the duration of their illness and patients with severe dysphagia meant that they cannot benefit from the tool.

An earlier study by De Pauw et al. [120] found that in 73 MS patients, using a combination of the 'John Hopkins Swallowing Centre Questionnaire'

and manofluoroscopy study (MFS), detected patients with 24% permanent and 5% transitory dysphagia. Manofluroscopy study is a combination of manometry and fluoroscopy studies (see section 1.8.3). The authors advised that radiological assessment such as MFS for MS patients with EDSS of 7.5 (if assessable) would be beneficial. Further investigation of the extent of sensory impairment that could result in prolonged initiation of deglutition reflex was suggested for future research.

Manor et al. [115] also demonstrated that in PD patients, the SDQ questionnaire was able to detect those with dysphagia successfully and it can be administered routinely during clinical visits by clinicians or self administered. The SDQ questionnaire comprises of 15 item (yes/no) screening questions on swallowing disturbances. It is reliable, with 80.5% sensitivity and 81.3% specificity. The authors reported that patients with an SDQ score of >11 should be referred for a more objective radiological assessment of dysphagia. The SDQ questionnaire could also be used to identify dysphagia associated with other aetiologies. The length of time to administer this questionnaire was not considered in the study and so this may limit the degree to which it could be adopted in a busy acute setting.

Most of the methods of assessment of dysphagia discussed previously have limitations for patients with cognitive impairment, assessing quantitative swallowing functions or observation of effects of dysphagia treatments. The study by Pinnington et al. [55] demonstrated that these limitations can be overcome by using the Exeter Dysphagia Assessment Technique in patients with PD. Its simple repeatability makes it suitable for dementia patients and as respiratory and deglutition functions of swallowing are detectable with this method, it lends itself to wider use. The authors suggested that future research will be needed to compare EDAT and VFSS for the detection of EDAT indicators in patients at severe risk of dysphagia

and that evaluation of the reproducibility of EDAT in non-elderly and a less homogeneous set of people with neurological dysphagia was also recommended.

A study by Nilsson et al. [110] used the ROSS test in PD patients to evaluate quantitative swallowing functions and reported that it can also be used as an indicator for further investigation of impaired swallowing and examining subclinical dysphagia. Both tests (EDAT and ROSS) can be used for assessment of quantitative swallowing functions, but experience, knowledge and training are essential for these methods [55,110]. The EDAT test is different from the ROSS test because of its repeatability, appropriate for people with dementia and its ability to measure respiratory functions (see appendix 4)

Routine assessment, referral to the SLT, compensatory strategies and swallowing rehabilitation, will often help to improve quality of life in patients with PD, MS and MD who have swallowing difficulties [108,114,118,121]. Diagnosis using invasive methods could be avoided in PD, MS and MD patients, as non-invasive methods have been shown to be valid and reliable in the detection of silent and symptomatic dysphagia [55, 124]. Assessing swallowing function using the history of cough during feeds or drinking and failing a water swallow test, can serve as a preliminary diagnosis of dysphagia and trigger early interventions [109,118,127].

Seven studies reported the validity and/or the reliability of dysphagia assessment tools [55,108-109,114-115,119,122]. This small number of studies contributes to the limitation in the production of guidelines and demonstrates a need for more evidenced based studies in this area of research. However, the tools which have been validated may be used as a means of follow up in future studies [121,130]. A common theme

between the studies is that dysphagia assessment is a necessary requirement in people with these conditions. In some instances specialist training and equipment are required for data collection and analysis purposes. A more detailed description of the dysphagia assessment methods which have been investigated in PD, MS and MD patients are now described further.

1.6.1 Assessment of dysphagia in Parkinson's Disease

Different types of PD are discussed in the literature, these include: secondary PD, Parkinson's-like syndrome, idiopathic PD, autosomal dominant PD, PARK 1-13, mitochondrial PD and Parkinsonism. They share a common pattern of symptoms and signs including impairment of oral intake, rigidity, tremors and bradykinesia. In these patients, dysphagia causes marked impairment in both the oropharyngeal and oesophageal phases of swallowing as a result of complex pathologies affecting the bulbar area of the brain [26]. These have been well detailed in previous studies and manifest as partial cricopharyngeal opening and pharyngeal constrictor muscle contraction, prolonged onset of deglutition reflex, tremor of the ligulae and rigidity of the mandible [26]. Although these problems are well known in people with PD, no evidence is available on routine dysphagia assessment or management at acute presentation.

The dysphagia screening or assessment tests available for patients with PD include the timed water swallow test, ROSS test, EDAT, dysphagia rating scale Rehabilitation Institute of Chicago's (RIC) clinical evaluation of dysphagia, Modified Dysphagia Rating Scale (MDRS), novel global rating scale, questionnaires (e.g. Swallowing Disturbance Questionnaire [SDQ] or clinical assessment forms containing varied numbers of questions on swallowing problems), interviews and non-invasive physical examination,

to determine the presence or absence of dysphagia. Studies on PD populations suggest that these screening tests can help identify those with dysphagia [55, 108-114]. The timed water test is the most common screening test used for PD patients [108]; here, patients are given a specified quantity of water to drink as fast as possible during a set time. The speed, volume and time of swallow are recorded. In this test, a slow swallowing speed indicates a swallowing dysfunction. The timed water test procedure is fast and easy to administer at the bedside and can be used routinely for screening PD patients in hospital. Many people have argued that water swallow tests are indecisive without a radiological assessment, but they are still useful for early detection and prevention of aspiration pneumonia [113]. Overall, the timed water test provides a greater understanding of the patient's ability to swallow [113].

The ROSS test has not been used widely amongst patients with PD. It is a quantitative test which is useful for detecting hidden dysphagia and assesses the time of vital actions during the ingestion phase; suction pressure, size of bolus and ingestion capacity [110]. The test requires training to be able to administer but it can indicate a requirement for further evaluation of a patient's swallowing.

Another important assessment in PD is the Exeter Dysphagia Assessment technique (EDAT) [55]. This test involves the use of a small spoon holding an amount of water or juice, which is brought close to the mouth. It is a valid, reliable and sensitive assessment used to identify even minute problems with swallowing [111]. There are no restrictions to its use since the apparatus is portable. For PD patients with dementia, this test is most appropriate because laid down oral directives are not needed. It also has the advantage of assessing various aspects of swallowing non-invasively and can therefore be repeated as no radiation is involved. The ability to

measure two important parameters of swallowing at the same time (respiration and deglutition function) gives EDAT an advantage over several alternatives methods of assessment. It can also serve as a bedside assessment, but not as a routine screening test as can the water test in acute admissions. Overall, it is cost effective and health personnel, if trained, can easily understand the mechanisms for its application.

The dysphagia rating scales mentioned above have also been found to be useful tools. The scales differ in respect to other studies, though many are combinations or a modification of the RIC Clinical Evaluation of Dysphagia [108,112-113]. There are three basic concepts to dysphagia rating scales: clerking of patients, assessments of initial eating abilities and monitoring the main cycles of swallowing using four different textures. These scales are able to measure swallowing problems, allocate patients into the appropriate treatment sets and discover asymptomatic dysphagia. When combined with the water swallow test, they have a relatively high sensitivity of 100% and specificity of 75% in patients with PD [108].

Questionnaires as a means of screening for dysphagia have been widely used by clinicians. For PD patients, the SDQ is the only questionnaire seen to be unique (specifically designed to detect early dysphagia in PD), but its acceptability is still in contention [114-115]. The questions are straightforward and enable an assessment of dysphagia to be reached and further referral to be made to the Speech and Language Therapist. The SDQ is shown to be valid and reliable with a sensitivity of 80.5% and a specificity of 81.3% in PD patients, however, it is not suitable for those with dementia because of their inability to recall things accurately. In the study by Fabiola et al., heterogeneous patient groups with neurological disorders were screened using a 25 item clinical assessment form (a type of questionnaire) and a 3oz water swallow test [126]. The results showed

aspiration risk in dysphagia patients with a positive predictive value of 71% and negative predictive value of 77%. Questionnaires have an economic advantage and can be a more reliable screening tool if combined with the timed water swallow test.

Interestingly, the NICE guidelines for patients with PD do not take complications such as dysphagia into account or co-morbidities which affect these patients on a daily basis [131]. The recommendation for PD patients to have readily available access to SLT is yet to be fully implemented, because there is no research evidence concerning the economic value of SLT services to them [131]. The effect of not considering these areas may result in poor patient management and outcomes.

The evidence of early detection of dysphagia in various types of assessments includes studies of PD populations with different disease severity, sample size and types. However, this area of research requires further investigation, since the importance of routine assessment when admitted to hospital is yet to gain recognition in hospital settings.

1.6.2 Assessment of Dysphagia in Multiple Sclerosis

Multiple sclerosis has three variants, namely: Relapsing-Remitting (RR), Primary-Progressive (PP) and Secondary- Progressive (SP). For people diagnosed as having MS, their disability increases with the progression of the disease, manifesting with increased severity of symptoms and signs. As a result of the progressive nature of the disease, vital areas of the central nervous system such as the brainstem, which plays a role in the swallowing mechanism, are severely damaged [120,132]. Memory impairment also contributes to worsening effects of dysphagia in MS. The pathological processes for dysphagia in this group are weakness of the

pharyngeal constrictors over a long period of time, delayed peristalsis and spasticity.

There are few screening tests which have been examined for this group of patients. The water swallowing test uses various quantities of water (timed and untimed) and has been shown to be valid, reliable, sensitive and specific for MS patients [109,122,124]. The sampled MS population indicates that the water swallow test is an important screening tool for dysphagia, even though in the studies examined, small numbers of patients were assessed.

The Dysphagia Multiple Sclerosis Questionnaire (DYMUS) was recently developed and validated for the MS population [119]. The DYMUS questionnaire included 15 questions initially, but after the validation process a consensus was reached on using 10 questions. The DYMUS questionnaire identified a significant proportion of patients' complaints with regard to swallowing problems; however the tool did not highlight their length of illness. Though the authors did not intend their studies to identify this, it would have been helpful if individuals with varying length of illness were identified to provide an insight for further research in the context of improvement of care.

Overall, DYMUS was able to detect 35% of patients with compromised oral intake. It had good internal consistency and scaled higher in patients with progressive MS, correlating with EDSS. It should be noted that this tool was limited to patients with a mild disease form. This tool seems to be suitable only for a certain group of MS patients, those with an early diagnosis of MS having less severe symptoms and able to assess radiological intervention, therefore it cannot be used to screen the overall population with MS. The timing of the questionnaire administration was not addressed in the study, nor was the individual's suitability for referrals

to SLT. It should be noted that this review is based on dysphagia assessments and is not a critique of the methods by which the research was carried out. This will enable adequate focus on the issue being addressed - whether these patients are screened or not using any screening method when admitted in the hospital. As suggested by the authors, there are studies already in progress to test the reliability of the DYMUS questionnaire as compared to other methods of diagnostic assessment in this population [132].

The second questionnaire considered was that from the John Hopkins Swallowing Centre [120], conducted on 309 consecutive patients with MS. It has 18 items and the MS patients used for the study were diagnosed as having dysphagia, based on positive scores on a minimum of one of the items. Considering the 309 patients screened, 73 patients had permanent dysphagia (24%) or transitory dysphagia (5%). Those with mild impairment were thought to be developing permanent dysphagia (EDSS 2-3), while those with severe forms of MS and increased disability demonstrated a high prevalence of about 65%.

It is important to note the limitations of using questionnaires as the only means of screening in this group and how to make adjustments for this. History taking, if properly conducted, is also used in MS patients as an initial screening tool, but the value of this depends on who is taking the history. There is sparse evidence in terms of methods of swallowing assessment in MS patients, and there is no evidence as to whether they are assessed or screened on admission to hospital.

1.6.3 Assessment of Dysphagia in Muscular Dystrophy

These are a group of genetic disorders associated with slow progressive muscle weakness. There are many different types of MD with different

patterns of muscle weakness associated with it. The mechanism of swallowing disorder differs in the various types as do symptoms, rate of progression, age of onset and gene make up in the different groups. Although there are symptoms unique to each type of MD, the three swallowing phases are all affected due to muscle weakness, resulting in dysphagia. Preparation and transport of the food is disrupted. This problem could manifest as lung infection, dehydration, malnutrition and other complications of dysphagia [7].

Screening for dysphagia in MD is yet to be established, due to the scarcity of literature concerning this population. Only a study by Mari et al. [109] has investigated the use of the water swallow test, including 5 patients having Myotonic Dystrophy along with other neurological patients. Most often, interviews in the form of history taking for swallowing problems are used to identify the patients with dysphagia. This approach depends largely on who is taking the history, in order to gather all vital information. Some studies carried out on patients with oculopharyngeal muscular dystrophy have utilized either interviews or interdisciplinary methods for the screening of dysphagia. These patients usually manage their swallowing until dysphagia has progressed or become severe [133-134].

Other studies have focused on radiological assessments such as VFSS or pharyngeoesophageal manometry, rather than screening tests [135]. Several trials performed on the treatment of dysphagia in people with MD and also a systematic review of these treatments have produced no evidence in support of their use [136]. Several factors could contribute to the lack of studies in this area and may include the population with dysphagia being very small, the patient location being widely distributed, severity of the disease, psychological, social and cognitive problems. In

spite of this, the level of care for MD patients with dysphagia, in terms of regular screening, management and their outcomes needs to be evaluated.

1.6.4 Bedside Dysphagia Screening Tools

The screening tools which fall into this category were validated in heterogeneous groups of stroke patients but they could be applied to other patients with dysphagia of neurological origin if proven to be effective. The rational for applying these to people with other neurological conditions is based on the premise that there are similarities in the strength, range or control of swallowing and especially air way protection. Therefore, there is a good justification to suppose that these scales can be used in other neurological conditions but need to be validated in people with such conditions. Whilst some are referred to as "assessment tools", they are actually screening tools [137-146]. Most of these screening tools include types of water swallow test and, if found safe, this is then followed by taking sips from a 50ml glass of water. The process is usually a series of pre-screening questions, followed by clinical examination and then the water test. The quantity of water used varies between studies.

A systematic review was conducted by Perry and Love on the various screening methods available to identify dysphagia in stroke patients and the outcomes after assessment [147]. Perry and colleagues showed that there was no conclusive evidence for a specific screening tool which can be considered the most appropriate. This is because although the studies showed high sensitivity and specificity rates, they varied in their methodology and design. The authors reported five dysphagia screening methods that met their inclusion criteria and these were the: Burke Dysphagia Screening Test (BDST) [138-139], Bedside Swallowing Assessment (BSA) [140], Standardised Swallowing Assessment (SSA)

[137], timed water test [142] and, from Daniels and colleagues, two documented clinical features from their previous studies [8, 148-149]. These swallow screening tests had comparable predictive validity and to some extent a varied combination of clinical features. Outcome measures were varied highly between the studies. The SSA was better able to identify patients at risk of aspiration pneumonia when compared to the 3oz water swallow test, but had less sensitivity than the BDST. In terms of specificity, the BDST produced much lower specificity, which led to an increased number of false positive results. The SSA is currently the only bedside dysphagia screening tool which has been shown to be reliable with trained nursing staff. The authors also highlighted the scarcity of reliability studies for dysphagia screening compared to studies on validity.

Other swallow screening assessments, involving the combination of oxygen saturation with the water swallow test, have shown the best sensitivity and specificity (sensitivity 73%-100%, specificity 62-76%) in the diagnosis of dysphagia and detection of silent aspirators [150]. A more recent tool which was developed to incorporate oxygen saturation levels, water test and mashed diet is thought to enhance the detection of dysphagia. This tool is called the Screening Tool for Acute Neurological Dysphagia (STAND) [151] and it was validated using VFSS in a small, random sub-sample (n=24) of patients with acute stroke. It may be very useful for smaller health providers but requires online procurement, information and training on correct implementation of the screening protocol [151].

Further screening methods, such as the gag reflex, pulse oximetry and swallowing provocation test, are used to detect patients whose swallowing is unsafe [152-154]. Though there are controversies in the use of these tests (as a result of low sensitivity, non-physiological, questions on timing

and small sample size), they could be used to some extent in the determination of patients whose swallowing is at risk.

The description of these bedside swallowing assessments, their validity and reliability has been well documented in the literature. Validity in swallowing assessment indicates the extent to which test measures reveal aspects of dysphagia. Reliability and repeatability in swallowing assessment is the extent to which results of the same method can be obtained by another researcher or by the same researcher on another occasion. The difficulty in repeating bedside swallowing assessments in patients with neurological dysphagia is recognized and may result in non-accurate measurements, due to differences in the timing of assessments.

With all these factors in mind, there is evidence in the literature for accurate diagnosis of aspiration with bedside swallowing assessment. The bedside swallowing assessment has been seen to be practical, sensitive to people at risk of dysphagia, reliable in screening and yet specific enough for the purpose. However, most of the studies on which this evidence is based show methodological flaws in terms of study design, inclusion and exclusion criteria of patients and are limited primarily to stroke patients.

Some bedside swallowing assessments, such as the 'timed water test' or water test use different volumes of water to those that have been used in other neurological conditions. PD, MS, MD patients have achieved positive results in the identification of risk of aspiration but there is a need for the continuous screening of dysphagia with water swallow tests in neurological patients, to avoid future complications by promoting better management.

1.7 Assessment of Dysphagia during Acute Hospital Admissions

To date, no studies have determined whether or not PD, MS and MD patients are assessed routinely for dysphagia on admission to hospital.

Some studies in other neurological conditions have shown the benefits of routine dysphagia assessment in acute admissions.

The study by Hinchey et al. [155] revealed that a routine dysphagia screening protocol reduced the incidence of pneumonia in patients with acute stroke. This resulted in patients being screened before administering medication, food or drink orally to ensure swallowing safety. All stroke patients, irrespective of severity, were screened. This was different from the routine screening conducted only for those with severe stroke. This result implies that only hospitals that practice a routine dysphagia screening protocol undertake screening on all their patients, while others may only conduct a swallow screening test on those patients who they believe might be at risk of aspiration pneumonia. This may also apply to PD, MS and MD patients who are not screened routinely when they are admitted unless they are suspected to be at risk of aspiration. The authors reported that the use of routine dysphagia screening on all the stroke patients admitted, led to a 3-fold reduction in the risk of aspiration pneumonia [155]. This finding is also in agreement with the study by Odderson et al. [156-157], which also used a formal dysphagia screening protocol alongside stroke guidelines.

The results obtained from studies such as this, will enable guidelines and management protocols to be established to enhance good clinical management. From the review, many studies have examined the usefulness of using the screening tests (especially the water swallow test) in these conditions and their limitations. The usefulness of the test may be limited in patients with cognitive problems. The findings from the water swallow test were dissimilar in each group in the studies and this could be explained by the heterogeneous population studied and the different interventions.

Although some dysphagia assessments which have been evaluated solely in many patient groups such as the EDAT in PD and the DYMUS screening questionnaire in MS, they could also be used for the purpose of being unique identifiers of dysphagia to those groups [55,132]. A well organised approach towards dysphagia screening in acute admissions for PD, MS and MD populations should facilitate and prompt further intervention if required.

1.8 Radiological Assessments

Despite the variety of screening methods available, radiological assessments are recognised to be the best diagnostic tool for dysphagia in the target groups. The review did not include radiological methods of assessment for dysphagia, however the current state of practice regarding radiological (VFSS, OPM, MFS, FEES, RS) and non-radiological assessments (SEMG) in dysphagia is discussed in section 1.8.1 to 1.8.6 of the thesis. The various types of radiological assessments have been mentioned previously and some have been validated for specified groups.

1.8.1 Video Fluoroscopy Swallowing Study (VFSS)

VFSS is widely used as the gold standard for assessment of dysphagia. In this assessment, the swallowing capacity is revealed through imaging, by monitoring the bolus during all the swallowing phases. It is a vigorous study which detects swallowing dysfunction accurately and provides information on the required treatment.

Pikus et al. [48] conducted a study to investigate swallowing dysfunction and relative risk of pneumonia using videofloroscopy studies. The study involved 381 patients with neurological conditions (including PD and MS) whose data were on a radiological computerized database. Each patient underwent a videofluoroscopic swallowing study with barium. The findings

revealed that patients with laryngeal penetration, tracheobronchial aspiration or silent tracheobronchial aspiration, were about 4 times (p = 0.008), 10 times (p< 0.0001), and 13 times (p< 0.0001), respectively, more prone to develop pneumonia compared to those with normal swallowing. The authors state that findings on videofluoroscopic swallowing studies can be used to guide management of patients potentially at risk for pneumonia [48]. A recent study by Baijens et al. [158] also highlighted the need for better diagnostic swallowing assessment by the use of well-defined videofluoroscopic parameters, with good intra and inter-rater reliability and which may be beneficial for PD patients with dysphagia.

Although VFSS is readily used in the three groups, it has remained a topic of debate because of its shortcomings. It is an invasive procedure and not suitable for all patients e.g. bed ridden patients, runs at a high cost, poses risk of exposure to radiation and requires a trained professional such as SLT and a radiologist before the assessment can be performed [67, 130]. It may also not be readily accessible to all patients, because some hospitals may not have the required equipment. VFSS is yet to be validated in MS patients and it has shown to be of limited value in patients with MD [127]. Differences in VFSS protocols are well documented in the literature and a uniform procedure will be of great benefit to neurological patients.

1.8.2 Oesophageal Pharyngeal Manometry (OPM)

OPM is the gold standard for assessment of oesophageal disorders and has been shown to be a useful diagnostic tool in PD, MS and MD patients with dysphagia. It complements the VFSS and FEES and gives useful quantitative information on pharyngeal or oesophageal disorders in

patients with dysphagia [159]. OPM techniques investigate pressure changes that arise when swallowing. The examination involves using a thin, flexible catheter which is gently guided through the nose or mouth into the oesophagus. This tube has many integral pressure sensors at specific positions all along its length. The pressure sensors enable the evaluation of the vital quantitative functions of the pharyngeal and oesophageal sphincters. This technique has been widely used for the assessment of oesophageal motor disorders, especially when barium studies are not helpful or when radiological results suggest motor dysfunction.

Sung et al. [160] found in their study conducted in early stage PD patients, that oesophageal manometry in the liquid swallow was abnormal in 22 (41%) and viscous swallow tests was abnormal in 31 (67%) patients. The authors reported that even before the clinical manifestation of dysphagia in this group, they could demonstrate pharyngeal and oesophageal dysfunction. An earlier study by Castell et al. [159] of ocularpharyngeal muscular dystrophy (OPMD) patients concluded that improved quantitative assessment of the extent of pharyngeal weakness and deficiency in UES relaxation during swallowing can be achieved by computerized manometric methods. The authors reported that this technique could be used to monitor disease progression in these patients.

The limitations of OPM are the requirement for extensive skill and knowledge, difficulties with pressure reading, suitable sensor design and unavailability of the equipment in most oesophageal manometry laboratories. Its function in the assessment of pharyngeal dysfunction is yet to be recognized when compared to oesophageal motor dysfunction [159-160].

1.8.3 Manofluoroscopy Study (MFS)

MFS is a combination of manometry and fluoroscopy studies. In an MFS investigation, a manometric probe with five micro transducers is passed transnasally and then the patient receives a bolus of liquid contrast material. The micro transducers are positioned together with video fluoroscopy and displayed on a screen. The fluoroscopy images and manometry data are recorded together on a special recorder [120]. This procedure provides a clear picture of the pharyngeal phase of swallowing and pressure determination at any height in the pharynx. The validity of MFS is well established in MS patients. The disadvantages associated with this assessment include limited availability, the requirement for an appropriate contrast material, transport, aids during the procedure, long duration and the invasive nature of the procedure.

1.8.4 Fibreoptic Endoscopic Evaluation of Swallowing (FEES)

FEES have been validated in patients with PD. The process involves the use of a flexible laryngoscope which is inserted through the nose into the hypopharynx. The swallowing function is video recorded when food or liquid is taken by the patient. This type of assessment is harmless, portable, suits all patients and is tolerated by patients. Langmore et al. [161] in their protocol for FEES state that it can be used for a full assessment of swallowing and investigating interventions for dysphagia management. Logemann et al. [162] however indicated that it requires experienced personnel to carry out the test, gives limited information on the oral stage of the swallow and forms a 'white out' phase during swallow apnoea, which makes the function of the swallowing mechanism less visible during the swallow [162].

Kelly et al. [163] report in their study that on comparison with VFFS, FEES was better at detecting the degree of penetration and severity of aspiration of a bolus or pharyngeal residue. The National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Chronic Conditions (NCCCC) (2006) in partnership with Royal College of Physicians (RCP) also recommend the use of FEES for PD patients to exclude silent aspiration [67,164]. Although this tool has not been validated in MS and MD patients, it is currently applied to these groups as well.

1.8.5 Radionuclide Scintigraphy (RS)

Radionuclide Scintigraphy (RS) is an important assessment tool for evaluating oesophageal dysmotility in situations where manometry is not easily accessible [165-167]. Wang et al. investigated oesophageal function of patients with Parkinson's disease using RS [130]. The study included 27 PD patients and 27 normal controls. All the participants were asked to drink 4ml bolus of solid gelatine containing 75 MBq Tc-99m pertechnetate. They were placed in a supine position over a gamma camera which was connected to a computer. The total mean transit time, the residual fraction after the first swallow, was then evaluated by the computer. Their findings revealed that patients with PD exhibit considerably slower transit time when compared with normal controls. The authors were also of the view that RS could be used to monitor dysphagia in prospective studies. The limitations of RS are that some information on abnormalities of peristalsis and functions of the lower oesophageal sphincter may be lacking, though its relevance clinically is still debatable [167]. Also assessment of swallowing in a supine position could be quite problematic; however the discussion on radionuclide scintigraphy (RS) was based on the state of current practice and studies in the assessment of swallowing problems.

1.8.6 Surface Electromyography (SEMG)

This investigation gives a detailed explanation and clarity of the pathology of swallowing mechanisms in the oesophagus [168]. It is another area of development in dysphagia which has been explored by researchers and provides information on the timing and amplitude of muscle activities during swallowing [169]. In a SEMG investigation, electrodes are placed at various sites on the surface of the skin (face and neck) to show the activity of the different muscles during swallowing [170]. Its reliability as a diagnostic tool for oropharyngeal dysphagia has also been proven [169]. Vaiman and Eviatar [171] in their study on surface electromyography as a screening method for evaluation of dysphagia and odynophagia emphasized that SEMG is a reliable indicator of muscle activity and can produce valuable information for screening in patients with dysphagia. The authors suggested that future research should include identification of early phase deglutition oropharyngeal disorders and that combination of SEMG and FEES can be used for swallowing assessment, to avoid exposure to radiation and would be beneficial for appropriate referral to the specialist. SEMG equipment is simple to use, non-invasive, free of radiation and affordable [172]. Hermans et al. [172], Gupta et al. [173] and Logemann [7] reported in their studies that SEMG can be used as an adjunct to bedside screening in patients with neurological conditions. SEMG has its shortcomings; it can only be used to monitor a small number of muscle sites, electrodes are conspicuous (which may affect compliance with some patients) and there are difficulties in interpretation and specificity of the recording in situations where there is transfer of energy from one muscle group to another (known as the 'cross talk' phenomenon) [171].

1.9 Relevance of Dysphagia Screening to PD, MS and MD

Dysphagia caused by PD, MS and MD primarily involves the oral and the pharyngeal phases of swallowing, it is therefore known as oropharyngeal dysphagia. In most cases, this impairment results from the progression of the neurological disease [6, 23]. Dysphagia is known to cause aspiration pneumonia, malnutrition, dehydration, increased susceptibility to infection, increased health expenditure and poor quality of life, leading to morbidity and mortality in PD, MS and MD [7]. Immediate diagnosis and management of dysphagia is therefore, essential for early detection in PD, MS and MD patients with swallowing impairment, who are at risk of aspiration. This includes identification of any abnormalities of the organs involved in swallowing (through further evaluation and instrumentation), nature or severity of impairment of the mechanism of swallowing, indication for nil by mouth (NBM), diet modification, tube feeding or other interventions which may also include swallowing rehabilitation. The SLT is expected to conduct a comprehensive swallowing assessment on these patients, but because of a shortage of SLT and lack of funding, this level of care is often not obtainable. The only practical and available option is the use of dysphagia screening tools (swallowing test questionnaire) and bedside screening tests (water swallow test) by trained health personnel (e.g. a nurse, DTN) to identify patients at risk of dysphagia and to trigger referral to speech and language therapy.

It is known as a sensitive tool if it is able to detect the presence of dysphagia and if the tool does not identify people without dysphagia it has high specificity [174]. The importance of early detection of dysphagia using routine swallow screening assessments is recognised internationally for patients with stroke and supported by stroke guidelines from United Kingdom, America, Australia and Canada [6,106, 175-178]. However, in

the PD, MS and MD group, this evidence is lacking. This renders the current study unique as it addresses this issue in later chapters of the thesis.

In neurological disorders, only two standardized clinical swallow assessment measure are available for patients with dysphagia - both were validated with stroke patients. They are the Mann Assessment of Swallowing Ability (MASA) and the Functional Oral Intake Scale (FOIS) [179-180]. The Mann Assessment of Swallowing Ability (MASA) is a 24 item tool (Appendix 5) that uses a scoring system to determine the severity of symptoms of dysphagia, aspiration and any changes that occur [179]. The severity of dysphagia is grouped into moderate dysphagia (if the MASA score is ≤ 139-167 and ≤ 148 for aspiration) and mild dysphagia (if the MASA score is ≤ 168-177 and ≤ 149-169 for aspiration). It is an easy tool to use and can also be used as a BSA. It has shown to be reliable (dysphagia {inter-observer reliability -kappa = 0.85} and aspiration ({kappa = 0.74}) and valid with good psychometric properties compared to VFSS (SE: 73%; SP: 89%) [179].

The FOIS contains 7 items (Appendix 5) that are sensitive to change in a stroke patient's functional oral intake [180] with established validity and reliability, making it a favourable tool to use for documentation of patients' oral intake status [180].

The advantages of using either or both of these standardized measures are that they give a detailed description of the symptoms of dysphagia and detect any change during the course of management. It is unfortunate, however, that even with the research evidence available, studies have shown that the majority of clinicians do not routinely make use of these measures for managing their patients [181-182].

McCullough et al. [182] investigated the clinical, bedside and videofluoroscopic (VFS) examination methods and measures that clinicians believe should be employed to assess swallowing, the methods they actually use in adults with neurogenic aetiologies and compared their preferences and practices with the methods and measures that are supported by research evidence [182]. Their study revealed that clinician behaviours vary in relation to which methods and measures they use for assessment of swallowing function in this population. However, the authors reported that clinicians generally use the methods they believed are correct for swallowing assessment and that the rate of usage for their chosen method is equally high [182].

These findings are in agreement with the study by Martino et al. [181] on dysphagia assessment practice patterns of SLT and their opinion on the importance of these practices. Martino et al. also reported that there were differences amongst the clinicians on the practice and opinion of many test manoeuvres [181]. The utilization of dysphagia assessment tests in their study showed that 36% were reported with high (>80%) utilization and 24% with low (<20%) utilization. In addition, 33% of instrumental assessments were greatly utilized. Clinician experience and teaching institutions had a greater influence on the utilization of swallow assessment tests for patients, the clinicians primarily used bedside swallowing assessments rather than the standardized measures of assessment (MANN and FOIS) [179-180]. They proposed that a hierarchy model is needed to explain this pattern of behaviour.

The study in this thesis also presents the clinical reasoning which underpins decisions concerning assessment of swallowing when patients with neurological conditions are admitted to hospital, which will provide explanations for swallow assessment behaviours by health professionals.

Health professionals should select diagnostic assessments for PD, MS and MD patients on a case by case basis, bearing in mind those which have been validated on each group. Those patients with co-morbidities, such as cancer, hypertension, seizures and diabetes, usually deteriorate faster and are at a higher risk of aspiration pneumonia. The routine use of standardized bedside swallowing assessment as an early screening test for dysphagia and aspiration risk in PD, MS MD patients remains an important part of their management and this study will assess whether swallow screening should be included in formal guidelines.

1.10 Management after Assessment

The review did not identify any studies that compared the management of dysphagia in PD, MS and MD patients assessed for dysphagia following their acute admission in hospital to those who were not assessed. The definition of management in this context means clinical history and examination (oral hygiene), swallowing assessment or screening, nutritional screening and intervention (Nasogastric or Percutaneous Endoscopic Gastrostomy feeding), and progress reviews.

The NICE guidelines for management of dysphagia in stroke patients recommend that patients with dysphagia should be monitored daily in the first week and that nutritional risk should be assessed within the first 48 hours of admission to hospital [67]. Swallow screening and nutritional assessment of these patients will identify patients at risk. In this thesis, United Kingdom (U.K.) guidelines and those from professional institutions are used as the primary source when discussing management. Guidelines from other organisations are cited where necessary.

1.10.1 Guidelines

Dysphagia has a significant impact on quality of life and treatment costs, therefore clinical guidelines have become a high priority for health governing bodies, and particularly for stroke patients [81,105-106]. In the U.K, the Scottish Intercollegiate Governance Network (SIGN) (No78) published guidelines on the identification and management of dysphagia in stroke patients [106]. However, the Department of Health also advised the National Institute of Health and Clinical Excellence (NICE) to include guidelines on nutritional support in adults [67]. Other clinical guidelines have also been produced in support of dysphagia management and nutrition. These include the Royal College of Speech and Language Therapists (RCSLT) clinical guidelines 2005 'Disorders of Feeding, Eating, Drinking and Swallowing', Nottingham University Hospital/Rushcliffe PCT Nursing Practice Guidelines 2005 ' Care of a Patient Receiving Enteral Tube Feeding via a Nasogastric tube'[1,107].

International guidelines on dysphagia have also been recognized by the American Heart Association/American Stroke Association (AHA/ASA) (2005) for stroke patients. Other generic guidelines applicable to all patients with dysphagia have been developed by other organisations including: American Speech and Hearing Association (ASHA) (2000), Canadian Association of Gastroenterology (CAG) (1998) and the World Gastroenterology Organization (WGO) Practice Guidelines (2007) to improve worldwide dysphagia management [175-178,183]. These guidelines emphasize identification of dysphagia within 24 hours of admission, the use of clinical bedside assessments such as the water swallow test, nutritional screening, risk of aspiration and training.

The guidelines also recommend a multidisciplinary team approach for the management of dysphagia in stroke patients, but the limited evidence for dysphagia management in patients with other neurological conditions such as PD, MS and MD may have resulted in the lack of routine dysphagia screening in these patients, to form part of the care pathway in hospital. Hospital management of dysphagia involves taking a history, reviewing systems and conducting systematic examinations to identify possible risk factors. If dysphagia is suspected, a swallow assessment is made by a trained nurse (if available) or patients are referred directly to speech and language therapy. Further investigation may be necessary such as a video fluoroscopy study and management of dysphagia may be surgical or non-surgical dependent on its cause. If management is non-surgical, the aim will be to reduce risks and the maintenance of hydration and nutrition. These aims are achieved through swallowing rehabilitation techniques, including diet modifications, postural changes, swallowing manoeuvres, oral motor exercises and nutritional counselling [14, 53-54,184]. Several studies of dysphagia management, have demonstrated some of the benefits of swallowing rehabilitation as a method of reducing the risk of aspiration pneumonia in these patients. [185-186]. A summary of the alternative management approaches is given in the following sections and summarised in figure 1.2.

1.10.2 Dietary Modifications

Diet modification has become increasingly common in the management of swallowing difficulties. The National Dysphagia Diet (NDD) published in 2002 by the American Dietetic Association, produced guidelines and standardized textures for four different levels of solids and liquids for the management of dysphagia [187]. However, the NDD stated that use of these guidelines should be interpreted with caution, as supplementary

research needs to be carried out in this area to establish quantities for use in cases of complicated dysphagia [187].

The four levels of liquid textures suggested by NDD include the following range of viscosities:

1. *Thin 1-50 centipoises* (a unit of dynamic viscosity*) (cP),*
2. *Nectar-Like 51-350 cP,*
3. *Honey-Like* 351-1,750 cP*, and*
4. *Spoon-Thick*>1, 750 cP [204].

The *thin* liquids are low in viscosity, e.g. water, milk, liquid nutritional supplements, ice cream, clear juice and yogurt [81]. *Nectar-Like* liquids are described as medium viscosity liquids such as milkshakes [81]. The *Honey-Like* liquids have a similar texture to that of honey and usually a commercial thickener is used to achieve the desired thickness and consistency (according to packaging instructions). The high viscosity liquids are known as *Spoon-Thick*. Commercial thickeners are also added to juices or beverages to make them *Spoon-Thick* [81].

The three levels of semisolid/ solid foods proposed by the NDD range from:

1. *NDD level 1: dysphagia-pureed*,
2. *NDD level 2: dysphagia-mechanical altered*,
3. *NDD level 3: dysphagia-advanced* soft and regular [81,187].

Pureed food is homogenous, pudding-like and requires very little chewing ability. *Mechanically altered food* is cohesive, moist, semi-solid foods require some chewing ability. *The dysphagia advanced soft foods* are foods that require more chewing ability. For *regular foods*, all types of foods are allowed [81,187]. It has been noted that difficulties in processing these food textures may be due to oral-preparatory and oral-stage deficits, due to disease progression (as previously discussed). It is

important to consider the individual needs when choosing diet textures as this will help to avoid food refusal.

1.10.3 Postural Changes and Swallowing Manoeuvres

Postural changes such as the "chin tuck" technique and swallowing manoeuvres, such as "effortful swallow", have been shown to limit aspiration in people with neurological conditions [81]. Other studies have confirmed the beneficial use of the "chin tuck" position and it should be considered as part of established practice. In the "chin tuck" technique, the cervical spine is flexed and the chin reaches to the chest. Patients are required to focus on their navel when swallowing a bolus, so as to maintain correct head positioning. [81]. This effortful swallow leads to an increase in the driving force of the tongue, enabling the bolus to bypass the valleculae. Patients are also instructed to constrict the muscles of the neck and throat as they swallow the bolus [81].

Robbins et al. [80] and Logemann et al. [188] compared the incidence of pneumonia in PD and dementia patients using a postural technique (chin tuck) and fluid modification (thickened fluids). The results showed that aspiration was reduced significantly in both conditions when fluid was modified to a 'honey' thick consistency. Further studies on the incidence of pneumonia by Robbins et al. [80] over a three month period, found that the frequency of pneumonia was far less when fluids were modified to a 'nectar' thick consistency more than using a 'chin tuck' technique.

In all these studies, the authors recruited patients who had cognitive impairment, which could have contributed to compliance difficulties when adopting the 'chin tuck' technique. In addition, the difference in the incidence of pneumonia between the 'honey' thick consistency and the

'nectar' thick consistency over the three months period may have been due to the small amount of oral stage control required in the former, so that the possibility of aspiration before the initiation of swallow becomes unlikely [189]. Also, because of increased viscosity in the 'honey' thick consistency fluids, it becomes difficult to clear any post pharyngeal residue, thereby increasing the risk of aspiration. Both studies also showed that the fluid modification groups experienced increased frequency of dehydration, urinary tract infections and fever than occurred in the 'chin tuck' group, but that the 'chin tuck' technique was preferred by most patients [80,189].

Quality of life (QOL) has been assessed amongst patients in these groups (i.e. those taking thickened fluids and those adopting the 'chin tuck' technique) from the study by McHorney et al. [190]. This study showed that those patients taking modified fluids had a lower QOL when compared to the 'chin tuck' group. These findings may have a vast impact on patient compliance when using thickened fluids. There is little research evidence in patients with muscular dystrophy; most of the studies described were carried out with stroke, PD and MS patients or in those who had dementia. The findings may therefore not be generalized to all degenerative progressive neurological conditions.

1.10.4 Oral-motor Exercises (OME)

Muscle weakness and wasting is known to be one of the primary causes of dysphagia in people with PD, MS and MD. However, there is limited evidence for or against the usefulness of oral motor exercises. In MS and PD oral motor difficulties usually result from damage to an area of the brain that controls the functions of oral muscles, due to disease progression [15]. These progressive neurological diseases are able to

affect an individual's oral motor function and the effect will vary, depending on the nature and severity of the disease and other associated complications.

Oral motor function can be described as a fine motor function involving the muscles of the tongue, lips, jaw and cheeks for chewing, drinking, speaking and other oral functions [191]. If the area of the brain controlling these muscles becomes damaged, this manifests as oral motor disorders, such as muddled speech; drooling of saliva/food/drink; weak muscle tone in the face; voice changes; and the inability to perform synchronized oral movements [15]. Oral-motor exercises (OME) are designed to exercise the muscles of the mouth. They include a variety of exercises designed to improve the mobility of the lips, tongue and jaws, to improve coordination, vocal fold adduction, laryngeal elevation or tongue base retraction. Adults with chronic neurological conditions such as PD, MS and MD, may benefit from OME. They are also designed to correct abnormal oral muscle behaviour's that interfere with feeding, especially in people with dysphagia [15]. OME may need to be modified according to different motor and sensory involvement in these conditions.

OME is usually recommended by the SLT. Several studies of OME have shown that the exercises are useful for enhancing tongue strength and improving swallowing difficulties in affected individuals [192-195]. MD patients may benefit from moderate-intensity strength training with less risk of damage to the muscles, but there is as yet no evidence as to whether this training can improve strength and motor function [196-198]. However, routine practice of OME may be necessary for successful swallowing rehabilitation in people with chronic neurological diseases.

1.10.5 Nutritional Counselling

One of the important goals of nutritional intervention is to maintain adequate hydration and nutrition. Nutritional counselling is a means of providing appropriate advice and guidelines on an individual's nutritional needs. It has three main components – management, intervention and training and is usually conducted by a dietician, whose role is to advise and monitor nutritional status. There are no specific dietary recommendations for people with PD, MS and MD who have dysphagia. However, new guidelines on the types of food textures required by patients with oropharyngeal dysphagia and for those who may be at risk of choking or aspiration, were developed in 2011 by the National Patient Safety Agency (NPSA) Dysphagia Expert Reference Group, in association with Cardiff and Vale University Health Board [199].

They recommended the following food textures: *B = Thin Purée Dysphagia Diet*, *C = Thick Purée Dysphagia Diet, D = Pre-mashed Dysphagia Diet, E = Fork Mashable Dysphagia Diet* [199]. In contrast to the NDD previously discussed (see section 1.10.2) this scheme has 4 categories. Fluids however, were not included in their recommendations. These guidelines replaced the previous food textures developed by the British Dietetic Association (BDA) and Royal College of Speech and Language Therapists (RCSLT). The guidelines were developed because of concerns for patient safety and to provide detailed guidance on types of food texture. The Dysphagia Diet Food Texture (DDFF) was designed primarily for people with premature swallowing difficulties. It is normally prescribed after a swallow screening assessment by a SLT or other team member who has undergone training based on the Inter-professional Dysphagia Competency Framework [200].

Nutritional counselling should be performed as the guidelines recommend, however appropriate food and dietary supplements should also be included and tailored towards meeting each patient's needs. The diet should be appetizing and well presented, to stimulate smell, taste, appetite and salivary production [201]. Presentation of food in smaller portions at the beginning of a feeding regime has been shown to result in greater fulfilment and a more pleasant experience [81].

In situations where a patient's nutritional intake is inadequate to meet the body's demands, alternative or assisted nutrition is usually provided. Enteral feeding through nasogastric tube and percutaneous enteral gastrostomy with parenteral fluids may be recommended in severe cases of dysphagia. Patients may complain of constipation, because of pathological changes which may occur in their bowels or as a side effect of their medications. In most cases a laxative, suppositories or dietary modifications can be used to alleviate the problem.

On occasions, nutritional advice can be disregarded. Whilst patients have the right to reject dietary modifications, they should be advised of the complications which may arise as a result. Clearly, such discussions are complex if the patient has cognitive impairments.

1.10.6 The Free Water Protocol

Difficulties encountered with patient compliance, when using thickened liquids and modified solid consistency diets, have been a source of concern for several years [190]. This has raised a debate on how to manage dysphagia when patients aspirate thin liquids. In order to resolve this issue, some clinicians have elected to use a "free water protocol", which was developed 25 years ago at the Frazier Rehab institute, Louisville,

U.S.A. The free water protocol allows patients who are nil by mouth or on thickened fluids, to drink water between meals and 30 minutes after meals under strict guidelines. The guidelines include oral hygiene before drinking water, sitting in an upright position, able to undertake three hours of physical rehabilitation per day for six days a week. The guidelines also stipulate that patients must have insurance, presumably to ensure that additional care can be provided if complications occur. The free water protocol is supported by research evidence in the following studies, Feinberg et al. [202], Holas et al. [203], Feinberg et al. [204] and Garon et al. [205], but not by the developers of the protocol.

The study by Garon et al. [205] investigated the effects of oral water intake on aspiration pneumonia, hydration and quality of life. The study compared two groups of stroke patients who were known to aspirate when taking thin liquids. The patients (n=20) were randomized to the free water protocol (n=10) or thickened fluids (n=10), for the duration of treatment and there was a 30 day follow up period. The results revealed that no patients developed pneumonia, dehydration or complications and intake of fluids was comparable between the two groups

Panther K. [206] reviewed 234 patients at the Frazier Rehab institute who followed the free water protocol and thickened fluids. The review indicated that only two patients developed pneumonia (2/234) and both of them were thought to have aspirated on solid food.

Karagiannis et al. [207] conducted a randomised-control trial, to determine the effects of people with dysphagia taking water orally. Patients were randomized to a control group (thickened fluids) or intervention (thickened fluids and free water) group. The study revealed that there was a

significant increase in lung complications in the intervention group (14.3) when compared to the control group who experienced no complications.

These results contrast with Garon et al.'s [205] findings, in which no cases of aspiration occurred. The sample size and the number randomized to each group was superior to the previous study (I=42, C=34). In contrast to the above, a pilot study by Carlaw et al. [208] on the outcomes of implementing the free water protocol, showed that there were no complications in either the control or experimental group.

The issues of independent and dependent patients on the free water trials were noted by Becker and colleagues [209] who conducted a study on the oral water protocol in rehabilitation patients with dysphagia. The patients were randomised to the water protocol or prescribed dietary fluid (26 patients). In terms of complications (pneumonia, UTI, death), the findings revealed that one patient in each group had pneumonia, two patients in each group had a UTI, two patients died in the treatment group and none died in the control group.

In summary, thickened fluid can lead to a reduction in aspiration and it does not lead to dehydration, however it is not the preferred choice for most patients. These studies indicate that the evidence is mixed and inconclusive. This could be attributed to the inclusion and exclusion criteria adopted. The findings also suggest that patients may not respond in a similar manner to an intervention and therefore careful assessment and monitoring is required.

Studies have varied in the management of dysphagia in neurological conditions and their results also differ, hence their limitations when making

a comparison. In addition, most of these studies involved stroke patients. It is unfortunate that no studies of these conditions have compared the management of patients assessed and those not assessed, to determine if there are any differences in management. It is expected that patients who are assessed will be identified early and benefit from early intervention [114], but often, these patients don't come to the attention of the health personnel until they present with acute symptoms [119,125]. From the studies on dysphagia to date, there has not been any research to determine the implications of a late diagnosis of dysphagia in people with neurological conditions or to assess routine screening and management guidelines.

In order for this to be possible, an observational study is needed to enable patients to be followed up for a reasonable length of time. Their management will then be determined and any differences in those assessed and not assessed will be noted. The level of expertise, experience and training will affect how these patients are managed and this should be considered when making an overall judgment on their management. The only available evidence on management after assessment is from stroke studies, in which management has been shown to be better than in those not assessed and this may serve as evidence for routine assessment in other conditions.

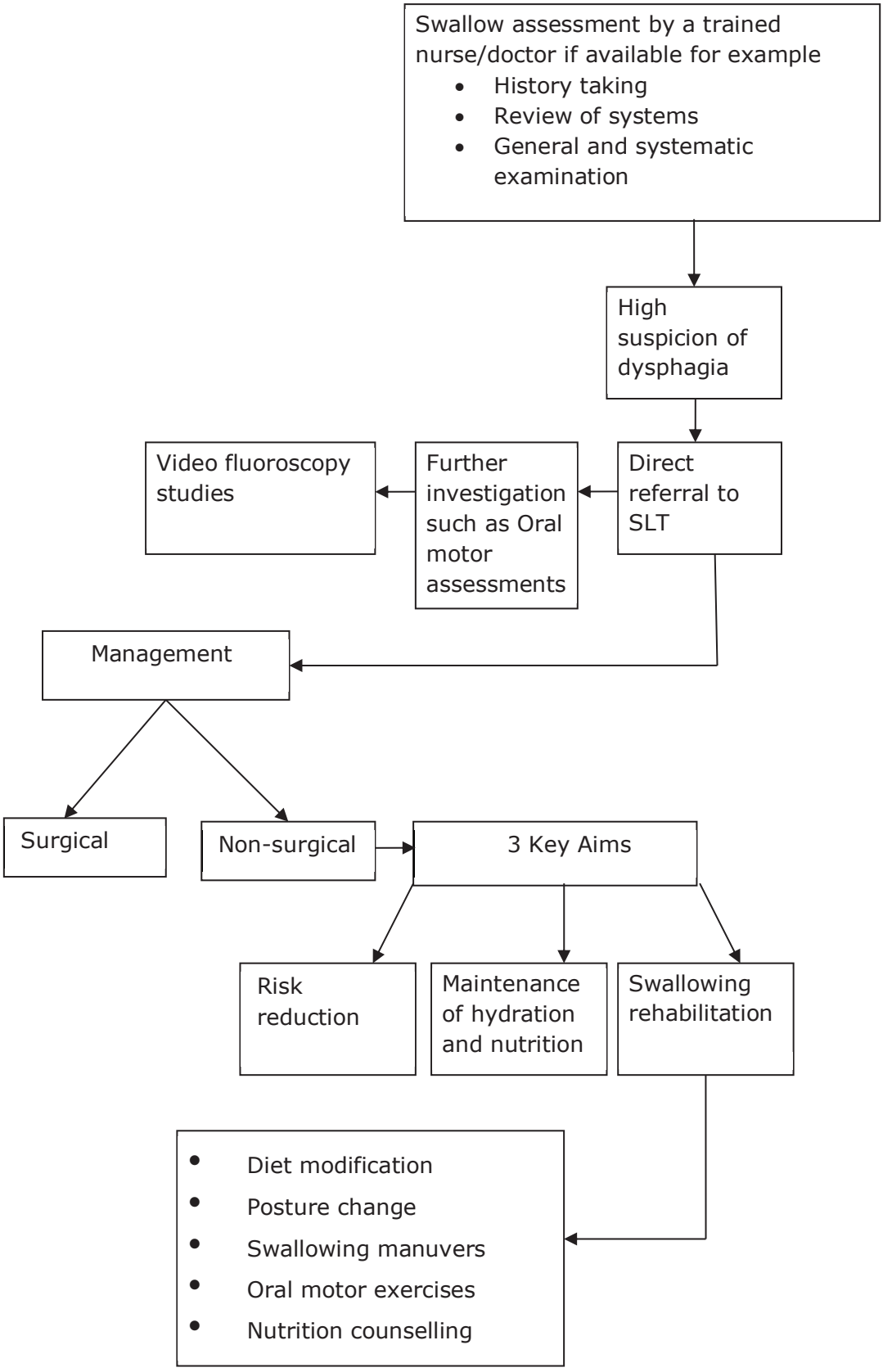

Figure 1.2 Management of dysphagia

1.11 Clinical Outcomes Following Assessment

1.11.1 Clinical outcomes

No previous studies have examined the clinical outcomes of patients with PD, MS and MD who have been screened and compared them with those who have not except in stroke studies. It is known that clinical assessment will initiate early intervention thereby preventing avoidable poor outcomes. These outcomes include dehydration, infections such as hospital acquired pneumonia, length of hospital stays, malnutrition and mortality. Some studies have been able to demonstrate good clinical outcomes through the ability to detect early aspiration risk, particularly through the use of the water test, thereby reducing poor outcomes [109]. Outcomes after assessment are well established in PD, MS and MD populations and the reasons may be attributed to the methods of assessment used and efficiency of SLT referral for intervention. Differences in outcomes could also be attributed in whole or part to differences in patients- those screened could be less well or advanced disease.

The systematic review by Martino et al. [210] on dysphagia screening and outcome measures included three studies that examined patient outcomes after swallow screening assessment. They included the 50ml water test used by Gottlieb et al. [145] and swallow screening assessment completed as part of stroke clinical guidelines by Odderson et al. [156-157] studies. These studies were conducted on patients admitted for stroke rehabilitation and on acute non haemorrhagic stroke patients. The authors of these studies compared those patients who were screened for dysphagia on admission and those not screened. These studies showed positive outcomes for those patients who received a swallow screening assessment. Of the three articles, two reported on outcomes of risk of aspiration

pneumonia and LOS whilst the other reported on mortality. The risk of development of aspiration pneumonia for those screened was reduced and clinically significant in both studies, with a relative risk reduction (RRR) of 81% to 85% and for significant mortality risk reduction to 70%.

LOS in the studies by Odderson et al. [156-157], the screened group had shorter LOS than the unscreened group. The authors, Martino et al. [210] emphasized that the small sample size of these studies is a major limitation and suggested future research on outcomes after assessment for screened and unscreened groups, to ascertain whether the benefits of screening will be measurable. They also advised that larger sample sizes will be required for robust, level-one evidence on swallow screening assessment.

Assuming that dysphagia is assessed regularly in these patients, it implies that there will be a decline in poor patient outcomes. However, it will be hard to conclude that reduction in poor outcomes is attributed to routine assessment in people with PD, MS and MD or to referrals to the SLT, based on diagnosis or risk of dysphagia without further established evidence.

Although the majority of studies have associated better outcomes with screening, there is no literature which has compared intervention with non-intervention in the PD, MS and MD populations. It is therefore difficult to determine whether there are any differences in their outcomes. This knowledge is a major impact of the dearth of literature in this area. It will be helpful if researchers explore this area in order to provide additional evidence on the value of swallow screening assessment in people with these conditions.

If dysphagia is not detected early and managed appropriately, these are the aforementioned complications of dysphagia in PD, MS and MD which

includes depression, anxiety, social withdrawal, increased dependence, weight loss and increased disability. Health promotion practice and management of dysphagia are influenced by a number of theories. The next section of the thesis discusses these theories and considers how they apply to dysphagia in people with neurological conditions.

1.12 The Theoretical Frameworks

This section considers the theories which can account for disability levels (disablement process and ICF models) and that provide alternative hypotheses on the management of disability. A brief summary of each theory and the underpinning evidence is given. Also the key similarities, differences and potential benefits of each model are outlined. Finally, an illustration is given of how each theory can be translated into practice to improve the assessment of dysphagia or routine swallow screening in PD, MS and MD patients.

1.12.1 The Disablement Process Pathway

The disablement process pathway was developed by Verbrugge and Jette to provide an explanation for the phenomenon of disability [211]. This pathway describes the diagnosis of disease process and its pathological basis whether congenital, acquired or environmental. The impairment which has occurred in specific body systems such as the neurological system may appear as dysfunctional or structural. The organs affected become limited in their functions, e.g. restriction of basic physical and cognitive actions. The result of these processes is a disability in carrying out the activities of daily living. The disablement process pathway is person centred but limited because environmental and social aspects of disability were not acknowledged fully. However, it has remained useful in disability research. This model is applied in this study to explain the

phenomenon of swallowing disability in people with neurological conditions. The flow chart below illustrates 'The Disablement Process Model.'

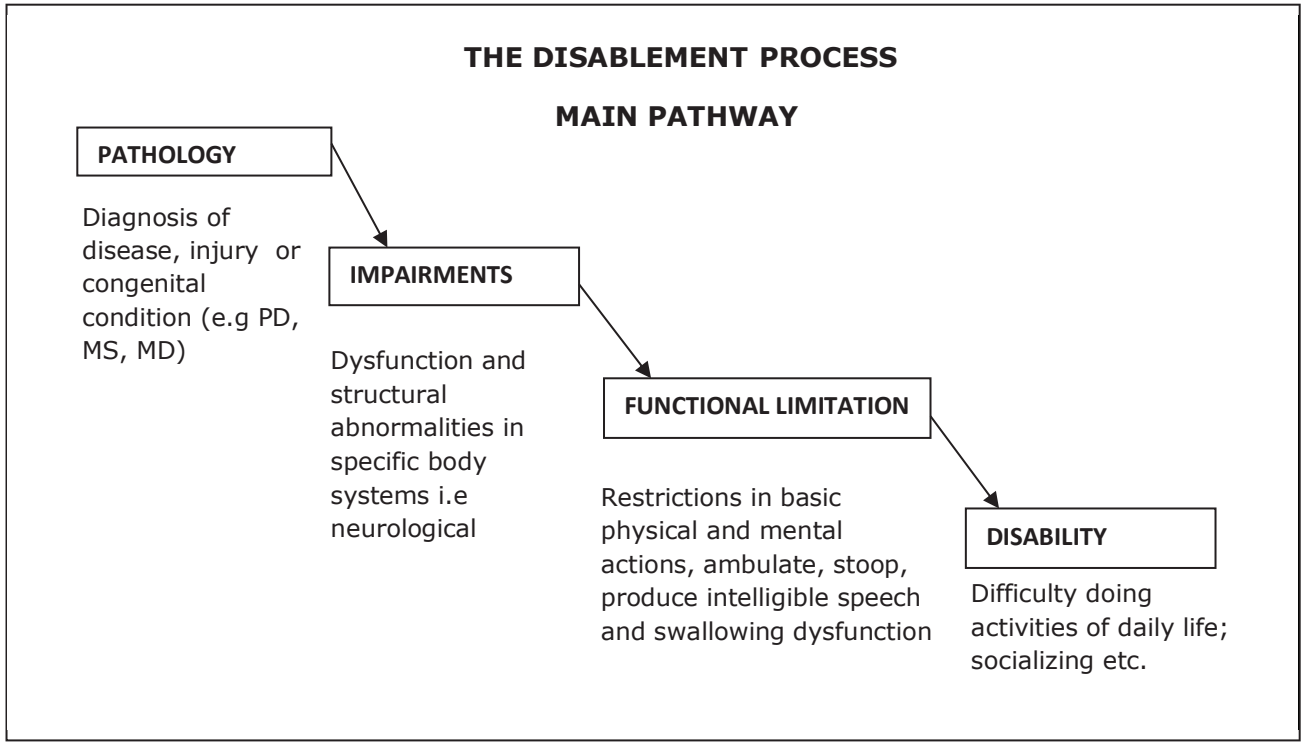

Figure 1.3 The disablement process pathway [211]

1.12.2 The ICF Model of Disability

The WHO International Classification of Functioning, Disability and Health (ICF) provides a further definition of the terms of 'impairment' (abnormal structure/function), 'disability' (difficulty in carrying out a task) and 'handicap' (disadvantage in social role) [212]. The components of ICF are 'Impairment', 'Activity', 'Participation' and Contextual factors i.e. 'Environmental and Personal factors'. [Table 1.4] The definitions of the ICF components are described in appendix 6. The ICF is a multipurpose classification which aims to provide a scientific basis for understanding and studying health and health related issues/status, outcomes and determinants. Secondly, it provides a common language for describing health and health related states in order to improve communication between clinicians, researchers, policy-makers and the public, including people with disabilities. Lastly, it also permits comparison of data between countries, disciplines, services and over time.

Table 1.4 The ICF scheme [212]

1980 scheme	ICF
Impairment (abnormal structure/function)	Impairment
Disability (difficulties in carrying out a task)	Activity
Handicap (disadvantage in social role)	Participation
PLUS	
Contextual factors	Environmental and Personal factors

Dysphagia is described in this study using the components of the ICF. The ICF is divided into two major parts: The first part is termed "*functioning and*

disability", and is concerned with body *"functions and structures"* and "*activity and participation"* [212]. The body *"functions and structures"* element is designed to determine the extent of impairment on the physiological functions of the body [212], while the "*activity and participation"* element tries to assess the performance of individuals in their present environment and their capacity for participation [212].

The second part of the ICF, termed "contextual factors", is concerned with both "*environmental"* (physical and social) and *"personal"* factors (age, gender and coping mechanisms) [212]. These components are used to indicate the severity of the limitation or restriction in people with dysphagia. The relationships among these different components of the ICF and dysphagia assessment in neurological conditions are described, and a rationale for adopting the ICF framework in this study is discussed.

Dysphagia assessment involves history taking and clinical examination, swallow screening assessment (SSA) and instrumental examination if required. In the clinical examination, the body "structures and functions" involved with the oral and pharyngeal phase of the swallowing can be assessed. The body "structures" include different parts of the neurological system, and deglutition structures, such as teeth, tongue, the jaw, and the larynx. [212] The body "functions" describes the swallowing process including the oral and pharyngeal phase of swallowing [section 1.2.1 a and b]. Both phases of swallowing require cognitive input to function effectively. As a result, body "functions" involved with memory, motivation and appetite is significant for a successful swallowing. There is need for these functions to be

assessed for evaluation of dysphagia in neurological conditions because they may contribute to risk factors for aspiration in this population.

Depending on the success of the clinical examination of swallowing, the parameters considered under the "activities and participation" factors regarding oral intake of food and drink could be examined [212]. The "activities and participation" factors describes the social aspects of swallowing and its effects in neurological dysphagia. These factors may include the following limitations due to the dysphagia: not feeding satisfactorily, restrictions on socialising and/or avoidance of social gatherings, lack of enjoyment and desire for food. Good history taking and administration of a swallowing screening questionnaire on feeding behaviours could help answer the questions on possible important "activities and participation" factors. Loss of food and dribbling of water from the lips, pouching of food could likely result in malnutrition. In addition, if either or both activities are affected, the patient's ability to socialise may be compromised.

The effects of "environmental" factors on patients with dysphagia (e.g., facilitating environment such as adequate infrastructure, level of care from family, individual carers and clinicians) can contribute to living successfully with dysphagia in people with neurological conditions [212]. These factors may contribute to poor feeding, although in these patients most of them usually have an underlying oral-pharyngeal dysphagia.

The "environmental" factors of the ICF can also be assessed as either facilitators or barriers to dysphagia assessment in neurological conditions. These facilitators include regular assessment of dysphagia, monitoring and

follow-up by clinicians, education of patients, carers and clinicians, the right food texture, care from family, relatives and friends or barriers, such as lack of guidelines, perceptions, attitudes and knowledge of clinicians on dysphagia, which may affect whether these patients are assessed for dysphagia during their hospital admission.

The "Personal" factors such as age, gender, race, behavioural characters (e.g. coping mechanisms) are those features of the person which does not cause or relate to their neurological condition [212]. Since the mechanism of swallowing food is behavioural, therefore they are subject to personal differences in food and liquid options as well as feeding methods. In terms of personality, some people respond to situations with despair, whereas others approach all situations rationally and methodically. In people with neurological conditions with dysphagia, these personal and behavioural characters may affect their management positively or negatively depending on their perception of having dysphagia. The ICF model states th*at "the components should be assigned with full knowledge of the persons whose behaviour is being evaluated, with the person having the right to object."* [212] Therefore, because of the health implications of dysphagia, ethical issues may arise when dysphagia management does not favour the personal and environmental factors in people with these conditions.

The two primary instrumental assessments for dysphagia are the videofluoroscopy studies (VFSS) and fiberoptic endoscopic evaluation of swallowing (FEES). These two investigations examine the body "functions and structural" components of swallowing [section 1.8.1 and 1.8.4]. Since these investigations assess swallowing in an unnatural environment for people with

swallowing problems, the interpretations from these investigations should be supported with information that assesses other components of the ICF framework.

Overall, dysphagia assessment in neurological condition must achieve these goals: adequate nutrition and hydration, reduced risk of aspiration and psychosocial problems such as social isolation and depression in neurological conditions with dysphagia. These goals can only be attained if people with these conditions are able undertake the "activities and participation" aspects of oral intake of food and drink successfully. There may be a risk of noncompliance with dysphagia diet recommendations if the "activities and participation" aspects of the ICF are not included in dysphagia assessment and intervention.

The flexible nature of the ICF scheme allows it to be applied to various kinds of research, particularly rehabilitation research. Thus, the ICF can be used to direct multidisciplinary efficiency studies of dysphagia management. With a broader view toward dysphagia assessment by following the ICF framework, people with dysphagia can be provided with interventions that would aid early diagnosis. In addition, swallowing and feeding behaviours need to be seen as multifaceted and not just as impairment of body "functions" (e.g., the level of delay of pharyngeal phase swallow). Only by reviewing neurological patients with dysphagia holistically can these factors be acknowledged. The ICF provides a basis for the provision of dysphagia screening services at an individual and institutional level in people with neurological conditions. (Appendix 7)

Even though the ICF model has been accepted worldwide, it has several limitations which need to be identified and amended if possible. Firstly, the ICF model provides a different meaning to our concept of disability, by changing the language that people use. The power of language in relation to peoples' views about disability cannot be over emphasized [213]. Secondly, the notion that disability covers all areas of the pathway is worth consideration, though this may be misleading at times because of the widespread use of 'disability' for particular problems.

Thirdly, the combination of "activities and participation" in one section of the ICF is a major limitation. Although they have different definitions and are categorized into separate sub domains (self-care, mobility, communication, interpersonal interactions and community, social and civic life), the sub domains are similar for both activity and participation domains. This makes it quite complicated to use and a greater understanding is needed for its application in disability research. Fourthly, the ICF model puts all these domains under the broad term "activity limitations" without distinguishing them separately. A substantial amendment will be required to acquire a better knowledge of the ICF model, just like that of the Disablement Process Pathway. It would be most convenient if a consistent language were used when addressing problems of disability. The ICF model would be ideal for disability research, if its functions were clearly appreciated and better understood.

1.12.3 The ICF Disablement Pathway

The ICF and the Disablement Process Model of Disability both describe the impact of pathology on a person's life. Whilst they share some similar concepts and give a rounded appreciation of disability, there are some

structural differences. Both systems also provide guiding principles on the management of disability for health care providers. Even though both models use different language to simplify the various elements of disablement, they both emphasize the totality of the individual by approaching the issue of disablement from four main areas - origin, organ, individual and environment. The two models provide a means of enhancing efficient communication and reducing difficulties in health management for health professionals in all departments [214-215]. These models have formed a basis for health interventions to be targeted to the needs of each patient [216]. The disablement models provide an explanation of the pathway of the patient's condition by using the following terminologies of injury or illness: impairments, functional limitations and disability.

Furthermore the progress of each individual's rehabilitation can also be monitored using these models making them useful to clinicians when managing disability issues in patients. The ICF and the Disablement Process models are centred on identification and management of a disabled individual to achieve desired goals. They therefore provide the theoretical basis in this study for assessment of dysphagia in people with neurological conditions. Finding more evidence-based treatment options and interventions is very important to the success of rehabilitation medicine [217]. Therefore disablement models help to encourage observational and interview research methods into the value and usefulness of medical interventions in disability. The justification for using these methods in this study is discussed in the section 1.13 of this chapter.

1.13 Research Methods and Justification

This study incorporated observational and interview research methods. Observational methods were used to explore the first four objectives and interview methods were adopted to explore the fifth objective of the study.

1.13.1 Observational methodology

Observational research involves measurement and classification as its main principle. A considerable amount of research in dysphagia has collected numerical data by addressing the questions on prevalence, assessments or complications. These data sets are analysed statistically because:

- The majority of data from previous research used for assessment of dysphagia has been collected by observational means;
- The use of observational methods makes provision for analysis that can investigate associations independently;
- Observational methods also allow associations between variables to be examined and for theories about the cause and consequences of dysphagia to be explored [218].

In a broad sense, observational methods give researchers the advantage of testing a hypothesis and are less susceptible to theoretical bias [218]. There may be reservations when using observational methods in research on dysphagia assessments, because its complexity can lead to difficulties in measurement. It is vital that researchers understand which aspects of dysphagia assessments their analyses are focused on and the populations to which their results can be generalized.

Some research questions are better answered using observational methods, but although observational methods may be the most suitable approach to a research question, it is essential to understand that these methods, as with

any other methodology, are subject to a researcher's decision on the analysis required and process of conducting that analysis [218]. It also brings thoroughness and transparency in the research by enabling repeatability and review by other researchers who may be interested in that subject area. When there are concerns with generalization and representativeness in a research area, observational methods are generally seen as the better option [218].

Sources of observational data include the administration of questionnaires, conducting structured interviews, focus groups and documentation from medical records. Documentation from patients' medical records is a common means of data collection and was used in this study. In the medical records, all vital information on a patient from all sources is stored, making it simple and inexpensive for the researcher to assess. However, where documentation may not have been appropriately completed or unknown abbreviations are used, this can limit the research scope. The accuracy of the data obtained from health records may be hard to ascertain and should be interpreted with caution during data analysis.

1.13.2 Qualitative methodology

The qualitative method is a less frequently used approach for research on dysphagia. Although research on dysphagia is largely dependent on quantitative methods, quantitative research cannot explain all individual behaviours on a given phenomenon [219].

The reasons for using a qualitative research methodology include:

- The study intended to determine the clinical reasoning used by clinicians for conducting swallowing assessments in patients with neurological

conditions. This was achieved by examining unobservable factors such as motivation, attitudes, feelings, thoughts and perceptions, which help to explain human behaviour.

- No previous theoretical framework was found on the reasons underpinning the decisions to conduct swallowing assessments. Inductive generation of theory could potentially be derived from this study for prospective studies on dysphagia assessments.
- Qualitative methods could be used to appreciate any unravelled phenomenon, add new perceptions to existing knowledge, or add more detailed information which might be hard to express, using a purely quantitative approach. Variables which may be examined by observational methods could be determined initially with qualitative methods, which can also support interpretation in situations where the outcome from observational research was insufficient to interpret or explain the research problem.

The majority of qualitative research uses the open-ended question format that facilitates the identification of new knowledge. Observational research investigates relationships between variables but falls short of investigating how the relationship was formed. By using a combination of observational and qualitative methods, it can be argued that this provides deeper understanding of research questions and the weaknesses of one method could be balanced out by the strengths of the other [220].

a) Semi-structured Interviews

Qualitative data can be collected using methods such as unstructured or semi-structured interviews. In general, the success of any interview depends on the skill of the interviewer, including their communication skills, interpersonal

skills, attentiveness, the ability to pause and prompt when required and the ability to create an enabling environment [220]. The decision to use semi-structured interviews in this study was determined by the need to gather supplementary information about the circumstances that influence a clinician's decision to evaluate a patient's swallowing capacity.

This approach also enables emergent themes to be uncovered, rather than depending on pre-defined questions prior to the interview. When using this method, the usual practice is that interview guide questions, prepared in advance, are presented to all the interviewees [220]. The questions are ordered in a similar pattern in such a way that the responses to the questions can be compared. In addition, questions known as prompts are incorporated into the interview schedule and can be asked during the interview to elicit more information; additional questions could be raised as a result of the responses provided [220]. Interviews also make it possible for the interviewee to express their opinions freely, particularly if a relaxed atmosphere is created.

However, the use of semi- structured interviews has its own limitations; there can be a tendency to use leading questions and preconceived ideas on the part of the researcher can influence discussions. Both of these factors could affect the quality and content of the data generated. This influence can be resolved if the transcribed interviews are reviewed jointly by both parties. A further consideration is the perception of the interviewer by the interviewees, commonly known as the 'interviewer effect' [221]. In such a situation, information gathered from the interviews may or may not be honest. The topic of discussion may also contribute to this effect and so it is advisable to ensure that interviewees have a full understanding of the reasons for the

study, before commencing their interview. This precautionary measure was taken before conducting the interviews on swallow screening assessments. Due to the importance of interpersonal skills in conducting a successful interview, prior training on interviewing techniques minimises errors and bias.

1.14 Discussion

As noted previously, dysphagia is a complication which can lead to poor outcomes in people with PD, MS and MD and therefore deserves the attention of health professionals. The lack of sufficient evidence to concerning dysphagia screening in these groups or factors that might influence good outcomes make it even more difficult to request the provision of guidelines.

Dysphagia in PD, MS and MD has been defined in various ways to include difficulties with solids, liquids or both, but each with different pathological mechanisms. The merit of early intervention relies on the participation of the health personnel who assess on admission, which could help to avert silent aspiration or risk of aspiration in mixed populations, conditions that ordinarily would lead to further complications or death.

The studies which have attributed early identification with better outcomes may be associated with the degree of the disease, more especially when dysphagia is in the mild form. There are no studies in PD, MS and MD patients which have examined whether the outcomes of those who were screened or assessed are different from those who were not. Even though there is no evidence depicting better outcomes in the screened populations in this group, dysphagia screening is a widely acceptable assessment for dysphagia.

The Scottish intercollegiate Guideline network has provided guidelines on early detection of dysphagia, using the water swallow test to avoid complications resulting from dysphagia in stroke patients. There is evidence to support adoption of this approach in this group [106]. The advantages of using the water swallow test in PD, MS, and MD patients have been described in the literature. The problems of repeatability and the timing of assessments using the water test as a bedside screening assessment in people with neurological dysphagia are weakneses and may result in inaccurate measurements. Studies are yet to be conducted in these areas of dysphagia assessment.

Initial interventions generally include referral to the SLT for a more thorough examination, which in turn may initiate a referral to the dietician. Following that appointment, recommendations for further management, such as NGT or PEG feeding if necessary, should be made. Other treatments, such as rehabilitation of swallowing could also be initiated. Acknowledging these measures is one aspect, but the key question still remains unanswered, as to whether there is evidence of better management and good outcomes for PD,MS and MD patients screened or assessed acutely that can inform routine clinical practice. The effect of dysphagia screening in these populations on management and functional outcomes is yet to be determined. The evidence is only on stroke, which has been widely researched.

An observational study is an appropriate method to monitor those who are screened and not screened in order to observe any differences in management and outcomes. The results may also guide appropriate decisions and raise the possibility of guidelines, which will address several issues that may have been overlooked previously.

The commonest complication which could result from a lack of screening in this population is aspiration pneumonia, which may lead to untimely death. The merits and demerits of screening in this population are hidden, due to serious gaps in the literature. In addition, just as in stroke services, the economic advantages of screening PD, MS and MD patients in terms of SLT led services needs readdressing for adequate input by SLT. This is likely to be achieved through further research to find answers to these questions and proffer possible solutions for them.

1.14.1 Limitations of the Review

The studies which were retrieved on dysphagia assessments in these conditions were limited in number due to a lack of research evidence in this field, particularly for muscular dystrophy. Studies on dysphagia screening in muscular dystrophy were very few which made evidence in this condition limited. Also other higher levels of evidence such as RCTs were not obtained in these conditions on dysphagia assessments. Only English language studies were reviewed, so other relevant studies may have been missed.

1.14.2 Gaps in the Literature

The actual cause of mortality in PD, MS and MD patients with neurological dysphagia still needs to be explored, to detect if it is as a result of complications from dysphagia such as aspiration pneumonia or due to the neurological disease. Dysphagia assessment in acute medical admissions for PD, MS and MD patients is not known and in terms of dysphagia screening, no tool has been developed specifically for patients with MD. Timing of assessments in PD, MS and MD patients is absent in the literature. Outcomes after assessment from screened and unscreened PD, MS, and MD populations are also absent.

1.14.3 Ethical Issues in PD, MS and MD Research

In addition to their swallowing dysfunction, people with PD, MS and MD also have language and cognitive deficits, thus obtaining consent from them for research purposes may be difficult. Randomized controlled trials with a control group might be unethical if there is lack of equipoise or due to safety concerns.

1.15 Conclusions

A common finding from the studies reviewed is that routine dysphagia screening and guidelines need to be established for high risk populations (such as PD, MS and MD) to ensure effective patient management, which will lead to better outcomes. Adequate training, skill and a multidisciplinary approach may be required for its realisation.

When assessing for dysphagia in patients with PD, MS, MD, the appropriate test should include clinical signs - such as failed water swallow test (which may be more predictive than others) and greater than one failed sign during the assessment. This review has shown that there are no trials to date which focus on dysphagia assessments following acute medical admissions for PD, MS and MD patients. Observational studies on methods of assessments for these conditions were noted from the review.

Each of the methods reviewed had advantages and disadvantages and should be considered in relation to individual needs when applying them to patients. Diagnostic radiological and non-radiological tests are available, but with limited evidence in the target group when compared to that for stroke patients. Further research is needed to answer the questions that arose in

the course of the review. There is also a need to address knowledge gaps, ethical issues through well-conducted research in order to minimize bias, ensure validity and reliability of results and further enhance generalisation from the study population.

The knowledge of the evidence from patients with neurological conditions regarding their swallow assessment is useful, however, application of this evidence in practice seems to be a difficult process. Theories on disability, ICF and disablement pathways when used together can be used to monitor the success of swallowing rehabilitation in PD, MS and MD patients. A key element in the achievement of this success is early identification of dysphagia in acute admissions. Therefore the study presented in this thesis aims to determine whether PD, MS and MD patients are assessed for dysphagia when they have an unplanned admission to hospital. Also, the clinical reasoning which underpins the decision of health personnel on whether to assess these patients for their swallowing is also included. A plan of the thesis is discussed below and finally the aims and objectives of the study are summarised in table 1.4.

1.16 Plan of the Thesis

The remaining aspects of this thesis are presented in four chapters and a summary of these is given below.

Chapter Two:

This chapter provides a detailed description of the methods. Approvals from regulatory bodies, study design, sample size justification, study population, definition of outcome measures, preparatory/piloting phase, data collection methods and the justification for these methods are presented in this chapter.

Chapter Three:

This chapter presents the data obtained in the observational aspect of the study. It includes data about the assessment, management, outcomes and the prevalence of dysphagia in patients with PD, MS and MD admitted acutely to the Royal Derby Hospitals NHS Foundation Trust and Nottingham University Hospitals NHS Trust (Queens Medical Centre (QMC) Campus).

Chapter Four:

This chapter presents the findings obtained from the interview element of the study. The element is an investigative study utilising semi-structured interview methods to examine clinicians' perceptions and the decision to screen for dysphagia when people with neurological conditions have an unplanned admission to hospital. It draws attention to a number of perceived causes and areas where intervention is needed. The chapter describes the themes that emerged from the interview data and are presented as: Identification of dysphagia, barriers and facilitators, infrastructure and provides a discussion of the findings. The key conclusions and limitations of this aspect of the study are also summarised in this chapter.

Chapter Five:

This chapter is a discussion of the findings derived from both the observational and interview aspects of the study. Comparisons are drawn from findings between these and previous research. The main outcomes of this study, study limitations and implications are highlighted in detail. Finally, this chapter details the key conclusions for the whole thesis. The relevant citations and documentation used for the study are provided in the appendices.

Table 1.5 Aims and Objectives of the Study

Aim of study

To determine if patients with PD, MS and MD are screened for dysphagia when they have an unplanned admission to hospital

Objectives of the study

1. To determine the proportion of patients screened for dysphagia during the first seven days following an unplanned admission to hospital.
2. To determine if patients who are assessed for dysphagia during the first seven days of admission to hospital are managed differently to those who are not assessed.
3. To determine if the clinical outcomes for patients who are assessed during the first seven days of admission to hospital differ from those who are not assessed.
4. To estimate the prevalence of dysphagia amongst patients who have an unplanned admission to hospital.
5. To determine what factors influence the decision to screen for dysphagia when people with PD, MS and MD have an unplanned admission to hospital.

CHAPTER 2: METHODS

CHAPTER 2: METHODS

2.1 Introduction

This chapter provides a description and justification of the methods used in this study. Information about the recruitment of participants, calculation of the sample size and the procedures used to collect and analyse data are described. The aim of the study was to determine if patients with PD, MS and MD are screened for dysphagia when they have an unplanned admission to hospital. The study was conducted in two stages. During the first stage observational methods were used and in the second stage, data were collected through a series of staff interviews. The chapter culminates with a summary of the methods.

2.2 Observational Methods

2.2.1 Study Design and Setting

The first aspect of the study utilised observational methods and included patients who had an unplanned admission to hospital with a diagnosis of PD, MS or MD. Patients were recruited from hospitals in the East Midland region - Royal Derby Hospital (RDH) and Queens Medical Centre Campus (QMC)).

RDH is the second largest hospital in the East Midlands, and is managed by the Royal Derby Hospitals NHS Foundation Trust. The hospital provides medical care for a local population of over 600,000 people in Derby and Derbyshire. It is also a major teaching centre for the University of Nottingham and is a base for the School of Medicine and the School of Health Sciences.

The QMC is situated in Nottingham and is one of the largest teaching hospitals in the United Kingdom. The hospital is run by the Nottingham University Hospitals NHS Foundation Trust and provides services to over 2.5 million residents of Nottingham and its surrounding communities. It also provides specialist services to a further 3-4 million people from neighbouring counties each year. It also houses the University of Nottingham Medical School.

The study was carried out at the Medical Assessment Unit (MAU) of each hospital. In both hospitals, a register is kept of all patients who are admitted each day. The primary aim of keeping a register of all patients is to ensure that health care records are associated with the correct patient. It also enables the efficient linking of patient's information such as administrative and medical information for continuing care. Patient management may be compromised if not registered as vital information may not be obtained for the patient.

Patients were also recruited from medical wards, if they were transferred from the MAU before they were seen by the researcher. This occurred due to the busy nature of the MAU and the high turnover of patients, as patients were usually only able/need to remain for approximately 4 hours. All the patients recruited to the study went through the MAU before being transferred to the wards. There were no cases of patients with these conditions who had not been to the MAU and were transferred directly to the ward.

An overview and structure of the MAU is described for readers who may not the familiar with this structure as it is not the usual ward setting. The RDH MAU has two side rooms and four cubicles known as 'Teams' (Team 1-4) with assessment beds in each of the teams giving a total of 56 assessment beds. In QMC, the MAU has a pre-assessment area and 4 cubicles which are called 'Bays' (Bay1-4) with assessment beds in each of the bays giving a total of 50

assessment beds. Each of the cubicles in both hospitals has a nurses' area located at a strategic position giving the nurses a view of all patients admitted for monitoring. Both hospitals have a consultant, ward manager and deputy ward manager who manage admissions in the MAU.

2.2.2 Development of the Research Protocol

A multidisciplinary team (clinical and academic staff with backgrounds in emergency medicine, rehabilitation medicine, neurology, psychology and occupational therapy) and the researcher were involved in developing the protocol for this study. Each member of the team provided inputs regarding the assessment of dysphagia in patients with these conditions and commented (where appropriate to their clinical area) regarding the use of dysphagia screening methods, assessment procedures and suggested strategies that would ensure participants could be screened and that the goals of the study could be met.

The protocol considered the recruitment of participants, gaining consent, participant reviews and water swallow assessment. Prospective participants were identified through a review of their medical notes (for patients with PD, MS and MD, aged 16 years and above). An initial explanation of the study and preliminary consent/assent was sought from the patient/patient's relative by a member of the usual care team. The medical notes of patients willing to participate in the study were reviewed again by the researcher to verify eligibility criteria. There were 264 patients who met the criteria to the study. Those patients who did not meet the eligibility criteria were not recruited for the study. The researcher then sought consent/assent from the prospective participants/participant's relatives to participate in the study. Two hundred patients gave their consent and were recruited in to the study. Demographic

information was collected from the notes of those who consented to the study. Each participant was reviewed at day seven after their admission to the MAU in hospital or at home (if the patient lived nearby). Swallow screening assessment if indicated and other outcome measures, were recorded as part of the review. In general, swallow screening assessments were performed on only those participants who were not assessed while in hospital or who have never undergone a swallow screening assessment previously. Below is a flow chart of the methods adopted in the observational element of the study.

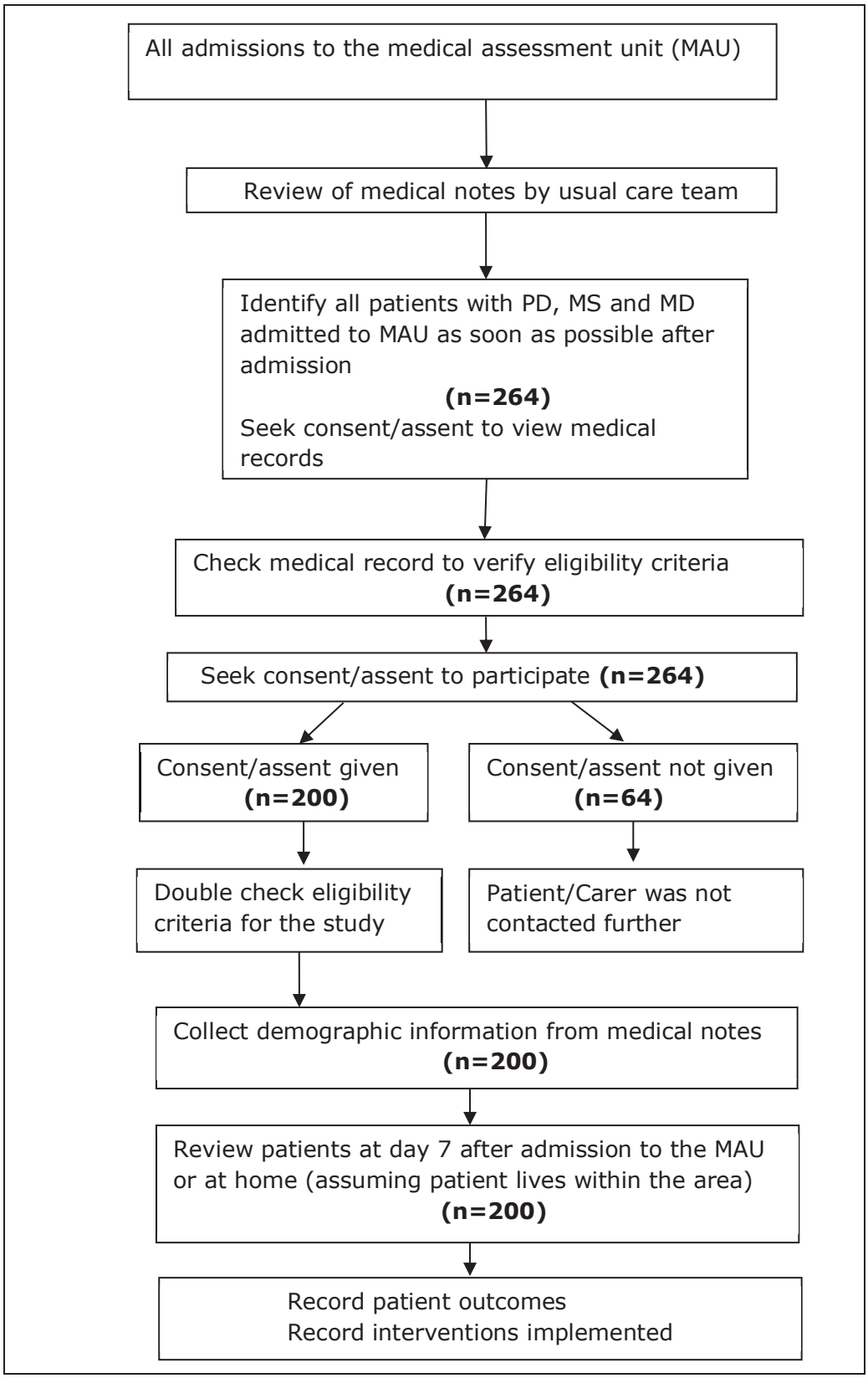

Figure 2.1 Flow chart of the observational methods

2.2.3 Protocol Amendment

Initially, ethical approval did not allow inclusion of patients who were unable to give consent. This decision was based on the grounds that members of the ethics committee felt that participation in the study would be unlikely to bring any benefits to the patient and that the aims of the study could be achieved without recruiting people who lacked capacity to provide consent. Some members of the committee were also under the misapprehension that the purpose of extending the inclusion criteria to this group was purely to increase the sample size or expedite data collection.

The actual reason for wishing to include people who could not give consent was to avoid sample bias (as the sample would not be a true representative of the population under study). It was also felt that patients who could not provide consent might be able to benefit from the study more than those who could consent. In view of this, the rationale for excluding those who did not have the capacity to consent was flawed from both a research and a clinical perspective, and one could even argue, it was unethical.

In some instances, patients were ”confused” on arrival and were judged by some members of the usual care team to be unable to give consent. It was therefore necessary to explain to colleagues that patients could still be eligible to participate if they improved subsequently and regained the capacity to communicate. These limiting factors were a source of concern as the usefulness of the study could have been affected if the study had been limited to those who could give consent or who could give consent when they initially arrived. The usefulness of the study could have been limited for two reasons; one was that these were patients being admitted acutely, often with

infections, which would often have been associated with an acutely confused state and resulting in a temporary loss of the capacity to give consent for a study; the other reason was that the natural history of these conditions meant that physical deterioration, such as would affect swallowing, proceeds at a similar rate to cognitive deterioration, so those patients who have dysphagia are as a population more likely to also lack capacity to consent.

The study was started whilst collecting evidence during the first month of data collection about the number of people who were potentially excluded on the grounds of capacity. After some months into the study, an amendment was submitted to the ethics committee, together with supporting evidence and the case was presented in person verberlly. These challenges, did not deter data collection and the study continued to make progress while awaiting a favourable re-consideration from the ethics committee. A favourable opinion was later received eight months after the study started to include those who lacked the capacity to consent as the outcome of this amendment. (Appendix 8)

2.3 Identification and Recruitment of Patients

2.3.1 Study Population

Participants were recruited as soon as possible after admission. Both hospitals have a high turnover of patients who present as an emergency admission with one of the specified conditions. The initial approach was from a member of the patient's usual care team. The researcher, or a member of the participant's usual care team, informed the patient of all aspects pertaining to participation in the study. It was explained that entry into the study was

entirely voluntary and that their treatment and care would not be affected by their decision. It was also explained that they could withdraw at any time and that in the event of their withdrawal from the study, the data collected would not be erased and their consent would be sought to use the data in the final analyses where appropriate.

2.3.2 Inclusion Criteria

Patients were invited to participate if they met the following inclusion criteria

1) All patients with one or more of the three neurological conditions - PD, MS, and MD.

2) Aged 16 years and above.

2.3.3 Exclusion Criteria

1) Patients who were unable to give informed consent to participate and for whom assent could not be obtained.

2) All patients with other neurological conditions as co-morbidities.

2.3.4 Characteristics of the Participants

Data extracted from the health records included the following: age, gender, medical history, time and date of admission, presenting complaint and diagnoses, relevant assessments, interventions given and/or arranged. The researcher was given appropriate training to ensure that the required information was extracted from the health records and retained in a secure location**.**

2.3.5 Definition of Outcome Measures

In this study, the outcome measures were based on the interventions which the participants received (or did not receive) during the admission. The criteria used to assess the outcomes for this study were defined as follows.

a) Detection of asymptomatic dysphagia

These were patients with asymptomatic dysphagia, who were found to have a swallowing impairment when assessed subsequently (i.e 7 days following admission).

b) Hospital acquired pneumonia

These were patients who developed pneumonia while in hospital whose reason for admission was something other than that infection and the infection was not present at the time of their admission.

c) Malnutrition

Body mass index (BMI) less than 18.5 is described as underweight which indicates malnutrition; greater or equal to 25 is described as overweight and 30 is described as obese, according to the WHO definition [222]. This was assessed by the following measures on admission- BMI, MUST, MAC, weight and food chart. These measurements were carried out by the nurses (though the accuracy of these measures cannot be acertained) and recorded on the patient's bedside nursing chart. The outcome of those who had any or all of these measures done was recorded.

d) Hydration (Fluid balance chart) assessment

Documentation of hydration assessments were carried out using the fluid balance chart, as this is what was being used routinely on admission.

e) Length of hospital stay (LOS)

The duration of admission in hospital was determined as the day of discharge minus the day of admission plus one. Patients who were admitted to hospital and were discharged on the same day had a length of stay of one day.

f) In - patient Mortality

Mortality was recorded in the study as the number of patients who died during the period of the study per person and the cause of death whilst an inpatient.

g) Morbidity

Morbidity was defined in this study as the number of patients who deteriorated in health during the admission. They developed other infections whilst admitted which contributed to their deterioration. Patients who had hospital acquired pneumonia, urinary tract infections for example during their admission and diagnosed by the usual care team were documented.

2.3.6 Dysphagia Screening Tool

Slightly different clinical dysphagia assessment tools were used in each hospital. There was only a minor difference in structure/wording of some the components of their screening tool. The swallow screening assessment tool (SSA) used here was a combination of those that were used routinely in both the QMC and RDH. The SSA tool consisted of an initial assessment of safety and was followed by three stages.

i) Initial assessment of safety

An initial assessment was conducted of the patient's level of consciousness and postural control as well as factors likely to affect swallowing safety.

These include lip closure, voice quality and voluntary cough. Those patients who were conscious and able to undertake the test were reviewed further.

ii) Stage1

The participants were then asked to sit up and were given 3 teaspoons of water. An observation of laryngeal elevation, significant drooling of water and signs of aspiration (coughing, choking, respiratory distress) and altered voice quality were made. The outcome of this first stage, determined whether stage two of the assessment was undertaken.

iii) Stage 2

Participants who 'passed stage 1' were given 60mls of water to take in sips from a glass. Careful observation was made and the ability of the participant to finish the water without any problems was noted. Swallowing was then graded as "safe" or "unsafe". The outcome of this second stage, determined whether stage three of the assessment was undertaken.

iv) Stage 3

Following a normal swallow in stage 2, the participants were observed at meal times for loss of food from the lips, difficulty chewing, pouching of food, coughing or choking, gurgly voice and reporting of any difficulty. Swallowing was then graded as "safe" or "unsafe".

An overall conclusion of safety of swallowing was made. Although this method may have higher false positives than other methods, it is probably the most widespread type of screening used by nursing staff within the trust and was therefore the method used in this study. In the majority of cases, this assessment was carried out around lunchtime so that observation of eating

and diet could also occur. Any swallowing assessment which highlighted abnormal swallowing was documented in the medical notes and reported to the nursing staff who could refer patients, if necessary, to the speech and language therapist.

There were some participants who showed delay in the oral phase, but with good swallows following and no signs of aspiration (for example wet voice, increased respiratory rate), managed a soft diet but took a prolonged time to eat. This group of participants also reported difficulty in swallowing medications, such as tablets in large preparations. These participants were also referred to the speech and language therapist for full assessment. Those patients who were unable to undergo a swallow screening, due to reduced level of consciousness or poor comprehension were defined as "unsafe" for oral intake.

2.4 Sample Size and Justification

The sample size calculation was based on the data obtained from the hospital coding department. During a one year period at RDH, 793 patients were admitted to the MAU with PD (n=536), MS (n=224) or MD (n=33). Figures 2.2, 2.3 and 2.4 illustrate the attendance of PD, MS and MD patients to the Royal Derby Hospital accident and emergency unit over a one year period. The relationship between the A&E and the MAU is the fact that most patients present initially at the A&E and they are subsequently transferred to MAU for an early senior medical review for sub speciality referral. This enables patients to have the correct management plan determined quickly and efficiently. The source of data was from the coding department of RDH. The coding department was asked to provide the attendance of adult patients with PD, MS

and MD conditions from 2009 to 2010 and to avoid double counting (re-attendance) in order to minimise errors in the data.

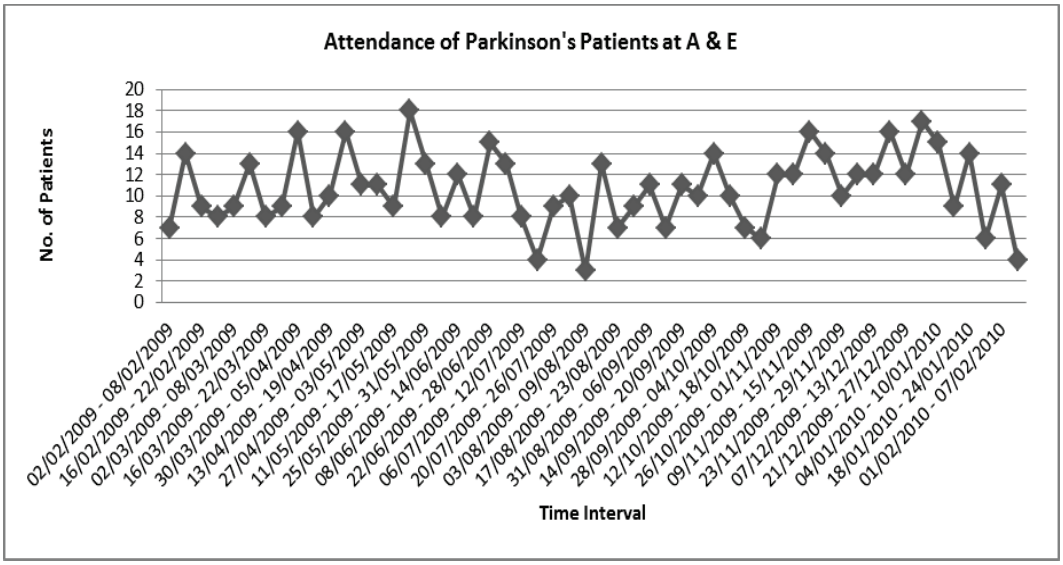

Figure 2.2 Attendance of PD patients at A&E over a one year period

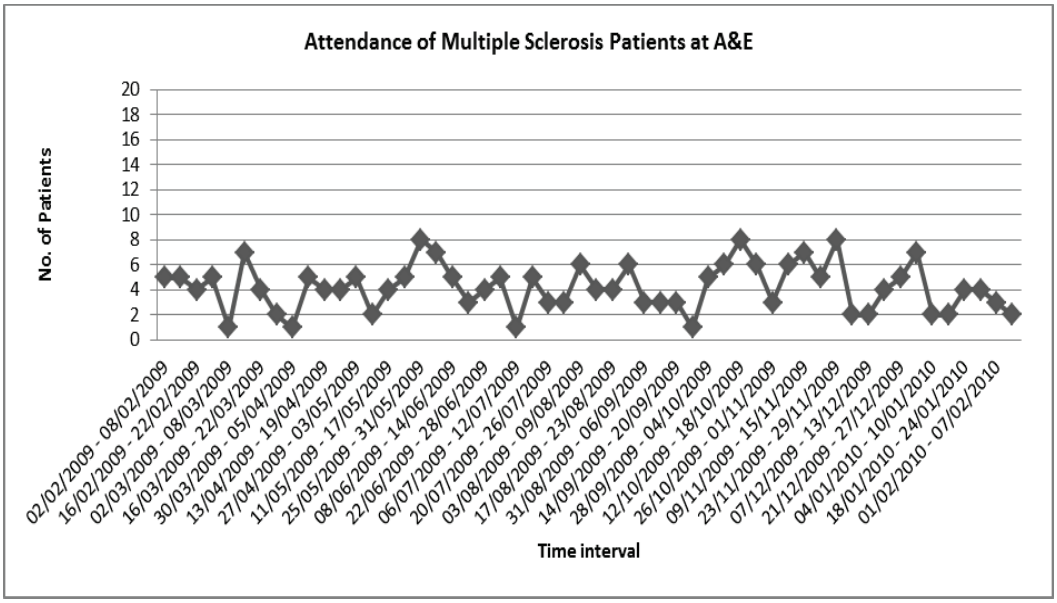

Figure 2.3 Attendance of MS patients at A&E over a one year period

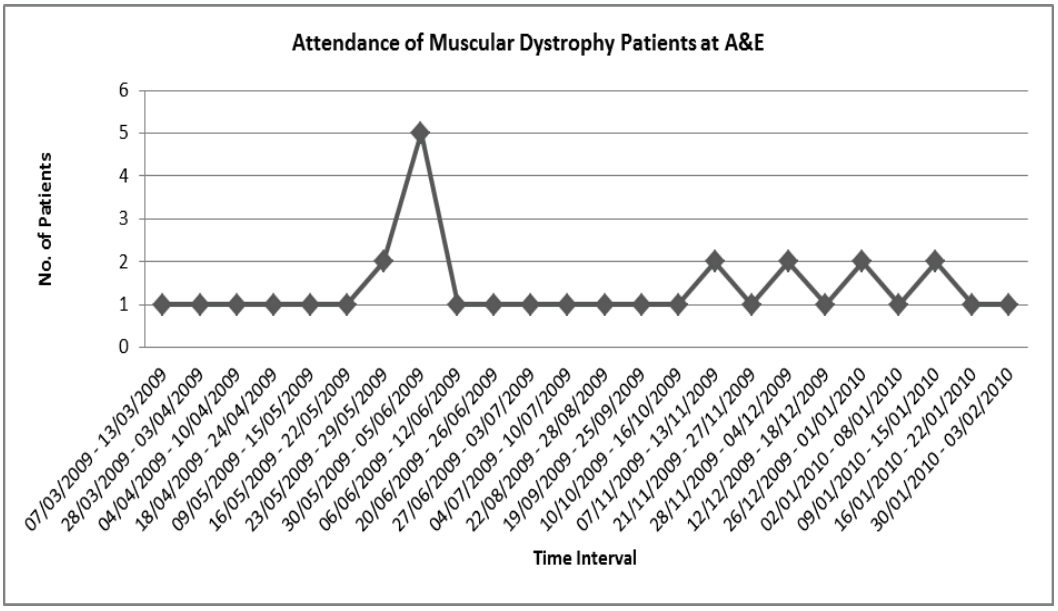

Figure 2.4 Attendance of MD patients at A&E over a one year period

The data in figures 2.2 and 2.3 for patients with PD and MS respectively, suggest that it was possible to recruit the people needed within the time frame. In MD patients (Figure 2.4) the graph shows an irregularity in attendance. This irregularity is obvious especially between 16/05/2009 – 30/05/2009.

It was not possible to establish how many people with these conditions were able to give consent in previous studies as the authors did not report this. However, in the study by Hammond and colleagues on: 'A Qualitative Examination of Inappropriate Hospital Admissions and Lengths of Stay', 40% of patients with neurological conditions were able to provide consent and this was therefore used to calculate the required sample size [223].

The n-Query Advisor (6.01) was used to estimate the sample size, based on the primary end point of the percentage of people that will consent of 40% (i.e., +/-5% precision). It was anticipated that with a one year recruitment

period for PD, MS and MD patients and assuming a percentage of 50% of the total population (n=793), then 219 PD, 140 MS, and 31 MD (390 in total) should be recruited, using a 95% Confidence interval with 5% precision. This is explained further below. The confidence interval for proportion (normal approx) (n large) was adjusted for finite population.

Table 2.1 Calculation of the sample size

Column	**PD**	**MS**	**MD**
Confidence level, 1-α	0.950	0.950	0.950
1 or 2 sided interval?	2	2	2
Expected proportion, π	0.399	0.399	0.399
Distance from proportion to limit, ω	0.050	0.050	0.050
Population size, N	536	224	33
n (Patients)	**219**	**140**	**31**
Total	**390**		

A total sample of approximately 390 patients was thought to be appropriate for the observational element of the study.

2.4.1 Re-calculating the Sample Size

In order to establish that the original sample size estimate was correct, and based on the same assumptions, the equation for sample size determination was used to recalculate the sample size for the study [224]. This is based on the primary end point of the percentage of people that were expected to consent 40% (+/-5% precision) and with a one year period when a total of 793 patients were admitted with these conditions to Royal Derby Hospital (RDH) and assuming a 95% Confidence Interval and 5% precision. A sample size of 390 patients was estimated using PD (n=536), MS (n=224) and MD

(n=33) patients, but if the total population of the three conditions (n=793) was used, then a sample size of 252 patients would be recruited. An explanation of how the equations were used to re-calculate the sample size is shown in Appendix 9(i) of this thesis.

2.4.2 *Post hoc* Sample Size Justification

Delays in obtaining ethical approval and in obtaining approval for amendment, made recruitment very slow. Irrespective of this, an interim analysis on the body of data collected (n=200) was undertaken to obtain a revised estimate of sample size.

The initial sample size could not be determined on the basis of the primary objective (as comparable data were not available at the time) and therefore the data used were statistics obtained from the Trust, concerning the number of people admitted during the preceding year with a diagnosis of PD, MS or MD. The calculation was also based on the percentage of people who were recruited or consented to a previous study carried out in RDH involving patients with long term neurological conditions [223]. The power calculation was repeated using data collected during the preliminary stage of the study.

The G Power software package was used for calculating the *post hoc* analysis using the output from SPSS. (Appendix 9 (ii)) The mean and standard deviation for the two groups were used to determine the effect size as 0.46. The sample size (68 and 132) for both groups and the given power and effect size were used to determine the power as 0.93. The given alpha, effect size and power was then computed to calculate the required sample size as 180. Based on the *post hoc* analysis, the actual sample size required for the study

was 180 patients; the study recruited a total of 200 patients and thus exceeded the required sample.

2.5 Preparatory Phase

Having established the protocol and the requisite definitions, the preparatory phase preceded the launch of the study. The purpose of this was to finalize all study documents and procedures and also to allow for any changes or corrections to be made.

During the preparatory phase, the assessments (such as the swallow screening test) and other aspects of the study were piloted to determine their acceptability and feasibility. Before commencing data collection, the MAU dysphagia questionnaire, swallow screening questionnaire, participant information sheet, next of kin information sheet, consent and assent forms were piloted. It was necessary to find out whether they were suitable for PD, MS and MD patients, their relatives and carers as the forms had not been used previously for this population. (Appendix 10-15). The information gathered was then used to make amendments to the information sheet where necessary. There was strict adherence to the protocol for which ethical approval was granted. The aims of this phase are discussed below.

2.5.1 Aims of the Preparatory Phase

1. To ensure that the study forms were written in a way that all participants or relatives would be able to understand.

2. To test the suitability of using the water swallow test (3 tea spoon test) and swallowing assessment questionnaire in participants with PD, MS and MD.

3. To determine the practicalities and other issues that might arise during the study and proffer the right solutions before commencing data collection.

2.5.2 Patients/Next of Kin Information Sheet

Detailed information on the study was prepared for eligible patients and their next of kin. This was used to inform the decision of participants and/or their next of kin when deciding to take part in the study, as it was important for them to know why the research was being done and what it would involve. Providing this written information enabled them to take time to read it carefully and discuss the issues with other people if they wished to do so. They were given 24 hrs to read the information sheet. A number of practicalities were considered, such as ensuring that they had a specific person to contact with any questions, problems or comments. They were invited to seek clarification if they needed further information before deciding whether they wished to participate. (Appendix 12-13)

2.5.3 Obtaining Consent/Assent

All participants were provided with written consent or assent forms (Appendix 14-15). The consent or assent form was signed and dated by the participant or next of kin respectively before they entered the study. The assent form was provided for people with temporary incapacity due to illness or permanent incapacity due to cognitive impairment. The participant's relative was able to give assent on behalf of the participant. The researcher explained the study and provided a participant or next of kin information sheet, ensuring that the potential participant or next of kin had sufficient time (24 hrs) to consider

participation. The researcher also answered any questions that were raised. Informed consent or assent was collected from each participant or next of kin before data collection commenced. A member of the patient's usual care team assessed the patient's capacity to give consent for the study. One copy of the consent or assent form was kept by the participant, one was kept by the investigator and a third was retained in the patient's hospital records. There were subsequent amendments to the final protocol (section 2.2.3), which affected the participation of some participants in the study; however continued consent or assent was obtained using an amended consent or assent form which was then signed by the participant or next of kin, as appropriate.

2.5.4 Good Clinical Practice Training

In line with the regulatory requirements for conducting research in a clinical setting, good clinical practice (GCP) training was undertaken to ensure that GCP principles were followed during the study. The training included the regulatory framework, conditions and principles of GCP, clinical trial activities, safety reporting in research, informed consent and documentation. The safety and well-being of research participants was very important when conducting the study; all other relevant training was undertaken before the study commenced.

2.6 Data Collection

The data for the observational study was collected using the MAU questionnaire and the swallowing screening questionnaire. The data provided information which would guide the screening of dysphagia in acute admissions. It also provided the researcher with some evidence on the prevalence of

unrecognized dysphagia in patients with PD, MS and MD admitted acutely. Acute infections, hospital acquired infections and other complications on admission to hospital were noted along with the interventions and timing of interventions received by the participants.

2.6.1 Data Protection

To maintain patient confidentiality all data collected throughout the study was stored in a password protected database. Identification data were stored separately. Each participant was given a code number to protect their identity.

2.6.2 Data Collection Process

The list of patients on the admissions units for each day, were compiled in each of the hospitals by the nurses. It enabled the identification of patients with one of the three requisite conditions. Data collection was conducted 5 days per week and included the weekends in both hospitals. This method was successful as it enabled the collection of data at the weekend. The days were chosen to reflect the potential differences in practice that might occur with weekend working. Nursing staff were asked if any of their patients with any of the three conditions were willing to participate in the study and to speak to the researcher.

The medical records of those who were willing to participate were reviewed to double check that they met the eligibility criteria. The researcher was then introduced by the usual care team to the patient. The purpose of the study and detailed information about the conduct of the study was then explained,

the patient information sheet was given to them and they were given 24 hours to decide whether or not they would like to consent to the study.

Demographic information (date of birth, age, gender, residence) was also collected. Some patients were unable to give consent due to the nature of their illness at the time of presentation due to their cognitive state or physical status. Consent was sought subsequently, when the usual care team felt they were well enough to be approached. For those that consented to the study, their medical, nursing and end of bed notes were reviewed at day seven of the admission to record the interventions that had occurred (food charts, supplements, referral to speech and language therapy (SLT), referral to the dietetic service, nasogastric tube (NGT) feeding, referral for a percutaneous gastrostomy (PEG)).

A record was made of any nutritional assessment that had been made (screening questions, weight, BMI, nutritional risk score, mid arm circumference (MAC)). Swallow screening assessments (SSA) were completed by the researcher for those who had not been assessed by day seven, this was documented in the medical notes and appropriate referrals were made to SLT for those who were found to have a swallowing problem. The medical assessment unit allows patients to stay for approximately 48 hours before they are transferred to other medical wards or discharged home. For those participants that were transferred to other wards, their medical notes were reviewed, swallow screening assessments were completed if not undertaken during the admission as part of their usual care. Referrals to SLT were also carried out and the usual care team informed of any swallowing problems identified. For those who had been discharged, their medical notes

were reviewed on the last day of admission while the swallow screening was carried out in the person's home.

a) Justification for the Water Swallow Test

The 'water swallow test' is a commonly used bedside swallow assessment for problems with swallowing in hospitals. It has been reported by several authors (Fabiola et al. [109], Nathadwarawala et al. [122], Perry and Love [147]) that this test can identify the risk of aspiration in patients with PD, MS, MD and other neurological conditions, who are more likely to develop dysphagia. It has been shown to have high specificity and sensitivity and established validity and reliability by these authors. It also has the advantage of being easy and quick to administer. For the purposes of this study, swallow screening assessments were required to identify PD, MS and MD patients who were not screened on admission and may be at risk of aspiration. The water swallow test was therefore suitable for the requirements of this study.

b) Justification for the Dysphagia Screening Tool

To ensure early diagnosis of dysphagia in patients with PD, MS and MD during their acute admission and to generate a measurable outcome measure, the use of a valid dysphagia screening tool (DST) was required. Many hospitals have developed their own DST, based on a review of the studies discussed sections 1.9.1 and 1.10.4 above. These tools contain questions on history and risk factors, patient's level of consciousness, lip closure and voice quality, signs of dysphagia (e.g. normal, weak or absent cough, drooling of saliva), presentation of small amounts water to the patient to check for abnormalities (laryngeal movement delayed or absent), cough (during or after swallowing), choking or stridor, wet or gurgly voice, dribbling of water and observation of

eating for difficulties (such as loss of food from lips, difficulty chewing, pouching of food, coughing or choking with food, gurgly voice, patient reports).

Most of the tools are designed in the form of questionnaires with tick boxes, so that when a section of questions answered signifies that swallowing is unsafe, the screening process is stopped and an immediate referral is made to the speech-language therapist. The DST are non-invasive, simple, take a short time to administer and detect signs of dysphagia before any comprehensive assessment is done. The guidelines from NICE (2006) and SIGN (2010) state that all stroke patients should have a swallowing assessment within 24 hours of admission to hospital [67, 106]. However, if it is vital for one particular group of patients who may be at risk of dysphagia to be identified early, accurately and managed, then all patients (including PD, MS and MD) should have access to this assessment irrespective of their diagnosis. The literature supporting the possible outcomes of unrecognized or late identification of dysphagia is generally lacking.

The use of DST ensures patient safety before any kind of oral intake and can be effective if DST is used routinely in hospital by trained nursing staff. The DST (swallowing test questionnaire) used in Royal Derby Hospital (RDH) and Nottingham University Hospital (NUH) contained similar questions to those described above. Therefore both questionnaires were combined to develop a uniform swallowing test questionnaire that is a representative of both trusts for use in this study.

2.6.3 Data Coding

The categorical data contained in both questionnaires (MAU and swallowing screening assessment) were coded by assigning discrete values to them. This

procedure was then used to assign values to the rest of the categorical data questions, which made it easier to input data into SPSS version 19 statistical software for subsequent analysis.

2.6.4 Checking and Cleaning of Data

Initially the data were checked and cleaned to ensure that the data set was of the highest quality. This involved both the detection and correction of errors in the data set. Missing data were coded as 9 and 99 depending on the question type; coding errors and typing errors on data entry were also corrected.

2.6.5 Data Analysis

The evaluation of data derived from the observational aspect of the study and the swallow screening assessment were completed with both descriptive and quantitative techniques. The observational data were analysed using the statistical package for social sciences (IBM SPSS) version 19. The analysis was carried out with supervision and advice provided by my supervisors and with statistical support. Patient demographics were determined using descriptive methods [means (+/-standard deviation) and proportions (frequency and percentages). A 95% confidence interval was used for the statistical tests. The statistical differences between groups were compared using the Chi-Squared Test (X^2) and the Mc Nemar test, to determine whether there was any difference in the proportion of participants who were assessed within the first week of admission and after the first week of admission for swallowing screening assessments, management and outcomes for categorical variables**.** The distribution of variables was tested for normality using histograms and the Kolmogorov-Smirnov test; all the variables were normally distributed.

Associations between categorical outcome measures (such as hospital acquired pneumonia) and the swallowing assessments were determined with the use of the χ^2 test. The variables were said to be statistically significant if the p-value was equal to or less than 0.05.

2.7 Interview Methods

2.7.1 Aim

To describe the clinical reasoning used by clinicians as they consider assessment of swallowing in patients with neurological conditions when admitted acutely to hospital.

2.7.2 Objective

To determine factors that may influence the decisions of clinicians to conduct a swallowing assessment in patients with neurological conditions or advise that one is undertaken.

2.7.3 Clinicians perceptions of swallowing screening assessments

A sample of clinicians were interviewed in order to determine the clinical reasoning that underpins their decision to assess swallowing when patients with PD, MS and MD have an unplanned admission. Clinicians were recruited for semi-structured interviews. Whilst clinical reasoning is known to be influenced by many factors, there is little evidence available concerning the

variables which determine when, who or how patients with neurological conditions are screened for dysphagia when admitted to hospital.

Gaining an understanding of these factors, should enable important information to be gathered regarding aspects of staff knowledge, attitudes and continuing professional development needs. It should also allow any organizational barriers to be uncovered which prevent related aspects of care from being implemented in an effective and timely manner. The participants were members of staff who were involved in the management of patients in RDH and QMC. Data were collected from 20 health professionals who make up the clinical team that care for these patients. The study design and methods of data collection used for the interview aspect of the study are described in section 2.8.5 of this chapter.

2.7.4 Characteristics of Staff Participants

A convenience sample of 20 clinicians was recruited through their ward managers and contacted by email. All were involved in the in-patient care of patients with neurological conditions. Those recruited included doctors; a dysphagia trained nurse, a rehabilitation nurse specialist, ward managers, various grades of nurses, physiotherapists, occupational therapists, a nutritionist and health care staff who work in one or more acute medical ward. The choice of this group of clinicians was selected from the usual care team by the heads of the management team, to ensure that the participants were those directly involved in the management of PD, MS and MD patients. They comprised all levels of medical care and specialties who have recently or currently worked, in acute medical wards.

2.7.5 Data Collection

Data were collected through semi-structured interviews. The participants who consented to take part were given an explanation of how the interview process would be conducted to enable them to ask any questions before the interview commenced. They were also assigned a unique code to preserve their anonymity. (Table 2.2) The topics for the structured interviews were decided in advance and included: experience and skill-mix on the ward, clinical reasoning, skill and knowledge, confidence, training and awareness. The interview guide consisted of ten questions (Appendix 16). In addition, each participant was asked to describe any difficulties or provide suggestions that they might have in relation to conducting swallowing assessments with people who have these neurological conditions. This ensured that all relevant data relating to swallowing assessment in these conditions were obtained. A total of 20 participants were interviewed [11 from QMC and 9 from RDH]). Table 2.2 shows the occupations and identification code allocated to each participant.

Table 2.2 Professional background and identification code of each interviewee

Professional Background of Each Interviewee	Identification Code (ID CODE)
Physiotherapist (QMC)	A6
Rehabilitation nurse (QMC)	B1
Medical doctor (QMC)	B3
Nurse (QMC)	B4
Nurse- Neurology (QMC)	B5
Nurse- MAU (QMC)	B6
Nutritionist (RDH)	B7
Occupational Therapist (QMC)	C1
Nurse- MAU (QMC)	C2
Health care staff (QMC)	C3
Ward manager- MAU (RDH)	D1
Dysphagia trained nurse (QMC)	D2
Nurse- MAU (RDH)	D3
Nurse- Acute Medical Ward (RDH)	D5
Medical doctor (RDH)	D6
Nurse- Acute Medical ward (RDH)	D8
Occupational Therapist (RDH)	D9
Physiotherapist (RDH)	D10
Speech and language therapist (QMC)	E 1
Speech and language therapist (RDH)	E 2

2.7.6 Data Collection Process

Clinicians who were directly involved in the management of this group of patients (PD, MS and MD) were invited to take part in one interview, conducted in person or by telephone. The researcher met with the ward managers of the acute medical wards and medical assessment units and explained the purpose of the interviews; these managers then informed the management team, asking those who were willing to grant an interview to contact the researcher. Those who showed an interest in participating were contacted by email to provide a further explanation of the aims of the study, how the interview would be carried out and its expected duration. The interviews were expected to last between 30 and 60 minutes, they were conducted in English and held at the hospital base of the interviewee.

Participant information sheets were also sent with the email for the participant to read, ensuring that sufficient time was given to consider the invitation. Any questions that the clinicians had concerning the study were discussed before the interviews commenced. They were also asked to provide a date, time and place which would be convenient for the interview to be held. Before the interview started, informed consent was collected from each participant showing their agreement to take part in the interview and for it to be tape-recorded. One copy of the consent form was kept by the participant and another was kept by the investigator. All the interviews started with a brief introduction to the aims and objectives of the study and the information outlined in the participant information sheet was explained. The interview guide mentioned earlier was used for this process. Each of the interviews were tape-recorded and as body language is sometimes important to understanding the full meaning of a statement, notes were taken while the

interview was in progress. Summaries were completed immediately after the interview and the participant was asked to review and confirm if the interpretation was correct to prevent errors or misinterpretations from occurring.

2.7.7 Data Coding

The data generated from the interviews were entered into NVivo software version 9 for qualitative analysis. Coding was the main process of analysis using the NVivo software, helping to determine all the important information. NVivo is able to create, edit, explore, and review documents and nodes. 'Documents' refer to the data that is being analysed in a study and can be 'rich text files' or 'proxy representing files' [225]. For example, the full tape-recorded interview with a participant was input in NVivo as an independent document. Researchers are able to make changes, edit or review the document as often as necessary.

The nodes were used for storing the themes that emerged from the data as they were placed into categories [225]. The 'free nodes' stored the uncommon themes while the 'tree nodes' grouped emerging themes together. In this study, the tree node was called 'participant opinions of swallowing assessment' and used the interview nodes to differentiate each of the interviews. These nodes could be combined or linked. The coding by node for the different aspects of the data is detailed in chapter 4 of the thesis.

The background information of participants interviewed was recorded in 'Attributes'; a special coding where values could be specified for information about the participant's work, role, length of experience in their field and other data represented by nodes or documents in the study [225]. They are used for highlighting responses to questions in relation to gender, age, experience

or the ways by which things are carried out which differ in certain places and times. [225]. This search facility added rigor to the study by, for example, showing the total number of interviewees who reported that the presence of a swallowing problem would prompt them to conduct a swallowing assessment or refer patients to Speech and Language Therapy (SLT). This helps to eliminate the issue of human error and helps to gain a true impression of the data collected. This knowledge also helped to determine from the participants interviewed, why people were so different in their understanding of the swallowing assessment in PD, MS and MD population.

2.7.8 Justification for using NVivo Software

Several computer software programmes for analysis of qualitative data are now available. In this study, NVivo 9, which is known as the Computer-Assisted Qualitative Data Analysis Software (CAQDAS) program was used to assist in the analysis of the qualitative data for the following reasons:

1. NVivo software enables qualitative researchers to analyse their data in an organized pattern. The main analysis would still have to be done by the researcher.
2. NVivo enables data to be stored in the original form and content through study documents. This enables easy accessibility and organization.
3. Data generated using NVivo is easily coded by nodes and could be revisited or viewed when required. Themes and thoughts could also be updated during the analysis of the data.
4. NVivo permits the setting up of documents or nodes attributes, addition of memos, construction of models and tables, editing codes, linking of data internally and externally.

5. It applies demographic variables in the study and investigates relationships between participants or their thoughts.
6. NVivo also provides the means for tapes and other audio materials to serve as models of study analysis and as resource to the research, as in this study. [225]
7. NVivo equally enables transparency, easy channelling of the researcher's thoughts and deriving the conclusions reached from the study.
8. Interviews conducted in virtually any language can be uploaded and analysed by NVivo.

With the NVivo software, the interview recordings which underpin the swallowing assessments made were imported easily and stored. It also enabled working with all the data in one application, thereby streamlining the analysis. In summary, NVivo software can organize, manage and explore and visualize large quantities of related information. It helps the researcher understand the data gathered and enables the presentation of research findings in an innovative way. [225]

2.8 Data Analysis

2.8.1 Data Transcriptions

The data analysed in this thesis consisted of the transcriptions from the semi-structured interviews and notes taken during the interviews. The interviews were transcribed accurately and word-for-word, to ensure that the transcripts were an actual representation of the verbal content. The transcripts were further cross checked against the tape-recorded data and corrections were

made where necessary. All the interviews were transcribed on the day or within two days after conducting the interview, to ensure accurate representation of the transcript to the oral form and to avoid forgetting the background in which the discussions were made and the exact body language used. These precautionary measures were carried out because of transcription issues and controversy seen amongst different studies. Many researchers are of the opinion that the transcribing from oral to written text may not be truly representative of the actual data [226].

2.8.2 Thematic Content Analysis

NVivo software has searching tools as part of its structure, which enable a researcher to cross-examine data. This improves the thoroughness of the data analysis by confirming (or questioning) some of the researcher's own thoughts. The disadvantage is that the software is limited in terms of addressing issues concerning themes that emerge during the data analysis process. As a tool to search through emerging themes and to provide a very good understanding of the data, NVivo is also limited. Due to these limitations, both manual and electronic methods were employed to analyse the data obtained from the semi-structured interview using thematic content analysis. The transcribed interviews were read initially by my supervisors in order to identify emerging themes. These were then discussed with the themes that emerged from the researcher’s experiences and a consensus on themes was reached. They were then checked again with the original data, to avoid bias and ensure validity of the data.

The anonymous quotes used in the study are the opinions that were expressed and each of them illustrates the emerging themes. A code was assigned to

each person interviewed for reasons of confidentiality. The insertion of the exact words used by the interviewees enables transparency of the analysis of the data by the researcher for the reader, which is one of the vital requirements for validity in qualitative research [220]. The findings are intended to present a vivid picture of the views of clinicians rather than a firm conclusion on the topic. Overall, while observational methods enabled relationships and associations to be assessed in an objective way, the additional use of qualitative data was seen to provide a better understanding of the information obtained through the observational methods.

2.9 Summary

In this chapter, the methods used to investigate dysphagia assessment in neurological conditions have been presented. The first method used was based on observation and gathered quantitative data to evaluate the assessment of dysphagia in people with PD, MS and MD. The second employed a qualitative interview approach to examine the reasoning adopted by clinicians when making decisions about the use of swallowing assessment in people with these conditions.

The rationale for using these methods has also been explained in detail previously. Hopefully, by adopting a multi-methods approach where both observational and interview data have been gathered, it will increase the validity and understanding of the subject. The analyses of the data using both electronic (statistical software package: SPSS for observational and NVivo for interview) and manual (thematic content analysis) have also facilitated rigor in the analysis, rather than the usual method of data analysis (the single approach). Having described the research methods that were

used in this study, the following chapters of the thesis (chapters 3 and 4) present the findings of the study as they relate to the research questions.

CHAPTER 3: OBSERVATIONAL FINDINGS

CHAPTER 3: OBSERVATIONAL FINDINGS

3.1 Introduction

The purpose of this study was to describe the use of dysphagia screening and assessment procedures amongst people with PD, MS and MD when they have an unplanned admission to hospital. The objectives of the study were: [1] To determine if patients are screened for dysphagia during the first seven days following an unplanned admission to hospital. [2] To determine if patients who are assessed for dysphagia during the first seven days of admission to hospital are managed differently to those who are not assessed. [3] To determine if the clinical outcomes for patients who are assessed during the first seven days of admission to hospital differ from those who are not assessed. [4] To estimate the prevalence of dysphagia amongst patients who have an unplanned admission to hospital.

Initially, the information about recruitment and demographic characteristics of the participants are given. Following demographic information, the findings of the observational studies are presented in the order of the objectives as listed above. An estimate of the prevalence of dysphagia amongst these patients is provided in order to highlight the scale of the problem amongst people with neurological conditions.

3.2 Preliminary Analysis of Study Participants

3.2.1 Participant Recruitment

Participants were recruited from Royal Derby Hospital (RDH) in Derby and Queens Medical Centre (QMC) in Nottingham between April 2011 and January 2012. Data collection commenced on the 1st of April 2011. Based on the average number of participants expected to be recruited per week (n=8), it was estimated that the initial sample size set (n=390) could be reached in approximately 52 weeks. This time frame allowed for annual leave and unexpected eventualities.

However, by the 30th of September 2011, the total number of participants recruited was only 144 (69%) participants, as we were presented with approximately six participants per week. Sixty-four patients, who could have been recruited by that stage were not, as it was not possible to recruit patients by obtaining the assent of a relative. (See Chapter 2 on discussion about the Ethical issues). The total number of patients who could have been identified through both hospitals via the provision of consent or assent was approximately 15 per week. Ethics approval was later received in October to recruit those who lacked the capacity to consent for the study. [Appendix 8]

Fifty-six further participants were recruited subsequently, including those unable to consent but whose relatives were able to give assent on their behalf; this second group constituted the majority of the 56 participants. A total of 200 participants were finally recruited into the study. [Figure 2.1] All the participants were identified initially by clinical staff and met the study inclusion criteria. As a result of the difficulties encountered during the recruitment period, a *post hoc* analysis was carried as discussed in chapter two (section

2.5.2) to ascertain the actual sample size required for the study. The ideal sample size was found to be 180 participants. Therefore the sample of 200 was adequate for analysis purposes.

Seasonal variations, type of illness and rate of recruitment changes were noted. Recruitment was very low during the months of November and December. Although most patients were eligible for the study, they had very severe illness on admission. This may have resulted in patient being less inclined to consent or participate.

3.2.2 Demographic Characteristics of the Participants

One hundred and sixty-six (83%) participants with PD, 29 (15%) with MS and 5 (3%) with MD entered the study. Ninety-three [n=93 (47%)] were from RDH and one hundred and seven [n=107 (54%)] from QMC.

The duration of the neurological condition for the majority of participants [n=135] was 0 to 15 years. Most participants were males [n=116 (58%)] and lived in their own homes [n=158 (79%)]. (Table 3.1) Mean age was 76 years, with a standard deviation of 15. All [n=199 (99%)] but one of the participants were recruited to the study one day following admission to hospital. Most participants were followed-up six days after recruitment to the study [n=178 (89%)]. (Table 3.2)

Table 3.1 Demographic data

Characteristics		Frequency (n=200)	Per cent
Type of neurological condition	PD	166	83
	MS	29	15
	MD	5	3
Duration of neurological condition	0-15yrs	135	68
	16-30yrs	30	15
	31-45yrs	3	2
	61-75yrs	1	1
	Not documented	31	16
Gender	Male	116	58
	Female	84	42
Participant's Age	16-39yrs	8	4
	40-49 yrs. etc.	5	3
	50-59yrs	13	7
	60-69yrs	17	9
	70-79yrs	51	26
	80-89yrs	88	44
	90yrs and above	18	9
Hospital	RDH	93	47
	QMC	107	54
Participant's place of residence	Nursing Home (NH)	27	14
	Residential Home (RH)	15	8
	Own House	158	79

Table 3.2 Time participants recruited to the study and followed up

Time recruited to the study and followed up		Frequency (n=200)	Per cent
Time recruited to the study after admission (in days)	On the day of admission	1	1
	One day after admission	199	99
Period between recruitment and follow-up (in days)	On the day of recruitment	1	1
	Five days after recruitment	13	7
	Six days after recruitment	178	89
	Seven days after recruitment	8	4

3.2.3 Presenting Complaint

Half of the participants [n=100] presented with musculoskeletal problems such as reduced mobility, stiffness, hip pain, ankle pain, joint swelling and back pain. Seventy–four (37%) participants were admitted with neurological complaints - collapse, limb weakness, confusion, poor balance, fall, generalized weakness, headache, pins and needles, seizures and tremor. Approximately one-fifth of the participants (21%) complained of gastrointestinal symptoms - reduced appetite, abdominal pain, diarrhoea, constipation, weight loss, vomiting, nausea, melaena and indigestion. Some of the participants [n=41, (21%)] also complained of respiratory problems - shortness of breath (SOB), cough, chest infection, productive sputum, exercise

intolerance and audible wheeze. A small percentage of the participants [n=3, (2%)] presented with cardiovascular problems - chest pain, orthopnoea, palpitations, faintness, paroxysmal nocturnal dyspnoea (PND) and social or psychological symptoms - alcohol overdose or withdrawal, self-harm and self-neglect.

Only 28 (14%) participants presented with dysphagic symptoms – coughing, choking on food and drink or difficulty swallowing. Of the 28 participants who presented with dysphagic symptoms, 21 (11%) had a swallowing assessment within one week of admission while 7 (4%) were assessed after one week of admission. Table 3.3 provides a summary of the complaints the participants presented with.

Table 3.3 Presenting complaints

Characteristics	Frequency (n=200)	Per cent
Dysphagic symptoms	28	14
Respiratory symptoms	41	21
Neurological symptoms	74	37
Gastrointestinal symptoms	42	21
Cardiovascular symptoms	3	2
Musculoskeletal symptoms	100	50
Socio-psychological symptoms	3	2

3.2.4 Participant Background/Co-morbidity

The participants had already been diagnosed with one of the three types of medical condition - PD, MS or MD, therefore this was not listed as a co-morbidity. The frequencies of co- morbidities were as follows: neurological (n=138, 69%), cardiovascular (n=104, 52%), gastrointestinal (n=100, 50%), musculoskeletal (n= 62, 31%), respiratory (n=24, 12%) and oncology systems (n=11, 6%). The co-morbidities presented by the participants that related directly to dysphagia are summarised below and in table 3.4.

- *Gastro-intestinal pathology*- vitamin B12 deficiency, dehydration, anaemia, constipation, folate deficiency, weight loss, oesophageal candidiasis.

- *Respiratory pathology*- long term oxygen therapy (LTOT), aspiration pneumonia, asthma, bronchiectasis, chronic obstructive pulmonary disease (COPD)

Table 3.4 Background pathology for co-morbidity of participants

Characteristics	Frequency (n=200)	Per cent
Gastrointestinal pathology	100	50
Respiratory pathology	24	12

3.3 Swallowing Assessment

3.3.1 Initial Assessment

Table 3.5 summarises the results of the assessment of swallowing that was undertaken by the researcher as part of the study. Physical factors associated with aspiration such as level of consciousness, lip closure, voice quality and voluntary cough in people with neurological dysphagia were assessed before the water swallow test [22]. These signs are peculiar to the oral preparatory phase of dysphagia as discussed in section 1.4.2. Sixty-eight participants (34%) received a swallowing assessment as part of their routine care, so they did not undergo any further assessment by the researcher. The remaining 132 participants, who therefore had not been identified by ward staff as needing a swallowing assessment, were assessed by the researcher. These participants had relatively weak voice quality - 49 (25%) and voluntary cough - 72 (36%). A few participants had an abnormal lip closure-10 (5%).

Table 3.5 Results of the initial assessment of swallowing

Characteristics		Frequency (n=200)	Per cent
Level of consciousness	Alert	131	66
Lip closure	Normal	121	61
	Abnormal	10	5
Voice quality	Normal	65	33
	Weak/Hoarse	49	25
	Wet/Gurgly	17	9
Voluntary cough	Normal	58	29
	Weak	72	36
	Absent	1	1

3.3.2 Stage 1 of the Swallowing Assessment (3 teaspoons of water)

During the first stage of the water swallow test, 3 teaspoons of water are given. Water is usually difficult for people with neurological dysphagia to swallow [34], so this assessment enabled participants to be detected who may be at risk of aspiration. A failed test was defined when participants had delayed or absent laryngeal movement, wet or gurgly voice, coughing, choking and dribbling of water during or after swallowing. The results of this first stage of assessment are summarised in table 3.6. More than half of the participants had a wet or gurgly voice – 111 (56%) and coughed during and after swallowing water on more than one occasion - 100 (50%). Laryngeal movement and dribbling of water was also abnormal for many participants - 87 (44%). Seventy-six participants (38%) passed the test at this stage. The 124 participants who failed the test were those not noted by the ward staff to have swallowing problems.

Table 3.6 Percentage of participants who passed stage 1 of the swallowing assessment

Characteristics		Frequency (n=200)	Per cent
Laryngeal movement	Normal	113	57
	Delayed	87	44
Cough during/after swallowing	Yes	100	50
	No	100	50
Choking/Stridor	Yes	67	34
	No	133	67
Wet/Gurgly voice	Yes	111	56
	No	89	45
Dribbles Water	Yes	87	44
	No	113	57
Observation	Pass	76	38
	Fail	124	62

3.3.3 Stage 2 of the Swallowing Assessment (60 mls of water)

This stage was only administered to 76 participants who passed stage one of the assessment (38%). In this analysis, the overall total number of participants [N=200] will always represent 100% and every percentage is referred to two hundred as the total number. During the second stage of the water swallow test 60mls of water was given, using a glass. The results of this second stage of assessment are summarised in table 3.7. Several studies have shown that increasing the quantity of water used increases the sensitivity of detecting aspiration [134-136].

Laryngeal movement was delayed in less than two-fifths of the participants (n=24, 12%), cough during and after swallowing in 30 (15%) and wet/gurgly

voice (n=27, 14%) was a constant and noticeable sign in many participants. Choking/stridor with water (n=11, 6%) was low when compared to the numbers at stage one. Only forty-one (21%) participants passed the water test at this stage. The findings in this stage are synonymous with pharyngeal phase dysphagia (section 1.21 of the thesis).

Table 3.7 Percentage of participants who passed stage 2 of the swallowing assessment

Characteristics		Frequency (n=76)	Per cent
Laryngeal movement	Normal	52	26
	Delayed	24	12
Cough during/after swallowing	Yes	30	15
	No	46	23
Choking/stridor	Yes	11	6
	No	65	33
Wet/gurgly voice	Yes	27	14
	No	49	25
Observation	Pass	41	21
	Fail	35	18

3.3.4 Stage 3 of the Swallowing Assessment (a meal)

Table 3.8 details the observation of study participants as they ate their meal during their acute admission. This stage of assessment was carried out on the 41 participants whose swallowing was normal in stage 2. In this analysis, the overall total number of participants [N=200] will always represent 100% and every percentage is referred to two hundred as the total number.

Any abnormalities in the major signs of aspiration while eating, such as coughing, chocking, gurgly voice and pouching of food, were considered as a failed test at this stage. A small proportion of participants experienced pouching and difficulty chewing their food (n=5, 3%), while some of them

(n=6, 3%) reported difficulties with swallowing items such as medication, food and drinks. Loss of food from the mouth and gurgly voice was evident in only one participant (1%) and none of the participants coughed or choked during eating. Of the 41 participants reviewed at this stage, the majority (n=39, 20%) passed the swallow screening assessment.

Table 3.8 Percentage of participants who passed stage 3 of the swallowing assessment

Characteristics		Frequency (n=41)	Per cent
Loss of food from mouth	Yes	1	1
	No	40	20
Difficulty chewing	Yes	5	3
	No	36	18
Pouching of food	Yes	5	3
	No	36	18
Cough/Choking	Yes	0	0
	No	41	21
Gurgly voce	Yes	1	1
	No	40	21
Patients Reports Difficulty	Yes	6	3
	No	35	18
Observation	Pass	39	20
	Fail	2	1

Figure 3.1 is a graphical representation of the number of participants who passed or failed each stage of the swallowing assessment.

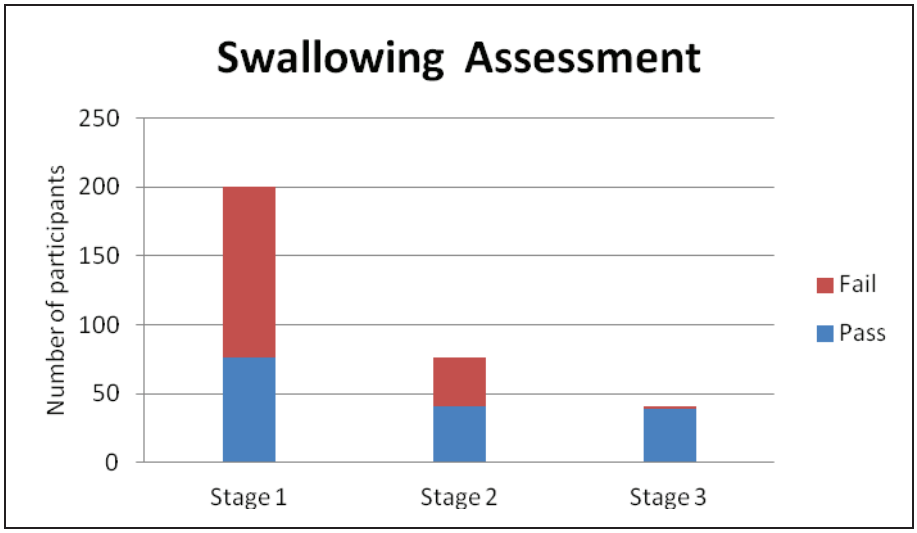

Figure 3.1 Progression of participants at each stage of the swallow screening assessment

Figure 3.2 is a graphical representation of the progression of participants in percentages at each stage of the swallowing assessment, showing the results of swallowing status in percentages.

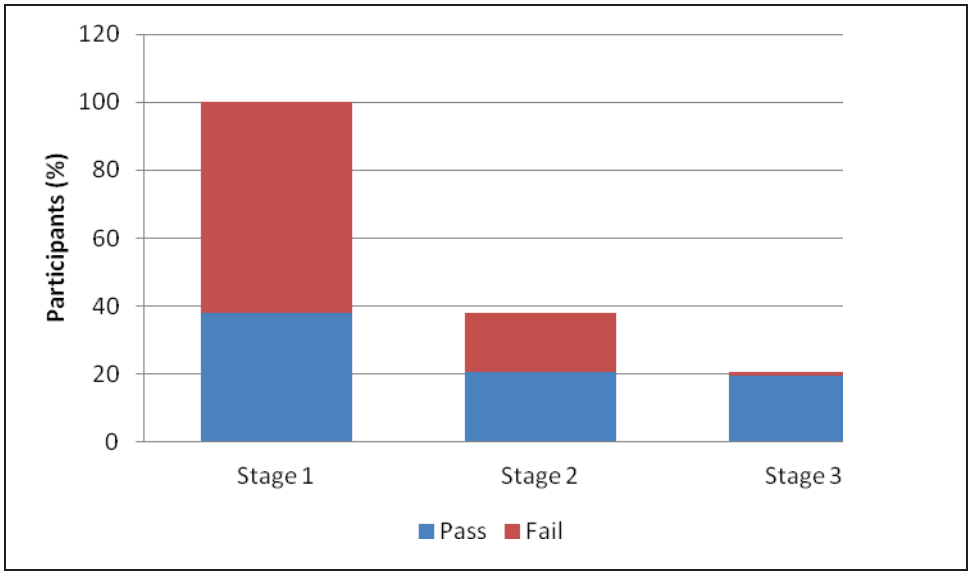

Figure 3.2 Swallowing status at each stage of swallow screening (expressed as percentages)

3.3.5 Stage 4 of the Swallowing Assessment

This is an overall result of the swallowing status of all the study participants. One hundred and sixty-four participants (82%) failed the swallow screening assessment as they had problems at some stage of their swallowing; the remaining participants (n=36, 18%) appeared to have no swallowing difficulties. [Table 3.9] The percentage of participants from each subset who experienced difficulties is summarised in tables 3.9.

Table 3.9 Swallowing status of all participants and each subset

Overall Swallow Status		Frequency (n=200)	Percent
PD	Pass	31	20
	Fail	135	68
MS	Pass	5	3
	Fail	24	12
MD	Pass	0	0
	Fail	5	3
Total	Pass	36	18
	Fail	164	82

3.4 Assessment of Patients with Dysphagia (Objective 1)

3.4.1 How many people are screened?

Sixty-eight (34%) participants underwent a swallow screening assessment (SSA) during the first week of admission as part of their routine care and 63

(93%) of these were judged to have dysphagia. Table 3.10 shows the results of the swallow screening assessment for all the participants and each subset.

Table 3.10 Results of SSA for all participants and each subset

Result of the SSA		**Within first week of admission by ward staff**		**After first week of admission by researcher**	
Swallowing Status		**Frequency (n=68)**	**Per cent**	**Frequency (n=132)**	**Per cent**
PD	Pass	5	7	26	20
	Fail	50	74	85	64
MS	Pass	0	0	5	4
	Fail	10	15	14	11
MD	Pass	0	0	0	0
	Fail	3	4	2	2
All¥	Pass	5	7	31	24
	Fail	63	93	101	77

All data were analysed using the Pearson chi-square tests: ¥=.005

3.4.2 How many people had unrecognised dysphagia?

Amongst those who were not assessed initially (n=132), a further 101 (77%) were found to have dysphagia when they were screened after the first week of their admission to hospital by the researcher [Table 3.10]. Nursing staff were made aware of these patients and referrals were made to the speech and language therapist (SLT) for further assessment. Recommendations were made for provision of soft diet and observation. Documentations were made in the medical notes.

3.4.3 How many were referred to the dietitians/speech and language therapists?

Of the 200 participants recruited to the study, 36 (53%) were referred within the first week of admission to the speech and language therapists (SLT) and the dietitians. The act of referral indicates that the ward staff detected a potential problem and thus this indicates a "positive SSA". Table 3.11 summarises how many people were referred to the SLT or dietetic department.

Table 3.11 Referrals to SLT or dietetic or both services

	SSA Performed within first week of admission by ward staff	
Referrals	**Frequency (n=68)**	**Per cent**
Not referred to SLT or dietetics	2	3
Referred to SLT only	30	44
Referred to dietetics only	0	0
Referred to both SLT and dietetics	36	53

3.4.4 How many were referred to dietitians/speech and language therapists without screening?

The proportion of patients who were referred to the SLTs, dietetics or both services without screening by ward staff but later had a SSA after the first week of their admission by the researcher revealed the following findings. Two per cent (n=3) were referred to SLT only, 1% (n=1) were referred to SLT and dietetics, whilst 87% (n=115) were not referred to either service. [Table 3.12]

Table 3.12 Referrals to SLT or dietetic or both services without screening by ward staff

	No SSA Performed within first week of admission by ward staff	
Referrals	**Frequency (n=132)**	**Per cent**
Not referred to SLT or dietetics	115	87
Referred to SLT only	3	2
Referred to dietetics only	13	10
Referred to both SLT and dietetics	1	1

3.4.5 Sub group Analysis of PD and MS Participants

Sub group analysis was carried out to compare the swallow screening assessment of the PD and MS participants because staff knowledge or the presentation of dysphagia may differ for each condition. Analysis could not be

carried out in MD because the numbers were too small but it is important to note that none of the five were identified as having a swallowing problem by ward staff and all were found to have dysphagia when assessed by the researcher.

3.4.6 Dysphagia Assessment in PD Participants

Amongst the patients who were recruited with Parkinson's disease (PD) [n= 166 (83%)], 55 (33%) of these had a SSA within first week of admission by ward staff. Fifty people (30%) were judged to have dysphagia. [Table 3.14]

Amongst those PD participants who were not assessed during the first week of admission, 85 (51%), were found to have unrecognised dysphagia by the researcher. [Table 3.14]

From a total of 166 participants with PD, the number who were referred to the speech and language therapist (SLT) was 57 (34%), while 43 (26%) were referred to the dieticians. [Table 3.13]

The proportions of participants who had a SSA [n=55 (33%)] and were referred to SLT, dietetics or both within and after the first week during the admission were as follows: 38% (n=21) had a SSA and were referred to SLT only, 58% (n=32) had an SSA and were referred to SLT and dietetics, 4% (n=2) had a SSA and were not referred to either speciality. [Table 3.15]

Table 3.13 Assessment of dysphagia in patients with PD

		Frequency (n=166)	Per cent
SSA within first week of admission by ward staff		55	33
SSA after first week of admission by researcher		111	67
Number of participants missed	Yes	85	51
	No	81	49
Referral to SLT	Yes	57	34
	No	109	66
Referral to Dietetics	Yes	43	26
	No	123	74

Table 3.14 Results of swallow screening assessment for participants with PD

		Frequency (n=166)	Per cent
Results of the SSA within first week of admission by ward staff	Pass	5	3
	Fail	50	30
Results of the SSA after a week of admission by researcher	Pass	26	16
	Fail	85	51

Table 3.15 Referrals of participants with PD to the SLT or dietetic services or both

	SSA Performed within first week of admission by ward staff		SSA not Performed within first week of admission	
	Frequency (n=55)	Per cent	Frequency (n=111)	Per cent
Not referred to either service	2	4	97	87
Referred to SLT only	21	38	3	3
Referred to Dietetics only	0	0	10	9
Referred to SLT and Dietetics	32	58	1	1

3.4.7 Dysphagia Assessment in MS Participants

Patients who were recruited with multiple sclerosis (MS) were 29. Ten of these participants (35%) had a SSA within the first week of admission by the ward staff and they were all judged to have dysphagia. [Table 3.16]

The remaining 19 (66%) participants were assessed after the first week of admission. Amongst those participants who were not assessed initially, 14 (48%) were found to have unrecognised dysphagia by the researcher. [Table 3.17]

Ten participants (35%) were referred to speech and language therapy (SLT) and 4 (14%) were referred to the dietetic service. [Table 3.16]

The proportion of participants who had a SSA [n=10 (35%)] and were referred to a SLT or a dietician (or both) within or after the first week of admission was as follows: 70% (n=7) had a SSA and were referred to SLT only, 30% (n=3) had a SSA and were referred to a SLT and a dietician. [Table 3.18]

Table 3.16 Assessment of dysphagia in participants with MS

		Frequency (n=29)	Per cent
SSA within first week of admission by ward staff		10	35
SSA after first week of admission By researcher		19	66
Number of participants missed	Yes	14	48
	No	15	52
Referrals to SLT	Yes	10	35
	No	19	66
Referrals to Dietetics	Yes	4	14
	No	25	86

Table 3.17 Results of swallow screening assessment for MS participants

		Frequency (n=29)	Per cent
Results of the SAA within first week of admission by ward staff	Pass	0	0
	Fail	10	35
Results of the SSA after first week of admission by researcher	Pass	5	17
	Fail	14	48

Table 3.18 Referrals of participants with MS to the SLT or dietetic services or both

	SSA Performed within first week of admission by ward staff		SSA not Performed within first week of admission	
	Frequency (n=10)	Per cent	Frequency (n=19)	Per cent
Not referred to either service	0	0	18	95
Referred to SLT only	7	70	0	0
Referred to dietetics only	0	0	1	5
Referred to SLT And dietetics	3	30	0	0

3.5 Management of Patients with Dysphagia (Objective 2)

3.5.1 Speech and Language Therapy (SLT) Review

Of the 200 participants included in the study, medical staff noticed that 70 (35%) of those who were assessed within the first week of admission had a swallowing problem and referred them to a speech and language therapist (SLT) for a swallowing assessment. Sixty-five (33%) of these participants had a swallow screening assessment (SSA) within the first week of their admission and were seen by the SLT, while 3 (2%) were direct referrals to the SLT but had no SSA prior to the referral. The remaining 2 participants were also referred to the SLT, but were not seen by the SLT until after the week following admission.

The results presented are for those who had received a SSA within the first week of their admission and were seen by the SLT. SLT interventions were delivered at a variety of times. The data presented in table 3.19 revealed a larger proportion of these participants (n=33, 51%) referred within the first week of admission were seen by the SLT either ≥4 days of the referral. The table below shows the total number of participants who had a SSA within the first week of admission, referred and were seen by the SLT.

Table 3.19 Day following admission participants referred to and seen by the SLT

Number of Participants = 65

		Referred to a SLT											
		On the day		**Day 1**		**Day 2**		**Day 3**		**Day 4**		**Day 5 or more**	
		No	%	No	%	No	%	No	%	No	%	No	%
Seen by the SLT	on the day	1	1.54	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	after 1 Day	5	7.69	5	7.69	0	0.00	0	0.00	0	0.00	0	0.00
	after 2 Days	3	4.61	7	10.76	0	0.00	0	0.00	0	0.00	0	0.00
	after 3 Days	0	0.00	6	9.23	3	4.62	2	3.08	0	0.00	0	0.00
	after 4 Days	2	3.08	2	3.08	4	6.15	1	1.54	0	0.00	0	0.00
	after 5 Days	1	1.54	1	1.54	4	6.15	2	3.08	1	1.54	0	0.00
	> 5 Days	2	3.08	2	3.08	2	3.08	1	1.53	1	1.54	7	10.77
Sub-Total:		**14**	**21.54**	**23**	**35.38**	**13**	**20.00**	**6**	**9.23**	**2**	**3.08**	**7**	**10.77**

3.5.2 Dietetic Review

The number of participants who were referred for a dietetic review within the first week of admission was 50 (25%). Those who referred patients included physicians, nursing staff and speech and language therapists (SLT). On average, it took four days for patients to be reviewed by the dietitians. As can be seen from table 3.20, a greater proportion of these participants [n=31 (62%)] were reviewed in four days or more by the dietitians.

Table 3.20 Day following admission participants referred to and seen by a Dietitian

Number of Participants = 50

		Referrals to the Dietetic Service													
		On the day		**1 Day**		**2 Days**		**3 Days**		**4 Days**		**5 Days**		**> 5 Days**	
		No	%	No	%	No	%	No	%	No	%	No	%	No	%
	On the Day	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Seen By Dietician	after 1 Day	0	0.00	2	4.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	after 2 Days	0	0.00	3	6.00	2	4.00	0	0.00	0	0.00	0	0.00	0	0.00
	after 3 Days	0	0.00	1	2.00	9	18.00	2	4.00	0	0.00	0	0.00	0	0.00
	after 4 Days	1	2.00	1	2.00	1	2.00	6	12.00	1	2.00	0	0.00	0	0.00
	after 5 Days	0	0.00	0	0.00	1	2.00	0	0.00	4	8.00	2	4.00	0	0.00
	> 5 Days	1	2.00	1	2.00	0	0.00	0	0.00	1	2.00	1	2.00	10	20.00
Sub-Total:		**2**	**4.00**	**8**	**16.00**	**13**	**26.00**	**8**	**16.00**	**6**	**12.00**	**3**	**6.00**	**10**	**20.00**

3.5.3 Nutritional Review

The nutritional review data were analysed for those who had a swallow screening assessment (SSA) within the first week of admission and compared with those who had a SSA after the first week of admission. This was to determine whether there were any differences in the management of these participants. The assumption made was that the usual hospital protocol for management of these patients should have been instituted from between 24 hours to the first week of admission.

3.5.4 Nutritional status (SSA within and after the first week)

All participants who were screened within the first week of admission by ward staff (n=68, 100%) had a nutritional review. Twenty-two participants (32%) were made NBM, 38 (56%) were on modified diet and fluids, and 8 (12%) were on normal diet and fluids [X^2=108.3, df=2, p=.000]. The differences observed in the oral intake status (type of diet) for both groups (those who had SSA within and after the first week) observed are not attributable to the timing of the SSA but could be due to differences in the population. Participants assessed within the first week by ward staff were more likely to be fed through the parenteral route [Table 3.21]. Twelve participants (18%) were already on NG feeding and 4 (6%) were being considered for, or a decision had been made to commence NG feeding. From the 132 participants the researcher assessed one week following admission only 76% (n=100) had undergone a nutritional review. One hundred and fourteen (86%) of those assessed after the first week were mostly on normal diet and fluids. Nasogastric feeding was not recommended however, for the majority of

participants who were assessed after the first week of admission [n=132(100%)] by the researcher.

The number of participants who were reviewed by the dieticians were far greater between those who had a SSA within the first week of admission [(n=30, (44%)] by ward staff and those who did not [(n=11, (8%)]. Food charts were also recorded more frequently in those assessed within the first week by ward staff [(n=32, (47%)]. While 18% (n=24) of the participants who were assessed later by the researcher had their food chart recorded for them. In participants who had undergone a SSA in the first week by ward staff, 49 (72%) were malnourished similarly 100, (76%) of those assessed later by the researcher were also malnourished; both groups showed impaired nutritional status. Table 3.21 shows the nutritional assessment of study participants within and after the first week of admission to hospital.

Table 3.21 Nutritional status of participants who had a SSA within and after first week of admission

		SSA within first week by ward staff		SSA after first week by researcher	
		Frequency n=68	Per cent	Frequency n=132	Per cent
Nutritional Status					
Oral intake status‖	NBM	22	32	2	2
	Modified diet and fluids	38	56	16	12
	Normal diet and fluids	8	12	114	86
Nasogastric Tube (NG FED)‖	Yes	12	18	0	0
	No	48	71	132	100
	Attempted NG	4	6	0	0
	Considering NG	4	6	0	0
Nutritional assessment attempted*	Yes	68	100	100	76
	No	0	0	32	24
Weight	Yes	65	96	93	71
	No	3	4	39	30
MUST Score	Yes	29	57	125	95
	No	39	43	7	5
MAC	Yes	2	3	0	0
	No	66	97	132	100
Dietetic review‖	Yes	30	44	11	8
	No	38	56	121	92
Food chart‖	Yes	32	47	24	18
	No	36	53	108	82
BMI	Yes	4	6	1	8
	No	64	94	131	99
Nutritional status‖	Well Nourished	19	28	32	24
	Malnourished	49	72	100	76

All data were analysed using the Pearson chi-square tests. ‖*P*=.000,‖*P >.570*

*Nutritional assessment attempted: participants had all or any of the nutritional indices reviewed.

a) Summary of results of nutritional management within and after the first week of admission

Participants who had a SSA within the first week of admission by ward staff had nutritional screening for example, they had been reviewed by the dietetic team and food chart recordings were carried out for them. Of the 68 participants who had a SSA within the first week of admission, 28 (41%) presented with symptoms of dysphagia (section 3.2.3) which were recognized and appropriate nutritional support (modified diet and fluids, NGT FED) was instituted. Even though the majority of participants [(n=114, (86%)] who had a SSA after the first week of admission were on a normal diet and fluids and did not require feeding through parenteral route, 100 (76%) of them were malnourished with only 32 (24%) participants being well nourished. Of these, 16 (12%) were on modified diet and fluids. Two participants who had SSA after the first week of their admission were made nil by mouth.

3.6 Outcomes of Participants with dysphagia (Objective 3)

The outcomes of participants who had a SSA within the first week of admission were assessed, to determine whether these outcomes differed from those who were not assessed whilst in secondary care.

Participants who had a swallow screening assessment (SSA) within the first week of admission by ward staff had a longer length of hospital stay (LOS). About 69% of those assessed within the first week stayed in the hospital for at least two weeks, they were however noted to be unwell at admission. Those who were assessed after the first week of admission by the researcher had reduced LOS. Fourty-two percent of those who were assessed after the first

week also stayed longer in hospital because their swallowing problems were not identified initially.

There was not a single case of death among the participants who had a SSA after the first week of admission, while 2(3%) of those who had a SSA within the first week died. It therefore heighlighted the severity of illness between the two groups, the after one week group being those who had less severe illness. The study revealed a significant difference in hydration assessment and record of these assessments in fluid balance charts for both groups. The results showed that 96% participants who had a SSA within the first week of admission were more likely to have their hydration assessed and the record of their fluid balance chart monitored. While 58% of those who had a SSA after the first week had their hydration assessed and the recording of their fluid balance chart monitored. This implies that ward staff were efficient and proactive in their management for the obviously unwell group.

The percentage of participants who were assessed within the first week and developed infections was 75%. Infections were also high (49%) in those who were assessed after the first week by the researcher. Therefore the risk of silently becoming unwell was therefore evident in this group. Hospital acquired pneumonia was approximately 62%, which was also higher in the group assessed within the first week by ward staff. The incidence of other infections, such as urine infections and pressure sores were also considerably higher in those participants who were assessed within the first week of admission, while the incidence of diarrhoea was relatively low in both groups. The results are presented in more detail in table 3.22.

Table 3.22 Outcomes of participants within and after one week of SSA

		SSA within first week of admission		SSA after first week of admission	
		Frequency (n=68)	Per cent	Frequency (n=132)	Per cent
Length Of Hospital Stay (LOS)	1 Week	5	7	24	18
	>1 Week	16	24	53	40
	2-3 Weeks	35	52	43	33
	>3 Weeks	12	18	12	9
Mortality¶	Alive	58	85	125	95
	Dead	2	3	0	0
	Deteriorated	8	12	7	5
Hydration‖	Yes	65	96	76	58
	No	3	4	56	42
Record Of Hydration Reviewed‖	No Fluid Charts	3	4	56	42
	Fluid Charts	65	96	76	58
Infections‖	Yes	51	75	64	49
	No	17	25	68	52
Hospital Acquired Pneumonia‖	Yes	42	62	42	32
	No	26	38	90	68
Urine infection	Yes	19	28	36	27
	No	49	72	96	73
Pressure sores¥	Yes	12	18	7	5
	No	56	82	125	95
Diarrhoea	Yes	3	4	7	5
	No	65	96	125	95

All data were analysed using the Pearson chi-square tests. s*P*=.003; ¶*P*=.033; ‖*P*=.000;¥*P*=.005

a) Summary of results of outcome measures

Participants who had a SSA within the first week of admission by ward staff had longer LOS , mortality and developed more infections such as hospital acquired pneumonia. This group had more severe illness and dysphagia, judging from the interventions (NBM, NGT FED, modified diet) they received within the first week of admission. [Table 3.22]

There were however, some aspects of the outcomes which reflected the benefits of early identification and management of dysphagia amongst those who had undergone a SSA within the first week of admission. Monitoring of fluid intake (fluid balance charts) was recorded more fully for those assessed within the first week of admission. Overall, the process seems to have favoured those who had a SSA after the first week of admission, because some of the participants whose dysphagia had been missed were managed later. If they had not received a swallow screening assessment, their conditions would probably have worsened. This group had fewer infections, so they stayed in hospital for a shorter duration but this group may have had less severe illness and so their early discharges could be a result of their nutritional management, which was insufficient for the detection of any nutritional abnormalities.

3.6.1 Prevalence of Dysphagia in Acute Medical Admissions (Objective 4)

The prevalence of dysphagia in acute admissions defined by a failed swallow screening assessment (SSA) was 82% as calculated below:

P = n/N x 100%

P= number of participants identified with dysphagia X 100%

Total number of participants examined.

P= 164 X 100

200

= 82%

where [p] is the prevalence, [n] is the number of participants identified with the disease or condition at a particular time and [N] is the total number of participants examined.

The positive and negative predictive values of initial identification of swallowing problem by the usual care team are 38% (63/164 x100%) and 86% (31/36 x100%) respectively. The sensitivity was 93% (63/68 x100%) and a low specificity of 24% (31/132 x100%). While the swallow screening questionnaire and the water swallow test used for those who were not assessed initially showed a positive predictive value of 62% (101/164 x100%), a negative predictive value of 86% (31/36 x 100%), a sensitivity of 95% (101/106 x 100%) and a specificity of 33% (31/94 x 100%). Although the VFSS were not carried out, the "gold standard" used in this instance was the researcher/SLT assessment. Below is a flow chart of the number of participants identified with dysphagia.

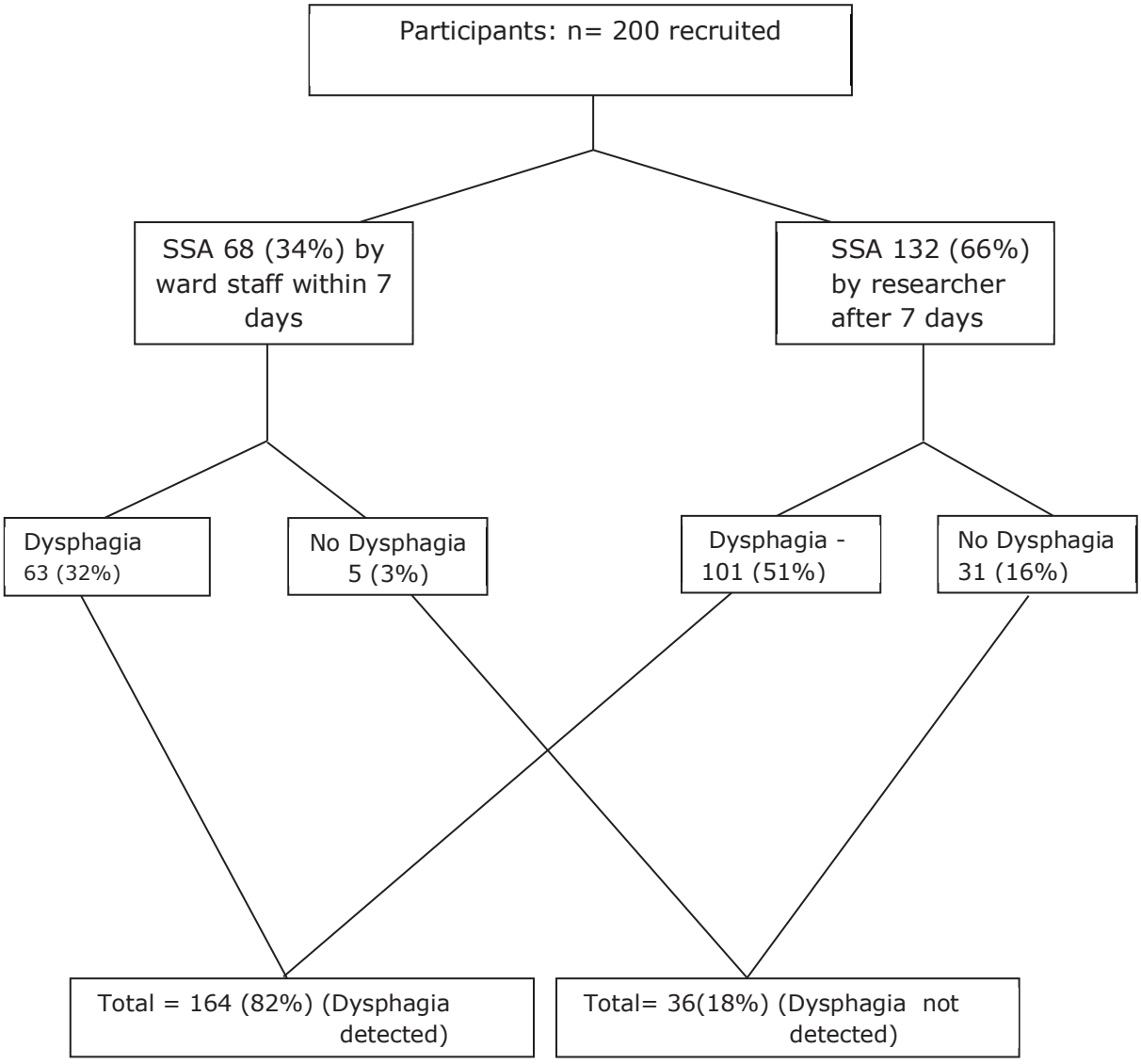

Figure 3.3 Number of participants identified with dysphagia

3.7 Summary of the Observational Findings

The results revealed that patients with PD, MS and MD are not screened routinely for dysphagia when admitted to hospital and 51% were found subsequently to have undetected swallowing problems. Patients who were

screened after the first week of admission by the researcher were found to have unrecognised dysphagia. The majority of the patients were neither screened nor referred to dietitians or speech and language therapists.

Patients who had a SSA within the first week of admission by ward staff were more likely to have better nutritional management and referrals to the speech and language therapy and dietetic service than those assessed after the first week. However, there were delays in SLT and dietetic review for these patients following referral. A large proportion of patients who were referred to the SLTs (n=31) or dietitians (n=32) were more likely to be reviewed in 4 days or more after their referral.

Some outcomes were better for those who had a SSA within the first week of admission. The main rationale for comparing outcomes between the two groups was more to test that the two groups were not the same rather than that they were different. Though this is a subtle point to make, it's basically saying that those assessed after the first week of admission were different, and less, in disease severity, but even so there were significant morbidity amongst them. Therefore, the threshold for screening was too high and was putting patients at risk. The number of patients with these neurological conditions admitted through the medical assessment units with dysphagia can be seen to predict an increase in dysphagia in acute admissions and in this population. Subgroup analysis also showed a higher number of PD patients but a lower percentage of PD patients admitted acutely who had unrecognized swallowing problems.

3.7.1 Limitations of the Observational Findings

There were some limitations during the course of this research which affected the findings of the study. These limitations include sample population, sample size, participant recruitment, methodological difficulties, referrals to the speech and language therapist (SLT) and dieticians.

a) Sample population

There were no definite criteria used in the choice of the neurological conditions studied. The choice was made based on the following similarities: chronic progressive conditions, aetiology (unknown, genetic/environmental factors), major cause of mortality (aspiration pneumonia) and impaired muscle function, which was responsible for swallowing and oropharyngeal dysphagia (commonest cause of dysphagia in the three conditions).

The commonest condition seen amongst those recruited into the study from both hospitals (RDH and QMC campus) was PD, followed by MS and then MD. This was consistent with our previous findings from RDH of the representative sample and the increasing number of PD patients admitted acutely to hospital. However, the study recruited only 5 MD patients over a one year period in both hospitals, which was far less than expected from data obtained from the RDH medical coding department of 33 MD patients over a year. [Tables 2.1] Participants who could not provide consent were not recruited initially, which also contributed to the limited number of participants with each of the conditions.

b) Sample size

The ideal sample size for the study, based on the initial calculation (using 95% CI and 5% precision) would have been 390 (Table 2.1). However, due to

delays in recruitment as a result of ethical issues (Chapter 2), a recalculation of the sample size was carried out based on the same assumptions and using the formula by Professor Glenn D. Israel [224]. This showed that a sample size of 252 was adequate, using the total population of the three conditions instead of using the total population of each of the conditions for the sample size estimation as previously. (Appendix 9(i))

A further *post hoc* sample size calculation was conducted to determine the revised estimate of the sample size and this was found to be 180 (section 2.4.2). The actual sample size which was required for the study was 180; the study recruited a total of 200 participants but a larger sample size (as based on the previous calculation) would have greater confidence in projecting the results across the population.

c) Participant recruitment

Many patients who could not provide consent to participate were not enrolled when the study commenced as the Ethics Committee did not approve this initially. These were participants who had problems with cognition, such as dementia patients or patients who had a temporary decrease in their level of consciousness. Ethical approval was later given to recruit these participants using an assent form with which the participant's relatives/carer/close friends took the decision on behalf of the participant for them to be recruited into the study. This limitation affected the sample population and size of the study, even though it finally became an actual representation of the population who had dysphagia in these conditions admitted to acute medical wards.

d) Methodological difficulties

Documentation in medical notes and nursing notes for participants was not done in some instances and as a result, the possibility of missing study-relevant information could not be ruled out. For example, there was insufficient documentation in the case of 31 participants as to the period of "duration of neurological condition". [Table 3.1] Nutritional and swallowing assessments may have been conducted but this was not documented, thereby underestimating the number of assessments actually performed. Therefore those patients who are likely or suspected to have dysphagia though they may have had their swallowing assessed previously should have their swallowing re-assessed on admission. During the interval between recruitment and follow up of the participants, it was observed that the majority of participants had either been transferred from the medical assessment unit to the wards or had already been discharged home. For those that were transferred to the wards without a swallow screening assessment, their swallow screens were completed and documented. Those that had already been discharged without screening were screened at their destination; this was part of the study protocol.

e) Referrals to the speech and language therapists (SLT) and dieticians

Participants who had a SSA after the first week of admission and were referred to the SLTs and dietetic service were not followed up due to the time constraints of the study. Follow up of these participants would have enabled both groups (SSA within and after one week of admission) to be compared and to determine if there were any differences in the timing of their review by the SLTs and dieticians. This would have contributed to the clinical

significance of the findings for those participants who were assessed for their swallowing and referred to either or both of the specialities within the first week of admission to hospital.

There are also other limitations that relate to some of the definitions and methods used for the study. These will form part of the discussions in Chapter 5 of the thesis.

CHAPTER 4: INTERVIEW FINDINGS

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4.1 Introduction

A key finding reported in Chapter 3 was that patients with neurological conditions were not screened for dysphagia when admitted to hospital and many of them were later found to have dysphagia. It was therefore felt necessary to undertake some qualitative interviews with clinicians to determine what factors prevented them from carrying out swallow screening assessments. Participants recruited to take part represented those clinicians who are involved in the management of patients with these conditions when admitted to hospital. The rationale, analysis and demographic characteristics of the interview data are described in sections 4.2 to 4.4. The themes that emerged from the interview data are presented as: Identification of dysphagia, barriers and facilitators, infrastructure (section 4.5 to 4.7) The key conclusions and limitations of this aspect of the study are summarised in section 4.8 and 4.9 respectively.

4.2 Rationale

Some studies have investigated the behavioural patterns of health professionals in relation to swallowing assessments and the methods used to assess people with neurological dysphagia, but none of these studies have tried to explore the reasons for these behaviours [181-182][section 1.15]. The observational findings reported in Chapter 3 revealed that a large proportion of patients with neurological conditions such as PD, MS and MD

[n=132] did not undergo a swallow screening assessment during the first week of admission and most patients [n=101] were found subsequently to have dysphagia. However, it was not clear why these patients were or were not assessed or referred to the speech and language therapist within the first week of admission. Similarly, the reasons which underpinned the decision to carry out an assessment or to refer patients were not apparent.

Using some of the theories that influence rehabilitation, such as the "ICF disablement model", it is possible to gain an understanding of a clinician's view of their health and the subsequent choice of action to address their problems [211-212]. [Section 1.12.2] This cannot be investigated solely by observational methods, therefore a qualitative investigation was carried out to ascertain clinicians' perspectives on the assessment of dysphagia when people with PD, MS and MD are admitted to hospital. A sample of 20 clinicians working at the Royal Derby Hospital (RDH) Derby or Queens Medical Centre (QMC) Nottingham was recruited for this aspect of the study. Data were collected through semi- structured interviews. Permission was received from all participants for the interviews to be recorded and analysed.

4.3 Analysis of the Interview Transcripts

The semi-structured interviews were audio-recorded, transcribed verbatim and coded using NVivo 9 software. The methods used to code the data and the justifications for using NVivo 9 have been described previously (see sections 2.8.7 and 2.8.8). The output and word frequency from the coding is represented in the corresponding section of the findings and in appendix 17. The interview transcripts were also analysed using thematic content analysis, as discussed in section 2.9.2.

4.4 Demographic Characteristics of the Participants

The demographic characteristics of the clinicians (n=20) who were interviewed are summarised in Table 4.1. Nine (45%) participants were based at the Royal Derby Hospital and the remainder were based at Queens Medical Centre (QMC) Nottingham. Most participants worked in a medical ward setting, such as a care of the elderly ward (n=13, 65%) or a medical assessment unit (n=5, 25%). Other participants were based in a respiratory (n=1, 5%) or neurology ward (n=1, 5%).

The participants varied greatly in the amount of work experience they had from 6 months to 38 years so the study reflects the views and perceptions of both newly qualified and experienced clinicians. Participants were recruited from a variety of relevant professional groups, such as speech and language therapy, dietetics, nursing and medicine, therefore, they will have been able to comment on several areas of dysphagia management. One nutritionist volunteered to participate in the study. Other nutritionists were approached but unfortunately did not have the time to participate in the study.

Table 4.1 Characteristics of the participants

OCCUPATION	SPECIALITY	EXPERIENCE	TRUST	CODE
Physiotherapist	Medicine	4 years	QMC	A6
Rehabilitation nurse	Medicine	8 years	QMC	B1
Doctor	Medicine	5 years	QMC	B3
Nurse	Respiratory	5 years	QMC	B4
Nurse	Neurology	5 years	QMC	B5
Nurse	MAU	9 months	QMC	B6
Occupational Therapist	Medicine	6 months	QMC	C1
Nurse	MAU	1 year 7 months	QMC	C2
Healthcare Assistant	MAU	5 years	QMC	C3
Dysphagia trained nurse	Medicine	38 years	QMC	D2
Speech & Language Therapist	Medicine	25 years	QMC	E1
Ward Manager	MAU	34 years	RDH	D1
Occupational Therapist	Medicine	3 years	RDH	D9
Nurse	MAU	6 years	RDH	D3
Nurse	Medicine	3 years	RDH	D5
Doctor	Medicine	4 years	RDH	D6
Nurse	Medicine	16 years	RDH	D8
Speech & Language Therapist	Medicine	9 years	RDH	E2
Physiotherapist	Medicine	3 years	RDH	D10
Nutritionist	Medicine	5 years	RDH	B7

MAU means: Medical Assessment Unit.

4.5 Identification of Dysphagia

The participants identified several factors that might influence their decision to assess swallowing when patients with PD, MS or MD are admitted to hospital.

4.5.1 Reasons for Conducting a Swallowing Assessment

Several participants reported they would be prompted to conduct a swallowing assessment if patients appeared to have a swallowing problem [Figure 4.1] The reasons given for conducting a swallowing assessment were generally consistent and have been merged to include the following seven themes, which are discussed below: pre-existing swallowing difficulties, symptom recognition, staff/relative anxiety, presenting complaint, patient's diagnosis, recognition of early screening in PD patients and communication difficulties.

i) Pre-existing swallowing difficulties

PD, MS and MD patients with pre-existing swallowing difficulties were thought to be at risk of persistent dysphagia. Participants were of the opinion that they should be assessed and referred to a speech and language therapist (SLT) for a re-assessment. Participants [code D2, C2] stated that in such situations, this would enable proper management and for continued follow up.

> *"if they have complex swallowing problems where they have been assessed several times and there are variations on what consistency of food they have, or if they have complicated problems with swallowing, I refer them to the SLT." [code D2]*

"if they have come in with weight loss and if they have come in with swallow issues that have already been identified beforehand, just ensuring that those follow ups have been done" [code C2]

ii) Symptom recognition

All of the participants noted that symptoms might indicate that a swallowing evaluation was necessary. These symptoms included coughing when food or drink is taken, choking, wet and gurgly voice and pouching of food. A participant [code D9] explained that in some cases patients hold food in the mouth, because it becomes lodged there for a long time due to their inability to swallow. In addition to clinical signs and symptoms, a small number of participants [code E 1 and E 2] stated that patients' referral for a suspected swallowing problem would also prompt a swallow screening assessment to be undertaken.

"Sometimes you come across patients that are holding either saliva or phlegm or bits of food in their mouth, so you can tell they are not taking it to at the back of their throat to swallow it" [code D9]

"If somebody refers a patient to me, if patients are coughing when they are eating and drinking, eating small amounts of food, holding food in their mouth known as pouching and not initiating a swallow" [code E1]

"If a patient has cough when eating and drinking, breathlessness, wet voice, unexplained chest infection, weight loss or if patients report of swallowing problems and we get a referral to see the patient" [*code E 2]*

iii) Staff and relative anxiety

Some participants [code B3, B4, D2, D5] reported that when medical staff or relatives are worried that a patient has a swallowing problem, this is an important motivator to conduct a swallow screening assessment or to refer the patient to SLT. Relatives are usually anxious about the complications that may result from dysphagia, the consequence then is increased anxiety in the patients' relatives.

> *"It's usually from experience when the nursing staff raises the concerns that the patient is having difficulty swallowing, and/or whether during their swallowing they start coughing up and is a high risk that the patient may aspirate and we would like to prompt a swallowing assessment." [Code B3]*

> *"I think we assume that everybody is okay when they come in and if we notice a problem, we would then get an assessment or if the family brings up a query or if the patient themselves mentions something" [code B4]*

> *"So they'll say he is not swallowing or he is coughing when he is swallowing or he is drooling or I don't think he is having the safe consistency or anything to do with eating or any complications to do with eating get reported to me and then I look at the situation" [code D2]*

iv) Presenting complaint

The presenting condition on admission was thought to have an impact on a clinician's decision to assess a patient's swallowing. When patients present with a history of swallowing problems, suspected aspiration pneumonia and

chest infections, these are thought to have resulted from problems with swallowing. These patients would be referred immediately to the SLT for a swallowing assessment. [code B7, D1]

> *"If they come in with chest infection or pneumonia it might be because of swallowing difficulties which has caused that problem, so if it is written in the notes to be referred and if they are not referred, when they come on to the ward they would be referred." [code B7]*

> *"Anybody probably coming with aspiration pneumonia will be referred, in this hospital because I have been here a year, it is usually the SALT that would come and do the swallow assessments. Also anybody who had come in with any suggestion of problems with their swallowing, we refer the person." [code D1]*

v) Patient diagnosis

Patient diagnosis was thought to have a direct effect on a clinician's decision to conduct a swallowing assessment. Participant B3 [a doctor], considered the impact of neurological conditions because they affect the sensorimotor part of the oropharyngeal phase of swallowing, resulting in neurologic dysphagia in patients with these conditions. When patients are admitted with these diagnoses or because of related swallowing problems, a swallowing screening assessment would be carried out [participant B5]

> *"if you are concerned that the patient has had some form of neurological incident where you think they may either have had a stroke or either TBI which will in turn impair their normal reflexes and then you would want to have a swallowing assessment then." [code B3]*

"any other diagnosis that came along to say that they may have some sort of swallowing issue." [code B5]

vi) Recognition of early screening in PD patients

Several participants [code D3, D5, D6, E1, E 2] elaborated on the importance of early identifications of swallowing problems in PD patients, so that alternative methods of oral intake can be instituted. This is especially the case with regards to their medications, because if swallowing difficulties are present it may make it difficult to take medications and this could cause further deterioration in swallowing function. A participant [code D3] linked this to patients who are admitted with PD and MS, dependent on the severity of their condition.

"If somebody comes in with PD, depends on the degree of PD and MS again, when somebody comes in with a PEG feed then obviously we want to assess." [code D3]

"I mean especially with Parkinson's patients we do like to make sure that the patients are able to take their Parkinson's medications, any types of problems, if they have got delay, difficulty or if we got any concerns whatsoever, if they are refusing eating or anything like that, we will get them referred to the speech and language team." [code D5]

"Basically what they present with and when they come in and it's identified that they have got PD and once that's highlighted, then sort of you go through roughly how is the swallowing, have they got any problems with swallowing, so you go through a methodological way in all these things." [code D6]

"If PD patients have a problem with their swallowing, to put an NG tube in place quite early to make sure they get their medications. There is a lot of awareness now for PD patients; the next frequency of patients is MS and MD not a lot. Muscular dystrophy patients tend to go to the neurology ward where they are seen by the specialist SLT team on the ward who will do the swallowing assessment for them if the need arises." [code E1]

"PD patients to make sure they get their medications because if they don't, their swallowing deteriorates further so we need to make sure their swallowing is safe and they can have a safe consistency and the awareness of PD is now becoming more." [code E2]

vii) Communication difficulties

Problems with communication were another area that participants believed would underpin their decision to conduct a swallow screening assessment. People with neurological conditions such as PD, MS and MD may develop both speech and swallowing difficulties when the motor or cognitive function of that area of the brain is affected, due to progression of the disease. Several participants [code D8, D9 and code E1] noted that patients who have stuttering, difficulty following through a conversation and cognitive limitations would prompt them to conduct a swallow screening assessment. Clinicians are therefore prompted to conduct a SSA in patients with communication difficulties. However, these are also one of the difficulties that they encounter when assessing swallowing in this patient group.

"First the verbal signs, their speech, if they are dribbling or anything like that things, if we are actually feeding them ourselves to look for

signs of coughing, choking, they can't hold food in their mouth, dribbles out, those sort of things." [code D8]

"if they are not able to speak properly and if when you are having a conversation and they are not able to formulate the words really, those sort of things." [code D9]

"Communication is a big problem with these patients. It is what we look at as part of our assessment. We need more increased awareness for these patients really." [code E1]

The chart below [Fig 4.1] is a representation of the coding by node with NVivo software describing the clinicians' perceptions of the clinical reasons for conducting a swallowing assessment on patients with PD, MS and MD. The word frequency is represented in Appendix 17(I).

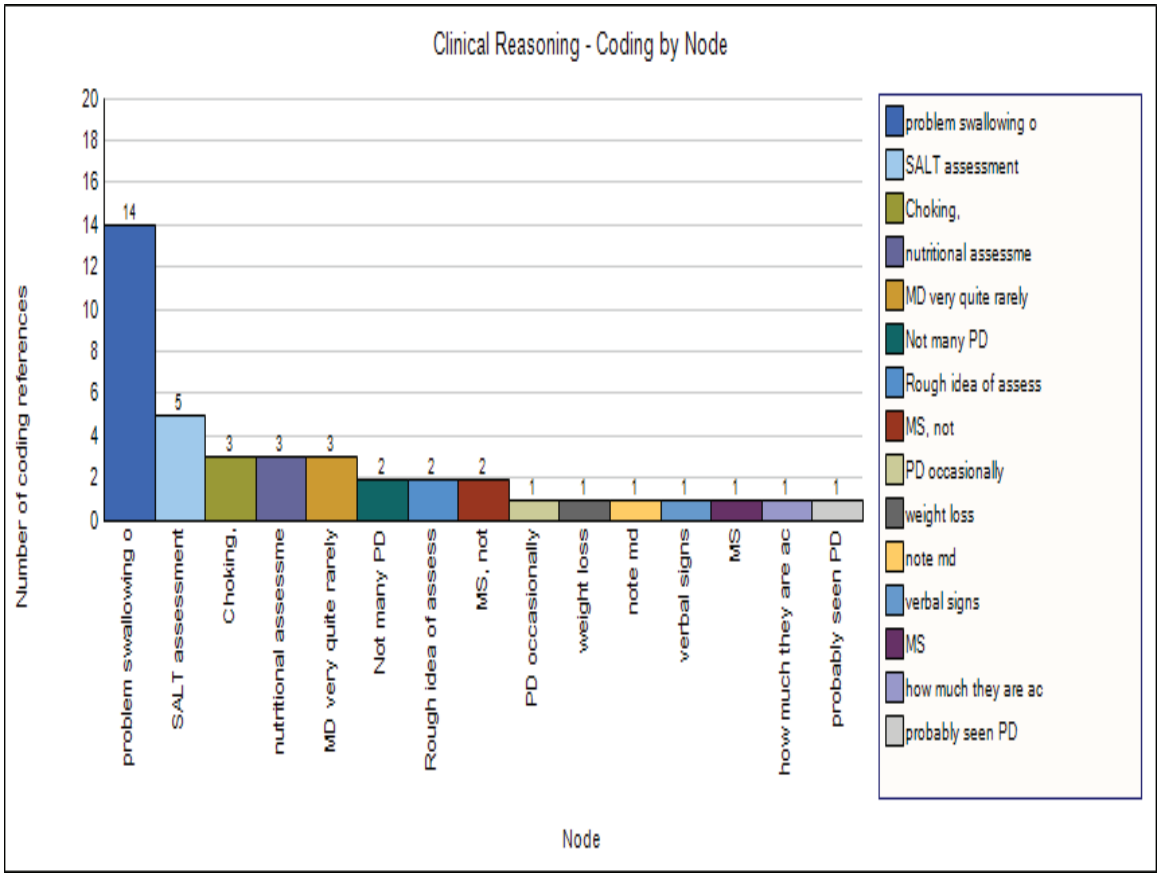

Figure 4.1 Participants coding by node on clinical reasoning

4.6 Barriers and Facilitators of Swallowing Assessments

The opinions of participants on barriers and facilitators for conducting a swallowing assessment on patients are presented under the following headings: Skills and knowledge of swallowing assessment, confidence in conducting swallowing assessments, training in swallowing assessment, awareness of swallowing assessmnent guidelines and difficulties associated with swallowing assessment.

4.6.1 Skills and Knowledge of Swallowing Assessment

The participants were asked about their ability to assess a patient's swallowing, the assessment method they use and the frequency of conducting swallowing assessments. Many participants reported that they had never assessed a patient's ability to swallow; these participants usually refer patients to the speech and language therapist. Some participants reported that they did not know any method of assessing a patient's ability to swallow. Regarding the assessment method used, few of them reported that they used the water swallow test and others reported that they refer patients to the Speech and Language Therapist (SLT) for swallowing assessments. The participants who commented on the number of swallowing assessments that they do per week, reported as follows: The first participant indicated that nine times out of ten the participants were already assessed, the second reported approximately ten assessments or more in a day while the third reported approximately ninety per week. The responses of the participants were coded by nodes using the NVivo software [Figure 4.2]. The frequency of the words used by the clinicians is represented in Appendix 17(II). Three broad themes emerged from the discussions with the participants.

i) Deskilling

The participants [code B5, D5, and D8] also discussed how infrequency of carrying out swallow screening assessments has made them cautious or reluctant to perform swallow screening assessments. They felt that these assessments were things they used to do before but were currently not allowed to and that with the availability of the SLT, they believed that their services were no longer needed in this area.

Whilst some of the participants [code B3, B5] were trained, they still preferred to refer these patients to the SLT because of their greater availability. One clinician [code D1] was of the view that when conducting a swallow screening assessment, the person should be seen as being highly skilled in the assessment.

> *"I think in my whole 41/2 years that I have worked there I have only done swallow tests myself about like 4 times." [code B5]*
>
> *"I think with obviously risking patient's aspirating, and then we are not allowed to do any formal assessments now, we have to refer them to SLT, we don't assess, we don't even attempt to feed the patient, we just refer them straight away" [code D5]*
>
> *"Yea, a long time ago, I did the DTN training but I have not used it, it's been a long time. We are not allowed to do it on any dementia patients apparently; It's a while ago, it must be 2 or 3 years ago when I last done it and I think I have come out of practice and how to even use the form and I think because we have got the nutritional assistants on the ward, so I am not needed any more." [code D8]*

"I know I have been trained as part of my training was to assess swallowing, but because we don't do it very often we just get all the experts to do it nowadays. But if I have to I will do it." [code B3]

"I think you need to be assessed as competent, so on this ward, some of the advanced practitioners can do that, other than that it is the SLT that do that." [code D1]

ii) Lack of Knowledge and Skills

Several participants stated that they had not received any formal training in conducting swallow screening assessments. As a result of this, they felt that they were not competent; however, some had used the test without training. Some participants [code A6, D3, C2] discussed how they had observed other people administering the water swallow test but had never done it themselves because they did not know how to do the test. While other participants [code D2, E1, E2], a dysphagia trained nurse and two SLTs, reported that they were knowledgeable in swallow screening assessment, it was part of their job and they had undergone formal training in this area. The quotes from some of the participants are shown below:

"No, I don't know how to use the water swallow test. Probably seen people doing it but I don't know how to do it." [code A6]

"I know some of the other nurses have done it, if they have done it before or worked on the stroke ward, they are confident and competent to do it, because I have never done it, I am reluctant to do it. I get the SLT team to come and do it." [code D3]

"No, no. I have not been trained to do it. Some of the doctors have sometimes done it and they come and like give them water on a spoon." [code B6]

"I have never been officially trained to do it. I think you need to be assessed as competent, so on this ward, some of the advanced practitioners can do that, other than that it is the SALT that do that." [code D1]

iii) Lack of uniformity of swallowing assessment methods

The participants indicated that they use different methods to assess a patient's ability to swallow. Some of these participants [code B3, B5, B7, C1, D1] used the water swallow test and referred patients to the SLT, others stated that they use thickened fluid and a soft diet and referred patients to SLT [code A6, D5, D8] and only a few [code B4, D2] used a combination of water swallow test, thickened fluids, soft diet and observation of the patient's eating and drinking at meal times. When there were any further problems, patients were referred to the SLT for a full assessment. Generally, the participants used no standardised methods but they all referred patients to the SLT if they identified any swallowing difficulties.

"We don't do any full assessment. Only very basically we try them with water if that is a problem, we look at ice-cream and yogurt and things that are just very basic and if they struggling with dry like meat, we put them on a soft moister food but it is not a proper assessment." [code B4]

"Only by doing a water test of tea spoon cold water, if they start coughing or dribbling at the mouth and all the signs which show that

they are not actually swallowing properly then I would refer them." [code B7]

"We can do informal assessment; in terms of we can try a patient on thickened fluids, soft diet, if we have got any concerns. We just refer to the SLT, no particular method, it's only when we see the signs or any concerns then we refer to SLT." [code D5]

These participants [code E1, code E2, both SLTs] used a detailed formal assessment method and also instrumental assessment as the need arose, as well as the methods mentioned above. One of the participants [code E2] described the water swallowing test as a basic screening test for those not skilled to do a full swallowing assessment and that they prefer to conduct the more difficult assessments.

"First the initial approach is the bedside assessment which comprises of the water test, giving people various quantities of water to drink and see how they can manage with that as well as the clinical assessments. I test people on a range of consistencies of food looking for clinical signs of swallowing problems. As part of the assessment we do the oromotor assessments as well, which includes the lips, tongue, palate which informs the overall picture to work out if somebody has a swallowing problem. In certain cases if unclear we do a video assessment but not done routinely because of cost and practicality and you can tell how they cope after." [code E1]

"I use different methods to do my assessments- oral cranial nerve assessment, positioning of patient, timing of swallowing, pulse oximetry. I don't use the water swallow test all the time because it is a

basic screening test. We go for the more complex test/assessments. It is the staffs that are not fully qualified to do the full assessment that does the screening test basically and flag up any issues, then refer for a complete assessment." [code E2]

Figure 1.2 below summarises the participants' responses concerning their skills and knowledge of swallowing assessments.

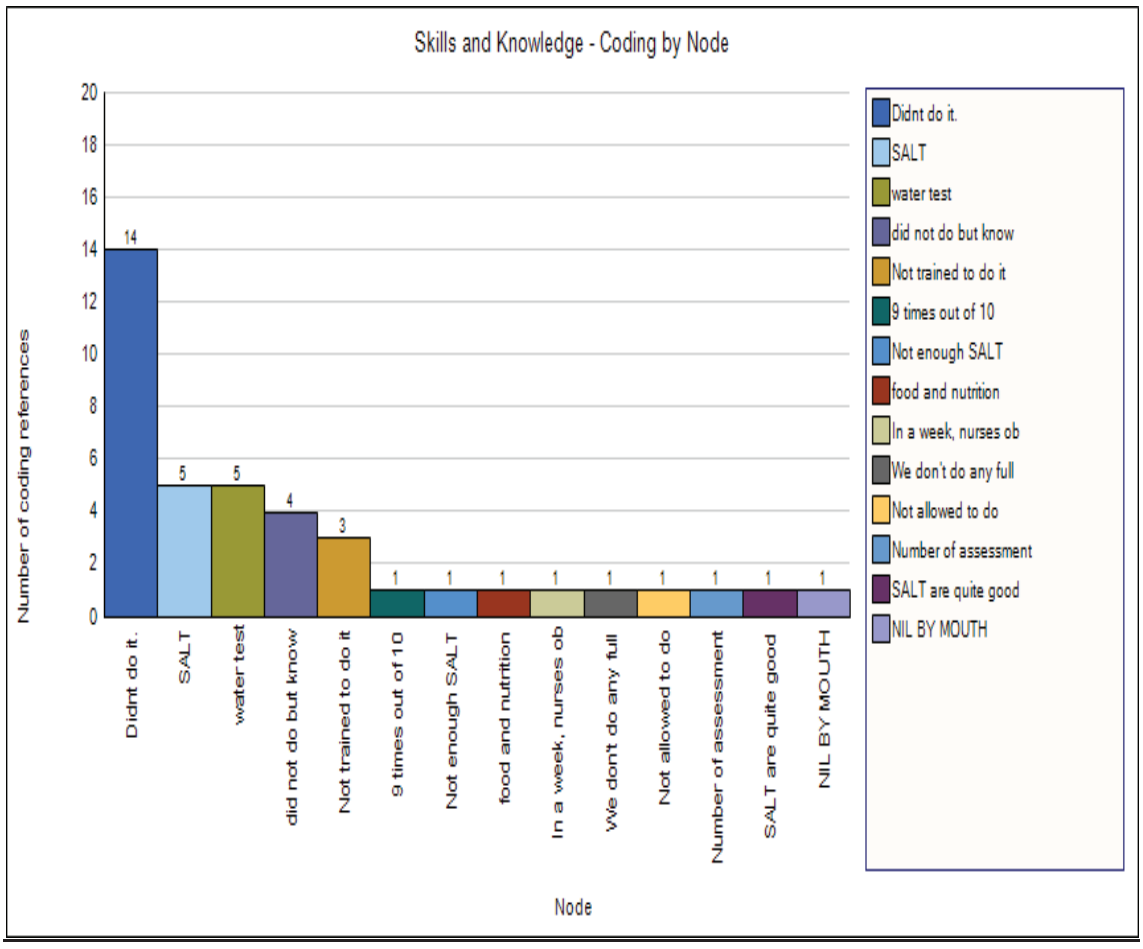

Figure 4.2 Participants coding by node for skills and knowledge

4.6.2 Confidence in Conducting Swallowing Assessments

The interviewees went on to discuss their level of confidence in assessing a patient's swallowing ability and the use of the water swallow test. Of the several participants interviewed, the majority of them reported that they were not confident enough to undertake a swallowing assessment or to administer the water swallow test in patients and seven were. One participant had not assessed patients or used the water swallow test previously, while two usually referred patients to the SLT due to lack of training. The participants also discussed how the issues of accountability, fear of risks of carrying out SSA, policy and practice affected their confidence in conducting swallowing assessments. The four themes which emerged from the interviews are discussed below.

i) Confidence

One of the participants [code E2], a speech and language therapist, felt that clinicians (especially the nurses) who currently conduct swallow screening assessments lacked appropriate theoretical knowledge and therefore should be taught to conduct basic screening assessments only. This view point could reflect their sense of professionalism and anxiety that an aspect of their role would be removed if other colleagues undertake such a task. Participants also discussed how policies and practice have made them lose confidence in conducting swallowing assessments. One of the participants (code D8), felt that the changes that occurred over time in polices or guidelines regarding the assessment or management of dysphagia had affected their level of confidence, especially when they are not yet familiar with current guidelines.

Those who were not using the necessary skills frequently may need refresher training to update them on current practice and to regain their confidence.

> *"Lots of nurses do have the basic skill but because of no the theoretical background, they have the limitation of doing a swallowing assessment. They can't do a full assessment. They can only do the basic swallow screening test, so knowledge on a swallow screening assessments would be better for them rather than a full swallowing assessment." [code E2]*

> *"I wouldn't say not in doing a full detailed assessment. Because myself and xxx one of the staff nurse like I said, like three years ago, I don't think we are both confident to do it anymore because protocol has changed anyway, the diet has changed or the modified diets have changed since we did it, so we perhaps need update."* [code D8]

ii) Accountability

Participants thought that effective management of dysphagia required a multidisciplinary team approach and that conducting a swallowing assessment was an area where roles and practice were still uncertain. This drew their attention to professional considerations such as responsibility and accountability [code D2 and code D5]. One staff nurse [code D5] described how the nursing staff were always in a difficult position when they needed to conduct swallow screening assessments and also have to manage other problems, such as risk of aspiration. In the event that anything should go wrong, then they would be accountable. Participant code D2, a dysphagia trained nurse (DTN), was of the opinion that people should bear responsibility

for their own actions, and that if after conducting a swallow screening assessment and they were not satisfied with the assessment, then referral should be made to the SLT for a full assessment.

> *"Yes, I am quite confident but you know, you are responsible for your own practice so if you do an assessment that you are not happy with you pause it and you ask for SLT to re-assess." [code D2]*

> *"It is just about accountability really in terms of say if something did happen and say a patient went to coroner, it sounds awful, but you do go back to that a lot of these things these days, okay so when did the patient aspirate, was it when they first came in and had that test." [code D5]*

iii) Fear of risks of carrying out SSA

A participant was of the opinion that knowledge and clinical competencies may have an effect on quality of care when conducting swallowing assessments on patients with neurological conditions. The participant (code D5), explained that because deaths of neurological patients have occurred as a result of aspiration, many nurses are anxious about conducting these assessments, especially when their knowledge of swallow screening assessments is limited. The participant further emphasized that adequate training in these assessments would help nurses to overcome these fears and regain their confidence.

> *"I would like to think I am but I think with so many things now on different wards, it's quite a lot that deters you from doing it, you know with patients who have aspirated, who have passed away, they are not*

sure whether it is due to…. it just deters you from doing it. l think a lot of nursing staff these days would be quite frightened to do anything like that. If they had the correct training then that is absolutely fine." [code D5]

Figure 4.3 below illustrates the participants' responses regarding their level of confidence for conducting swallowing assessments.

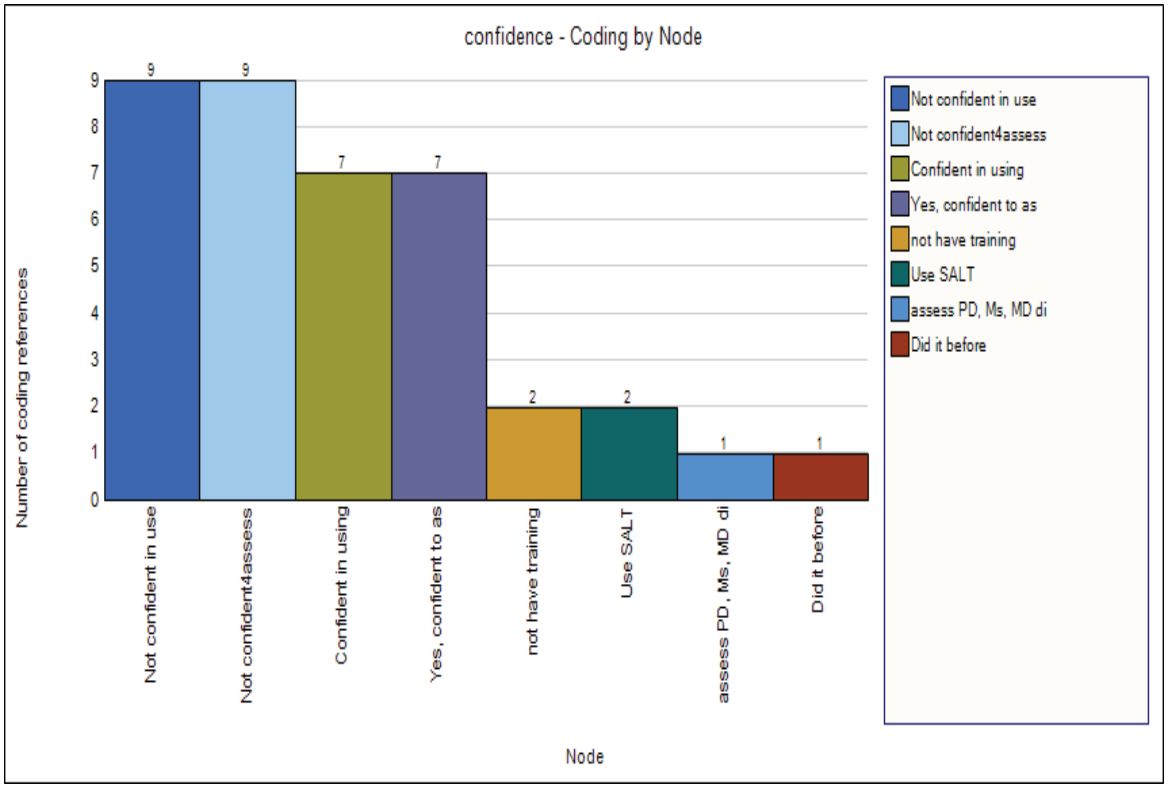

Figure 4.3 Participants' coding by node for confidence for swallowing assessment

4.6.3 Training in Swallowing Assessments

Participants were asked whether they felt there was a requirement for more training to be provided on assessment of swallowing and if they have been taught any swallowing assessment methods, such as the "water swallow test." The majority of the participants considered training as a requirement on the ward, but a small number of participants [a doctor and a nurse] felt there was no requirement for such training. When considering the assessment method which the participants have been taught, some people reported that they had received formal training on swallowing assessment and on the water swallow test, few of the participants reported that the training requirements depended on the speciality of the staff, while many of the participants reported that they have never received any training on swallowing assessment methods. There were however other participants who reported they had received informal training on the water swallow test by observing other nurses or SLTs for example while they were conducting a test on the ward.

Participants identified many reasons why more training and updates should be available on swallowing assessments for clinicians. They recognised that swallowing function can vary during an admission and that for this reason, all nursing staff should to be aware of the signs to alert specialists of the need for further assessment. The clinicians' perceptions were grouped into the following seven themes: shortage of SLTs, resources, training of nurses in swallowing screening assessments, rationale for training of health professionals to improve out of hours cover, economic burden, increased awareness by specialized units and frustration from inappriopriate practice and referral.

i) Shortage of SLTs

Participants stated that the reason it would be good for nurses to have more training on swallowing assessments was because of the increased waiting time for a speech and language therapist to come and assess a patient. There are not sufficient Speech and Language Therapists (SLTs) in hospitals and so they are compelled to prioritise referrals to make sure that life threatening complications associated with dysphagia are avoided. Most patients have to wait a longer time to be seen by the SLT but if more nursing staff were trained, they felt this would go a long way to reduce waiting times.

> *"quite often there are not enough speech and language therapist available and we might have to wait a day or two for them to actually to come to the ward and assess a patient. If we had people on the ward who could do it on straight away, it saves a lot of time and effort because the patient is going to start to dehydrate or whatever because they have to wait for some time." [code B1]*

> *"That would be good because if somebody has got a swallowing problem, we can't give them their medications and it sometimes takes a long time for somebody to do an assessment on them. It would be good if we could do that. Yes training is necessary." [code B6]*

SLT participants [code E1 and E2] explained that in order to respond to the needs of patients and all those "at-risk groups" who may have swallowing difficulties, the service had developed a prioritisation system. This was implemented due to the volume of work and number of referrals the service received per day. Patients are prioritised when referred according to their

nutritional needs, diagnosis of PD, the patient's medical background, new swallowing problems and returning patients who have been marked for follow up.

> *"It is very busy and hectic here and l have to see all these patients. I have to prioritise them. Firstly , if people were made NIL BY MOUTH with no alternative in place for feeding , then l have to see those people first to make sure that nutrition is in place because that is very important for their recovery you see. But there are various patients and each of their needs varies, so it is important to take care of those with nutritional needs first." [code E1]*

> *"We are always busy, lots to do and when the referrals come we have to prioritise on when the referral was made, complex patients who are made NIL BY MOUTH, PD patients to make sure they get their medications because if they don't, their swallowing deteriorates further. Also the patient's background history, new problems from nursing homes and at times, if it's a patient that we have known before to have problems with swallowing for further review, these we have to prioritise when patients are referred to us." [code E2]*

ii) Resources

A number of participants [code D2, D10, E1, E2] were of the opinion that due to the limited number of SLTs and funding, provision of an efficient service in terms of training more nurses to assess swallowing would be difficult. This is not only because of the increasing demand for speech and language therapy services in acute medical admissions, but the resources to meet these increases by employing more SLTs and training more nursing staff are unavailable. For example in the Royal Derby Hospital and Queens Medical

Centre, the number of SLTs available are insufficient to allow time to conduct training sessions for nurses on all acute medical wards and the funds to undertake such a project are lacking. However, if the funding was available a dysphagia trained nurse specialist could coordinate the training for all nurses on an acute medical ward.

> *"For the water test it is all about time and funding, can they spare somebody from SLT to come on the ward, each and every elderly care ward to train each every nurse to do the water swallow test? It isn't viable and cost effective for them. It would be handy because l train the trainer, I train the people so it will useful if they give me that role, if every nurse goes through that training and make it mandatory especially on the care of the elderly." [code D2]*

> *"Yea, I think that would be a good thing to have because obviously the SLT in the hospital covers so many different wards and are seeing so many different patients and they are quite a small team as well, so if there was a capacity to have more people or different people who could assess, l think it would be a good idea." [code D10]*

> *"The SLT department is not funded well enough and there is shortage of staff. Funding and staffing go hand in hand, we are short staffed and pushed and we feel the pressure in case load and we feel pressurized for time to see patients and do these training as well, so you see we are choked for time even to deliver the training for medical team to be able to manage dysphagia well before we come to assess the patients." [code E 1]*

"SLTs cover these wards and medical wards but we are only a few of us and there is no funding to increase the number of SLT to cope with the demand for the service." [code E 2]

iii) Training of Nurses in Swallowing Screening Assessments

Training of nurses in swallow screening assessments (SSA) was debated a great deal. Some of the participants' emphasied the importance of training the nurses on SSA, whereas others presented the barriers including lack of training time. Some of the participants [codes B4, E1, E2] felt that training was necessary in order to increase awareness of dysphagia amongst nurses and reduce prolonged periods of time in which patients were on "nil by mouth". It was also felt this would prevent conflicts with relatives and increase staff confidence. One participant [code E2] felt that nurses lacked understanding of the theoretical basis behind swallowing assessments and therefore only the basic screening tests are suitable. Training should include the provision of different food consistencies as this would provide nurses with other options for carrying out swallow screening assessments. The need to train nurses who work in emergency departments was also emphasized.

"Yes, because rather than just admitting and making everybody NIL BY MOUTH and getting insulted and they are already stretched, if we could do a basic assessment and would maybe prevent that referral, it would be useful yea definitely." [code B4]

"Yes, I think it would be good to train all medical staff on the ward. It is an on-going awareness to train the whole medical team down to the doctors as well, because of the turnover of staff here, so there is an on-going need to increase awareness." [code E1]

"Lots of nurses do have the basic skill but because of no theoretical background, they have the limitation of doing a swallowing assessment. They can only do the basic swallow screening test, so knowledge on swallow screening assessments would be better for them rather than a full swallowing assessment. The training should also include not only water swallow assessments but other options which the nursing staff or medical staff can use to identify swallowing problems like trying various food consistencies. There should also be formal training for nurses in A&E and MAU because there are no trained nurses to assess patient's swallowing in A&E." [code E2]

In contrast, other participants [code B3, B5, C2] felt that nurses do not need any further training because they may not use the skill frequently, they work as a team and can help each other if the need arises to assess a patient's swallowing and there was a feeling that nurses would continue to refer to the SLT even after training, so there was not a need to train them. Interviewee code C2, suggested that training a few more nurses would be more effective than training them all.

"I think if you train the nurses they would probably sort of hand over the responsibilities to the SLT anyway who have more dedicated responsibility and far more specialized in assessing swallowing, so even if you train other professionals they will probably go back to the speech and language therapist I think." [code B3]

"I don't think we need any more training to be fair, and is down to individual nurses how confident they feel about doing it and because

we all work as one base of a team if one nurse is not confident about something another nurse would be." [code B5]

"I think what the problem might be is that we wouldn't do it very often, so it would be a skill that we would have to keep re-learning, perhaps it might be worth training only a small amount of nurses, rather than training everybody and everybody not using it, perhaps just sort of more of the senior roles then." [code C2]

The issue of training time, the group of health professionals that require the training and the staff that would conduct the training was also raised as a concern by a SLT [code E1]. This is because of low staffing levels which would invariably result in lack of time to train clinicians in the use of swallow screening assessments. There are some disciplines whose expertise relates to daily living activities such as feeding, eating and swallowing. However, these disciplines do not usually have specialist knowledge and skills in relation to swallowing in the patients they manage. The participant also noted that the problem really lies with the health care assistants who feed the patients at mealtimes without knowledge of feeding difficulties.

"we are choked for time even to deliver the training for medical team to be able to manage dysphagia well before we come to assess the patients." [code E 1]

"The issue is the health care assistants involved with feeding these patients because they are the ones that feed these patients. We are involved in training the health care team, we had a very long debate whether to train them or not, whether we can invest one and half hours

a month to train them to look out for signs of swallowing problems so they learn the "Skills for good feeding" what to look out for that somebody is having a swallowing problem." [code E1]

iv) Rationale for training of health professionals to improve out of hours cover

Most of the participants noted that there were frequently no speech and language therapists (SLT) or dysphagia trained nurse (DTN) specialists available to assess swallowing out of their working hours, especially during the weekend and on public holidays. As a result of this, when patients are admitted to a MAU or acute medical ward outside of those hours and require a swallowing assessment, they are placed on "nil by mouth." They are sometimes deprived of medications, food and drink for up to four days during the admission until a SLT or DTN is available to assess the patient's swallowing. It was noted that weekends were particularly difficult, because the nutritional needs and hydration of the patient would not be met until the first available weekday, making the patient's relatives very worried.

"Yes, I think it should be done here especially because for the weekend we are open 24/7, you can't necessarily get that service so my biggest worry here is that we are not giving people adequate fluids." [code D1]

"Yes, ideally patients move on within 48 hours some of them don't on occasions but even 4, 5, 6 hours they can be here and they have not had a swallow assessment and relatives start asking why can't they have a drink, can't they have something to eat and we are saying no because we need to have the swallow assessment and at weekends as well there is no speech and language therapist. So somebody can go

without food for that weekend and then perhaps on a Monday the SLT will come down and say yes they are fine , so the whole weekend we have kept them NIL BY MOUTH, we don't need to." [code D3]

"Oh, definitely, we have had patients before in the past, who we had to hydrate over the weekend with only IV fluids., they have not had their nutritional needs met, they have just been hydrated and that was it. So definitely when you see it like that, yes." [code D5]

"Definitely it will be really helpful, because these kind of patients have swallowing problems it would be really useful because weekends they may be under staffed and there is one or two covering the whole hospital and may not be able to come and see these patients on time so in that way it would be beneficial" [code D6]

One participant also highlighted that even if some people on the ward were trained to conduct a swallowing assessment, the possibility of getting them to assess a patient's swallowing on another ward was very slim because their schedule may be very busy.

"It is beneficial that there are several on the ward because like bank holidays and things like that, SLT only work Monday to Friday so if you need to have somebody, a dysphagia trained somebody, there is nobody around. There is on other wards but very difficult to get people from another ward to assess your patients because obviously they are busy on their own ward, so patients would probably go NIL BY MOUTH for four days which depending on the condition of the patient whether we can NG feed them." [code B7]

v) Economic burden

The previous point concerning out of hours assessment was expanded further by participant D2, who discussed the impact of delayed assessment on the economy. This interviewee was of the opinion that when patients are not assessed on time, it can affect their nutritional status which in turn results in poor recovery, increased length of hospital stay (LOS) and increased cost to the National Health Service (NHS). The effect of the economy on staffing levels has complicated the problem further. This person emphasised that early swallowing assessment is key to ensuring a speedy recovery.

> *"If there are no dysphagia trained nurses (DTN) or SLTs, they are not going to have food over the weekend. Nutrition in my view is a very important part of recovery. If you've got food, you can fight infection, food is energy and if you have energy in your body, you can fight off infection, and you can actually recuperate a lot quicker, it is a knock on effect, people are not assessed, they are in here longer, it is costing us money, we are losing jobs and the trust is in a big state. It is all about recognising that you want your patient to stay, it all about being proactive and recognising that assessments are done on time. It's not always easy but that how it should be." [code D2]*

vi) Increased awareness by specialized units

As specialist knowledge of some neurological conditions such as stroke and Parkinson's disease has increased, it has led to the establishment of specialised units that offer a multidisciplinary care. The Royal Derby Hospital is unusual in having a PD ward. These services are thought to meet the needs of patients well. Medical staff who work in those units are trained to recognise the complications associated with these neurological conditions (such as

dysphagia). Also as there is often a greater presence of SLTs in such units, this can re-enforce their knowledge of dysphagia and its management. Two participants [code D2 and D3] detailed the training advantages of specialist units and felt they produce staff who are confident and competent in their duties.

> *"Recently I worked in ward 401 which is the care of the elderly where we manage patients with PD. It is a recently renowned ward with Dr x. Dr x is a Parkinson's consultant and he has launched the ward to be partly Parkinson's and all the staff have been trained in view of Parkinson's disease and how we manage it and how we actually service people with PD. We not trained in every area of disease but we do try and manage them as best as we can." [code D2]*

> *"If other nurses have worked on the stroke ward, they are confident and competent to assess a patient's ability to swallow." [code D3]*

> *"I mean because the ward we are on now has become one of the Parkinson's ward specialist ward as we are actually getting more Parkinson's patients in, we have just literally being not so long ago having new lectures and we have being having them from different people- we have had a lecture from SLT, from the dietician, from the Parkinson's consultant regarding all of the above really, regarding different aspects towards Parkinson's." [code D5]*

vii) Frustration from inappropriate practice and referral

Participant E1, a speech and language therapist, wondered why patients were not fed through an NGT if medication was being given by this route, to enable them to obtain adequate nutrition. This indicates the need for training in SSA.

This observation could lead to frustration if staff feel that delivery of the service is being affected by the procedures others follow.

> *"If PD patients have a problem with their swallowing, it is to put an NG tube in place quite early to make sure they get their medications but what I don't quite understand is that when I go to assess these patients, they can have the NG tube for their medications but they can't use it for feeding, why? So many times, they are giving them their medications through the NG tube but no nutrition via that same tube." [code E1]*

This clinician also felt that although most nurses recognise that coughing during a meal is a risk factor, there are other problems associated with dysphagia (such as decreased level of consciousness or obstructive dysphagia) which the SLT are unable to manage and this lack of knowledge may result in inappropriate referrals by other staff. Considering the SLTs' work load and limited staffing, these referrals could be a source of frustration. Training of ward staff would be helpful to avoid such referrals.

> *"Also on the other hand the sort of the things that would make me not to assess a patient's swallowing is inappropriate referrals, the patient is too ill, too drowsy to be eating at all in such a case I will not do a swallow assessment because the person is not well enough for eating and drinking." [code E1]*

The chart below shows the participants' responses regarding training for swallowing assessments. [Figure 4.4]

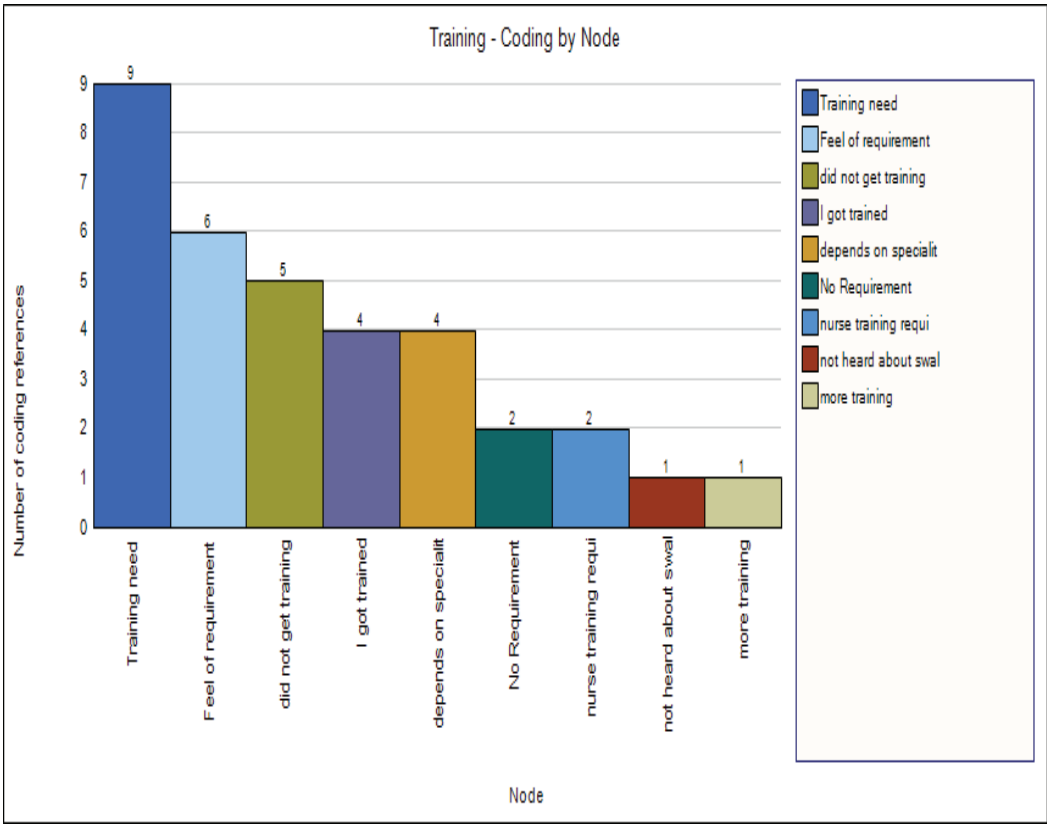

Figure 4.4 Participants' coding by node on training for swallowing assessments

4.6.4 Awareness of Swallowing Assessment Guidelines

To discover if there were guidelines on dysphagia assessment available for patients with PD, MS and MD, the interviewees were asked about their awareness of any relevant guidelines. Many participants said that there were no guidelines or protocols for the assessment of dysphagia in these conditions. The awareness of guidelines for dysphagia assessment and the graphical representation are discussed below. [Figure 4.5]

These participants [code A6, B3, B4 , B6 ,C1, C3 , D1 , D2 , D3 , D5 , E1 , E2] had no knowledge of nor were they aware of the existence of any guidelines

on swallowing assessment for people with PD, MS and MD. Some participants [code D1, D2, E2] discussed the availability of stroke guidelines, while another participant [code E1] noted the existence of medication guidelines for the management of PD but didn't know of any guidelines for MS and MD. The other participants [code B1, B5, B6, B7, C2, D6, D8, D9] were not sure of the availability of these guidelines and thought that there may be some but they hadn't seen or studied about them. The participants either used their initial evaluation or referred to SLT if they felt a patient had problems with their swallowing.

> *"If there are any guidelines, I haven't seen them. So we basically go on our initial assessments from what we see and hear to see if we are going to give them fluids and food." [code B6]*

> *"I don't think there is any specific for those conditions except for stroke." [code D1]*

> *"No, I don't think there are any guidelines for PD, MS, MD. They have one for stroke and that is new which just came on since we were on the stroke ward. For the dysphagia trained nurse guidelines, we were told if it is a complicated case refer them to the SLT, which is what is in the guideline." [code D2]*

> *"There are no guidelines specific for PD, MS and MD conditions but there is certainly a guideline for PD patients regarding their medications." [code E1]*

Participant E2, felt that provision of dysphagia screening guidelines for PD, MS and MD, would ensure that the patients with unrecognised swallowing problems would be identified.

"There are no guidelines for PD, MS or MD. For stroke patients' yes, because patients who come in with stroke have acute dysphagia following their acute onset of stroke while the other conditions have progressive dysphagia. But some guidelines would be helpful to check their background swallowing, any swallowing related problems and also to make sure that no new onset swallowing problems which have developed unrecognised, that is detecting new swallowing problems." [code E2]

The chart below shows the participants awareness of dysphagia guidelines for PD, MS and MD. [Figure 4.5]

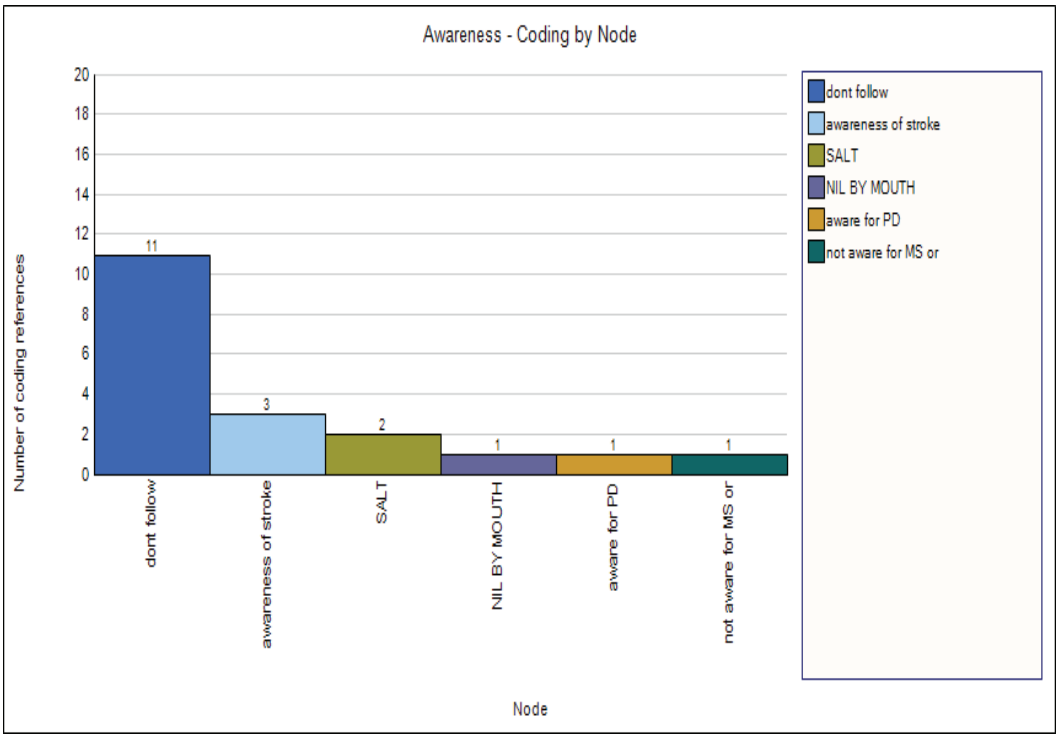

Figure 4.5 Participants' coding by node on their awareness of guidelines for swallowing assessments.

4.6.5 Difficulties Associated with Swallowing Assessments

The participants then went on to discuss some of the difficulties associated with carrying out swallowing assessments in patients with neurological conditions and five themes emerged from the discussions. These difficulties included: phase of the disease, adherance issues, behavioural problems, cognitive impairments and administration of medications.

i) Phase of the Disease

Participant C2, discussed the phases of the disease (variations in disease severity or variations in symptoms associated with the disease) and how it affected the patients, especially when it becomes complicated with an infection thereby making the swallowing assessment difficult.

> *"It can be difficult because they have phases, it can be good sometimes and bad at times and so sometimes if they have got an infection it can appear worse at times and it's not permanent." [code C2]*

ii) Adherance issues

The assessment of patients with dysphagia or suspected dysphagia involves several methods, ranging from simple bedside screening assessments, the water swallow test, administration of different food and liquid consistencies and observation of eating and drinking. Debates concerning the use of thickened fluids and non-adherance to this regime are on-going and were raised in this study [81, 78-80]. One participant described the difficulties encountered when giving patients thickened fluids and noted that they are often unwilling to consume modified drinks when they have recovered.

> *"people are bit oh you can't put them on this softener and you can do it for a couple of days while they are poorly and then get better, people*

seem quite reluctant to change things if they have been down… and thickener is a problem." [code C2]

iii) Behavioural problems

Patients, who take central nervous system (CNS) depressant medications such as antihistamines, neuroleptics, anticonvulsants and sedatives as well, may be at risk of their swallowing deterioriating [227]. Sedatives are usually administered to patients who have behavioural problems such as agitation; these patients become very lethargic due to the side effects of the medication which can cause further deterioration of their dysphagia. Participant D5, emphasized that behavioural problems observed in these patients, such as refusal of swallowing assessments and medications, were attributed to some of the medications the patients were currently receiving and that made the management of their swallowing problematic.

"Yes, definitely, definitely, through the side effects of the medications, they are on, they can say no, we are not having it, so the patient's behavioural, it might not necessarily be that they have got swallowing problem, it might just be behavioural at that time because of the side effects of the meds." [code D5]

iv) Cognitive impairments

Assessment of swallowing and parenteral nutrition can be challenging in patients with cognitive impairments as the severity of their impairment can affect their understanding of swallowing assessments or the provision of alternative routes of feeding. Two participants [code D5, D10] highlighted the difficulties faced when trying to conduct capacity assessments for parenteral feeding or swallow screening assessment when patients are suspected of, or already have swallowing difficulties. Patients may sometimes

resist insertion and feeding through the nasogastric tube (NGT) or any type of assessment. This situation can result in conflict between patients and their family members, until an appropriate decision is taken.

> *"If patients are unable to tolerate food and fluid we do have to go down the nasogastric tube (NGT) route then that is another issue because if the patient has quit or if the patient has got capacity or not, we have to do capacity assessments and we have to go down that route which can be distressing for the patient not only for the patients but for the relatives, you can get them fighting over it, going what is in the best interest of the patient, I can go quite in-depth really." [code D5]*

> *"Yes, I think their cognition is going to affect or some patient's cognition is going to affect how you can complete an assessment with regards to anything, obviously as part of my assessments, it can be quite difficult if the patient is either confused or got dementia on top of their neurological problem. So there is that side of things I suppose." [code D10]*

v) Administration of medications

The importance to PD patients who have swallowing problems, to take their medications routinely has been emphasised as a crucial aspect of care when patients are admitted acutely. The introduction of specialised units and guidelines for administration of medications for people with PD, has led to an increased awareness of swallowing difficulties associated with the condition. PD patients with dysphagia usually complain of an inability to swallow their medications safely. Some PD medications such as Levodopa, have been shown by previous studies to control the symptoms of dysphagia, though some studies argue that the evidence is still unclear [102-103]. Three participants

[code B7, D6, E1] described how, when PD patients are admitted with dysphagia, administration of their medication is usually difficult because of their inability to swallow medication comfortably. Medication guidelines indicate that a nasogastric tube (NGT) should usually be inserted to enable patients to take their medications as early as possible and to avoid worsening of their symptoms.

> *"But normally like if it is Parkinson's patients in particular because this is a Parkinson's ward now they would NG that patient just to get the medication down, if they are not having their medications it would make their swallowing even more difficult and the way that they are moving and everything it would involve because they are not having the medications and speech and language therapist will not come and assess the patient unless they have had their medications because they would not get a good enough correct picture of their swallowing." [code B7]*

> *"The main thing is their tablets; Parkinson's patients need regular medications at regular intervals, so swallowing is quite crucial for them, so if they are not able to swallow then there is a huge problem actually." [code D6]*

4.7 Infrastructures for Swallowing Assessments

The participants gave their suggestions on the necessary infrastructure that would enable clinicians to conduct swallow screening assessments in patients with neurological conditions. Their suggestions are presented below.

4.7.1 Suggestions to Improve the Process of Swallow Screening Assessments

Participants were asked about the choice or use of swallowing assessments that might be beneficial for patients with these conditions. Participants gave several suggestions and these included the following: development of a dysphagia pathway, education of ward staff, routine swallow screening assessment, application of stroke dysphagia guidelines to patients with other conditions, provision of an alert system, proper history taking, provision of an on-call or an out of hour's speech and language therapy (SLT) and additional resources.

i) Development of dysphagia pathway for PD, MS and MD Patients

In the previous discussion many participants [code A6, B3, C1, B4, B6, C3, D1, D2,D5, E1, E2, reported that they had the lack of knowledge of dysphagia guidelines for people with these conditions and that this had affected the management of swallowing problems. Some participants [code C2, D2, D5, D6, D8, D10, E1] provided reasons to justify and suggestions for the development of guidelines in this area. Participant C2 was of the opinion that having a guideline for each of these conditions would create greater awareness of dysphagia amongst such patients and serve as a guide for swallowing assessment in the patients affected. To reinforce this position, participant D2 agreed that development of dysphagia guidelines would provide clear directives for health professionals on the assessment of dysphagia. Participant D5 thought that because of the unavailability of SLT over the weekends or out of hours, guidelines would serve as a reference point and support clinicians who are responsible for performing assessments during these periods and would also improve consistency in patient record taking.

Lastly, two participants [code D6, D8] considered that the guidelines would enable SLTs to direct adequate attention towards this area as with stroke patients and, this would be convenient should any other swallowing problems arise.

> *"I think having something specific to them would be better because obviously there are certain things you would like to look out for in them that you just don't necessarily look for in this general swallow things and I think more awareness is never a bad thing." [code C2]*

> *"So I think with neurological diseases may be they have to devise their own guidelines. I think every condition should have, because I guess MS, MD and PD they fall may be in a similar disease pattern because they are neurological and progressive and maybe they could fall into the category of flow chart. It would be helpful so that people have clear instructions, so we need guidelines really for these patients." [code D2]*

> *"But obviously during the weekend we could do with things like that just so that we've got that backup, just say we can refer to those guidelines and we can document and it is written in the notes. We can say that we did use the guidelines." [code D5]*

> *"If they have proper guidelines and if there is a devoted SLT team basically to look at neurological conditions apart from stroke because stroke they focus on but these kind of conditions like PD, MS, MD, Motor neuron disease, I don't know how it works now in this hospital, if they have definite plan and definite thing in place that would be really useful for them." [code D6]*

"It would be nice to have a guideline like stroke do have to know what to put in place if we have any issues that will be good, something that can go in the rhesus folder people can look at, any time of the day that would be good." [code D8]

In an effective summary of the suggestions provided by the other clinicians, participants D10 and E1 [a physiotherapist and a speech and language therapist], emphasized that development of dysphagia guidelines for PD, MS and MD would enable early recognition of dysphagia, prevent aspiration and prolonged nil by mouth with its associated complications, improve dysphagia management and should be available uniformly in all hospitals..

"Something there that just either highlights people or can guide people on what needs to be done because l think it is a problem, patients come in and not being put on the right management or left NIL BY MOUTH for so long and you get secondary problems from either being left having not eating, or eating junk, or eating the wrong thing and aspirate. So l think some kind of guidelines would be beneficial just so you got that consistency through the whole hospital system as well from A&E to MAU to the ward to even then going home, because you know patients go home or aspirate at home as well. So l think it will just standardize everything and make sure the care is the best it can be l suppose." [code D10]

"There should be more clear guidelines in place for what should be done for these patients because most of the swallowing tools are specific for stroke patients. So it may be good to have regular guidelines for the management of people with these conditions. " [code E1]

ii) Education of ward staff

Overall, it seemed that most clinicians had fairly limited knowledge and experience of swallow screening assessment in patients with neurological conditions. Extending knowledge through continuing professional development courses on dysphagia screening assessments (especially the "water swallow test") were suggested [participants B1, B4, D2, D6] as methods by which early recognition and complications of dysphagia could be avoided. One participant [code B4] also mentioned that it would be beneficial for patients, as it would prevent them waiting for days for a swallowing assessment by an SLT, especially during out of hours when therapists are not usually available.

> *"if we can do the basic assessment, it will definitely help because they can be 2 or 3 days without, NIL BY MOUTH waiting for the SLT or over the weekend which is obviously detrimental to them so if we can do a basic assessment and get them eating and drinking, it would definitely help." [code B4]*

> ***"****I think it is a good idea to train everybody in the water swallow test, I think that would be part of your observation check list, at least if they can't have food they can have fluids, nutrition fluids." [code D2]*

> *"It will be a lot better actually. Sometimes it may be a bit difficult because we are not trained in the way SLT people are trained as per swallowing, so sometimes when we are not sure we just keep them NIL BY MOUTH and I think, if we get trained or if there is a guideline that would be more useful for the patients because if it is not necessary we just leave it." [code D6]*

iii) Routine swallow screening assessment

A consensus opinion was expressed by the participants that swallowing safety should be assessed routinely when patients with PD, MS and MD are admitted to hospital acutely. These participants [code B4, B5, D5, B8, D10] gave reasons which included prevention of unrecognised dysphagia and aspiration and pre-knowledge of patient's swallowing status and dietary needs before they are transferred to the wards, which saves time in patient management.

> *"Yes if they can, then that would be very useful, when they get up here we already sort of know what exactly we are dealing with and we sort of cuts out the risk of aspiration, if we are giving them normal fluids and they should have been on thickened, it cuts out that risk." [code B4]*

> *"Oh, definitely, definitely without a doubt it would save a lot, going on time management, it would save a lot of time if they were assessed down stairs. I mean we always re-do the assessments if we not sure, when they come up to us, if we are not happy when we see the patient, it's just about making your assessments when they come up to us. Yes I think it will be really beneficial." [code D5]*

> *"I suppose it is getting an assessment done as quickly as possible, maybe having it as a standardized thing, the patients get assessed for their swallow when they come through A&E or MAU or something like that, so the risk of aspiration is reduced even more so, so whether it is something that needs looking at like earlier on from hospital admissions and by the time they get up on the ward, the staff on the ward know what the requirements are for each patient." [code D10]*

However, one participant [code B3] held a different opinion, that it would be better if assessments were limited to those patients who have problems with their swallowing and not determined by the type of neurological condition the patient was admitted with.

> *"I would still agree to say best if you go on individual bases and if you feel that someone needs a swallowing assessment, then they should have it but just because they have got PD, MS or MD that they should have it straight away by default, I would think that would probably be unnecessary." [code B3]*

iv) Application of stroke guidelines to patients with PD, MS or MD

It is common knowledge that stroke presents have a sudden onset of a neurological event, which is also partly preventable and treatable, while other neurological conditions such PD, MS and MD, are chronic and progressive diseases with a spectrum of severity. The stroke dysphagia guidelines exclude people with other neurological conditions as stated in the SIGN guideline below:

> *"The guideline does not apply to people with neurological conditions other than stroke, or to people with subarachnoid haemorrhage."[106]*

However, participants felt that the stroke guidelines have provided clinicians with clear information about the best management of dysphagia which is at least partly evidence based. The views of three participants were that application of stroke guidelines would enable patients with PD, MS and MD to have similar priorities to stroke patients when referred to SLT [code B1] and this would help to prevent the complications of dysphagia [code C3] and serve as a useful guide for management. For this to be effective in a MAU,

participant D1[a ward manager], added that provision of training for specific groups of nurses assessed as highly skilled in swallow screening assessments would be more valuable, particularly when the speech and language therapists (SLT) are not available.

> *"I think definitely that PD and other patients should have the same access to SLT." [code B1]*

> *"Yes it would be beneficial, because then it cuts out the risk of patients choking, the patient will be admitted and made NIL BY MOUTH straight away but in medical it is not the practice." [code C3]*

> *"I think it would be beneficial but l think you'll have to have a core group of staff; in MAU there is always a sister on the unit, so if you got those trained up and competent, then there would always be somebody available to do a simple quick assessment especially during weekends." [code D1]*

Alternatively, participant B6 thought that the stroke dysphagia guidelines should only be applied to patients with these neurological conditions (PD, MS, MD) who also have swallowing difficulties, to serve as a guide for their management and not for every patient with the neurological condition.

> *"if they have come in with increase in swallowing difficulties or signs of problems with swallowing, then l would want the assessment across the board. l don't know if it is necessary for all of those patients but if it is highlighted, and there is a problem, yes it would be good to have a guide. We would know if there is a problem, then we could say yes there is a swallowing problem and we could go down, as opposed to*

across the board everybody who comes has to go through there." [code B6]

v) Alert systems

An alert system for detecting people with swallowing difficulties was another suggestion offered to improve management of dysphagia in people with PD, MS and MD. One participant [code A6], a physiotherapist, felt that provision of a trace system for swallowing difficulties would enable early identification of dysphagia, in patients with no previous history of dysphagia.

"If a patient has difficulty with their food, we have a trace system, it may be good to have a separate system for people like PD who maybe, don't yet have a swallowing problem and may have them to have an alert of some sort. It might be beneficial." [code A6]

vi) Proper history taking

Two people [code D1, D3] believed that taking a proper swallowing history from either the patient or relatives would reveal any problems with the patient's swallowing which were previously unknown. The clinicians stated that knowledge of a patient's normal swallowing pattern before admission to hospital would also help to determine if a swallowing assessment was required and ensure that proper management was established.

"I think when the patients come in we don't always know, we should question them to see what their condition was like pre-hospital, and that isn't always available especially if they've come in and they are not particularly well, if they come in on their own because they come in here as emergencies and so we don't always know what their normal is

like, so it's all about assessment really and how well you assess the patient." [code D1]

"Most people come in with the relatives, so it is something you can ask, if it is the husband or the wife- how are they normally at home and if we've got the ability to do the swallowing test, we can then try them." [code D3]

vii) Provision of an on-call or out of hour's service by SLT

All the participants believed that the unavailability of SLT out of hours, especially over the weekends and bank holidays, contributed greatly to patients not having a swallowing assessment and often resulted in patients being left without food or fluids for approximately three days when admitted to hospital acutely. Participant B7, a nutritionist, suggested that provision should be made for SLTs to work out of hours so that patients would be assessed on time and management commenced immediately.

"I think that it would be a good idea if they had an on-call SLT or even to get SLT to do shifts like because they finish like 4 or 5 o'clock and after that you can't get SLT till the next day so if they did shifts or had so many on call, or like for the medical units, if we need to get somebody to be assessed by quickly, it can be done." [code B7]

viii) Provision of additional resources

All participants acknowledged the difficulties associated with accessing SLT services, due to limited staff levels which result in unacceptably prolonged waiting times for patients. During the usual working hours of the SLTs, participants B5 and D5 acknowledged that SLTs were very efficient, even though only a small number of therapists are available. Two participants

[code E1, E2], both SLTs, recommended that funding should be made available to recruit more SLTs to work out of hours, just as in stroke services. There should also be provision made for medical staff to be involved in feeding and management of swallowing difficulties in patients with these neurological conditions. They also stated that pressures of work and limited evidence of dysphagia in people with PD, MS and MD has affected the quality of dysphagia management in this population when compared to stroke patients.

> *"They are quite good. They are stretched; there isn't enough of them. Definitely there are not enough of them. So they do try." [code B5]*

> *"Yes, yes, l think definitely, l mean in the week it is fine, in the week the SLT team are fantastic when they here, they are not usually delayed when we do say they it is pretty urgent; the come really quick, they are good, l can't fault them." [code D5]*

> *"It all goes down to funding and research evidence which stroke patients have as an advantage over the other conditions. It is all about research evidence to provide more funding and the need for these things to be in place for other neurological patients." [code E1]*

> *"We really need extra funding to have SLT services over the weekend for these patients. The stroke unit have got a SLT that covers them for the weekend so patients are not made NIL BY MOUTH for days until Monday when we have to come in and the work load as well would be huge, then we start pressing for time to meet up and we can't be everywhere at the same time, we try our best but the demand is very high with only few of us around to cover all the acute wards and general medical wards in hospital." [code E2]*

The chart below represents the difficulties and suggestions made by participants on swallowing assessment in PD, MS and MD patients.

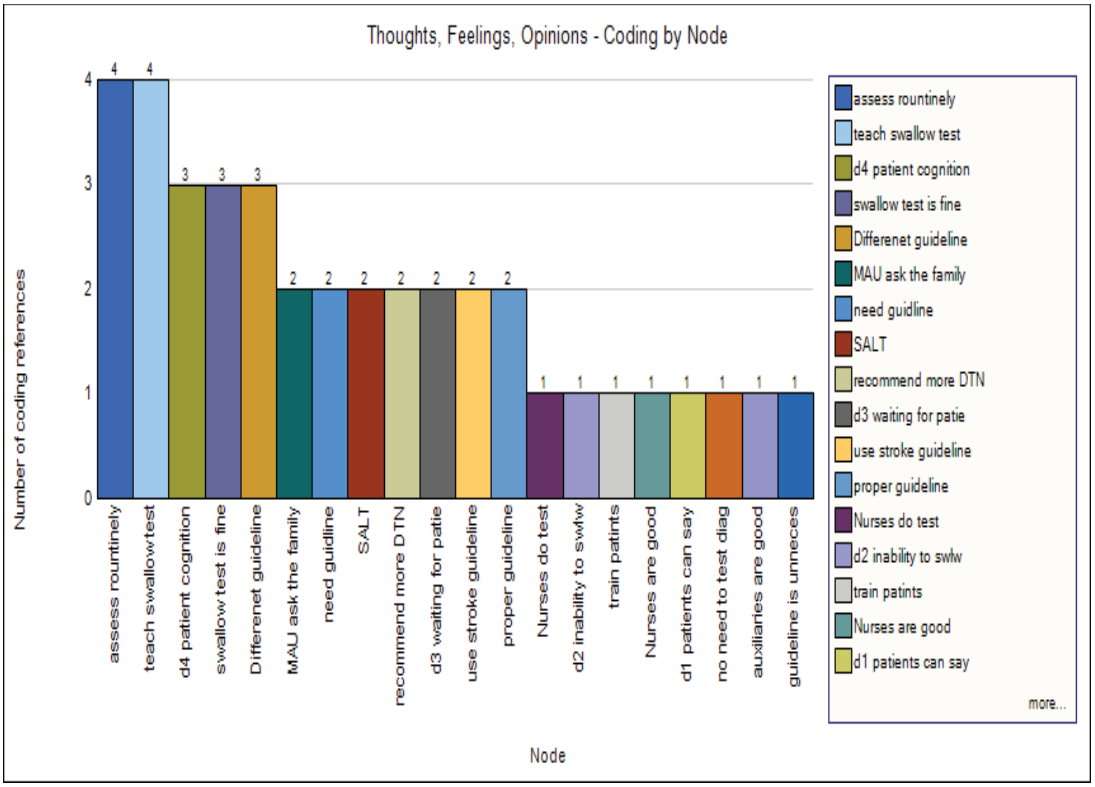

Figure 4.6 Participants coding on difficulties and suggestions for swallowing assessments in PD, MS and MD patients

4.8 Summary of Interview Findings

The results of this aspect of the study focused primarily on the reasons which underpin a clinician's decision to assess for dysphagia in people with PD, MS and MD, and suggestions to improve swallowing assessments during their acute admission. The major reasons for swallowing assessments (as perceived by the clinicians interviewed) included pre-existing swallowing difficulties, symptom recognition, staff/relative anxiety, presenting complaint, patient's diagnosis, increased awareness in specialised units and

communication difficulties. Limited knowledge was thought to affect assessment practices in these patients. Levels of understanding of swallowing ability, knowledge, skills and realisation were inconsistent across participants. There were mixed views regarding professional confidence, as some clinicians expressed reservations about being able to maintain confidence and experienced a lack of confidence because they had no swallowing assessment experience. Expressions of fear were also noted by clinicians due to the potential legal ramifications associated with the risk of premature death arising from aspiration. Some clinicians were involved in assessing patient's skills whilst eating but did not have specialist training in the assessment of swallowing capacity (for example occupational therapists, physiotherapists and healthcare assistants). The prolonged waiting time for swallowing assessments to be undertaken in patients was thought to be contributory to poor outcomes. Targeted training and education of ward-based clinicians in the use and application of swallowing assessments would be greatly beneficial as this would increase their knowledge of signs which are suggestive of unsafe swallowing. It would help to regain their confidence levels, avoid inappropriate referrals and reduce the problem of 'deskilling' in this area.

Development of a dysphagia pathway or guidelines, provision of an alert system and proper history taking would further inform clinicians and support effective management of patients with PD, MS and MD. It was suggested by some clinicians that routine swallow screening assessment and application of stroke dysphagia guidelines may also be helpful, but not all were agreed. Addressing the shortfall in the provision of SLTs and the introduction of on-call SLTs to work during out-of-hours were also suggested as interventions. Some of the SLTs expressed frustration at the pressures of work and were of

the opinion that the paucity of research evidence on dysphagia in people with PD, MS and MD has affected the overall management of dysphagia when compared to other neurological conditions.

4.9 Limitations of Interview Findings

The limitations discussed below relate to the influence of the clinicians' perceptions of dysphagia assessments in other neurological conditions and the data collection methods.

i) Influence of clinicians' perceptions of dysphagia assessments in other conditions

The focus of this element of the study was limited to swallowing assessment in people with PD, MS and MD. However, the participants also conduct dysphagia screening assessments in people with other chronic progressive neurological conditions and acute non-degenerative neurological conditions. As a result, their perceptions and practices regarding swallowing assessments may have affected their opinions.

ii) Limited data collection methods

There were no additional data collection methods to enhance the information obtained from the clinicians' interviews, for example semi-structured interviews of patients with PD, MS or MD. The patients' views and perceptions may differ from that of the clinicians and if guidelines were to be developed it would be important to obtain their opinions. However, since the participants were directly involved in the daily care of patients with these conditions, their views may not differ greatly from those of the patients.

iii) Procedural reactivity

This is a situation where the social class, gender and ethnicity of the researcher can affect the responses from the participants in the presence of the researcher. It may suppress the information that would have been disclosed to a researcher with different characteristics. Also, in the presence of an audio recording device, which is not a usual feature of the environment, it could have affected the response of the participants. However, this situation was not observed during the interviews.

iv) Limitations of Audio recording

The interviews were recorded with an audio device. In a situation where the device suddenly develops a fault during the recording and no adequate back up, it could affect the quality of the data obtained. Also, the timing of the audio recorder may affect the progress of the interview if it suddenly stops recording during the interview process. These were adequately addressed before commencing the interviews.

The other limitations on the conduct of the interviews, re-call bias, response bias and generalisability of the study findings are discussed in Chapter 6.

CHAPTER 5: DISCUSSION

CHAPTER 5: DISCUSSION

5.1 Introduction

People with chronic progressive neurological diseases often report problems with their swallowing [4-5, 8]. However, there has been a paucity of research in this area and little evidence has been gathered about the prevalence of dysphagia amongst such patients when they are admitted to hospital. The majority of previous studies have concentrated on dysphagia in disease-specific populations and have therefore recruited patients via specialist or community services [228-229].

The study described in this thesis sought to address some of these gaps in research evidence and adopted a mixed methods approach. As noted previously (section 1.15), the primary purpose of the study was to determine if patients with PD, MS and MD are screened for dysphagia when they have an unplanned admission to hospital. The second aim was to uncover the factors which influence clinical decision making and determine whether or not an assessment is undertaken during the early stages of admission.

This chapter discusses the observational and interview results reported in chapters 3 and 4 and compares these findings with the existing literature. The chapter also reflects on the strengths and limitations of the study, the clinical implications of the findings and outlines suggestions for future research. The aims and objectives of the study serve as a platform for this discussion which is structured accordingly. The objectives and methods adopted in the study are summarised below in Table 5.1

Table 5.1: Summary of research objectives and methods

First Research Aim	Second Research Aim
Objectives:	**Objective:**
1) To determine if patients are screened for dysphagia during the first seven days following an unplanned admission to hospital. 2) To determine if the management of patients who are assessed during the first seven days of admission to hospital differ from those who are not assessed. 3) To determine if the clinical outcomes of patients who are assessed during the first seven days of admission to hospital differ from those who are not assessed. 4) To estimate the prevalence of dysphagia amongst patients who have an unplanned admission to hospital.	5) To determine what factors influence a clinician's decision to assess for dysphagia when people with PD, MS and MD are admitted to hospital.
Sample Recruited: Patients with PD, MS or MD (n=200) Multiple Sclerosis (n=29) Muscular Dystrophy (n=5) Parkinson's Disease (n=166)	**Sample Recruited:** Clinicians (n=20) Doctors (n=2), Dysphagia trained nurse (n=1) Health care assistant (n=1), Nurses (n=8) Nutritionist (n=1), OT (n=2) PT (n=2) Rehabilitation nurse (n=1) SLT(n=2) Ward Manager (n=1)
Methods: Multi centre, prospective short observational study of patients admitted acutely. Review medical records MAU dysphagia questionnaire Swallowing questionnaire / water swallow test Record of interventions / outcomes	**Methods:** Qualitaive study (grounded theory approach) Semi structured interview Interview guide questions Record and transcription of interviews

5.2 Observational Research Findings

The main observational research findings are structured in relation to the four objectives of the study.

5.2.1 Screening for Dysphagia (Objective 1)

The findings from this study show that following an acute admission, approximately 34% of patients were screened for dysphagia as part of their routine care within the first week of the admission. It is difficult to make direct comparisons as no previous studies have investigated patients with chronic progressive neurological conditions in acute admissions. Therefore, the only other data with which this percentage can be compared are those reported in studies of stroke patients.

Odderson et al. [156-157] found that a high proportion of stroke patients were assessed for dysphagia, during an acute hospital admission (87% and 100% respectively). In every day clinical practice, an audit is used to evaluate clinical practice against best practice. A recent SSNAP audit data set for England and Wales in September 2013, reported a mean of 68 of the proportion of stroke patients who were given a formal swallowing assessment [230]. These results could differ, as patients followed the stroke clinical pathway which includes a protocol for dysphagia screening, assessment and management of dysphia in contrast to other chronic neurological conditions). In this study, among those who had a SSA within the first week of admission, 93% were diagnosed with dysphagia and a further 77% [n=101] of patients who were screened after the first week of admission as part of routine care were also found to have dysphagia. The overall proportion of patients found to have dysphagia in this study was 82%. This finding is noteworthy because

the study by Giraldo et al. [231] reported a high proportion of dysphagia (82%) in patients with a variety of neurological and muscular diseases. Another study by Paolo et al. [232] reported 79% of stroke patients diagnosed with dysphagia after an initial dysphagia screening. The proportion of patients diagnosed could be dependent on several factors such as the setting, the method used to determine the diagnosis, operational definitions of dysphagia, severity of the conditions (for example in an unconscious state) and the competency of the person conducting the assessment.

The findings of this study were derived from the medical assessment unit of two NHS hospitals where patients who had any one of three diagnoses (PD, MS and MD) were admitted. Two dysphagia swallow screening assessment methods (the swallowing screening questionnaire and the water swallow test) were employed to identify patients with dysphagia. The combination of both methods has been shown in previous studies by Fabiola et al. [109] and Nathadwarawala et al. [122] to be a valid and reliable method of screening for dysphagia and the risk of aspiration at the bedside. In this present study, the methodology was able to detect 77% of patients with dysphagia who had not been identified previously as part of routine care. The methodology used produced a sensitivity of 95%, a specificity of 33%, a positive predictive value of 62% and a negative predictive value of 86% which is comparable to these studies [122,233].

Our operational definition of dysphagia was quite strict in terms of identifying those who would be at risk of aspiration and nutritional compromise. A heterogeneous group with a range of problems with dysphagia was taken, some of whom were definitely unsafe and who would be candidates for

nasogastric tube feeding (NGT feed) if swallowing did not improve (such as those on NBM). All those who failed the swallow screening assessment at any one of the three stages were considered to be at risk for both aspiration and under nutrition. This identified sufficient people in whom nutritional management could be examined and revealved some information about how well this was being carried out.

All patients who presented with dysphagic symptoms (n=28/200) were found to have dysphagia when a SSA was undertaken. These patients [n=28/68 (41%)] were screened as part of routine care within the first week of admission. These figures include those who were made nil by mouth, NGT and on modified diet and fluids. The results indicate that PD, MS and MD patients who present with swallowing problems and are at nutritional risk are common place in the acutely medically unwell population. There were patients who did not present with symptoms of dysphagia [n=35/68 (51%)] but who were also found to have dysphagia when assessed by the researcher. It is therefore important to recognise the symptoms and signs of dysphagia in patients at presentation, as this has been shown by previous research to aid early diagnosis [8].

The study results indicate that an important contributory factor for dysphagia is age. [Table 3.1] As the majority of participants were elderly, this could account for the presence of dysphagia due to the presence of co-morbidities. The mean age of patients admitted acutely were the older population which is consistent with previous studies by Jaradeh [4], Robin [34] and Robbins et al. [35]. They were identified with risk factors for dysphagia as well having an 'unsafe' swallowing when the swallow screening assessment was administered.

This could be attributed to a reduction in oral, pharyngeal and oesophageal functions with age in people with neurological conditions, as shown in the study by Sonies et al. [9] and Kwashima et al. [30], and also as a consequence of their co-morbidities.

Follow-up of the in-patients on day seven revealed several important findings. The patients' medical records indicated that 77% of the patients who would have benefited from being screened for dysphagia on admission were not. One assumption could be that the patients had improved (in terms of eating and drinking), were too ill to have their swallowing assessed or were made nil by mouth at presentation. This finding was not surprising, as few of the clinicians involved reported that they had the requisite skills and confidence to undertake a SSA. [Figure 4.2 and 4.3] The majority of clinicians had not received any formal training in SSA and those who had been trained had more than a four-year lapse since training. Frequency of use of such clinical skills as dysphagia screening was limited, which appeared to result in deskilling due to a lack of practice. This explanation was supported by the findings of the second study.

As noted above 77% of patients were diagnosed with dysphagia when they were screened after the first week of admission by the researcher. [Table 3.10, page 3-17] The success of the usual management system to identify dysphagia was 38% [63/164]. This indicates that dysphagia is not being detected in all patients with neurological conditions (PD, MS and MD) admitted acutely at the medical admissions unit and that a large proportion of these patients were missed [101/132 = 77%]. This is particularly relevant because of the known complications of dysphagia, meaning that there were 101

[101/200=51%] people in this study who were exposed to those risks, such as pneumonia, malnourishment, dehydration, prolonged length of hospital stay and an increased risk of mortality. The evidence of these complications arising in PD, MS and MD patients has been shown in previous studies [23, 24, 11].

The swallow screening assessments (discussed previously in section 1.6) which have been validated in PD, MS and MD patients and are suitable for bedside screening, could be adopted as part of a routine assessment stategy for people with these conditions [55, 109, 119, 122]. It was evident from this study, that the standards recommended by the SIGN guidelines on assessment of dysphagia are not being implemented in this population, although these guidelines were only meant for stroke patients [106]. It could be argued that the lack of guidelines/dysphagia pathway was a major contributing factor for the majority of the patients who did not receive a SSA within the first week of their acute medical admission.

i) Referrals to speech and language therapists and dietetics

Of the total number of patients (those who had swallow screening assessment (SSA) within the first week of their admission) with 'unsafe' swallowing, only about half of these patients were referred to both specialities or just to SLT. [Table 3.11] The NICE guidelines on dysphagia recommend that all patients with indicated swallowing problems on admission should be referred to a SLT within 24 hours and not more than 72 hours after admission [67]. The findings of this study indicate that NICE guidelines are not being followed in acute medical admissions units, at least in the two hospital settings studied. Further recommendation for referral to the dieticians on dietary advice, full nutritional assessment, individualised nutritional advice and supervision for

patients with suspected aspiration risk and inadequate oral intake, who may require dietary modification or instrumental interventions (nasogastric tube feeding (NGT feed), gastrostomy (PEG feed)) were also made in the NICE guidelines [67] and should be adhered to by the clinical team.

The poor referral rate could be attributed to lack of guidelines/dysphagia pathway in this population as discussed previously but it could also be that referrals to SLT and dietetic departments were made but not documented or that patients were made nil by mouth and so were not referred to these specialities. Guidelines published by the RCSLT emphasise the need for referrals to both specialities, as evidence from previous studies has shown that length of hospital stay (LOS) for patients with severe medical conditions is between 5.7 to 12.6 days [1, 89-91]. SLTs can help to reduce the length of hospital stay (LOS) for an average of 5.5 days by working together with dieticians to manage each patient's oral intake [1, 89-91,157]. However, this study showed the opposite; those who had a swallow screening assessment (SSA) within the first week of admission had a long LOS of no less than 2 weeks, which may also be attributed to poor referrals to the SLTs and the dietitians.

The findings of this study show that clinical practice during an acute admission is not consistent with practice guidelines which have been developed for patients with related conditions. Good clinical management of dysphagia could be upheld through dissemination of these findings by publication and to appropriate bodies. Another interesting finding from this study, was that there was no record of any cases or concerns of medical staff referring 'inappropriate' patients (those who cannot be assessed e.g. unconscious

patients, patients unable to eat, those with poor food intake, those with pain on swallowing) to the SLT. Rather, the opposite was the case, where 'appropriate' patients (missed dysphagia group that were later identified by the researcher) were not referred to the SLTs. These patients were, however, referred subsequently to both specialities one week after admission and therefore benefited from their services. They received formal SLT assessment and dietetic input. A merit of this study is that the research provided the opportunity for those groups of patients to be referred. It is important to identify patients with the greater need for SLT, as there are limited speech and language therapy services. [Section 4.5.3(i)]

5.2.2 Management of Patients with Dysphagia (Objective 2)

The second objective of this study investigated whether the patients who are assessed for dysphagia within the first week of admission to hospital are managed differently to those who are not assessed. The study reviewed the length of time it took speech and language therapists and the dietitians to review all of the patients referred within the first week of their admission. Data were also obtained about the length of time taken by the SLT and dietitians to review patients who were referred after a week. Nutritional reviews completed within the first week of an acute admission and those carried out subsequently are also discussed.

i) Speech and language therapy and dietetic interventions

The management of dysphagia involves a multidisciplinary team approach, which ensures that patients receive a comprehensive assessment and the required treatment [1, 7, 67, 106, 175-178]. Speech and language

therapists (SLTs) and dietitians have a vital role to play during the acute admission particularly of patients who are recognised to have swallowing difficulties. The Royal College of Speech and Language Therapists (RCSLT) has recommended that patients who have a failed SSA should be reviewed by a SLT within two working days of their referral [1]. In this study, all the patients who were referred to SLT and dietetics within the first week of acute admission to hospital were seen by both specialities, but a large proportion of these patients were seen more than four days following the referral. The reasons for these delays may be due to prioritisation of referrals (for example in suspected or diagnosed aspiration risk /pneumonia), shortage of SLT/dietetic staff, non-availability of out of hours SLT/dietetic services or patients not referred on the day they were supposed to be referred. These reasons relate to some of the findings from the second part of the study [Section 4.6.3 (i)].

Previous research in stroke patients has shown that early intervention (for example a SSA, efficient SLT and dietetic services) in the management of dysphagia results in better outcomes [109,156-157,109]. These outcomes have been targeted to early SLT intervention [106, 6]. Our study revealed that the outcomes of those patients who had a SSA within the first week of admission were poor in some aspects (LOS, mortality and hospital acquired pneumonia (HAP) which may have resulted from delays in commencement of SLT and nutritional intervention or poorer health. In other neurological conditions (for example stroke), the RCSLTs recommends that there should be a minimum of one SLT in an acute ward for every ten patients [1]. If the number of SLTs for every ten patients falls short, it would affect early intervention and overall management of dysphagia [1]. Therefore delays in SLT and/or dietetic interventions for those who had a SSA within the first

week of admission could have contributed to poor outcomes, similar to the findings from other studies [11,23-24]. The proportion of patients (those who had a SSA within and after the first week of admission) reviewed by the SLTs (85%) in this study was far more than that reported by Odderson et al. [156] on stroke patients (53%), which indicates that swallowing problems in this population are evident.

ii) Nutritional management

As part of identifying whether nutritional assessments had been done, patients who had a SSA within and after the first week of their admission to hospital were reviewed. A number of required areas of documentation were included. Nutritional assessment consists of identification (including measurements), monitoring and dietetic referral. Previous research has shown evidence of early and routine nutritional assessments to determine a patient's nutritional status; these form part of the recommendations in the NICE and SIGN guidelines [67, 106].

Studies by McWhirter et al. [58], Kellyie et al. [59], Elia [61] and Mowe et al. [70] reported that under nutrition was generally not identified in hospital However in this study, all of the patients who had undergone a SSA within the first week of their admission had a nutritional assessment. Only a small proportion of participants who were assessed for dysphagia did not undergo a complete nutritional assessment. Nutritional supplementation, which involves oral and enteral feeding, has been shown to be of benefit to people with severe neurological dysphagia [78]. In the present study, a large proportion of patients who had a SSA within the first week of admission either received nasogastric tube (NGT) feeding or modified diet and fluids. This contributed

to adequate nutritional intake and assisted weight stabilisation in these patients. The findings confirm that these patients were the severely dysphagic, with significantly increased LOS, HAP, mortality and malnutrition. These associations were in agreement with the results from previous studies [62-65]. Only a small proportion of patients who had SSA after the first week of admission received nutritional interventions as they were thought by the usual care team to have fewer or less severe swallowing problems.

In this study, it was noted that the admissions document includes a section for nutrition status but does not include one concerning swallowing difficulties. Assessments were not formalised and most patients recommended for NBM status were acutely sick. The patients who had a SSA within the first week of admission were felt to be at high nutritional risk by the managing clinicians. Therefore, their nutritional risk assessments (anthropometry-weight, malnutrition universal screening tool (MUST) score), presence of food/fluid chart and dietetic referral were more likely to be managed. A greater percentage of these patients had their weight, MUST score, fluid/food chart documented within the first week of admission, which suggests that the clinicians who screened may be more inclined to provide appropriate nutritional advice or refer patients to the dietetic service. The patients who had a SSA after the first week week were felt to be at low nutritional risk by the managing clinicians which may have resulted in their nutritional risk assessment not being managed adequately.

Before the study commenced, there were concerns as to whether nutritional screening within the first week of admission was associated with a reduction in malnutrition and other complications. This may be explained by a "clinicians'

effect" in addition to the benefits of early screening. This effect suggests that clinicians who were aware of and implemented the nutritional guidelines would also be efficient at encouraging reduction of malnutrition. However, because the nutritional status of both subsets was not statistically significant, it is unlikely that the results were affected by this effect. Overall, the nutritional assessment of patients who had a SSA within the first week and after the first week of admission was not associated with a reduction in malnutrition, however management of the people who had a SSA within the first week of admission was satisfactory.

5.2.3 Outcomes of Patients with Dysphagia (Objective 3)

The third objective of this study examined the outcomes of patients who had a swallow screening assessment (SSA) within the first week of admission and those patients who had a SSA after the first week of admission. These outcomes were length of hospital stay (LOS), mortality, hydration, hospital acquired pneumonia (HAP), and other infections such as urine infections, and diarrhoea. The associations between these outcomes and the importance of early and routine screening for dysphagia are indicated in this study.

i) Hospital acquired pneumonia (HAP)

Swallow screening assessment (SSA) within the first week and after the first week of admission in patients with neurological conditions and occurrence of hospital-acquired pneumonia has not been investigated previously by randomised controlled trials (RCT). This is probably due to the associated

ethical constraints that would prohibit randomising patients with these conditions to have no dysphagia screening. Therefore, an observational method was used to determine the potential benefits of carrying out a SSA in these conditions. Previous stroke research and this study, has revealed differing results of high risk of pneumonia in patients who had SSA compared with those who did not have a SSA [155]. The findings of this study showed that a greater percentage of patients who had a SSA within the first week of admission had a HAP. [Table 3.22] This finding was not surprising, because the patients who were more likely to be screened for their swallowing within the first week of admission were those with severe swallowing difficulties. Therefore patients may have been selected carefully for a SSA by their usual care team, depending on the severity of their neurological condition and the dysphagic symptoms they presented with on admission. A proportion of participants who had a SSA after the first week of admission also had a HAP; this subset of patients (who were not screened initially) had more episodes of HAP than those who passed the SSA while those who failed the SSA had more episodes HAP than these participants. These findings show that the clinical reasoning that underpins a clinician's decision to conduct a SSA is not always fit for purpose (the threshold for screening is high thereby putting patients at risk). The severity of dysphagia may have contributed to the prolonged hospital stay and subsequent development of a HAP [7]. This study showed that the proportion of participants with a HAP was higher in those who had a SSA within the first week of admission than in those who were screened at a later date. It was not surprising that those who were more obviously ill and had a SSA within the first week of admission had more episodes of HAP. An important finding from the results was those who had dysphagia and were missed because it wasn't obvious, with a proportion of them having potentially

unavoidable HAP. The proportion of patients who had a HAP in all the participants (both those assessed within and after the first week) was greater than those who passed the SSA, indicating that the majority of these participants were those who failed the SSA. Therefore, all patients with neurological conditions should have a SSA when admitted to hospital.

ii) Length of hospital stay (LOS)

Length of hospital stay (LOS) was significantly increased in patients who had a SSA within the first week of their medical admission. This group of patients were found to be severely dysphagic (93%) and this finding was consistent with previous studies by Guyomard et al. [85] which reported that patients with dysphagia have longer LOS. The patients who were screened after the first week of admission (the less dysphagic group) had a shorter LOS. These findings differ with those obtained by Odderson and colleagues [156-157] as they noted that patients who were screened had a shorter LOS than those who were not screened for dysphagia.

This can be explained by other determinants of LOS such as age, medical diagnosis, severity and nature of illness, co-morbidities, patient management and medical complications [92]. (Section 1.2.3(d)) Sonies et al. [9] reported that dysphagia is associated with increasing age, which can result in longer LOS. This is similar to the findings of our study, as the majority of our patients were elderly (80-89 years) and less likely to be discharged early from hospital due to the severity of their illness and dysphagia. (Table 3.1) Co-morbidities could also be another contributing factor for prolonged LOS in the study. A large proportion of the patients had multiple co-morbidities which

may be related to their neurological condition, so it was expected that LOS will be prolonged in these patients [92].

There were delays in SLT and dietetic interventions for those screened within the first week of admission. Those who were screened after the first week had delayed screening and interventions also which contributed to them staying in hospital for longer than they may have done. Medical complications such as malnutrition and HAP were observed in the screened group which are associated with longer hospital stays [62-63]. Evidence from the literature has shown that in patients who have dysphagia, LOS is significantly increased.

iii) Mortality

There were two cases of mortality among patients who were screened by ward staff within the first week of admission but none amongst those who were screened by the researcher at a later stage. The percentage mortality (3%) found in this study for those screened initially was much lower than in the findings from previous studies of stroke patients by Martino et al. [210], where the relative risk reduction of mortality for patients who were screened was 70%. This study could not use mortality as an end point because of the small number of deaths that occurred.

Robbins et al. [39] reported that aspiration pneumonia is a leading cause of death with increasing age. In this study, most patients were of the older age group and a large number of those who were screened initially may probably have been at risk of aspiration or had suspected aspiration pneumonia. Previous studies by Butler et al. [42], Pikus et al. [48] and Martin-Harris [49]

have revealed that people with swallowing problems occasionally aspirate minute quantities of food or fluid and known aspirators, complicated with dysphagia, they were more likely to develop aspiration pneumonia. Therefore the findings from this study confirm the results of previous studies because the 'risk of aspiration', 'pneumonia' and 'severity of dysphagia' were shown to be high in this group. Any or all of these factors may have resulted in the death of these patients.

A large proportion of patients with neurological conditions admitted through the medical assessment unit suffered from swallowing difficulties, which is associated with increased morbidity. A total of 15 patients screened within and after the first week (n=8, n=7 respectively) of admission deteriorated in this study. The cause of deterioration was due to complications of dysphagia and in this study, HAP may be a major contributing factor [7, 233-234]. It is clear that interventions are required to prevent these poor outcomes. Routine dysphagia screening is needed in order to predict morbidity in patients with neurological conditions.

iv) Hydration

In the study, it was observed that hydration assessment and fluid balance charts were recorded for a larger proportion of participants (96%) who were screened within the first week of admission. About 76% of those who were screened later had their hydration recorded. This observation showed proper hydration monitoring by medical staff for those who were screened early, but it may not reflect their hydration status. The present study did not evaluate hydration but examined documentation of hydration measures including oral

and intravenous fluid intake. The study intended to also examine documentation of urine and plasma osmolality for the patients, unfortunately there was no documentation found. Previous studies have shown that dysphagia can cause dehydration in people with neurological conditions, therefore it was felt that those who were screened and had unsafe swallowing should be regarded as at risk of dehydration on admission and their hydration was monitored [7, 74-76]. The study focused on patients who were screened within and after the first week in relation to monitoring of hydration and so their hydration status was not really evaluated.

The majority (59%) of participants who were screened within the first week of admission were placed on a modified diet and fluids compared to 12% of those who were screened after a week. This strategy was intended to reduce the risk of aspiration [191]. It may also result in under-hydration or dehydration in the participants who were screened within the first week as they may have found it difficult to consume thickened fluids, an issue which has been highlighted in earlier studies [78, 81]. Poor adherence to, modified diets, including thickened fluids, has been debated for several years and complicates the management of dysphagia amongst those who aspirate on thin fluids [202-209]. Garon et al. [205] and Carlaw et al. [208] have reported no complications with the use of the 'free water protocol' in contrast to a study by Becker et al. [209] and Karagiannis et al. [207] which showed that aspiration of water was associated with development of aspiration pneumonia.

The association of malnutrition and dysphagia during the first week of admission was not significant amongst either sub-set of participants;

consequently it was difficult to establish if any differences existed between participants with respect to hydration. Overall, the findings of the study showed that hydration was monitored effectively amongst those who were screened within the first week of admission. One assumes that clinicians will screen patients for dysphagia at an early stage during an admission if dehydration is expected. It is also anticipated that dysphagia will be found amongst many of those who are dehydrated.

v) Infections

The results indicate that dysphagia was complicated by infections (mainly hospital-acquired infections) amongst a higher proportion of patients who were screened within the first week of admission. The overall percentage of infection was 75% for those screened early and 49% for those screened at a later stage. Urine infection, diarrhoea and HAP developed amongst all participants. These events occurred commonly in the group screened early, but the findings derived from the group screened later were consistent with those seen in previous stroke studies [235].

Several factors were associated with the increased infection rate in patients who were screened within the first week of admission, including increased LOS. This finding is similar to a previous study by Atman et al. [236]. Secondly, the severity of the medical condition of the patients was probably a contributory factor to increased infections. There was an increased occurrence of pneumonia in the group of patients who were screened within the first week compared to the later group, probably due to the severity of their dysphagia. This finding is consistent with the studies by Pikus et al.

[48] and Martin–Harris [49], which showed that patients with dysphagia have an increased risk of pneumonia especially when complicated with aspiration. Thirdly, urinary tract infections were prevalent in these patients but more especially in those who were screened within the first week of admission.

Age has been shown to be a relevant factor in the development of dysphagia and infections in neurological conditions [4, 34-35]. A large proportion of the patients recruited to the study were elderly and more likely to be catheterised, due to the severity of their condition, particularly in patients screened within the first week. Prolonged catheterisation may have resulted in urinary tract infection. Most of these patients were frail, had decreased mobility and immunity (due to infection, malnutrition and neurological disease) and increased LOS, which may be responsible for the development of pressure sores in those who were not catheterised [93,235]. Other infections such as gastroenteritis occurred in very small episodes in both sub-sets of participants which could also be associated with prolonged hospital stay. These findings are very low compared to figures reported previously from national health statistics on hospital acquired infections [86]. The results suggest that hospital acquired infections were a major determinant of outcomes for patients who were screened for dysphagia within the first week of admission.

5.2.4 Prevalence of Dysphagia in patients with neurological conditions (Objective 4)

The findings from the observational aspect of the study showed that dysphagia was common (82%) in this sample of patients with neurological conditions and that it was present in a proportion consistent with previous studies. Giraldo et al. reported a high proportion of dysphagia in 82% of patients with

neurological and muscular diseases [231]. However, Regan et al. [29], Smith et al. [27] and Kawashima et al. [30] reported a lower prevalence of dysphagia in acutely unwell patients, at about 30%, 45%-46% and 30% respectively. Dysphagia was present in 66% of patients with Parkinson's disease, in 12% of patients with multiple sclerosis and in 3% of patients with muscular dystrophy in acute medical admissions. This finding is comparable to previous studies in Parkinson's disease patients, but considerably lower than the proportion seen in other studies of people with multiple sclerosis and muscular dystrophy.

Kalf et al. [23] reported that more than 80% of PD patients had dysphagia, Poorjavad et al. [24] reported dysphagia in 32% of patients with multiple sclerosis, similarly George et al. [25] and Calcagno et al. [118] reported more than 35% of patients with muscular dystrophy have dysphagia. The differences in these findings can be attributed to the setting, the population of patients studied by different authors (age, type of neurological condition, nature of illness and severity, sample size), recruitment issues (ethics) and the method and timing of swallow screening assessment. The results confirm that people with chronic neurological conditions with swallowing problems are common in acute medical settings.

5.3 Interview Research Findings

The second stage of the study sought to determine the reasoning that underpinned decisions to screen for dysphagia in people with neurological conditions, the difficulties associated with dysphagia screening and possible solutions. The reasons, difficulties and solutions identified by clinicians are

grouped under headings as they relate to identification of dysphagia, barriers and facilitators, and infrastructure.

5.3.1 Identification of dysphagia in PD, MS and MD

The main reasons that were reported for carrying out a swallow screening assessment in people with chronic progressive neurological conditions were presence or complaints of dysphagic symptoms, previous/present diagnosis of dysphagia, medical staff/relatives' concerns about swallowing and patients with speech or language impairments. Patients who have swallowing problems may present with various signs and symptoms such as coughing or choking during or after swallowing, loss of food from the lips, pouching of food, wet or gurgly voice after swallowing, dribbling of water or saliva, recurrent chest infections and unexplained weight loss [5,17].

It was evident that the majority of the clinicians interviewed were aware of the signs and symptoms of dysphagia which would prompt them to conduct a screening that would result in diagnosis [8]. However, as swallowing function can vary, clinicians need to be aware that swallowing difficulties can arise or deterioriate during an admission, therefore they need to be aware of these signs and request further assessments. Although most clinicians recognised coughing associated with food or fluid is an important indicator of dysphagia, other problems are associated with dysphagia, such as decreased level of consciousness, which SLTs may not be qualified to manage. Not understanding this difference may result in inappropriate referrals and defer appropriate treatment. Previous studies by Smithard et al. [140] stated that impaired level of consciousness and weak voluntary cough are important

factors to consider in the identification of dysphagia. They also noted that the presence of either one or both of these factors could predict the incidence of aspiration as well as with videofloroscopy [140]. The clinicians suggested that education of ward-based staff on SSA parameters could be achieved through ward-based clinical education, taught sessions or online information.

Using the most appropriate method of SSA and management of dysphagia in patients with neurological conditions relies on recognition of a patient's previous or current diagnosis and severity of dysphagia [15]. Input from consultations with clinicians revealed that the majority identify patients with pre-existing swallowing difficulties and those who are recently diagnosed. However, some of the clinicians did not associate the diagnosis of neurological conditions with dysphagia risk. A possible explanation for this finding is that people with these conditions may not be aware of or complain of swallowing problems. These patients remain unidentified and could present with silent aspiration [237]. In addition, patients can develop several compensatory mechanisms to cope with their swallowing difficulties. Although these mechanisms help to prevent aspiration, if their swallowing deteriorates and they are not re-assessed, it could result in an untimely death [118,133,238]. Therefore, if patients are able to use compensatory strategies, it is possible that the presence of dysphagia will be missed or overlooked by clinicians. Some patients, such as those with dementia, may not be able to follow instructions and therefore compensatory mechanisms (though some of them rely on understanding) may be the most suitable option for the clinicians or carers who are helping to manage the dysphagia [15].

Many people with neurological conditions lack the ability to recognise when they have a swallowing problem and may not cough when food enters into their airway and often, the clinical signs and symptoms are not evident. The clinicians interviewed were of the opinion that if medical staff or relatives' observe anything unusual about a person's swallowing this should be a valid reason for re-assessing swallowing. This suggests that clinicians may be aware of both the obvious and subtle signs and symptoms of dysphagia. When managing these patients, Logemann states that clinicians and all those who provide care should be aware of the possibility that the patient may be aspirating silently [15]. Silent aspiration is known to be a frequent occurrence in neurological patients with dysphagia and its detection depends on a high index of suspicion and careful observation by clinicians, relatives or carers for unusual changes in voice quality and impaired cough reflex [56-57]. However, it is difficult to detect silent aspiration except with video fluoroscopy, therefore clinicians and carers need to be alert to slight changes in behaviour that may indicate aspiration is occuring [140].

The disease progression of chronic neurological conditions may not only affect the swallowing area of the brain (brainstem), but may also have a considerable effect on other parts of the brain, such as the speech area (frontal lobe of the cerebral hemisphere). It was apparent that the clinicians were aware that patients who have communication difficulties may also be dysphagic and requested a screen or referral to the speech and language therapist. The study by Logemann reported the coordination of swallowing and speech functions as it relates to dysphagia [15,193,239].

The findings from this study indicate that the clinicians were actively involved in the management of patients with dysphagia. They were also aware of the signs and symptoms that should prompt them to undertake a screening assessment or to refer patients to speech and language therapy but were not aware that dysphagia was a common occurrence in neurological conditions.

5.3.2 Barriers and Facilitators

In terms of conducting a swallow screening assessment in people with chronic progressive neurological conditions, a major concern was the skills, knowledge, confidence and training of clinicians who are involved in the management of dysphagia in these patients. There are individual, interpersonal and organisational factors which may be acting as barriers or facilitators in the management of dysphagia in people with these conditions. Individual barriers such as lack of knowledge and formal training, deskilling, lack of uniformity in swallowing assessment methods, frustration, accountability, fear of carrying out swallowing screening assessments were reported to affect the assessment of dysphagia in patients during acute admissions. It was noted from the clinician interviews that only few nurses reported that they assessed swallowing. This is surprising since they practiced in the elderly care wards and specialised units (stroke and Parkinson disease wards).

The majority of the clinicians had not received any updates with regard to SSA within the last four years and some of those who conducted SSAs had received no training. Frequency of use of SSAs was also limited, which could result in deskilling due to lack of practice. Many factors could account for these findings. Firstly, the involvement of speech and language therapists in this

field could be a contributing factor [176]. Secondly, the majority of clinicians did not receive any training in the use of SSAs during their graduate studies. Thirdly, acquisition of skills and knowledge was made by observation of 'experts' as they conducted the assessment on the ward. Fourthly, there was lack of uniformity in both the administration and sharing of knowledge about these assessments.

As a consequence of these problems, clinical skills, knowledge and confidence in dysphagia management can deterioriate, which may be compounded by lack of accountability and fear of conducting a SSA. However, considering the different kinds of skills expected of clinicians who work in acute medical wards, it is not unusual to encounter clinicians who have limited experience of dysphagia and find it difficult to identify or manage dysphagia. The participants felt that targeted training on how to monitor and conduct basic swallowing tests (such as the water swallow test) would be beneficial.

Barriers that were sometimes thought to prevent a swallow screening assessment from being carried out included adherance issues, behavioural problems, cognitive issues, phase of neurological dysphagia and administration of medication. These barriers relate to each other, as the occurrence of each factor may bring about another. In patients with cognitive disorders, for example, unintentional difficulties can occur in carrying out the screening procedure, in taking medication, food or fluid. This finding is in keeping with previous studies by Terrado et al. [81], Robbins et al. [80], Logemann et al. [188] and McHorney et al. [190] which highlighted the impact of cognitive problems on adherance in people with neurological conditions. This is further complicated in patients who are receiving regular medications

(such as sedatives and anti–depressants) in the chronic phase of the disease, which sometimes affect their cognition and may manifest as behavioural issues during screening or administration of medications [227]. It was suggested that proper history-taking, exploration of a patient's beliefs, provision of greater support for patients e.g. identification of medicines, medicine charts/alarms and involvement of individuals, relatives and carers for supportive care would be of benefit.

At the organisational level, perceived barriers to carrying out swallow screening assessments frequently related to prioritisation, polices and practice, time delay and lack of knowledge in specialities involved in swallowing safety. The RCSLT has stated that prioritisation was necessary "to allow the therapist to judge the relative priority of the individual's need in relation to the needs of others requiring intervention" [1]. The clinicians proposed that the delays in accessing speech and language therapy services were due to the small number of speech and language therapists (SLTs) and that a priority-based service may account for limitations in the number of swallow screening assessments being carried out. This perception was confirmed by the observational study. The organisation of services meant that only the few SLTs available would be able to assess the patients' referred and this was priotised on the basis of risk. It is therefore necessary to explore the option of including patients with long term neurological conditions amongst the list of "at risk" patients to reduce the waiting time for an assessment. Also poor knowledge of changes in policy and practice of swallowing guidelines has affected the confidence of some clinicians who used to carry out dysphagia screening. This limitation of knowledge was seen by some clinicians (whose roles relate directly or indirectly to swallowing safety) as being attributable to

the organisation of their services and lack of training. Participants felt that provision of education that is targeted at these specialties and updates on dysphagia screening would restore confidence and ensure that patients are managed effectively.

5.3.3 Infrastructure

Major findings from the interview study were the lack of infrastructure such as resources (funding, lack of out of hours SLT services) and the absence of dysphagia guidelines. The concerns about the lack of funds to employ more SLTs to assess patients' referred for swallowing difficulties during working hours and especially out of hours, has led to a feeling of frustration on the part of the SLTs and perceived lack of efficiency from the perspective of other clinicians, especially the nurses. This was also reflected in the observational study. This finding is also consistent with previous studies by Janca et al. [240] as part of the launching of the global initiative project on neurological disorders, that there was limited information on the funding, lack of guidelines and burden of disease in patients with neurological conditions [240-242].

Studies aimed at developing a new technique that would be used to establish the usefulness of interventions in relation to the cost on burden of disease (the global burden of disease (GBD) study) have been initiated [94] [section 1.2.3 (G)] and the outcomes of these studies are currently being implemented. Provision of out-of-hours SLTs (as within the stroke service) is another way of resolving many of the problems the clinicians reported when caring for patients who are admitted with swallowing problems. However, research

evidence is required to justify funding of more SLTs for an out-of-hours service for patients with neurological conditions.

Another area where funding was discussed by the clinicians was training of clinical staff for dysphagia screening. Patchy experience of training opportunities led to dissimilarity in screening tools used and training resources. Very low confidence levels and deterioration of competencies in swallow screening were reported by the majority of the clinicians interviewed. A more practical solution would be to provide funds for either the SLTs or the dietitians to use a similar training package and a dysphagia screening tool with robust assessment measures, starting with training of ward-based clinicians in a systematic approach to ensure that every clinician is trained. However, the problem of the limited number of SLTs available for conducting the training could mean that the SLTs may have to reduce their trainers' time on the ward and shorten the programme. Medical doctors could attend separate training on the administration of a swallow screening tool, instead of attending the full programme. One of the clinician participants, a DTN, suggested that she could train clinicians in groups of four at a time, which would reduce the overall cost of training.

Poor awareness of dysphagia and swallow screening guidelines in patients with these conditions also resulted in an increased number of unidentified dysphagia patients and poor inpatient management. The clinicians were of the view that a lack of dysphagia guidelines for these conditions affected their management as there were no set recommendations to follow. It also contributed to fear when conducting swallow screening assessments due to the risk of accountability in the event of any adverse events.

Provision of dysphagia guidelines in people with neurological conditions may aid the efficiency of patient management. Applying existing dysphagia guidelines, such as the stroke guidelines, to people with other neurological conditions was thought to be another method of improving the management of dysphagia [106]. Implementation of the stroke guidelines would encourage routine swallow screening assessments in these conditions and improve the quality of care by preventing prolonged waiting times for screening and avoiding early complications of dysphagia. However, one participant stated that it would be a waste of resources (for example nurses' time) because not all patients with neurological conditions have swallowing difficulties, so screening should be conducted only on appropriate patients. Whilst the overall aim of routine swallowing screening is to ensure the safety of patients, it may be necessary to evaluate the relative risks and decide whether or not to adopt routine screening as a uniform approach, even though it has been proven to be effective in stroke patients [210]. In this study, the efficiency of screening for dysphagia was shown with the use of the swallow screening tests (the swallowing questionnaire and the water swallow test) which enabled patients to be detected with unrecognised dysphagia. Furthermore, these swallow screening tests followed the psychometric properties of a good screening test in the study. (Section 1.3) It was inexpensive, easy to administer and not time consuming; therefore it would be feasible for clinicians to use. It also showed high sensitivity and a high positive and negative predictive value.

To increase awareness of dysphagia in people with neurological conditions, the suggested intervention was to introduce an alert system that would enable

early identification of dysphagia in patients with no previous history, by notifying clinicians of their current swallowing problems when admitted to hospital. There has been an increased awareness of dysphagia in stroke and Parkinson's disease patients' since the creation of specialised care units as noted during the interviews with clinicians. Therefore, patients with multiple sclerosis and muscular dystrophy may also benefit from creation of specialised wards to avoid widespread admission to different wards where they may not receive any dysphagia screening.

Improving dysphagia screening in people with neurological conditions requires multidisciplinary expertise and the removal of individual, inter-personal and organisational barriers through provision of resources, development and implementation of guidelines, adoption of routine swallow screening and dysphagia training for clinicians.

5.4 Comparison of Study Findings

Findings from the interviews support the findings that were derived from the observational aspect of the study i.e. patients with chronic progressive neurological conditions are not screened routinely for dysphagia when admitted to hospital and many would not have been identified unless an assessment of swallowing had been undertaken by the researcher following the initial seven day period. The interviews with clinicians show that the majority of the interviewees were not screening patients for dysphagia. The main reasons reported for this were lack of knowledge and training, reduced confidence levels, difficulty accessing speech and language therapy services

and lack of guidelines on screening for dysphagia which resulted in the increased number of unidentified dysphagia seen in the observational study.

Interpersonal and organisational factors may also have played a major role in dysphagia being missed. Funding and provision of guidelines would facilitate dysphagia screening in neurological conditions by providing educational programmes on dysphagia screening, an alert system, improved awareness by creation of specialist units, and more speech and language therapists (SLT)/dysphagia trained nurses (DTN).

The small number of SLTs and DTNs conducting dysphagia assessments were consistent with the findings from the observational study, where it took the SLTs about four days to assess a patient's swallowing after a referral. In contrast to the clinician concerns about "inappropriate" referrals, there were no records in the observational study of referrals being judged to be inappropriate by the SLTs. This could be explained by the fact that the medical staff were selective in the choice of patients to screen, this may have helped to prevent inappropriate referrals. But it also suggests that some patients with swallowing problems may have been missed as the expectation might have been for at least a few of the referrals to be "inappropriate". The choice of patients selected for screening by the medical staff (those they felt had swallowing difficulties) were seen in the observational study to reveal that the clinicians' reasons for conducting dysphagia screening were inconsistent and those who were not screened also had dysphagia. Presently, the observational and interview findings support the use of routine dysphagia screening in people with neurological conditions when admitted to hospital as an emergency.

5.5 The Knowledge-to-Action Cycle

Evidence from the observational and interview elements of the study revealed that swallow screening assessments (SSA) are not carried out routinely. Clinicians are eager to conduct regular SSAs when patients have an unplanned admission to hospital; however, they are constrained by individual, interpersonal and organisational factors.

As discussed in Chapter 1 (Section 1.4), the knowledge acquired from this study could be translated into practice using the "knowledge to action cycle", a model proposed by Graham etal. [243]. This is a model in which researchers and users of knowledge interact. It seeks to close the knowledge to practice gap and identifies the barriers and facilitators which can impede or support this process [243]. The knowledge that would be translated and the target population should be considered and the relationship between knowledge creation and action is established in the cycle [243]. The "knowledge to action cycle" is a process which is made up of two phases; the first phase is a triangle known as the knowledge creation, which is encircled by the second phase known as the action cycle. A description of an application of this model to a known medical issue: improving the use of dysphagia screening assessments in people with neurological conditions based on the findings of this study is proposed below (Figure 5.1), to enable the translation of knowledge gained from this study to be applied.

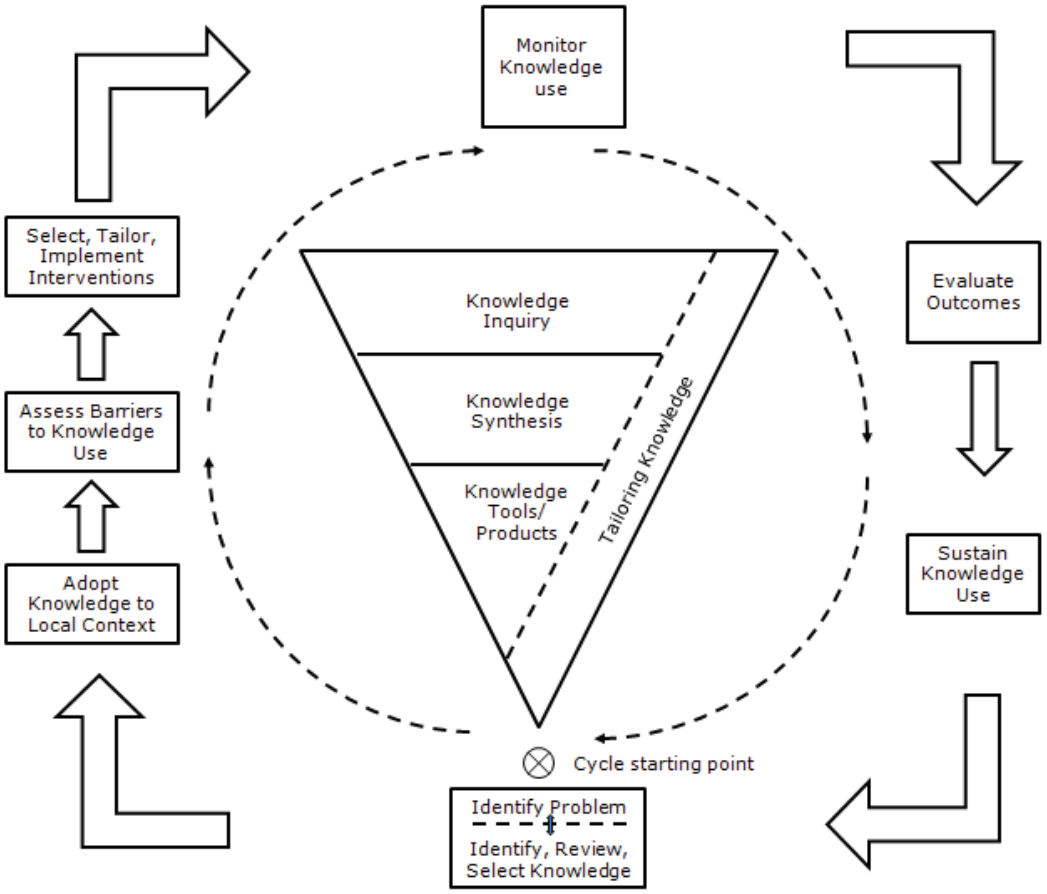

Figure 5.1 The Knowledge-to-action cycle [243]

i) Identify the problem

Dysphagia occurred in 82% of hospitalised patients with neurological conditions in this study which was consistent with findings from previous studies [231]. The present study also noted that 77% (n=101) of patients who were not screened initially in the first week of their admission, had unidentified dysphagia. The majority of the patients had an increased risk of aspiration pneumonia, prolonged length of hospital stays, hospital-acquired pneumonia, hospital-acquired infections, malnutrition and mortality. Several factors were identified as causes of increased risk of dysphagia including old

age and severity of the neurological condition. Strategies for early identification of dysphagia have been shown to be successful in neurological conditions but are often under utilised. Since various factors can contribute to the development of dysphagia in neurological conditions, swallowing rehabilitation interventions, development and implementation of guidelines appear effective in its detection and management [14, 53-54,106,184].

Development, implementation and sustainability of guidelines in neurological conditions may be a huge challenge in the clinical setting. An approach based on the knowledge-to-action cycle (Figure 5.1) would provide the opportunity for relevant clinicians - ward managers, medical doctors, occupational therapists, rehabilitation specialists, physiotherapists, speech and language therapists, nutritionists, dysphagia trained nurses, healthcare staff and nurses to come together as the target audience for knowledge translation.

ii) Knowledge creation

In the middle of the knowledge-to-action cycle is a triangle, which is known as knowledge creation. As knowledge travels down the triangle, it is synthesised and develops to be more of a resource to the population in need [243]. At each phase of knowledge creation, knowledge creators tailor their actions to the needs of the target population. With this model, researchers and clinicians can identify the results of studies on dysphagia assessments in people with neurological conditions (for example, results of this present study) and use them as a reference for the action cycle.

iii) Adapt knowledge to local context and assess barriers to knowledge use

The action cycle centres on the processes that would be required to enable the implementation of knowledge in clinical settings, including identifying problems; reviewing, selecting, tailoring, implementing and monitoring the use of knowledge, assessing interventions for knowledge translation and discovering approaches that guarantee sustained knowledge use [243].

In this study, for example, it was revealed that 77% of patients with chronic progressive neurological conditions were found to have undetected swallowing problems. This suggests that currently patients with neurological conditions (except stroke) are not screened routinely for dysphagia when admitted to hospital and consequently, dysphagia may not be identified or managed promptly. As a result of this finding, a proposal to conduct routine dysphagia screening and provision to meet continuous educational needs in swallow screening assessments for clinicians is therefore presented. The interviews among clinicians were used to affirm the evidence from the knowledge creation phase and enabled the discussions of any barriers to the use of this knowledge in their clinical setting.

Several barriers were identified from interview study (section 5.3.2) and these barriers would be used as the backbone for this discussion. One of the most important barriers reported was lack of dysphagia guidelines/pathways for people with neurological conditions. Development of dysphagia guidelines for this population or adoption/modification of the stroke guidelines was proposed, to prompt early and routine screening of swallowing capacity. The anticipated effect would be an increased workload on the speech and language therapists

(SLTs), therefore proposals for increased funding to recruit more SLTs and training of clinicians were also made. Furthermore, future studies that would show economic savings amongst other health benefits by having more speech and language therapists would also be required.

iv) Select, Tailor, Implement Interventions

Given the success of routine dysphagia screening, development and implementation of dysphagia guidelines in stroke and evidence of improved outcomes, it is our expectation that similar results would be obtained in patients with chronic progressive neurological conditions. Therefore, dysphagia screening should be conducted routinely for people with these conditions and the guidelines applied to existing dysphagia management in hospitals. This would increase awareness and serve as a guide on dysphagia screening for clinicians (particularly nursing staff) when people with long term neurological conditions are admitted to hospital. Other strategies that will assist in overcoming specific barriers include educational training (on water swallow test for nurses especially in MAU, though this changes knowledge and not behaviour) which is also tailored to address any hospital barriers. Time to administer SSA would also be considered by creating check lists for patients with neurological conditions, to ensure that they have had a SSA done and determination of when a SSA could be included during an acute admission process in MAUs. It is also important to identify people whose influence within the hospital, to affect the routine swallow screening in this population. Also known as champions, ward managers, MAU consultants and SLTs could be employed in this capacity.

v) Monitor Knowledge Use

Monitoring the use of knowledge for recognition and prevention of complications from dysphagia is the next phase of the action cycle and various approaches were considered. One of the difficulties here is trying to implement an innovation (for example routine SSA and guidelines) and then not following it up. The theoretical use of knowledge describes changes in knowledge, understanding, and attitudes [243]. People can easily learn to do something but knowledge alone cannot translate to organisational change [243]. Having regular discussions with clinicians to clarify their experiences and difficulties with sustainability and strategising how the implementation of the routine SSA and dysphagia guideline/pathway in neurological conditions is progressing would be a way to monitor knowledge use. Strategies such as the use of electronic educational devices and regular seminars or workshops on dysphagia screening would also be employed. Another approach is to implement an actual change in behaviour or practice outcome measures e.g. measuring outcomes at a different level and determining the desired outcome.

vi) Evaluate outcomes and sustain knowledge use

Evaluation of the outcomes of routine dysphagia screening in people with neurological conditions could be carried out at three levels: the patient level, clinician level and organisational or hospital management level. For example, data could be collected from patients who received an intervention (such as routine SSA and implementation of a dysphagia guideline) for a year and then compare with the findings of this study. Alternatively, data could be collected for that from one year before intervention and for one year after intervention (routine SSA and implementation of guideline). This would enable comparison

of outcomes in the same patients. This approach may be limited because of time, equipoise, ethics and change overtime due to the progressive nature of these conditions. Having regular audits may be another useful method of evaluating of outcomes. At the patient level, improvement in outcome measures such as reduced risk of aspiration pneumonia, shorter length of hospital stays (LOS), decreased susceptibility to infections, adequate nutritional intake, adequate hydration, reduced morbidity/mortality and satisfaction of care would be evaluated. At the clinician level, several things could be evaluated such as changes in decision making (production of guidelines for PD, MS and MD patients), efficiency of staff in recognising swallowing difficulties, conduction of SSAs and satisfaction with delivery of services.

At the organisational level, there will be a review of overall patients' outcomes such as improved swallowing safety, clinicians' efficiency at recognition and skill in screening of dysphagia. To maintain sustainability of knowledge use, some strategies have been considered, including reporting progress of outcome measures routinely (for example, re-evaluation of routine screening) and refining if not effective in neurological conditions, continuous educational training, multidisciplinary/ team meetings, identification of individuals accountable for continuing to update practice, support for staff who contribute positively to practice and financial support for attendance to courses and training as part of continuous professional development. This study is a good example of the knowledge to action cycle now being applied into practice.

In summary, to implement a change (knowledge translation to practice) such as a routine swallow screening assessment for patients with neurological

conditions when admitted acutely, these key factors should be considered: identification and tailoring strategies, understanding barriers, identifying the facilitators, identifying decision makers and fostering relationships and the implementation strategy.

5.6 Limitations

The limitations of the findings from the study presented in this thesis are discussed below. The limitations relate to ethical issues on recruitment, bias of the research, the generalisability of research findings from observational and interview studies, confounding potentials and limitations of the extent of the research.

5.6.1 Recruitment limitations

As stated earlier (section 2.2.3) initially recruitment was limited by the ethics committee to people who could consent to participate. Once approval was gained to incorporate people who lacked capacity to consent, the recruitment strategy was amended to focus on those who could not consent. Whilst there are advantages and disadvantages to this approach, it was necessary in order to ensure the final sample of participants recruited reflected the population.

There may be differences in recruitment rate, seasonal variations, and types of illness with which participants presented at the time of recruitment. This potential design problem was resolved by recruiting people who lacked the capacity to consent in the study with assent as well as those with capacity. The study was now an actual representation of both populations rather than a

skewed population, atypical of those who usually come into hospital with dysphagia, if the amendment had not been approved.

5.6.2 Limitations of observational methods

Participants in this study were studied collectively and also on the basis of whether they were assessed within or following the first week of admission. These participants were not randomised to different groups and they had different characteristics. In view of this it is not possible to make direct comparisons or to infer causal associations between the findings and the timing of the assessments. The decision not to randomise patients was due to several ethical and the practical constraints including the progressive nature of the conditions studied. The study tried to determine whether these patients irrespective of their different characteristics were assessed and any differences in management and outcomes within and after a week of their unplanned admission in order to provide an evidence base for routine SSA in these conditions.

The study used observational methods for determining whether patients were screened within or after the first week of admission. Swallow screening assessments were carried out by nurses and some by the researcher. In principle, these assessments may have been biased by the researcher whose theoretical approach could have affected the observation, analysis and interpretation of data. This may have resulted in the reporting of negative aspects of the patients especially if other methods of data collection were not employed. This was avoided however, because during the initial stages of the research, the researcher was taught to practice reflexivity to enable her to understand the biases that may have affected the correct interpretation of

what was observed. Also, the qualitative aspect of the research helped to explain or verify the results of the observational aspect of the study.

In this study, the expertise of the assessors (nurses and the researcher) was not considered which could have affected the results. However, it was thought that both assessors should have the requisite knowledge and skill to carry out a SSA and this was found not to be the case for the nurses in the interview study. This also contributed to bias and was a limitation of the observational study. Preconceived groupings may have been imposed from the researcher's theoretical perspective in the study, instead of allowing them to emerge from the population under study. Researcher bias is one of the aspects of observational research that has led to the opinion that observational research may be subjective. Therefore, the quality of patients correct observations depend on the skill of the researcher to observe, document, and interpret what has been observed.

Another limitation is that the SSA tests were not compared with VFSS. The study showed that the SSA tests detected dysphagia and were found to have a sensitivity of 95% and specificity of 33%. However, in the acute phase of neurological illness an important concern is whether there is a risk of aspiration or not and if oral feeding was appropriate. This would be possible to detect by conducting a VFSS. Although a thorough examination of swallowing may be necessary in patients with neurological conditions, it is usually problematic to subject these patients to such procedures. VFSS may have greater importance in patients with persistent dysphagia, bearing in mind that in some neurological conditions such as stroke, swallowing mechanisms recover in the majority of patients within two to three weeks of acute onset as discussed previously. In addition, the clinical importance of conducting VFSS

in all patients could be debated, as the clinical bedside signs of aspiration have been shown to predict the development of pneumonia as well as VFSS. [48]

5.6.3 Limitations of the use of data from the coding department

The total number of patients with PD, MS and MD who were admitted within a one year period was obtained from RDH in order to calculate the sample size for the study. Specific instructions were given to the coding department to avoid double counting (re-attendance) in order to minimise errors in the data. Problems associated with this approach such as incorrect entry of codes especially if the codes are complicated or unfamiliarity of the codes, obscuring of data, re-attendance and coarsening of data may have affected the accuracy of the data obtained from the coding department. However, the decision to obtain data from the coding department was based on the premise that data from the coding department may comparatively be accurate and provided a method of obtaining the data required about these conditions in the absence of other sources of data.

5.6.4 Potential Sources of Bias

In the observational aspect of the study, the screened group contained 34% of patients screened within the first week of admission while the unscreened group had 66% of patients who were later screened after the first week of admission. There could have been the possibility of selection bias in this sub-set of patients by the usual care team. Clinicians screened only patients whom they felt were at risk of aspiration or were suspected to have dysphagia due to the symptoms they presented, resulting in some bias in the sub-sets. However, it should also be pointed out that dysphagia screening should ideally

be conducted for all patients whose conditions are at risk of dysphagia. Thus, participants who were screened after one week were generally not screened earlier because it was felt they were not at risk and did not present with symptoms suggestive of dysphagia. It may be appropriate that the majority of the patients screened earlier on admission had dysphagia and were suspected to be at risk of aspiration pneumonia.

Lead time bias is another potential confounding factor in any screening study which is inevitable. Although the patients who were screened within one week of admission may have had their dysphagia diagnosed early, this study did not establish that early diagnosis was associated with increased survival. Also, there may be some length of time bias in which those with the early or mild forms of dysphagia are detected when screened because they have not developed full blown dysphagia, which invariably led to better outcomes. This was observed in patients who were screened after the first week of admission in the study.

In the observational study, gender bias may have had its own contribution. Out of 200 participants recruited, there were only 84 female participants and the remainder were all male. The gender ratio (male to female ratio) for these conditions is PD (1.5:1), MS (1:3) and MD is negligible. The expected number of female participants for these conditions was 88. From the study, though the number was close to as expected, it was uncertain to what extent the results would be generalisable to females with neurological conditions.

The quality of the interview data was partially dependent on the memory of the interviewees and this could have introduced re-call bias. Similarly, the

clinicians may have intentionally responded to some questions incorrectly, resulting in a response bias. Also clinicians who were interviewed were likely to be interested in that area thereby over estimating the extent of their knowledge or the knowledge of the people. Therefore, they may not have been a true representation of the greater population of clinicians.

5.6.5 Generalisability of the Findings

Another concern to highlight in this study is the disappointingly small number of patients who had swallow screening assessments. It is possible that patients were screened but the outcomes were not documented. Of 200 participants included in the study, only 34% were screened by ward staff within the first week of admission. This was as a result of many factors including the lack of research evidence to support routine swallow screening within the PD, MS and MD population, lack of training and confidence amongst clinicians and the availability of only a small number of the speech and language therapists offering services within working hours and none at all during out-of-hours.

In general, those with neurological conditions tend to have multiple co-morbidities, making standard hospital care difficult to achieve. Although PD, MS and MD populations in this study had the advantage of full NHS care, many of the participants did not come to the hospital until their dysphagia had worsened and they were at risk of aspiration. This would probably also be a problem in the implementation of routine swallow screening for patients with neurological conditions. These findings may be generalisable to these two hospitals (RDH and QMC) and possibly to all NHS hospitals in the UK. It does not extend well to patients with MD as the numbers were too small but the

principles are similar, so it is at least useful information. However, with the right training and awareness programmes, screening for dysphagia in neurological condition could be a valuable policy. The reader should therefore interpret the findings from this study carefully.

5.6.6 Confounding Variables

The practicalities of the study involved patient agreement being sought initially by the usual care team on admission and the initial review being undertaken within the first 24 hours or week (which also allowed the 'usual care' to proceed with their management). Reviewing participants at seven days enabled a swallowing questionnaire and swallow screening assessment/referral to be completed if it had not been carried out previously. This could have introduced the possibility of confounding potential for knowledge of the study itself by the usual care team (and involvement in recruitment/consent of patients) to influence 'usual practice' on admission.

This, of course, would have reduced the potential to observe differences between study sub-sets. However, this was not the case because the busy nature of the medical assessment units (MAUs) could not allow an immediate change in 'usual practice' to occur.

5.6.7 Scope of the Research

The primary reason for the study being carried out was to determine if dysphagia was identified or overlooked when patients with neurological conditions are admitted to hospital and to assess the impact of this practice on the treatment that followed and its outcomes. It was also hoped that

anomalies in practice would be reduced if the findings were shared with clinical colleagues and if they had an influence on policy.

As MAUs are usually very busy working environments, it was anticipated that dysphagia screening may be neglected while patients are in hospital. While the study has been able to inform readers of how many patients who were screened for dysphagia within the first week of admission, it was not able to establish that early screening led to increased survival (though the study was not designed for this purpose). The findings from the observational data indicated that dysphagia screening with the water swallow test may be an easily accessible method which could be used to screen people with chronic progressive neurological conditions and enable dysphagia guidelines/pathways to be followed. However, more studies are necessary in this field. For example, although the stroke guidelines for dysphagia diagnosis are generally accepted and clinically practicable, some hospitals may not be willing to apply these guidelines unless the patient has a recognised swallowing problem. This raises the contentious issue of cost and risk. It is not known if early detection of dysphagia based on routine swallow screening would prevent the risk of aspiration and premature death? If this hypothesis was supported by research evidence, then screening every patient with a neurological condition would require more dysphagia trained nurses and speech and language therapists, which would invariably cause an increase in costs but would probably decrease the risk of aspiration. Without screening the costs associated with complications arising from unrecognised dysphagia (e.g. increased LOS) would probably be higher.

In the USA, the cost of complications from untreated dysphagia in hospital inpatients was estimated in 2002 as 15 billion dollars [87]. However, the cost effectiveness of dysphagia screening, which is a vital component in any screening study, was not accounted for in this study. The findings from the study do not prove that dysphagia screening will affect survival or could increase survival time. Furthermore, the study could not determine the effect of time of entry to the study on patient outcomes, especially in those patients who were recruited later in the study. These are very important factors relating to swallow screening assessments in neurological conditions and need careful consideration. This may be perceived as a limitation if not considered fully. However, due to the vast nature of this area of study and the time frame for study completion, it was not possible to examine these factors.

5.7 Recommendations

This study sought to determine the use of dysphagia screening and assessment procedures amongst people with PD, MS and MD when they have an unplanned admission to hospital. The main reasons for not conducting routine swallow screening assessments (SSA) have been highlighted. From the findings of both studies, it is necessary to draw attention to important areas of intervention and future research to commissioners, knowledge brokers, health providers, clinicians and health professional bodies. Before implementation, there is a need to examine whether the strategies detailed in the recommendations would be effective for routine SSA in patients with neurological conditions. The findings from the research may have given the impression that interventions in these areas would be beneficial but they do not confirm they would be beneficial. Eight major recommendations

concerning swallow screening assessment and future research in neurological conditions have been drawn from this study and these are discussed below. Of the eight recommendations, four were made from the observational data and four from the interview data.

5.7.1 Recommendations arising from the Observational Findings

1) Development of guidelines/pathway for neurological conditions

All clinical groups caring for patients admitted to hospital have an interest in ensuring good care of their patients. To achieve this they need to be up to date with current evidence-based practice. Screening for dysphagia in patients with neurological conditions when admitted to hospital was found to be inadequate in this study, indicating a problem with guidance as to expectations for dysphagia management for patients. Policy-makers may want to consider the development of a dysphagia guideline or pathway of care for patients with these conditions to improve and standardize the quality of their care, while reducing complications associated with missed dysphagia. Guidelines or pathway development in these conditions would be seen as a means of support to the implementation of this evidence. It would also serve as a benchmark for evaluating the management of dysphagia in neurological conditions.

2) Re-assessment of swallowing in patients with neurological conditions

A large number of patients admitted to hospital were noted to have unrecognised dysphagia from the observational data obtained. Patients who are likely or suspected to have dysphagia should have their swallowing re-assessed as an important aspect of the admission process. This can be achieved using a standardised bedside screening test to identify patients at risk to be referred for a more comprehensive assessment. It would further ensure that patients' nutrition and hydration needs are met on time. Re-assessment of swallowing in patients who were not screened within the first week of admission may have aided them towards better outcomes. Likewise, implementing a re-assessment of swallowing as a routine in all patients with neurological conditions would be beneficial.

However, as discussed previously (section 5.2.2), it would be necessary to evaluate the risks of implementing routine dysphagia screening in this population to determine the appropriate screening approach for patients. A randomised controlled prospective study, conducted over 5 years in the neurological population, on the general survival rate for patients with these conditions who had dysphagia screening within the first week of admission and those not screened (but would receive screening later after one week) could be very informative. The study would be useful to compare survival, dysphagia detection and the stage of dysphagia at detection. However, this may be difficult to achieve due to ethical issues and the progressive nature of these conditions. More observational studies may be required in this area. Future research would also be needed to determine if there are any

differences in the medical staff who conduct swallow screening assessment in relation to 'accurate' identification of patients with dysphagia.

3) Examine the impact of having limited speech and language therapist services at RDH and QMC

The limited availability of speech and language therapists in both hospitals was responsible for the prolonged waiting time for assessments of dysphagia in stage one. In the interview data, the limited number of these therapists was also noted as a concern by the clinicians interviewed. The creation of specialised units for PD at RDH and QMC may therefore be having an impact on dysphagia awareness and early SLT services for patients with this condition in these wards.

Although the limited SLT cover was found to have led to several delays in assessment of dysphagia in the observational aspect of the study, it is likely that the limited SLT service will be affecting not only patients with PD, MS and MD but also those presenting with other acute neurological conditions or non-neurological causes of dysphagia. As discussed previously, 70%-80% of elderly patients with neurological diseases present with some form of swallowing problems and an estimated 94% of these patients are diagnosed with aspiration following dysphagia. [34-35] In the observational aspect of the study, most of the patients who had swallowing difficulties were also elderly.

More research would be required to determine the number of patients whose swallowing deteriorated and had complications whilst waiting for SLT assessment. If this evidence is established, provision of funding for

recruitment of more SLTs would be justified. Furthermore extending the SLTs assessment priority list to include patients with neurological conditions would provide an immediate solution to delays in assessing these patients. Dissemination of the findings from this study to both hospitals would be useful to aid the provision of resources for the management of patients with dysphagia.

4) Extend the admission document to include a question within the nutritional section on swallowing difficulties

There appears to be some problems with the identification of the nutritional needs of patients with swallowing difficulties. Feeding difficulties are a marker of dysphagia and disease progression in people with neurological conditions. Swallow screening questions are designed to determine the oral status of a patient and look for any symptoms or complaints of swallowing problems. It was observed in this study that the absence of questions on swallowing within the nutritional section in the admission document may also be responsible for non-recognition of dysphagia. The hospital management team should consider the inclusion of swallow screening questions in the admission document which could direct the admitting clinician's thoughts on a patient's swallowing safety and possible nutritional intervention when completing the nutritional section of the document. An audit may be required to determine the benefits of this new addition to the success of identification of patients at nutritional risk.

5.7.2 Recommendations arising from the Interview Findings

1) Determine the benefits of having speech and language therapist (SLT) services extended to out-of-hours.

One of the major causes of patients with neurological conditions not being assessed was a delay in the provision of SLT services. These are unavailable at the weekend, except for stroke patients. Extending the services to include a weekend SLT provision may have aided the assessment of patients identified with swallowing problems in this study, rather than making them nil by mouth until the next working day. Health commissioners should ensure that these services are in place during out-of-hours (weekends and bank holidays) so patients with neurological conditions can have their swallowing assessed by the SLTs so that on-going management plans for adequate oral intake may be implemented by the usual care team. However, this would require additional funding and therefore, it would be necessary to conduct further research to justify the need for out-of-hours of SLT services.

2) Examine the feasibility of employing a systematic approach for training health professionals on swallow screening assessments.

One of the key findings of the interview research was that major barriers to swallow screening assessments were a lack of knowledge and skills regarding swallow screening methods, lack of confidence to conduct dysphagia screening, deskilling due to lack of use of knowledge, fear of conducting swallow screening assessment and accountability. Clinicians made three recommendations as to how swallow screening assessments could be improved.

a) To develop a systematic approach where all health professionals would be trained to screen for dysphagia, initiate early intervention and refer appropriate patients to the speech and language therapist for a full assessment and further management.

b) To use a uniform training package/programme across all wards to ensure that the correct knowledge on screening tools and methods for swallow screening assessments are taught and consistent across all health professionals. Mechanisms would also be instituted to ensure that regular update courses were provided and skills maintained to avoid deterioration of clinical standards.

c) Employing the use of dysphagia trained nurses (DTNs) to undertake the training of health professionals would enable the speech and language therapists (considering that they are only few of them available in each trust) to have more time for their referrals and assessments of patients. It may also considerably reduce the cost.

3) Consider clinical initiatives to address dysphagia screening in neurological conditions

The findings from the study represent the views of a sample of clinicians in two hospitals. Clinicians recognised that there is lack of evidence of screening in this population. Therefore continuous quality improvement monitoring of dysphagia screening, for example by having regular audits, should be considered by hospital administrators. Other initiatives such as the identification of the most suitable time for screening and the most appropriate person to conduct SSA in patients may also be achieved from this process.

4) Consider research initiatives to address dysphagia screening in neurological conditions

Clinicians thought that the lack of research evidence on appropriate swallow screening tools for people with neurological conditions affected their dysphagia management. This is because most of the screening tools have their evidence based from stroke patients. Commissioners and agencies funding rehabilitation research should prioritise and support dysphagia screening and outcomes research in people with neurological conditions. The complexity of these conditions makes it impossible for a single individual to find a solution to this problem, therefore, interdisciplinary research collaborations that would address the issues of dysphagia in this population may be beneficial.

These conditions are known to be a drain on an overburdened healthcare system and are poorly understood, under-recognised and, as a result, may be mistreated, even by experienced clinicians. [110,244] There is therefore an urgent need for increased research funding into these debilitating conditions. A Committee involving clinicians and researchers in rehabilitation, administrators and funding bodies should be created to examine the research support and care given to dysphagia in neurological conditions (PD,MS and MD). The Committee should also focus on reducing the burden of these conditions through developing new and effective management and prevention to reduce the economic and health burden of these conditions in the United Kingdom.

5.8 A Reflection on the Research Challenges

There are a number of challenges which l experienced during the course of completing my PhD. A reflection on these challenges, and the lessons learnt from overcoming them, was thought to be a useful part of the process of completing this thesis.

The aim of the first part of the study was to describe the use of dysphagia screening and assessment procedures amongst people with PD, MS and MD when they have an unplanned admission to hospital; this presented a number of challenges.

The first study challenge was obtaining ethical approval for the study. As discussed previously (section 2.2.3) ethics approval was limited to patients who could consent for the study. This was a great challenge because l could not obtain consent from most of the patients and I had to consider the limited time available to complete the study. A first substantial amendment to include those whose assent could be obtained was made to the Ethics Committee, which took more than three months to review and yet it resulted in a failed amendment. The determination to continue recruiting participants for the study and to re-apply for another amendment increased with the support from my supervisors, thereby making the difficulties look less substantial. The second amendment from Ethics was successful, making recruitment easier, though it came through at the later stage of the study. This is one aspect of the study that I am extremely proud of, that by working with highly experienced supervisors in the field of disability research, with their wealth of knowledge and expertise l was able to overcome these hurdles.

As discussed above there were a number of difficulties in the recruitment of patients. Due to problems with recruitment it was relatively clear from the onset that the sample size calculated would not be obtained within the time frame allocated for the study. This resulted in the re-calculation of the sample size, based on the data collected. Although the study met the required sample size after the post hoc analysis, it would have been better to have a larger initial sample to increase the validity of the study.

There was also the challenge for study participants especially PD patients whose tremors made it difficult for them to hold a pen comfortably, of completing the consent form. To overcome this challenge, l gave the participants with this difficulty a special pen with a broad base that enabled them to have a better grip when completing the form.

The interview element of the study involved recruiting clinicians to take part in the study. There were challenges in recruiting clinicians to take part in the semi-structured interviews and l had become more aware of the limited time available for clinicians during the course of the PhD. This challenge was overcome simply, by trying to meet with any appointments suggested, though on several occasions these appointments had to be re-scheduled for a later date. Continuous efforts with the invitations to take part were made, until the required sample was achieved and the interviews conducted successfully.

The aim in examining the factors that influence a clinician's decision to assess for dysphagia when people with neurological conditions are admitted to hospital was achieved. However, this resulted in more time being dedicated

to this aspect of the study which was not allowed for in the original study plan. It was difficult to assess a method which would have prevented these difficulties from occurring as allocating sufficient time for recruitment of clinicians was the only available option. However, there were inevitable difficulties in some specialties, for example the SLTs, who are very low in numbers in the hospital with an extremely busy work schedule and standard hours; getting a convenient time and date was not always possible.

Overall, the highest challenge of the PhD was to make sure that the study remained focused. As described throughout the thesis, the health care system is extremely complex. The findings highlighted in this study demonstrate the extent of this issue as it relates to the patients, clinicians and organisations and the time invested in planning the study has therefore been substantial. I have learnt many important lessons during the period of my study and l am very grateful to all those who have taken part or contributed in any way to the successful completion of the research.

5.9 Addition to the Body of Knowledge

This study adds to the body of knowledge on the limited evidence available in the area of dysphagia assessment in people with chronic progressive neurological conditions. The novel study presented in this thesis addressed the gaps found in the literature and broadened the research objectives. No other study has investigated the prevalence of dysphagia in people with PD, MS and MD during their unplanned admissions to hospital, nor is there any other known study which has merged the findings from three major aspects of

dysphagia (assessment, management and outcomes; Chapter 3) in people with these neurological conditions globally.

This research provides useful clinical knowledge on dysphagia management and outcomes. It highlights in people with these neurological conditions the consequences of a lack of routine dysphagia screening, such as aspiration pneumonia and untimely death. This information is very important to health care professionals, governing bodies, funding agencies, researchers, people with neurological conditions and their carers. The contribution of this study as an addition to the body of knowledge is discussed below:

The study presented in this thesis applied the ICF disablement framework. It therefore provided a comprehensive description of dysphagia screening and assessment procedures in neurological conditions. To date previous studies have investigated dysphagia screening and assessment procedures in a specific neurological condition. No studies have sought to examine dysphagia screening and assessment procedures in acute medical admissions for people with neurological conditions, nor have they attempted to provide explanations for decisions to assess for dysphagia when there is an unplanned hospital admission for this group of patients. The study presented here is therefore unique in several ways and the findings have implications for clinical practice as discussed below.

This study has revealed emerging evidence of possible under-recognition and consequent under-management of dysphagia occurring in patients with neurological conditions. This study provides emerging evidence for screening, potential barriers and suggestions for appropriate management of dysphagia

in neurological conditions. Once this study is established by other studies in the future (for example ,randomised controlled studies or other observational studies), these initial findings would most likely have direct implications on clinical practice and subsequently guidelines, pathways and national policies on dysphagia for people with these conditions. With an increased evidence base, perhaps dysphagia screening and assessment procedures for people with neurological conditions will be recognised within multi and interdisciplinary team intervention strategies.

Eight recommendations were made from the study that may be useful for improving dysphagia screening and assessments in people with neurological conditions, making this study distinctive.

This is the first study using qualitative methods to explore clinicians' perspectives on swallow screening assessment in patients with chronic progressive neurological conditions. The use of semi-structured interviews made it possible to obtain the views of clinicians involved in the usual management of these patients.

A major contribution of this study to the body of knowledge is the provision of new prevalence data on dysphagia in 'acute medical admission'. As discussed in Chapter 1 section 1.2.2, previous studies have not examined the prevalence of dysphagia in a heterogeneous 'acute medical admission'. The majority of the prevalence data on dysphagia is from stroke studies; only a small number of studies have examined prevalence of dysphagia in neurological conditions.

In summary, the unique contributions of these studies therefore are: revealing the under-recognition and management of dysphagia in neurological conditions; examination of the reasons behind the decisions to conduct SSA in these conditions; use of semi-structured interview methods; inclusion of a clinician perspective; examination of the prevalence of dysphagia in acute medical admissions; and recommendations for improved quality care.

5.10 Conclusions

Dysphagia intervention strategies aim to reduce the risk of aspiration in vulnerable populations such as neurological conditions by the use of swallowing rehabilitation. [185-186] However, the use of dysphagia screening and its prevalence in neurological conditions must initially be established in order to enable provision of evidence-based management interventions.

The literature review for this study showed that there was a need for research to provide this initial evidence. This study began by assessing the use of dysphagia screening and assessment procedures amongst people with PD, MS and MD when they experience an unplanned admission to hospital. This study was then extended, to determine the factors that influence a clinician's decision to assess for dysphagia in people with these conditions. It therefore represents a holistic examination of the management of dysphagia in neurological conditions.

Clinical observations in the study enabled the confirmation of this neglected research need within the neurological population. The study has found that dysphagia screening and assessment procedures in patients with neurological conditions were not carried out routinely and lacked consistency in practice. Failure to identify patients with swallowing impairments whilst they were inpatients led to delays in the provision of early dysphagia management and swallowing rehabilitation. Selective screening by clinicians contribute to unrecognised dysphagia and poor patient management. This is most probably due to the lack of a recognised dysphagia pathway in these conditions.

Those who were most likely to have SSA were those who presented with dysphagic symptoms or were known to have had dysphagia previously. Due to the complexity of neurological conditions, other multiple co-morbidities can contribute and complicate dysphagia when present.

Psychological and social factors influence the patient's attitude to their dysphagia and this is explained by the ICF model of health (section 1.12.2). The possibility of clinicians overlooking dysphagia in these conditions (except when it becomes full-blown) in the patient is to be expected, as is revealed in this thesis.

A lack of skill and knowledge of SSA (e.g. using the basic screening test of a water swallow) has affected the confidence of many clinicians, preventing appropriate dysphagia screening in patients with these conditions. Provision of training on SSA for clinicians is therefore central to ensuring that their confidence to conduct SSA is restored. The clinicians' perceptions of the

difficulties encountered when conducting SSA in this population and suggestions of possible solutions to these difficulties were gathered from the study.

The overarching problem appears to be the limited number of SLTs available to perform a full swallowing assessment when the patient requires one. Sub-optimal provision and the necessity to prioritise SLT services in the hospital have had an additional cumulative effect on the time delays between patient referral and SLT reviews. Response time is dependent on the number of SLTs available and the number of patients classified as a priority. The situation is worsened during the weekends and at bank holidays, when SLT services are not available. The shortcomings in this service provision are obvious to all clinicians and are preventing patients from receiving proper and timely management of their dysphagia. A substantial increase in funding would be necessary to provide a more efficient SLT service for patients with these conditions. However, with the financial burden on inpatient care for people with neurological conditions, there may be difficulties in obtaining approval for additional funding. It is therefore essential to engage people who can champion this cause, to make an effective presentation for more funding and the inclusion of neurological conditions amongst prioritised conditions.

This study has shown the importance of routine SSA and guideline/pathway development in neurological conditions to enable early, holistic dysphagia management. This study has also revealed emerging evidence which suggests that dysphagia is prevalent in acute medical admissions; however, larger study samples would be required to confirm these findings. Again, this is subject to the availability of funds which has also affected the evidence

gathering in this area. Governing bodies should prioritize disability research in this field.

It is hoped that this study has provided useful actions that will enable development of a model of rehabilitation of dysphagia in neurological conditions.

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APPENDICES

Appendix 1. Summary of Causes of Dysphagia

The aetiology of dysphagia is multi-factorial and has been grouped into different classifications: oropharyngeal, oesophageal, functional and others which are further subdivided into neurological, muscular conditions, mechanical obstruction and congenital causes [2]

a) Oropharyngeal dysphagia

Neurological causes – stroke, PD, MS, MD, brainstem tumours, amyotrophic lateral sclerosis, Huntington's disease, myotonic dystrophy, occulopharyngeal dystrophy, myasthenia gravis, peripheral neuropathy, Bells palsy, pseudo bulbar palsy, dementia. *Muscular conditions (myopathies)* - polymyositis, dermatomyositis. *Congenital causes* - learning disability (LD), cerebral palsy. *Mechanical obstructive causes* - tumours, inflammatory masses, anterior mediastinal masses, extrinsic structural lesions, cervical spondylosis, traumas or surgical resection, Zenker's diverticulum [2].

b) Oesophageal dysphagia

Neuromuscular causes- achalasia, scleroderma, spastic motor disorders, nutcracker oesophagus, diffuse oesophageal spasm, Hypertensive lower oesophageal sphincter. *Mechanical obstructive causes*- tumours (ca oesophagus, ca larynx, ca thorax, mouth ca), strictures, intrinsic structural lesions, extrinsic structural lesions, lower oesophageal rings (Schatzki's ring), oesophageal web, foreign bodies, radiation induced, chemical induced, medication induced, vascular compression, peptic oesophagitis, pharyngeal

pouch, candida oesophagitis, oesophageal leiomyoma, systemic sclerosis, gastro-oesophageal reflux disease, tuberculosis [2].

c) Functional dysphagia

This is a term used to describe dysphagia where there is no known organic cause but can be classified as oesophageal dysphagia. Examples include achalasia, myasthenia gravis, bulbar or pseudo bulbar palsy, systemic sclerosis. [2]

d) Other causes of dysphagia

Respiratory pathologies have been associated as a cause of dysphagia such as chronic obstructive air way disease [3].

Appendix 2. Electronic search strategy

Table A: **Search Strategy for MD: OVID Medline, EMBASE, CINAHL, AMED, British Nursing Index and Cochrane Databases**.

No.	Searches
1	Deglutition disorders .mp [mp=title, original title, abstract, name of substance, subject heading, unique identifier]
2	Dysphagia.mp. [mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
3	Oropharyngeal dysphagia.mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
4	Neurological dysphagia. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
5	Neurogenic dysphagia. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
6	Swallowing dysfunction.mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier].
7	Swallowing problems. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
8	Feeding problem. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
9	Swallowing impairment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	Neurological. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
12	Neurological disease. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
13	Neurological illness. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier
14	Neurological conditions. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
15	Neuromuscular conditions. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
16	Neuromuscular disease. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
17	11 or 12 or 13 or14 or 15 or 16
18	Assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
19	Dysphagia assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
20	Swallowing assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
21	Water swallow. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
22	Water test. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
23	18 or19 or20 or21 or 22

24	Hospital admission. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
25	Medical assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
26	Medical assessment unit. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
27	Medical decision unit. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
28	Inpatient. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
29	In-patient. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
30	Inpatients. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
31	Inpatient's. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
32	24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
33	Muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
34	Myodystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
35	Myopathy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
36	Muscle atrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
37	Corticobasal degeneration. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
38	Becker muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
39	Congenital muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
40	Distal muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
41	Duchenne muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
42	Emery-dreifuss muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
43	Fascioscapulohumeral muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
44	Limb-girdle muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
45	Myotonic dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
46	Oculopharyngeal muscular dystrophy. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
47	33 or 34 or35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46
48	Prevalence. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
49	10 and 47 and 48
50	10 and 23 and 32 and 47
51	10 and 23 and 47

52	10 and 17 and 47
53	32 and 47 and 48
54	49 or 51 or 52 or 53
55	Limit 54 to (English language and humans and 'all adult(19 plus years)')

Table B: Search Strategy for PD: OVID Medline, EMBASE, CINAHL, AMED, British Nursing Index and Cochrane Databases

No.	Searches
1	Deglutition disorders .mp [mp=title, original title, abstract, name of substance, subject heading, unique identifier]
2	Dysphagia.mp. [mp=title, original title, abstract, name of substance, subject heading, unique identifier]
3	Oropharyngeal dysphagia.mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
4	Neurological dysphagia. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
5	Neurogenic dysphagia. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
6	Swallowing dysfunction.mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier].
7	Swallowing problems. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
8	Feeding problem. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
9	Swallowing impairment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	Neurological. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
12	Neurological disease. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
13	Neurological illness. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
14	Neurological conditions. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
15	Neuromuscular conditions. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
16	Neuromuscular disease. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
17	11 or 12 or 13 or14 or 15 or 16
18	Assessment. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
19	Dysphagia assessment. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
20	Swallowing assessment. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
21	Water swallow. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
22	Water test. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]

23	18 or19 or20 or21 or 22
24	Hospital admission. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
25	Medical assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
26	Medical assessment unit. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
27	Medical decision unit. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
28	Inpatient. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
29	In-patients. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
30	Inpatients. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
31	Inpatient's. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
32	24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
33	Parkinson's disease. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
34	Parkinson's disease. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
35	Parkinsonism. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
36	Parkinsonian syndrome. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
37	Parkinsonian disorders. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
38	33 or 34 or 35 or 36 or 37
39	Prevalence. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
40	10 and 38 and 39
41	10 and 23 and 32 and 38
42	10 and 23 and 38
43	10 and 17 and 38
44	40 or 41 or 42 or 43
45	Limit 44 to(English language and humans and 'all adult(19 plus years)')

Table C: **Search Strategy for MS: OVID Medline, EMBASE, CINAHL, AMED, British Nursing Index and Cochrane Databases.**

No.	Searches
1	Deglutition disorders .mp [mp=title, original title, abstract, name of substance, subject heading, unique identifier]
2	Dysphagia.mp. [mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
3	Oropharyngeal dysphagia.mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
4	Neurological dysphagia. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
5	Neurogenic dysphagia. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
6	Swallowing dysfunction.mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier].
7	Swallowing problems. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
8	Feeding problem. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
9	Swallowing impairment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	Neurological. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
12	Neurological disease. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
13	Neurological illness. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
14	Neurological conditions. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
15	Neuromuscular conditions. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
16	Neuromuscular disease. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
17	11 or 12 or 13 or14 or 15 or 16
18	Assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
19	Dysphagia assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
20	Swallowing assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
21	Water swallow. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
22	Water test. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
23	18 or19 or20 or21 or 22
24	Hospital admission. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
25	Medical assessment. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]

26	Medical assessment unit. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
27	Medical decision unit. mp.[mp=title, original title, abstract, name of substance, , subject heading, unique identifier]
28	Inpatient. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
29	In-patient. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
30	Inpatients. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
31	Inpatient's. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
32	24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
33	Multiple sclerosis. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
34	Disseminated sclerosis. mp.[mp=title, original title, abstract, name of substance, subject heading, unique identifier]
35	33 or 34
36	prevalence
37	10 and 35 and 36
38	10 and 23 and 32 and 35
39	10 and 23 and 35
40	10 and 17 and 35
41	32 and 35 and 36
42	37 or39 or 40 or 41
43	Limit 42 to (English language and humans and 'all adult(19 plus years)').

Appendix 3. Number of Titles and abstracts retrieved

	Ovid (Medline) Database Articles		Embase Database Articles		Cinahl Database Articles		Amed Database Articles		British Nursing Journal Index Articles		Total	
	Titles	Abstracts	Titles	Abstracts	Titles	Abstracts	Titles	Abstracts	Titles	Abstracts	Titles	Abstracts
PD	12	12	5	4	12	9	1	1	2	0	32	26
MS	9	9	4	4	6	4	2	1	1	1	22	19
MD	7	7	8	6	5	4	0	0	0	0	20	17

Appendix 4. Swallow screening and assessment methods

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Swallowing disturbance questionnaire (SDQ)	Manor et al. (2007) [115].	PD (n= 57)	Doctors Nurses Other health personnel.	<u>Merits</u> Can be routinely administered during clinical visits Subjective Comprehensible <u>Demerits</u> Not suitable for patients with dementia. Length of time to administer not considered.	80.5% sensitivity 81.3% specificity Reliability reported	Leve l 2	SDQ score of >11 should be referred for a more objective radiological assessment for dysphagia.
Repetitive oral suction swallow test (ROSS test)	Nilsson et al. (1996) [110].	PD (n= 75) Stage IV	Trained health personnel Doctors	<u>Merits</u> An objective method of assessing quantitative swallowing functions. Could be used for examining subclinical dysphagia <u>Demerits</u> Experience, knowledge and training are essential.		Level 2	Can be used as an indicator for requirement of further investigations into impaired swallowing.

Screening /assessment tools	**Author**	**Study population**	**Administrators**	**Merits & Demerits**	**Study outcomes** • **Valid** • **Reliable** • **Sensitive** • **Specific**	**Level of evidence**	**Authors suggestions & Future research directions by authors**
Exeter Dysphagia Assessment Technique (EDAT)	Pinnington et al. (2002) [55].	IPD (n=12) Compared with (n=14) Healthy subjects.	Trained health personnel. Doctors Nurses SLTS	<u>Merits</u> Detection of asymptomatic dysphagia. Observation of effects of dysphagia treatments in PD patients. An ideal outcome measure for interventional studies. Easy repeatability Suitable for dementia patients. Can be used as a bedside assessment tool. <u>Demerits</u> Requires skilled personnel for the test.	Reliability and validity examination were reported to be high.	Level 2	An important tool which could be used for observing the effect of treatment and disease patterns in PD patients. <u>Future research</u> To compare EDAT and VFSS for the detection of EDAT indicators of patients at severe risk of dysphagia. Evaluation of the reproducibility of EDAT in non-elderly and less homogeneous set of people with neurological dysphagia.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
3oz water swallow test and Pre-screening questions (25 item clinical assessment form)	Fabiola et al. (1997) [109].	Patients with neurological conditions. (n=93) PD (n=27) MS (n= 7) MD (n= 5) AML (n=6) CVA (n=28) TBN (n=7) ABT (n=13)	Doctors Nurses Other health staff	<u>Merits</u> Very cost effective. Straightforward method of screening. Able to detect patients at risk of aspiration. Easy and quick to use. Bedside screening. Could be used to direct swallowing rehabilitation for individuals <u>Demerits</u> Timing of assessment not determined. Not suitable for all patients.	3oz water test: Positive predictive value is 84% Negative predictive value is 78% Low sensitivity Pre-screening assessment: Sensitivity is 74% Positive predictive Value is 71% Negative predictive value is 77%.	Level 2	The water test and pre-screening questions can be used to direct individual swallowing Rehabilitation when radiological evaluation is not assessable.

Screening /assessment tools	**Author**	**Study population**	**Administrators**	**Merits & Demerits**	**Study outcomes** • **Valid** • **Reliable** • **Sensitive** • **Specific**	**Level of evidence**	**Authors suggestions & Future research directions by authors**
(RIC) Clinical evaluation of dysphagia. (Dysphagia rating scale)	Kennedy et al. (1993) [113].	PD (n=9) CVA (n=9)	Health personnel Nurses	<u>Merits</u> Easy to administer. Broad to accommodate methods used for bedside swallowing test. <u>Demerits</u> Interpretation of the scale may prove difficult some times. Physical examination-oral hygiene and posture not included. Limited to patients with cognitive problems.	Not reported.	Level 2	To develop better assessment methods which will serve where radiological test cannot be assessed. <u>Future research</u> Research on improvement of existing dysphagia screening or assessment methods.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Modified dysphagia rating scale (MDRS) (Based on Kennedy etal.)	Volonte et al. (2002) [114].	IPD (n=65)	Health personnel Nurses	<u>Merits</u> Detection of asymptomatic dysphagia Easy to administer Objective Can be used to assess patients' health conditions for proper management. <u>Demerits</u> Not suitable for patients who cannot take nor understand commands.	Able to detect 70% of IPDS with dysfunctional swallowing at the oral phase.	Level 2	Frequent dysphagia assessment for IPD patients.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Novel global rating scale	Clarke et al. (1998) [108].	IPD (n=64)	Health personnel Nurses	<u>Merits</u> Able to categorize patients into different treatment groups. Recognition of dysphagia for food. Determination of prevalence of dysphagia. Easy to administer and interpret. Could be used as a tool for direct referral to SLT. <u>Demerits</u> Patients with memory deficits are limited by this scale.	High sensitivity of 100% and High specificity of 75% for questions on swallowing difficulty with food. Low positive predictive value of 32% on problems of dysphagia for food.	Level 2	Routine dysphagia screening for patients with IPD. SLT referrals for further management should be made for those with dysphagia. Also suggested yearly assessment for IPD patients. <u>Future research</u> A comparative study of the results of SLT assessment and VFSS.

Screening /assessment tools	**Author**	**Study population**	**Administrators**	**Merits & Demerits**	**Study outcomes** • **Valid** • **Reliable** • **Sensitive** • **Specific**	**Level of evidence**	**Authors suggestions & Future research directions by authors**
Timed water test Pre-screening questions.	Nathadwara wala et al. (1992) [122].	Neurological patients. (n=81) MS (n=18)	Nurses SLTS	<u>Merits</u> Needs little or no tools for the test. Can be included as part of regular assessments for people with neurological conditions. Administration is fast. <u>Demerits</u> Not suitable for elderly population. Not suitable for those with severe swallowing problems. Cannot be used as a replacement for SLT or radiological assessment.	96% Sensitivity 69% specificity 60% positive predictive value of swallowing speed and negative predictive value of 40% Established reliability and validity	Level 2	Swallowing speed could be a useful tool for observation of progress of dysphagia management.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
DYMUS questionnaire	Bergamaschi et al. (2008) [119].	MS (n=226)	Nurses	<u>Merits</u> A special tool for identification of dysphagia in MS patients. Does not require training. <u>Demerits</u> Patients with severe dysphagia cannot benefit from the tool. Inability to account for duration of illness. Timing of administration not considered.	Validity and reliability examined and established.	Level 2	Valuable method of choosing patients who may require further investigations. <u>Future research</u> To examine if any relationship exists between questionnaire scores and instrumental scores. The reliability of DYMUS questionnaire compared to other methods of diagnostic assessment.

Screening /assessment tools	**Author**	**Study population**	**Administrators**	**Merits & Demerits**	**Study outcomes** • **Valid** • **Reliable** • **Sensitive** • **Specific**	**Level of evidence**	**Authors suggestions & Future research directions by authors**
John Hopkins Swallowing Centre questionnaire And MFS	De Pauw et al. (2002) [120].	MS (n=309)	Nurses Trained health personnel	<u>Merits</u> Objective assessment Ability to detect dysphagia <u>Demerits</u> Not suitable for patients with impaired memory. Training required.	Not reported.	Level 2	Radiological assessment such as MFS for MS patients, with EDSS of 7.5 if assessable. <u>Future research</u> Investigation of the extent of sensory impairment that could result in prolonged initiation of deglutition reflex.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Video Fluoroscopy Swallowing study	Pikus et al. (2003) [48].	Neurological patients including PD and MS (n= 381)	Trained health personnel such as a SLT and a radiologist	Merits Detects swallowing dysfunction accurately and provides information on the required treatment. Demerits An invasive procedur, not suitable for all patients, expensive, risk of exposure to radiation.	Validity and Reliability reported	Level 2	Findings on VFSS can be used to guide management of patients potentially at risk for pneumonia Further evaluation of screening methods of dysphagia, such as EDAT and DYMUS questionnaire against VFSS
Oesophageal Pharyngeal Manometry (OPM)	Sung et al. (2010) [160]	PD (n= 53)	Trained health personnel	Merits Useful information on upper oesophageal sphincter (UES) is relaxation for bolus passage, helping to direct treatment appropriately Demerits Experience, knowledge and training are essential.		Level 2	Improved quantitative assessment of the extent of pharyngeal weakness and deficiency in UES relaxation during swallowing can be achieved by computerized manometric methods.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Manofluoroscopy Study (MFS)	De Paw A. et al (2002) [120]	MS (n=30)	Trained health personnel	Merits Provides a clear picture of the pharyngeal phase of swallowing and pressure determination at any height in the pharynx. Demerits Llimited availability, the requirement for an appropriate contrast material, transport, aids during the procedure, long duration and the invasive nature of the procedure.	Reliability and validity examination were reported to be high.	Level 2	An important tool which could be used for observing the effect of treatment and disease patterns in MS patients.

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Fibreoptic Endoscopic Evaluation of Swallowing (FEES)	Langmore et al.(1998) [161]	Patients with neurological conditions.	Trained health personnel	<u>Merits</u> For a full assessment of swallowing. It is harmless, portable, suits all patients and has good endurance level for the patient. <u>Demerits</u> Gives limited information on the oral stage of the swallow Forms a 'white out' phase during swallow apnoea, which makes the function of the swallowing mechanism less visible during the swallow	Validity established in PD patients	Level 2	It can be used for identification and description of swallowing mechanisms and investigating interventions for dysphagia management

Screening /assessment tools	Author	Study population	Administrators	Merits & Demerits	Study outcomes • Valid • Reliable • Sensitive • Specific	Level of evidence	Authors suggestions & Future research directions by authors
Radionuclide Scintigraphy (RS)	Wang et al(1994) [130]	PD (n=27) and (n= 27) normal controls	Trained health personnel such as a radiologist	Merits Evaluation of oesophageal dysmotility when manometry is not easily accessible Demerits Information on abnormalities of peristalsis may be lacking.	Validity and Reliability reported	Level 2	The authors were also of the view that RS could be used to monitor dysphagia in prospective studies.
Surface Electromyography (SEMG)	Vaiman and Eviatar (2009) [171]	Patients with dysphagia included.	Trained health personnel	Merits Reliable indicator of muscle activity. Demerits There are difficulties in interpretation.	Reliability reported	Level 2	Future research should include identification of early phase deglutition oropharyngeal disorders.

Appendix 5: MASA and FOIS Standardised Assessments

Table 2.3 The MASA scoring scale [263]

Severity grouping	MASA score- dysphagia	MASA score- aspiration
Moderate	≤139-167	≤ 148
OR the same score may match that of mild aspiration in aspiration rating		
Mild	≤ 168-177	≤149-169

Table 2.4 FOIS items [264]

Level 1	Nothing by mouth
Level 2	Tube dependent with minimal attempts of food or liquid
Level 3	Tube dependent with consistent oral intake of food or liquid
Level 4	Total oral diet of a single consistency
Level 5	Total oral diet with multiple consistencies, but requiring special preparation or compensations
Level 6	Total oral diet with multiple consistencies without special preparation, but with specific food limitations
Level 7	Total oral diet with no restrictions

Appendix 6: Definitions of ICF Components

- **Body Functions** are physiological functions of body systems, including psychological functions).
- **Body Structures** are anatomical parts of the body, such as organs, limbs and their components.
- **Impairments** are problems in body function or structure, such as a significant deviation or loss.
- **Activity** is the execution of a task or action by an individual.
- **Participation** is involvement in a life situation.
- **Activity Limitations** are difficulties that an individual may have in executing activities.
- **Participation Restrictions** are problems an individual may experience in involvement in life situations.

Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives

Appendix 7: Application of the ICF in this Study

At the individual Level

- For the assessment of individuals: What is the person's level of functioning? *(Any swallowing dysfunction?)*
- For individual treatment planning: What treatments or interventions can maximize functioning? (*Such as SSA, dietician review, NGT, PEG*)
- For the evaluation of treatment and other interventions: What are the outcomes of the treatment? How useful were the interventions? *(Future outcomes-Prevention of complications of dysphagia)*
- For communication among physicians, nurses, physiotherapists, occupational therapists and other health works, social service works and community agencies. *(Dissemination of findings – policy making and provision of guidelines on SSA in people with PD, MS and MD)*
- For self-evaluation by consumers/patients: How would I rate mycapacity in mobility or communication? *(Improvement of swallowing)*.

At the institutional Level

For educational and training purposes

- For resource planning and development: What health care and other services will be needed? *(Routine SSA in MAU)*
- For quality improvement: How well do we serve our client? *(Regular audits on SSA in PD, MS and MD patients)*
- For management and outcome evaluation: How useful are the services we are providing? *(Low incidence of complications of dysphagia and this can be assessed by the present study)*
- For managed care models of health care delivery: How can the service be improved for better outcomes at a lower cost? *(Provision of training on SSA methods for nurses and dysphagia guidelines)*

Appendix 8. Ethics Approval

NHS
Health Research Authority

NRES Committee East Midlands - Nottingham 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839436
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10 July 2012

Dr Joy Molokwu
PhD Student
Division of Rehabilitation Medicine
Level 2 Rehabilitation Block
Royal Derby Hospital
Uttoxeter Road
Derby
DE22 3NE

Dear Dr Molokwu

Study title:	**Dysphagia assessment in people with neurological conditions- Parkinson's disease (PD), Multiple Sclerosis (MS) and Muscular Dystrophy at risk of dysphagia in acute medical assessment unit.**
REC reference:	**10/H0403/101**
Protocol number:	**10079**
Amendment number:	**Substantial Amendment 13.06.2012**
Amendment date:	**13 June 2012**
IRAS project Nu:	**56629**

The above amendment was reviewed 06 July 2012 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 13.06.2012	13 June 2012
Covering Letter		22 June 2012
Participant Consent Form: Consent Form - Staff	2.0	12 June 2012
Participant Information Sheet: Participant Information Sheet - Staff	2.0	12 June 2012
Protocol	4.0	22 June 2012

Appendix 9. Re-calculating the sample size

(i) Formula For Calculating A Sample For Proportions (n_0)

Equation 1: $$n_0 = \frac{Z^2 pq}{e^2}$$

Where:

n0 = is the sample size of proportion

Z^2 = is the abscissa of the normal curve that cuts off an area at the tails (1 - equals the desired confidence level, e.g., 95%)

e = is the desired level of precision

p = is the estimated proportion of an attribute that is present in the population, and q is 1-p.

Z is found in statistical tables which is the area under the normal curve.

Finite Population Correction for Proportions

Equation 2: $$n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}$$

Where:

n is the sample size of finite population (actual sample size)

N is the population size.

Determining the Sample size of proportions (equation 1), n_0

$$n_0 = \frac{Z^2 pq}{e^2}$$

Abscissa of the normal curve, Z. 1.96

Expected proportion, p. 0.399

1 - p = q. 0.601

Desired level of precision, e. 0.05

$$n_0 = \frac{(1.96)^2 0.399 * 0.601}{}$$

$$= \frac{(0.05)^2}{369}$$

Determining the Sample size of finite population correction of proportions (equation 2), n

$$n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}$$

Population size, N PD =536 + MS=224 + MD=33

$$n = \frac{369}{1 + \frac{(369 - 1)}{536}} + \frac{369}{1 + \frac{(369 - 1)}{224}} + \frac{369}{1 + \frac{(369 - 1)}{33}}.$$

$$= 219 + 140 + 31$$

= 390 patients sample size

Population size, N= Sum (PD+MS+DM) = 793

$$n = \frac{369}{1 + \frac{(369 - 1)}{793}}.$$

= 252 patients sample size

(ii) **Post hoc Analysis of Dysphagia Data**

The procedure used to obtain output for the tested variables from SPSS is shown below:

1. Select Analyse/ compare means/Independent sample T tests
2. Input length of hospital stay review (**LHSR)** as the test variable
3. Input **Has patient undergone a swallowing assessment** as grouping variable
4. Click on define groups as 1 and 2
5. Click ok

Group Statistics for *post hoc* -analysis

Group Statistics					
	Has the Patient Undergone a SSA	No	Mean	Std. Deviation	Std. Error Mean
Q18 LOS	YES	68	2.75	0.853	0.103
	NO	132	2.35	0.874	0.076

Independent Samples Test for *post hoc* –analysis

Independent Samples Test										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Differen-ce	95% Confidence Interval of the Difference	
									Lower	Upper
Q18 LOS	Equal variances assumed	0.747	0.388	3.104	198	0.002	0.402	0.129	0.146	0.657
	Equal variances not assumed			3.128	138.309	0.002	0.402	0.128	0.148	0.655

Appendix 10. MAU dysphagia questionnaire

MAU DYSPHAGIA STUDY

Participant Data Collection Sheet 1

Trust: RDH ☐

QMC ☐

Ward: ☐

Participant's Code Number: ----------

Participant Residence: ----------(NH, RH, Own house /Alone, other)

Date of admission: ------/----------/---------

Date of recruitment: ----/----------/---------

Date of follow-up:-------/----------./----------

Day of week: ----------

Date of birth: ----------/----------/--------- Age: ---------- (years)

Gender: M ☐

F ☐

Type of neurological condition: ---------- (PD, MS or MD)

Onset of neurological condition: ----------

Severity of neurological condition: ---------- (mild, moderate, severe)

Presenting Complaint: ----------

Background / Co-morbidities: ----------

Diagnosis: ----------

Activities of daily living (ADL): ---------- (Self, Carers, Relatives, Others)

Swallow Screening Review (SSR):

1. Has patient undergone a Swallow Screening Assessment?
   a. Yes ☐ State the type of assessment (if Yes):--------
   b. No ☐
   c. Unable to assess due to decreased level of consciousness ☐

2. When was the Swallow Screening Assessment carried out?
   a. On the day of admission ☐
   b. One day after admission ☐
   c. Two days after admission ☐
   d. Three days after admission ☐
   e. Four days after admission ☐
   f. Five days after admission ☐
   g. Other, please state----------

3. Who did the Swallow Screening assessment?
   a. Nurse ☐
   b. Doctor ☐
   c. Dysphagia trained nurse ☐
   d. Speech and Language Therapist (SLT) ☐

4. What method was used for the Swallow Screening assessment?
   a. Observation of eating? ☐
   b. Observation of drinking? ☐
   c. Both a and b ☐
   d. 5 – tea spoon test ?/ water test ☐
   e. Swallow screening questionnaire ☐
   f. Other, please state ----------

5. What was the Result of the Swallow Screen?
   a. Pass ☐
   b. Fall ☐
   c. Poor ☐

6. Was the Patient referred to SLT?
   a. Yes ☐
   b. No ☐

7. When was the patient referred to SLT after admission?
    a. One day ☐
    b. Two days ☐
    c. Three days ☐
    d. Four days ☐
    e. Five days ☐
    f. Other, please state ----------

8. Was the Patient seen by SLT as in-patient?
    a. Yes ☐
    b. No ☐

9. When was the patient seen by the SLT?
    a. On the day of admission ☐
    b. One day after admission ☐
    c. Two days after admission ☐
    d. Three days after admission ☐
    e. Four days after admission ☐
    f. Five days after admission ☐
    g. More than five days after admission ☐

10. Was the Patient referred to the Dieticians?
    a. Yes ☐
    b. No ☐

11. When was the patient referred to the Dieticians?
    a. On the day of admission ☐
    b. One day after admission ☐
    c. Two days after admission ☐
    d. Three days after admission ☐
    e. Four days after admission ☐
    f. Five days after admission ☐
    g. More than five days after admission ☐

12. Was the Patient seen by Dieticians?
    a. Yes ☐
    b. No ☐

13. When was the patient seen by the Dietician?
    a. On the day of admission ☐
    b. One day after admission ☐
    c. Two days after admission ☐
    d. Three days after admission ☐
    e. Four days after admission ☐
    f. Five days after admission ☐
    g. More than five days after admission ☐

Nutritional Review (NR):

14. What is the patient's oral intake status now?
    a. NBM ☐
    b. Modified diet and fluids ☐
    c. Normal diet and fluids ☐

15. Is the Patient being NG fed?
    a. No ☐
    b. Yes ☐
    c. Attempted NG ☐
    d. Considering NG ☐
    e. Withdrawal of nutrition (Palliation) ☐
    f. Patient does not require NGT due to sufficient oral intake ☐
    g. Others, please state: ----------

16. Have there been any of the following attempts at nutritional assessments?
    a. Weight ☐
    b. MUST score ☐
    c. MAC ☐
    d. Dietician review ☐
    e. Food chart ☐
    f. Other, please state:----------

17. What is the Patient's Nutrition Status now?
    a. Well nourish ☐
    b. Undernourished ☐
    c. Malnourished ☐

Length of Hospital Stay Review (LHSR):

18. How long did the patient stay in the hospital before discharge?
    a. 1 week ☐
    b. More than 1 week ☐
    c. 2 – 3 weeks ☐
    d. More than 3 weeks ☐

Mortality Review (MR):

19. Is patient alive or dead?
    a. Alive ☐
    b. Dead ☐

Hydration Review (HR):

20. Has there been any attempt to assess hydration in the patient?
    a. Yes ☐
    b. No ☐

21. If yes to Q20 above, which of the following attempts was made?
    a. Fluid balance chart ☐
    b. Others, please state:----------

Infections:

21. Did patient develop any infection during the period of admission?
    a. Yes ☐
    b. No ☐

22. What type of infection did patient have?
    a. Aspiration pneumonia ☐
    b. Urine infection ☐
    c. Pressure sores ☐
    d. Hospital acquired pneumonia ☐
    e. Other, please state ----------

Appendix 11. Swallowing screening questionnaire

SWALLOWING TEST

Trust: RDH ☐ **Participant's Code Number** ☐

QMC ☐ **Date & Time** ☐

INITIAL ASSESSMENT OF SAFETY

Conscious Level

1. Alert ☐
2. Drowsy ☐
3. Unresponsive ☐

Assess only those patients who are responsive and would be considered for feeding.

Assess only when the patient is sitting upright.

PRELIMINARY ASSESSMENT

Lip Closure

1. Normal ☐ 2. Abnormal ☐

Voice Quality

1. Normal ☐ 2. Weak/Hoarse ☐ 3.'Wet'/Gurgly ☐ 4. Absent ☐

Voluntary Cough

1. Normal ☐ 2. Weak ☐ 3. Absent ☐

PROCEED TO STAGE 1

If at any point in stage 1, 2 & 3 the swallowing was felt to be unsafe ☹ **→ STOP and answer the final question.**

STAGE 1: GIVE A TEASPOON OF WATER 3 TIMES and FEEL FOR LARYNGEAL ELEVATION.

IF ☹ then stop test and complete the last question.

Laryngeal movement on attempted swallow?

1. Normal ☐ 2. Delayed ☐ 3. Absent ☹ ☐

Cough during or after swallowing on more than one occasion?

1. No ☐ 2. Yes ☹ ☐

Choking/Stridor?

1. No ☐ 2. Yes ☹ ☐

'Wet' or gurgly voice after each teaspoon?

1. No ☐ 2. Yes ☹ ☐

Dribbles water?

1. No ☐ 2. Yes ☹ ☐

If the swallow is normal proceed to stage 2

STAGE 2: GIVE 60mls OF WATER IN A GLASS and FEEL FOR LARYNGEAL MOVEMENT

Laryngeal movement

1. Normal ☐ 2. Delayed ☐. Absent ☹ ☐

Cough noted during or after swallowing?

1. No ☐ 2. Yes ☹ ☐

Choking/Stridor?

1. No ☐ 2. Yes ☹ ☐

"Wet" or gurgly?

1. No ☐ 2. Yes ☹ ☐

STAGE 3: If the swallow is normal in Stage 2 → OBSERVE THE PARTICIPANT EATING THEIR FIRST MEAL. Observe for the following difficulties:-

	Yes	No
1. Loss of food from lips?	☐	☐
2. Difficulty chewing?	☐	☐
3. Pouching of food?	☐	☐
4. Coughing/Choking?	☐	☐
5. Gurgly voice?	☐	☐
6. Patient reports any difficulty?	☐	☐

Safe  ☐ Difficulty observed  ☐

Do you feel that the swallowing is safe?

1. Safe ☐ 2. Unsafe ☐

Now Follow Referral Procedure if Appropriate.

Assessor: ..... **Signature:** ... .

Appendix 12 Participant information sheet

(i) **PATIENT INFORMATION SHEET**

Title: Dysphagia (difficulty in swallowing) assessment in people with neurological conditions - Parkinson's Disease (PD), multiple sclerosis (MS) and muscular dystrophy (MD) admitted to acute medical assessment units.

Investigators: Dr Anuri Joy Molokwu, Dr Ben Pearson, Dr Margaret Phillips and Dr Lorraine Pinnington.

You are being invited to take part in a research study. The study is being organised by the University of Nottingham and will take place in two NHS Trusts - Derby Hospitals NHS Foundation Trust (Royal Derby Hospital) and Nottingham University Hospitals NHS Trust (Queens Medical Centre Campus). Before you decide to take part in this study, it is important for you to know why this research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about it if you wish.

- Part 1 tells you the purpose of the study and what will happen to you when you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Patient information sheet- Part 1

What is the purpose of the study?

We want to find if swallowing ability is assessed when people with Parkinson's disease, multiple sclerosis and muscular dystrophy are admitted urgently to hospital.

We are trying to find out if people with Parkinson's disease, multiple sclerosis and muscular dystrophy admitted through a medical assessment unit are:

- assessed for swallowing problems
- referred to Speech and Language Therapists(SLT) or to dieticians
- managed differently if they are assessed compared to those who are not assessed

- have different outcomes if they are assessed compared to those who are not assessed

Swallowing problems are known to occur more often in people with neurological conditions such as Parkinson's disease, multiple sclerosis and muscular dystrophy. Assessing for these may reduce the chance of people with these conditions contracting chest infections and pneumonia. This is because food can go into the lungs during swallowing (called 'aspiration') if there are swallowing problems and cause infection in the lung. A pneumonia caused in this way is called an 'aspiration pneumonia' and in serious cases can be life threatening.

Some people who find it difficult to swallow safely have less food and drink resulting in weight loss, poor nutrition, loss of water, being more prone to infections (bugs) and recover more slowly.

In this study we are going to use a simple test of swallowing which involves drinking a small amount of water.

This research, we hope, will help us produce guidelines for routine assessment of swallowing in Parkinson's disease, Multiple Sclerosis and Muscular Dystrophy patients in hospital.

Why have I been chosen?

You were chosen because you have one of these three conditions - Parkinson's disease, multiple sclerosis or muscular dystrophy and have been admitted to the Royal Derby Hospital / Queens Medical Centre. We plan to invite about 390 people to take part in this study.

Do I have to take part?

No. It is your decision whether or not to take part. If you decide not to take part or to withdraw from the study at a later stage, it will not affect the standard of care you receive.

What will happen to me if I take part?

Before you decide to take part in the study, a detailed explanation will be given to you about what the study will involve and any concerns or questions which you may have will be addressed. You will be able to keep this information sheet as a reference and you will be asked to sign a consent form. You will still be free to withdraw from the study at any time without giving a reason.

At first, your medical notes will be reviewed to make sure that there is no reason why you should not participate in the study. Some information about your admission and neurological condition will also be recorded from your medical notes.

At day 7 of your admission to hospital or immediately you have been discharged from hospital if you live close to the hospital, in which case you will be visited with your permission and you will be asked by one of the researchers about your medical history and your eating and drinking history using a questionnaire about swallowing. This will take approximately five

minutes. Your notes will be checked to see if any swallowing problems were noted. If you have swallowing problems we will check if you have been referred to a speech and language therapist.

Those people who did not undergo any screening, they will be screened and if we notice that their swallowing is difficult, we will refer them to a speech and language therapist.

The second part of the study will involve recording your level of care on admission to hospital. Your food and fluid intake, how long you have stayed in hospital, any recent infections (bugs) whilst in hospital, problems with wound healing and any tests which were carried out to help your recovery within the period of your admission will be noted.

We will check if your condition has improved, looking in particular for progress of the management throughout your stay in hospital.

Expenses and payments

There will be no payments for participating in this study. This study is not expected to cost participants anything.

What will I have to do?

If you decide to take part in this study, we will ask you to give us permission to look at your medical and nursing notes for the information we require and to assess your swallowing using a simple screening test – which involves drinking a small amount of water.

What are the side effects of taking part?

We are not anticipating any side effects from this study. One of our tests involves drinking a small amount of water. Some people may cough slightly while drinking water and if that happens we will stop the assessment. The water test is safe, user friendly and non invasive.

What are the possible disadvantages of taking part?

The time taken to complete the assessments- we estimate this will be approximately 10 minutes.

What are the possible benefits of taking part?

Your participation in this study will enable us find out if you have problems with your swallowing which you may not be aware of. This knowledge may reduce the risk of chest infections occurring. Also any other requirements such as speech and language therapy assessment, dietician, assisted feeding methods and further tests which you may require will be recommended.

The information we get from this study will provide a basis for the provision of guidelines for the management of patients with Parkinson's disease, multiple sclerosis and muscular dystrophy who have swallowing problems (dysphagia).

What happens when the research study stops?

When the research study is finished, we will look at the data, and decide if routine screening for patients who have Parkinson's disease, multiple sclerosis or muscular dystrophy patients with the water swallow test is useful or not. The results of the study will be published in a journal and this could result in further studies or a change in practice for dysphagia management in these patients.

We will publish the results such that participants of this study will not be identified**.**

If the information in Part 1 has interested you and you are considering participation, please read on for more information in Part 2 before making any decision.

Patient information sheet- Part 2

What will happen if I don't want to carry on with the study?

You can decide to withdraw from the study at any time. We would like to use the information we have collected from you up to your withdrawal. If you don't want us to, your information will be destroyed and this will not affect your medical care in any way.

What if there is a problem?

In the unlikely event of any problem and you are harmed during the research, there will not be any arrangements for compensation. If you are harmed and this is due to someone's negligence then you may have grounds for legal action for compensation against the University of Nottingham/Derby Hospitals NHS Foundation Trust (RDH)/Nottingham University Hospitals NHS Trust (QMC campus), but you may have to pay your legal costs. This is the same as for any research study. The normal hospital complaints mechanism will still be available to you.

If you have concerns about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions on 01332 789816. If you remain unhappy and you wish to complain formally you can go through the hospital Patient Advice and Liaison Service (PALS) on 01332 787258 for Derby Hospitals NHS Foundation Trust (RDH) or 0115 924 9924 extension 65412 or 62301 for Nottingham University Hospitals NHS Trust (QMC campus).

Will my taking part in this study be kept confidential?

Yes. You will be given a study number which we will use to record your information on our computer. Your medical records and information collected during the study will only be assessed by the researchers and personnel from appropriate regulatory bodies. The forms used to collect the data will be kept in a locked filing cabinet at the University of Nottingham, Division of Rehabilitation Medicine, labelled only with a code number. All our procedures for handling, processing, storage and destruction of patient data will be compliant with the Data Protection Act 1998.

What will happen to the results of the research study?

The results of this research will form part of a PhD thesis. The findings of the study will be submitted for publication and to conferences for presentation. You will not be identified in any report/publication unless you have given us permission for it. The results will also be made available to participants on request.

It will lead to a change in practice that will be beneficial to people with Parkinson's disease, multiple sclerosis and muscular dystrophy.

Who is organizing and funding the research?

The study is being organised by University of Nottingham/Derby Hospitals NHS Foundation Trust (RDH) /Nottingham University Hospitals NHS Trust (QMC campus). The University of Nottingham is the Sponsor of the study.

Who has reviewed the study?

This study has being reviewed and given favourable opinion by the local research ethics committee in Derby.

What happens now?

If you will like to take part in this research, please complete the attached consent (or assent) form and return it to Dr Joy Molokwu. If you do not want to take part in this research you will not need to do anything further and you will not be approached again for this study.

Further information and contact details

If you have any questions or concerns, please do not hesitate to contact:

Dr Joy Molokwu, University of Nottingham, School of Graduate Entry Medicine and Health, Division of Rehabilitation Medicine, Level 2, Royal Derby Hospitals NHS Foundation Trust, Uttoxeter Road, Derby, DE22 3NE.

Tel: 01332-789816 (direct) or 01332-785680.

Email: mzxam4@nottingham.ac.uk

The Derby Hospitals NHS Foundation Trust (RDH) and Nottingham University Hospitals NHS Trust (QMC campus) Patient Advice Liaison (PALS) services can also provide information about being in a research study. These teams can be contacted on 01332 787258 (RDH) and 0115 924 9924 extension 65412 or 62301 (QMC campus) respectively.

Thank you for taking the time to read this information sheet. You will be given a copy of this information sheet and consent form to keep.

(ii) **PARTICIPANT INFORMATION SHEET – STAFF**

Title: Dysphagia (difficulty in swallowing) assessment in people with neurological conditions - Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy (MD) admitted to acute medical assessment units.

Investigators: Dr Anuri Joy Molokwu, Dr Margaret Phillips, Dr Lorraine Pinnington

You are being invited to take part in a research study. This research is being undertaken for a PhD. The study is being organised by the University of Nottingham and will take place in two NHS Trusts - Derby Hospitals NHS Foundation Trust (Royal Derby Hospital) and Nottingham University Hospitals NHS Trust (Queens Medical Centre Campus). Before you decide to take part in this study, it is important for you to know why this research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about it if you wish.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

It is known that patients with PD, MS and MD are not always screened routinely for dysphagia when admitted to hospital. We aim to gain an understanding of the factors that may influence a clinician's decision to conduct a swallowing assessment or advise that one is undertaken by someone else in the team. This would enable important information to be gained about aspects of staff knowledge and their continuing professional development needs. It should also allow any organizational barriers to be uncovered which prevent feeding related aspects of care from being implemented in an effective and timely manner. The research is being conducted as part of a programme of study leading to a PhD at the University of Nottingham.

Why have I been chosen?

You have been chosen because you are involved in the care of patients with neurological conditions when admitted to hospital. A sample of around 15 people will be invited to take part in this research.

Do I have to take part?

No. It is your decision whether or not to take part. If you do decide to take part you are free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you decide to take part, you will be asked to participate in a semi-structured or telephone interview. The interview will involve discussing the factors which influence if, when and how swallowing safety is assessed when patients are admitted to hospital and if any barriers might prevent assessments of swallowing from being carried out. The interview will last between 30 to 60 minutes, and if you agree, the interview will be audio-taped.

Expenses and payments:

There will be no payments for participating in this study. This study is not expected to cost participants anything.

What do I have to do?

If you agree to take part in this study, you will be asked to take part in a semi-structured personal or telephone interview depending on your preference.

What are the possible disadvantages of taking part?

The time taken to complete the interviews - we estimate this will be between 30 to 60 minutes.

What are the possible benefits of taking part?

We hope that the information we gain from this study will enable important information to be gained about aspects of staff knowledge or attitudes and continuing professional development needs. It should also allow any organizational barriers to be uncovered which prevent swallowing assessments from being carried out.

What if there is a problem?

If you have concerns about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions on 01332 789816. If you remain unhappy and you wish to complain formally you can go through the hospital Patient Advice and Liaison Service (PALS) on 01332 787258for Derby Hospitals NHS Foundation Trust (RDH) or 0115 924 9924 extension 65412 or 62301 for Nottingham University Hospitals NHS Trust (QMC campus).

Will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of your data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for no longer than 12 after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or your family member at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen to the results of the research study?

The results of this research will form part of a PhD thesis. The findings of the study will be submitted for publication and to conferences for presentation. You will not be identified in any report/publication unless you have given us permission for it. The results will also be made available to participants on request.

It may lead to a change in practice that would be beneficial to people with Parkinson's disease, multiple sclerosis and muscular dystrophy.

Who is organising and funding the research?

The study is being organised by the Royal Derby Hospitals NHS Trust (RDH) and Nottingham University Hospitals NHS Trust (Queens Medical Centre Campus (QMC)) and being funded by the University of Nottingham.

Who has reviewed the study?

This study was given favorable ethical opinion for conduct in the NHS by the "Nottingham 1" Research Ethics Committee.

What happens now?

If you would like to take part in this research, please complete the attached consent form and return it to Dr Anuri Joy Molokwu. We will then arrange to speak to you and arrange a suitable date for the semi-structured personal or telephone interview to take place. If you do not wish to take part in this research you need do nothing further and you will not be contacted again about this study.

Further information and contact details

If you have any questions or concerns, please do not hesitate to contact:
Dr Lorraine Pinnington, University of Nottingham, School of Graduate Entry Medicine and Health, Division of Rehabilitation Medicine, Level 4, Clinical Sciences Building, Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE.

Email: L.Pinnington@nottingham.ac.uk

Dr Joy Molokwu, University of Nottingham, School of Graduate Entry Medicine and Health, Division of Rehabilitation Medicine, Level 2, Rehabilitation Block, Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE.

Tel: 01332-789816 (direct).

Email: mzxam4@nottingham.ac.uk

The Derby Hospitals NHS Foundation Trust (RDH) and Nottingham University Hospitals NHS Trust (QMC campus) Patient Advice Liaison (PALS) services can also provide information about being in a research study. These teams can be contacted on 01332 785156 or 0800-783-7691 (RDH) and 0115 924 9924 extension 65412 / 62301 or 0800 183 0204 (QMC campus) respectively.
Thank you for taking the time to read this information sheet. You will be given a copy of this information sheet and consent form to keep.

Appendix 13 Next of Kin information sheet

NEXT OF KIN/PROXY INFORMATION SHEET

Title: Dysphagia (difficulty in swallowing) assessment in people with neurological conditions - Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy admitted to acute medical assessment units.

Investigators: Dr Anuri Joy Molokwu, Dr Ben Pearson, Dr Margaret Phillips, Dr Lorraine Pinnington.

Your partner/relative/friend is being invited to take part in a research study. This research is being undertaken for a PhD. The study is being organised by the University of Nottingham and will take place in two NHS Trusts- Derby Hospitals NHS Foundation Trust (Royal Derby Hospital) and Nottingham University Hospitals NHS Trust (Queens Medical Centre Campus). Before you decide whether you are happy for your partner/relative/friend to take part, it is important for you to understand why the research is being carried out and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish.

Please ask if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of the study?
Swallowing problems are known to occur in people with neurological conditions such as Parkinson's disease, multiple sclerosis and muscular dystrophy. If a swallowing problem exists, food may pass into the lungs during swallowing (called 'aspiration') and can cause chest infections (bugs) and pneumonia. A pneumonia caused in this way is called an 'aspiration pneumonia' and in serious cases can be life threatening. By assessing swallowing, we hope to be able to avoid some of these infections and related problems from occurring.

Some people who find it difficult to swallow safely have less food and drink resulting in weight loss, poor nutrition, loss of water, being more prone to infections (bugs) and recover more slowly.

This study aims to find out if people with PD, MS and MD admitted acutely in hospital are:

- screened/or assessed for dysphagia or not

- referred to Speech and Language Therapists (SLT)/ or dieticians
- managed differently if they are assessed compared to those who are not assessed
- have different outcomes if they are assessed compared to those who are not assessed

Why has my partner/relative/friend been chosen?

Your partner/relative/friend has been chosen because they have Parkinson's disease, multiple sclerosis or muscular dystrophy and have been admitted to the Royal Derby Hospital/ Nottingham University Hospitals NHS Trust (QMC campus). A sample of around 390 people will be invited to take part in this phase of the research.

Does your partner/relative/friend have to take part?
No. It is up to you whether or not they take part. If you do agree for your partner/relative/friend to take part this information sheet will be given to you. You will keep it and sign a consent form. You are free to withdraw your relative/friend from the study at any time without giving a reason. If you do not agree for your partner/relative/friend to take part or if they are withdrawn from the study, it will not affect the standard of care he/she receives.

What will happen to my partner/relative/friend if they take part?

If you agree for your partner/relative/friend to take part, a detailed explanation will be given to you about what the study will involve and any concerns or questions which you may have will be addressed. We will document some information about their hospital admission and neurological condition from their medical and nursing records.

Expenses and payments:

There will be no payments for participating in this study. Your partner/relative/friend involvement in this study is not expected to incur any costs.

What do they have to do?

If you agree for your partner/relative/friend to take part in this study, you would be asked to give us permission to look at their medical and nursing notes for the information we require and to do a simple swallow screening assessment.

Those people who did not undergo any screening initially, will be screened and if we notice that their swallowing is difficult, we will bring this to the attention of a member of the usual care team, so they may be referred to a speech and language therapist. The swallow screening test will involve taking sips of water (no additives) from a glass. If she/he has already been screened during the admission, there will be no need to repeat the test.

What are the possible benefits of taking part?

There may be no direct benefit. However, their participation in this study will enable us find out if they have problems with their swallowing which they may not be aware of. If a problem is identified, this information will enable the care team to give additional advice which would help to reduce the risk of a chest infection occurring. Also, any other requirements such as SLT assessments, dietician, assisted feeding methods and further tests which they may require will be recommended.

We hope that the information we obtain from this study will provide a basis for developing guidelines for the management of patients with Parkinson' Disease, Multiple Sclerosis and Muscular Dystrophy who have swallowing problems.

What if something goes wrong?
In the event of any problem and they are harmed during the research, there will not be any arrangements for compensation. If they are harmed and this is due to someone's negligence then you may have grounds for legal action for compensation against the University of Nottingham/ Derby Hospitals NHS Foundation Trust (RDH)/Nottingham University Hospitals NHS Trust (QMC campus), but you may have to pay your legal costs. This is the same for any research study. The normal hospital complaints mechanism will still be available to you.

If you have concerns about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions on 01332 789816. If you remain unhappy and you wish to complain formally you can go through the hospital Patient Advice and Liaison Service (PALS) on 0115 924 9924 extension 65412 or 62301 for Nottingham University Hospitals NHS Trust (QMC campus) or 01332 787258 for Derby Hospitals NHS Foundation Trust (RDH).

Will my partner/relative/friend's taking part in this study be kept confidential?

Yes. They will be given a study number which we will use to record their information on our computer. All information will be kept strictly confidential. If you give permission for you partner/relative/friend to take part, their medical records and information collected during the study will only be assessed by the researchers and personnel from appropriate regulatory body. All our procedures for handling, processing, storage and destruction of patient data will be compliant with the Data Protection Act 1998.

What will happen to results of the research study?

The findings of the study will be submitted for publication and to conferences for presentation. Your partner/relative/friend will not be identified in any report/ publication unless you have given us permission for it. The results will also be made available to participants on request.

Who is organising and funding the research?

The study is being organised by the University of Nottingham/ Derby Hospitals NHS Foundation Trust (RDH)/Nottingham University Hospitals NHS Trust (QMC campus). The University of Nottingham is the Sponsor of the study.

Who has reviewed the study?

This study has being reviewed and given favourable opinion by the local research ethics committee in 'Nottingham 1'.

What happens now?

If you would like your partner/relative/friend to take part in this research, please complete the attached assent form and return it to Dr Joy Molokwu. If you do not wish for your partner/relative/friend to take part in this research you will not need to do anything further and you will not be approached again for this study.

Further Information

If you have any questions or concerns, please do not hesitate to contact:

Dr Lorraine Pinnington, University of Nottingham, School of Graduate Entry Medicine and Health, Division of Rehabilitation Medicine, Level 4, Clinical Sciences Building, Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE.

Email: L.Pinnington@nottingham.ac.uk

Dr Joy Molokwu, University of Nottingham, School of Graduate Entry Medicine and Health, Division of Rehabilitation Medicine, Level 2, Rehabilitation Block, Royal Derby Hospital, Uttoxeter Road, Derby, DE22 3NE.

Tel: 01332-724842 / 01332-789816 (Direct).

Email: mzxam4@nottingham.ac.uk.

The Derby Hospitals NHS Foundation Trust (RDH) and Nottingham University Hospitals NHS Trust (QMC campus) Patient Advice Liaison (PALS) service can also provide information about being in a research study can be contacted on 01332 787258 (Derby) and 0115 924 9924 extension 65412 or 62301 (QMC campus) respectively.

Thank you for taking the time to read this information sheet. You will be given a copy of this information sheet and consent form to keep.

Appendix 14 Consent form

(i) **CONSENT FORM- PATIENT**

Centre number:
Study number:
Patient identification number for this trial:

Title of Project: Dysphagia (difficulty in swallowing) assessment in people with neurological conditions - Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy to acute medical assessment Unit.

Investigators: Dr Anuri Joy Molokwu, Dr Ben Pearson, Dr Margaret Phillips and Dr Lorraine Pinnington.

The patient should complete the whole of this sheet himself/herself

Please initial box

1. I confirm that I have read and understand the information sheet (version 6 12th July 2010) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

   Who have you spoken to? Dr/Mrs/Ms …….

2. I understand that my participation is voluntary and free to withdraw at any time, without giving a reasc without my medical care or legal rights being affect ☐

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the University of Nottingham Division of Rehabilitation Medicine, from regulatory authorities/ Derby Hospitals NHS Foundation Trust and Nottingham University Hospitals NHS Trust (Queens Medical Centre Campus) staff where it is relevant to taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree that a screening assessment of my swallow may be carried out if relevant. ☐

5. I agree to take part in the above study. ☐

Name of patient	Date	Signature

Name of person taking consent	Date	Signature

(if different from researcher)
I have explained the study to the above patient and he/she has indicated his/her willingness to take part.

Researcher	Date	Signature

(ii) **CONSENT FORM – STAFF**

Centre number:

Study number:

Patient identification number for this trial:

Title of Study: Dysphagia (difficulty in swallowing) assessment in people with neurological conditions - Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy (MD) admitted to acute medical assessment units.

REC Ref: *(*10/H0403/101*)*

Investigators: Dr Anuri Joy Molokwu, Dr Ben Pearson, Dr Margaret Phillips and Dr Lorraine Pinnington

Please initial box

1. I confirm that I have read and understand the information sheet version number 1.0 dated 12th June2012 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant and 1 for the project notes

Appendix 15 Assent form

ASSENT FORM- PATIENT'S NEXT OF KIN

Centre number:

Study number:

Patient identification number for this trial:

Title of Study: Dysphagia (difficulty in swallowing) assessment in people with neurological conditions - Parkinson's disease (PD), multiple sclerosis (MS) and muscular dystrophy (MD) admitted to acute medical assessment units.

REC Ref: (10/H0403/101)

Investigators: Dr Anuri Joy Molokwu, Dr Ben Pearson, Dr Margaret Phillips and Dr Lorraine Pinnington

Please initial box

1. I confirm that I have read and understand the information sheet version number 8 dated 27th May, 2011 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my partner's/relative/friend's participation is voluntary and that she/he is free to withdraw at any time, without giving any reason, and without her/his medical care or legal rights being affected. I understand that should she/he withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my partner's/relative's/friend's medical notes and data collected in the study may be looked at by authorised individuals from the University of ☐

Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my partner's/relative/friend's participation in this study. I understand that my partner's/relative/friend's personal details will be kept confidential.

4. I understand and agree that a screening assessment of my partner's/relative's/friend's swallow may be carried out if relevant. ☐

5. I know of no reason why my partner/relative/friend would not agree to participate in the study if she/he had capacity to consent and she/he has not expressed the view that they did not wish to take part in the research. ☐

6. I know of no reason why my partner/relative/friend would not have wished to take part in the above research study and l assent on her/his behalf to take part. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from Principal Investigator)	Date	Signature
_____	_____	_____
Name of Principal Investigator	Date	Signature

Appendix 16 Interview guide questions

Experience of skill-mix on the ward:

1. Please tell me a little bit about you- what is your role and for how long have you worked in this field?

Clinical reasoning:

2. What are the most important things that would prompt you to assess a patient's swallowing? [Reasons for conducting a swallowing assessment]

Skill and Knowledge:

3. Do you ever assess a patient's ability to swallow? [Skill]
4. Describe the assessment method you use? [Skill and knowledge]
5. How many assessments of swallowing do you do per week? [Frequency of use of the swallowing assessment skill]

Confidence:

6. Are you confident of being able to assess a patient's swallowing ability? [Confidence]
7. Are you confident in using the water swallowing assessment method? [Confidence]

Training:

8. Do you feel there is a requirement on the ward for more training with regards to swallowing assessment? [Training]
9. Have you been taught a swallow assessment method (e.g. water swallow test)

Awareness:

10. Do you follow any guidelines on swallowing assessment for people with neurological conditions such as PD, MS and MD? [Awareness of any guidelines)

Thoughts, Feelings, Opinions:

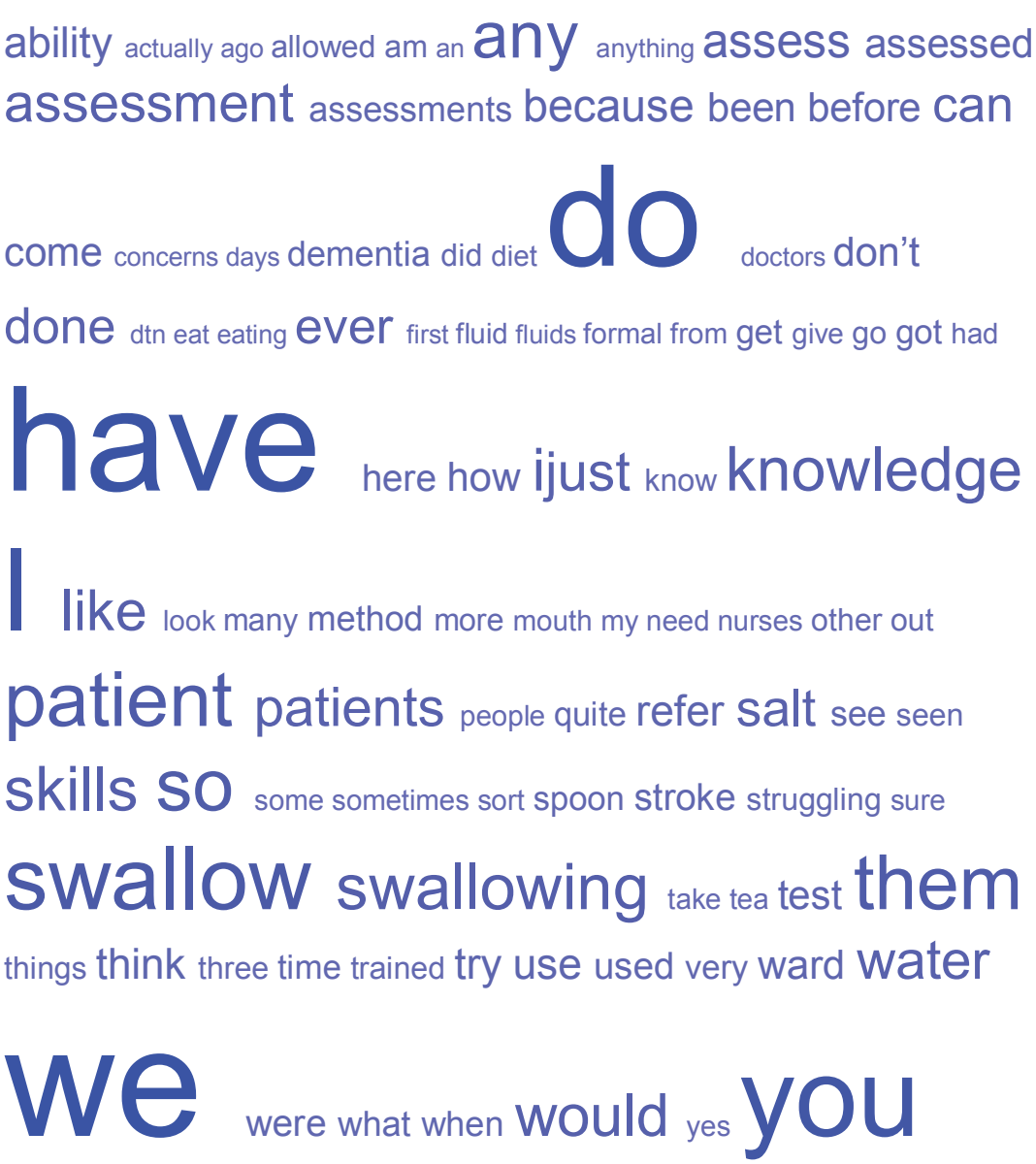
Please tell me of any difficulties or suggestions you might have with swallowing assessment in people with PD, MS and MD?

Appendix 17 Word frequency tags:

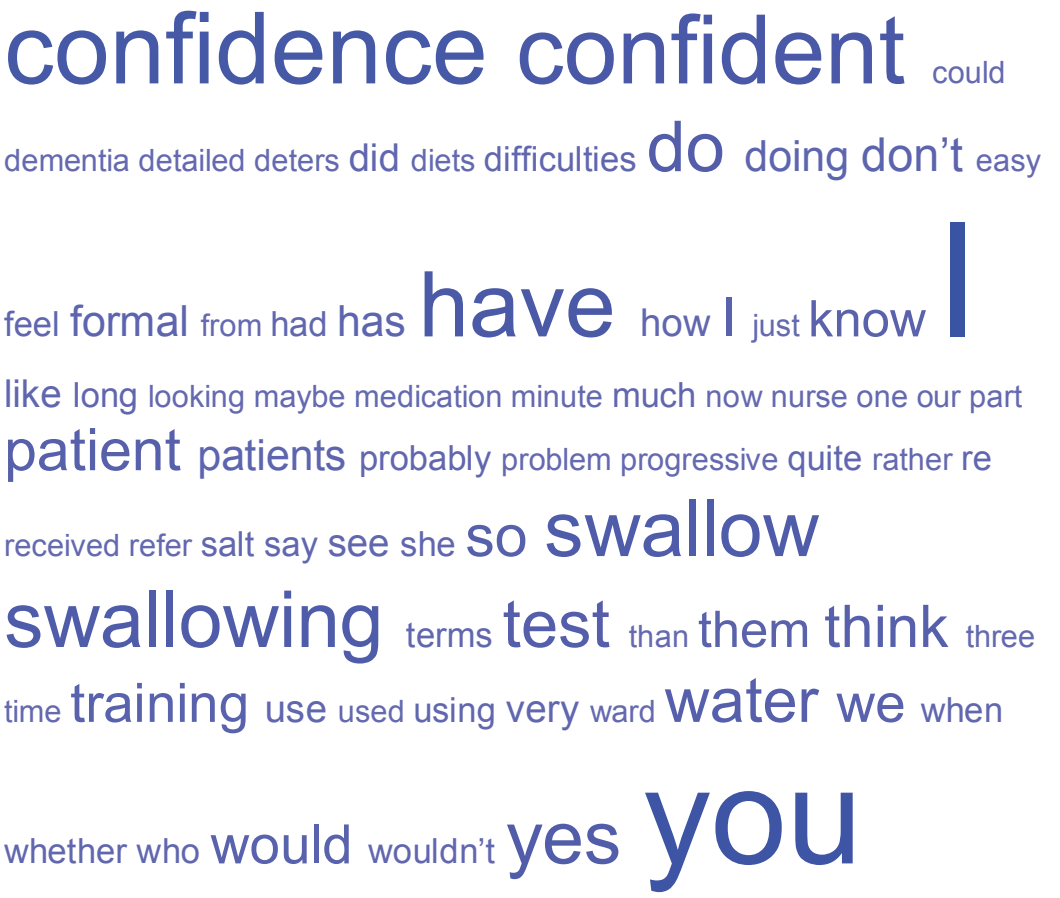
i) Clinical Reasoning

able across actually an any anything ask assess assessment assessments basically because been can clinical come coughing cup difficulty do don't done drink eating feeding first food from get go got had half has have haven't having he here how i important I like look make may MD might mouth MS need normal nursing obviously only out Parkinson patient patients pd probably problem problems prompt quite reasoning refer referred salt say see so some somebody sort spoon staff step sure swallow swallowing tea tell them themselves things think those up very ward water we were what when where would you

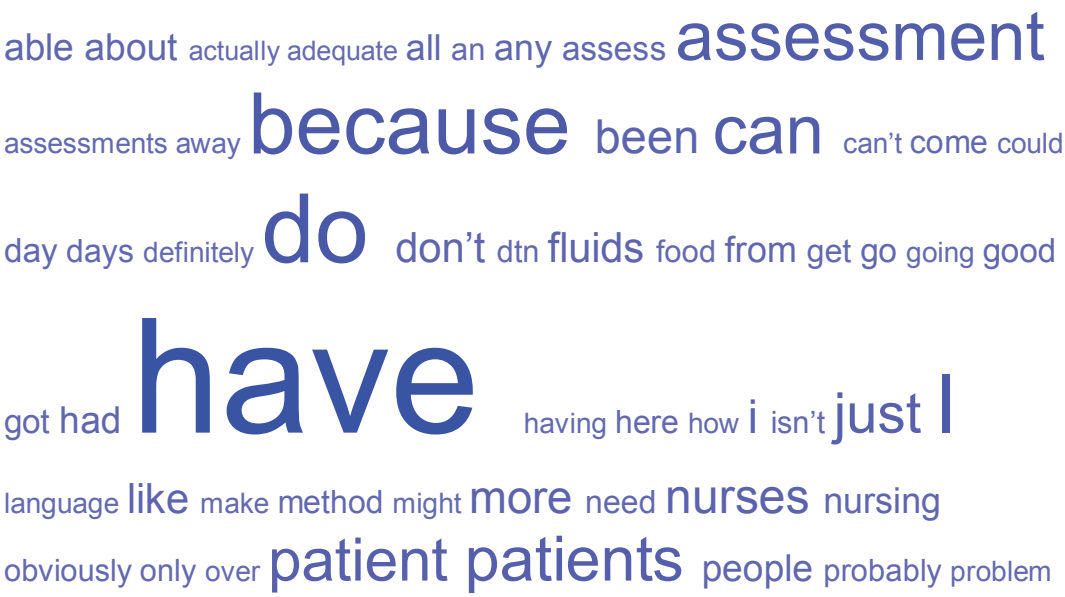
ii) Skills and Knowledge



iii) Confidence


confidence confident could
dementia detailed deters did diets difficulties do doing don't easy
feel formal from had has have how I just know I
like long looking maybe medication minute much now nurse one our part
patient patients probably problem progressive quite rather re
received refer salt say see she so swallow
swallowing terms test than them think three
time training use used using very ward water we when
whether who would wouldn't yes you

iv) Training

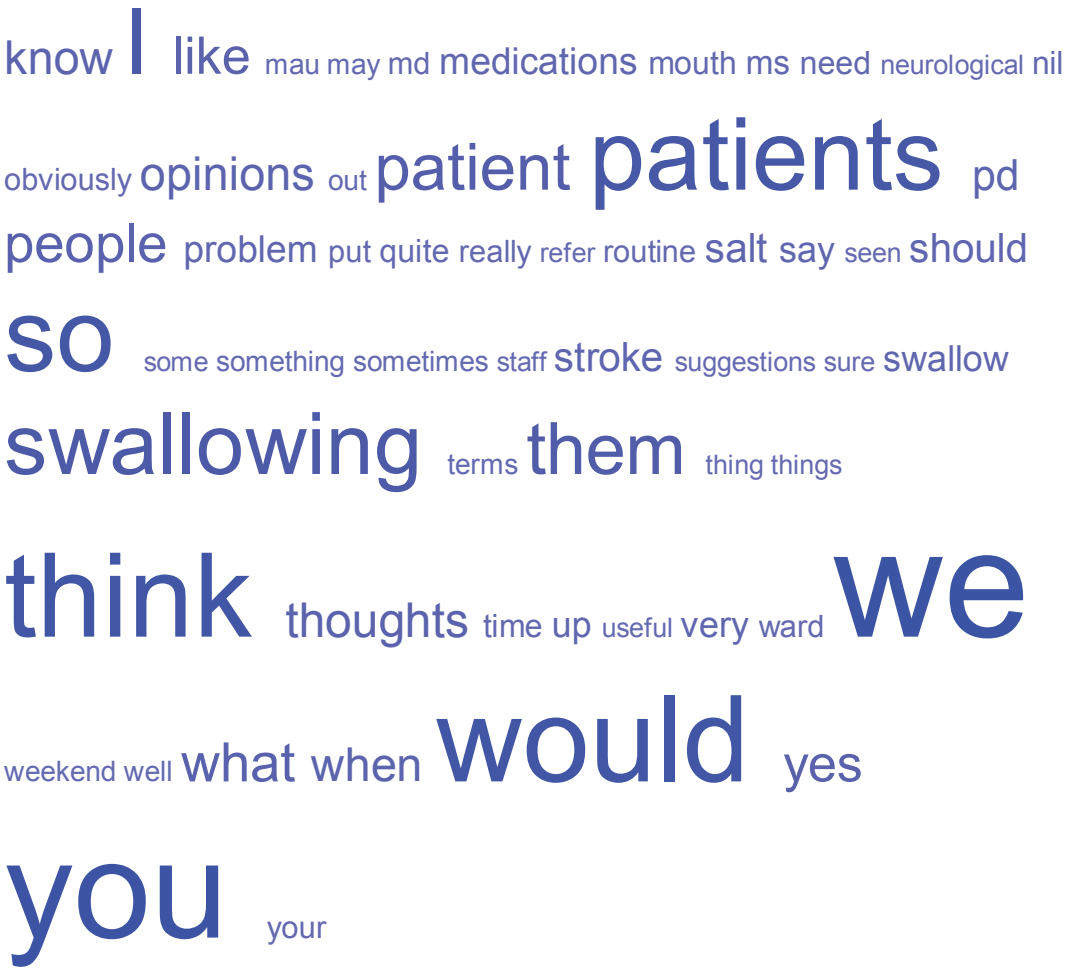

able about actually adequate all an any assess assessment
assessments away because been can can't come could
day days definitely do don't dtn fluids food from get go going good
got had have having here how i isn't just I
language like make method might more need nurses nursing
obviously only over patient patients people probably problem

v) Awareness of Guidelines on Swallowing Assessments

know I like md medical mouth ms neurological never nil obviously patients pd people possibly refer regarding salt say seen so sort stroke sure swallow swallowing tea terms them think those up usually ward water we well what when whether would you

vi) Difficulties and Suggestions on Swallow Screening Assessments

about already always an any assess assessed assessment assessments because been beneficial can can't come conditions could definitely difficult difficulties do don't done down eating even feelings food get go going good got guidelines had has have having how i just


know I like mau may md medications mouth ms need neurological nil
obviously opinions out patient patients pd
people problem put quite really refer routine salt say seen should
so some something sometimes staff stroke suggestions sure swallow
swallowing terms them thing things
think thoughts time up useful very ward we
weekend well what when would yes
you your