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SPEECH AND LANGUAGE THERAPY

The impact of acquired neurological oropharyngeal dysphagia on the health-related quality of life of care home residents

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‘This thesis is the result of the author’s original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.’

Signed:

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ABSTRACT

Speech and Language Therapists (SLTs) have a key role in the management of oropharyngeal dysphagia. Dysphagia has many adverse consequences and negatively impacts quality of life (e.g. weight loss, embarrassment, depression). Dysphagia is prevalent among the care home population, affecting between 50% and 75% of residents. However, minimal research has explored the impact of dysphagia upon the health-related quality of life (HRQOL) of care home residents. Without such data, SLTs will be ill-equipped to meet the needs of this client group. This investigation sought to gain insight into the HRQOL issues for care home residents with oropharyngeal dysphagia caused by an acquired neurological disorder.

A qualitative methodology based on the principles of descriptive phenomenology was adopted. Interviews, mealtime observations and reflexive discussions were used to collect data from seven residents with acquired neurological oropharyngeal dysphagia and six residents without dysphagia. Interviews and discussions were transcribed verbatim and common themes were identified using a framework for phenomenological analysis. Observational data were examined for corroborations/contradictions with participants' accounts.

Participants with dysphagia described the physical, social and psychological impact of dysphagia, commented on their degree of satisfaction with diet modification and provided insight into their awareness of dysphagia and its overall impact. They also discussed other aspects of their mealtime experience, referring to their enjoyment of eating and mealtimes; barriers to mealtime enjoyment; choice at mealtimes and eating desire, findings which were similar to those obtained from the control participants. The observational data mainly corroborated with participants' accounts.

Based on these findings, SLTs should ensure that they consistently adopt a holistic approach to the management of care home residents with acquired neurological oropharyngeal dysphagia, collaborate with and provide education and training to care home staff.

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 Introduction

This chapter introduces the topic of investigation and provides important and relevant background information (1.2 - 1.7). Following this, the purpose and importance of this study is stated (1.8) and a brief description of the study method is provided (1.9). This chapter concludes with a brief outline of the structure of the thesis (1.10).

1.2 Swallowing: The process of deglutition

Swallowing is the process by which food and fluid are transported safely from the oral cavity to the stomach (Aviv, 1999; Gleeson, 1999). Perry (2001) describes food and eating as a “life support mechanism” (p.837), however as well as being crucial for physiological well-being, food contributes to cultural, social and psychological quality of life (QOL) (American Dietetic Association, 2005). Ney, Weiss, Kind and Robbins (2009) succinctly articulate the importance of a functional swallow, stating that, “The capacity to swallow effectively and safely is a basic human need and pleasure” (p.395).

Physiologically, the process of swallowing, or deglutition, is complex and can be considered in terms of three main phases: the oral phase, the pharyngeal phase and the oesophageal phase (Schindler and Kelly, 2002). Whilst division of the swallowing process into phases aids the study of deglutition (Gleeson, 1999), swallowing is a “continuous process” (Daniels and Huckabee, 2008, p.42). Swallowing can be initiated consciously, although generally it occurs subconsciously (Gleeson, 1999). A diagram illustrating the passage of a ‘bolus’ of food during the three phases of swallowing is appended (Appendix 1).

The oral phase, which commences upon entry of food/liquid into the oral cavity (Daniels and Huckabee, 2008), can be divided into the oral preparatory phase and the oral transport phase (Schindler and Kelly, 2002). During the oral preparatory phase, food is prepared for swallowing, by means of mastication of the bolus of food (Prasse and Kikano, 2004). The addition of saliva aids breakdown of food/liquid (Prasse and Kikano, 2004). The oral transport phase then commences, which involves posterior movement of the bolus by the tongue (Logemann, 1998). Generally, oral transport takes less than 1 second (Gleeson, 1999). The oral phase is a voluntary component of the swallowing process (Aviv, 1999).

The pharyngeal phase is an involuntary component of the swallowing process (Aviv, 1999) and when this phase is triggered, several events occur (Gleeson, 1999). During this phase, velopharyngeal closure occurs to stop the reflux of material into the posterior nasal space (Aviv, 1999). Elevation and anterior movement of the hyoid bone and larynx occurs (Logemann, 1998) and airway protection takes place, involving adduction of the true and false vocal folds and inversion of the epiglottis (Corbin-Lewis, Liss and Sciortino, 2005). The elevation of the hyoid bone and larynx contributes to airway entrance closure (Logemann, 1998). The bolus is transported through the pharynx by progressive contraction of the pharyngeal constrictor muscles and the upper oesophageal sphincter, which separates the pharynx from the oesophagus, opens (Corbin-Lewis et al, 2005). The duration of pharyngeal transit is typically 1 second or less (Gleeson, 1999).

The oesophageal phase of swallowing is also under involuntary control (Aviv, 1999) and involves progression of the bolus through the oesophagus to the stomach (Perry, 2001). The bolus enters the oesophagus at the upper oesophageal sphincter and is pushed through the oesophagus by peristaltic movements, a process which takes between 8 and 20 seconds (Logemann, 1998). The process of swallowing is considered to be complete when the bolus passes through the lower oesophageal sphincter (Schindler and Kelly, 2002).

1.3 Impairment of the swallowing process: Dysphagia

The highly intricate and coordinated process of swallowing can become disordered and impaired swallowing is also referred to as ‘dysphagia’ (Palmer, Drennan and Baba, 2000), originating from the Greek ‘dys’, meaning ‘difficulty’ and ‘phagia’, meaning ‘to eat’ (Prasse and Kikano, 2004). Oropharyngeal dysphagia refers to difficulty swallowing due to problems within the oral or pharyngeal phases of swallowing (Rosenbek and Donovan, 2006), while oesophageal dysphagia refers to difficulty within the oesophageal phase (Prasse and Kikano, 2004). The Speech and Language Therapist (SLT) has a key role in the assessment, diagnosis and management of oropharyngeal dysphagia (Royal College of Speech and Language Therapists, RCSLT, 2009), and this is the disorder under investigation in this study.

Although dysphagia is a disease in itself, it is also a symptom connected with numerous different kinds of disorders/diseases (Cichero, 2006). Oropharyngeal dysphagia can result from acquired neurological disorders, such as stroke; Parkinson’s Disease; Progressive Supranuclear Palsy and Myasthenia Gravis; or from developmental disorders, such as Cerebral Palsy and Down Syndrome (Cichero, 2006; Sheppard, 2006). Other causes include: head and neck cancer; Chronic Obstructive Pulmonary Disease; Scleroderma and certain medications, for example anticholinergics and antipsychotics (Cichero, 2006).

Dysphagia can cause significant morbidity and mortality (Palmer et al, 2000). Untreated, dysphagia can result in serious medical consequences such as, malnutrition; weight loss; dehydration and aspiration which can lead to coughing, an obstructed airway or aspiration pneumonia (Prasse and Kikano, 2004). Aspiration has been defined as the “entry of material into the airway below the level of the true vocal folds” (Ney et al, 2009, p. 395) and aspiration pneumonia “develops after the aspiration of colonized oropharyngeal contents” (Marik and Kaplan, 2003, p. 328-9). ‘Silent aspiration’ is the term used to refer to instances where aspiration occurs in the absence of symptoms indicative of aspiration, like coughing or throat clearing (Ney et al, 2009). Adverse social and psychological effects of dysphagia include anxiety; shame; depression and isolation (Ney et al, 2009). Dysphagia is associated with a reduced QOL (RCSLT, 2009), which is unsurprising given the multifaceted importance of food and drink. The QOL impact of oropharyngeal dysphagia is the focus of this investigation and a detailed consideration of the concept of ‘QOL’ and its relevance in healthcare, along with a review of previous research which has explored the QOL impact of dysphagia is provided in Chapter 2 (page 15).

1.4 Acquired neurological oropharyngeal dysphagia

This study is concerned with oropharyngeal dysphagia caused by acquired neurological disorders and a brief overview of the disorders of relevance to this study is provided here.

The most common neurological cause of oropharyngeal dysphagia is stroke (Corbin-Lewis et al, 2005). A stroke (also termed a Cerebrovascular Accident, CVA) occurs when the cerebral blood supply is interrupted, normally due to blockage by a clot or the bursting of a blood vessel (World Health Organisation, WHO, 2013). Interruption of the cerebral blood supply results in damage to the brain due to a lack of oxygen and nutrients being supplied (WHO, 2013). In Scotland, stroke is the third main cause of death and the primary cause of disability (Scottish Intercollegiate Guidelines Network, SIGN 108, 2008). 70 000 people in Scotland are living with the aftermath of stroke and there are around 12 500 new stroke events each year (SIGN 118, 2010). With age, the risk of stroke increases (Daniels and Huckabee, 2008). Between 40% and 60% of acute stroke patients are reported to have dysphagia (Sura, Madhavan, Carnaby and Crary, 2012). With regards to the clinical course of dysphagia post-stroke, Sura et al (2012) report that although it has been found that functional swallowing resumes for many during the first month post-onset, difficulty swallowing has been found to persist for some beyond six months.

Parkinson's Disease (PD) is a progressive neurodegenerative disorder which occurs as a result of the death of cells in the substantia nigra, which contain dopamine (National Collaborating Centre for Chronic Conditions, 2006). The substantia nigra is an area of cells located in the mid-brain and dopamine is a neurotransmitter substance (Corbin-Lewis et al, 2005). The typical features of PD are a unilateral resting tremor, a slowness in initiating movement, rigidity of the limbs and gait or balance problems (Corbin-Lewis et al, 2005). Per 100 000 people in Scotland, there are between 120 and 230 individuals with PD (SIGN 113, 2010). Like stroke, the incidence of PD increases with age (SIGN 113, 2010). A meta-analysis conducted by Kalf, de Swart, Bloem and Munneke (2012) indicated that subjective oropharyngeal dysphagia occurs in over one third of community-dwelling individuals with PD, with higher numbers in advanced PD, and when measured objectively, affects four out of five individuals with PD. Although more common in the later stages of PD, dysphagia may occur in the early stages and in some cases may be the presenting symptom (Coates and Bakheit, 1997).

Another degenerative neurological disorder is Progressive Supranuclear Palsy (PSP). The disorder affects the frontal cortex as well as connections to the basal ganglia and brainstem (Cichero, 2006). The consequences of PSP include axial rigidity, supranuclear gaze palsy, pseudobulbar palsy and dementia (Cichero, 2006). Dysphagia is common in PSP (Cichero, 2006). In one retrospective study based on post-mortem-confirmed cases, subjective dysphagia was reported in 83% of a sample of individuals with PSP (Muller et al, 2001).

Myasthenia Gravis (MG) is a neuromuscular, autoimmune disease typified by voluntary muscle weakness and fatiguability (Cichero, 2006). The disease affects the way in which nerve impulses are transmitted to muscles (Corbin-Lewis et al, 2005). Typical patient complaints are weakness, diplopia, drooping eyelids, dysphonia and dysphagia which becomes worse during the course of the day (Cichero, 2006). Other reported symptoms include, nasal regurgitation of fluids, choking on foods and secretions, loss of facial expression and dysarthria, including hypernasality (Cichero, 2006). Weakness tends to become worse as the day goes on or with protracted physical activity (Baser, 1999). During the course of MG, dysphagia occurs in approximately 50% of individuals (Prosiegel, 2012).

1.5 The management of oropharyngeal dysphagia

Speech and Language Therapists (SLTs) have a key role in the assessment, diagnosis and management of oropharyngeal dysphagia (RCSLT, 2009). Multi-disciplinary working is an important aspect of dysphagia management in order to ensure the provision of “a timely, efficient, integrated and holistic period of care” (RCSLT, 2005, p.63). Besides the SLT, the multi-disciplinary team is usually comprised of doctors, nursing staff, Dietician, Physiotherapist, Occupational Therapist, Pharmacist and Radiologist (Logemann, 1998). When working in care homes, SLTs will also work with care staff as these will be the individuals responsible for implementing management recommendations.

Regarding oropharyngeal dysphagia, management can be compensatory or rehabilitative in nature (Sura et al, 2012). Compensatory procedures aim to eliminate symptoms of dysphagia, while rehabilitation strategies (or therapy procedures) work to alter the physiology of the swallow (Logemann, 1998). The various approaches to the management of oropharyngeal dysphagia include: postural changes; swallow manoeuvres; modification of food/liquid consistencies; non-oral feeding (e.g. placement of a Percutaneous Endoscopic Gastrostomy (PEG) tube); oral motor exercises; neuromuscular electrical stimulation (Sura et al, 2012).

Dietary modification is the most frequently used compensatory approach in oropharyngeal dysphagia intervention (Ney et al, 2009) and given its relevance to the present investigation, is the only approach to management considered here. According to Sura et al (2012), dietary modification aims to "improve the safety and/or ease of oral consumption and thus maintain safe and adequate oral intake of food/liquid" (p. 291). Certain food/liquid consistencies are considered to be more appropriate for different impairments of the oropharyngeal swallowing mechanism (Logemann, 1998). For example, thickened liquids may be appropriate for an individual with poor orolingual control or a delayed pharyngeal swallow, while an individual with poor mastication may be suited to a chopped or puréed diet (Daniels and Huckabee, 2008). In individuals with dysphagia of a neurological origin where difficulties may be experienced in controlling the bolus, thin liquids, foods which fragment or which consist of multiple textures may be most problematic (Perry, 2001). It is important that collaboration with the dietician occurs to ensure that a modified diet continues to meet an individual's nutritional needs (Langmore, 1999). Furthermore, the SIGN guideline for the management of dysphagia following stroke (SIGN 119, 2010) states that individuals with persistent dysphagia should be subject to regular review. The Dysphagia Diet Food Texture Descriptors (National Patient Safety Agency, NPSA, 2012) provide detailed guidance for health professionals and catering staff relating to the four food texture categories. The document describes the characteristics of each dysphagia diet food texture and what characteristics should not be present/what kinds of foods are not appropriate. It should be noted that despite the frequent use of dietary modification in the management of oropharyngeal dysphagia, there is limited evidence available to support the efficacy of this approach (RCSLT, 2009).

An important piece of research in this area is the randomised clinical trial conducted by Logemann et al (2008) which sought to determine which intervention (chin-down posture, nectar-thickened liquids or honey-thickened liquids) would be most successful in immediately eliminating aspiration on thin liquids in 711 individuals with PD and/or dementia. Participants received the three interventions in a random order while being assessed using videofluroscopy. The study found that immediate elimination of aspiration on thin liquids occurred most frequently with the honey-thickened liquids, followed by nectar-thickened liquids and then the chin-down posture. The participants with PD were given the opportunity to assess each intervention for their preference and a smaller percentage of these individuals rated the honey-thickened intervention as easy or pleasant compared with the chin posture intervention or the nectar-thickened intervention and these differences were statistically significant. This finding illustrates the importance of taking clients' views of interventions into consideration, as the intervention considered most acceptable to clients may not be the intervention which is most clinically effective. As the authors acknowledge, the interventions included in this study were examined for their immediate effects and therefore assumptions cannot be made regarding the effectiveness of the interventions long-term.

The second phase of this study was a randomised controlled trial conducted by Robbins et al (2008), which compared the effectiveness of the chin-down posture and thickened liquids (nectar-thick and honey-thick) on the incidence of pneumonia in 515 individuals with dementia and/or PD during three months of treatment. The three month cumulative incidence of pneumonia was lower for the chin-down posture group than for the thickened liquid groups. Furthermore, the pneumonia incidence was lower in the nectar-thick group compared with the honey-thick group. However, these findings were not statistically significant and thus definitive conclusions cannot be made. There is a need for many more randomised controlled trials to be conducted in order to gain greater insight into the efficacy of dietary modification in reducing the occurrence of aspiration and aspiration pneumonia.

It can be hard for individuals to have certain consistencies removed from their diet (Logemann, 1998). For instance, puréed food and thickened liquids may not be appealing and this can impact upon the amount of food and liquid consumed, placing individuals at risk of malnutrition and dehydration (Langmore, 1999). Dissatisfaction with modified diets may also lead to lack of compliance, with individuals continuing to consume consistencies which have been deemed unsafe (Colodny, 2005), making them vulnerable to medical complications (Davis, 2007).

1.6 Swallowing and ageing

This study is concerned with elderly individuals and therefore it is important to acknowledge that the prevalence of dysphagia increases with age (Morris, 2006), with two main reasons for this.

Firstly, the process of ageing itself causes changes in the swallowing mechanism (Ney et al, 2009). Changes to the swallowing process as a result of ageing in the absence of any pathology can be termed 'presbyphagia' (Forster, Samaras, Gold and Samaras, 2011). These age-related effects can impact the swallowing mechanism in many ways and some examples are provided here. For instance, diminished strength in the facial muscles results in reduced masticatory strength (Schindler and Kelly, 2002), while having poor dentition or wearing dentures which do not fit well may increase the amount of chewing required to ensure the bolus is prepared for swallowing (Cichero, 2006). Dryness, or xerostomia, can hamper the flow of the bolus, leading to the existence of residue along the swallowing tract (Ney et al, 2009). The existence of residue in the pharyngeal recesses can place an individual at risk of aspiration (Ney et al, 2009). Pharyngeal swallowing is delayed in older adults compared with younger adults and older individuals often need to swallow multiple times in order to achieve effective clearance of a bolus from the pharynx (Schindler and Kelly, 2002). Although an increase in aspiration does not occur with age (Logemann, 1998), the age-related changes to the swallowing mechanism contribute to a "diminished functional reserve" (Ney et al, 2009, p. 396), placing an older individual more at risk of dysphagia if an illness were to place stress upon this reserve (Schindler and Kelly, 2002; Ney et al, 2009).

Secondly, with age, the incidence of cerebrovascular and neurodegenerative diseases increases (Marik and Kaplan, 2003), and the association between such disorders and dysphagia has been documented above. Dysphagia resulting from disease may be aggravated by age-related swallowing changes (Cichero, 2006).

1.7 The care home population and the problem of dysphagia

The most recent report regarding demographic trends in Scotland's population states that Scotland has an ageing population (National Records of Scotland, 2012). This ageing of the population is due to a relatively low birth rate and an increasing life expectancy (Scottish Government Social Research, 2010). With increasing age, there are more diseases which impact upon functioning (Brajkovic, Godan and Godan, 2009). In the majority of cases, declining health or loss of independence are the reasons why older adults leave independent living for life in a care home (Scocco, Rapattoni and Fantoni, 2006). As of the end of March 2012, there were 32 555 long-stay residents in care homes for older people (Information Services Division Scotland, 2012). It was estimated that on the 30th of June 2011, Scotland's population was 5 254 800 (National Records of Scotland, 2012), and thus, approximately 0.6% of the Scottish population are long-stay residents in care homes for older people.

Swallowing difficulties are prevalent in the care home population (Thomas, 2008). Marik and Kaplan (2003) state that between 50% and 75% of care home residents have dysphagia[1], while Steele, Greenwood, Ens, Robertson and Seidman-Carlson (1997) state that between 40% and 60% of institutionalised elderly individuals have identifiable signs and symptoms of oropharyngeal dysphagia. Only one relevant UK-based study has been located. Smithard (1996) obtained information via questionnaires regarding the prevalence of neurological, eating and swallowing problems among residents of 16 nursing and residential homes in two areas of London (this

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[1] Marik and Kaplan (2003) use the term 'nursing home', which is commonly used to describe long-term care settings in America. However, for the sake of consistency and clarity, the current UK equivalent, 'care home' has been utilised.

study was undertaken before ‘care home’ became the umbrella term for nursing and residential homes). However, an overall figure of the prevalence of dysphagia within each kind of home was not provided. Rather, figures relating to the prevalence of various indicators of swallowing problems were obtained e.g. 30.6% of nursing home residents exhibited slowness in eating and 14.5% required liquidised food. Residents could have been included within more than one of these categories.

The care home population is the target population for this study and within Chapter 3 (page 61) consideration is given to the mealtime experience within the care home setting, with a particular emphasis on aspects other than dysphagia which contribute to the eating and mealtime experience of care home residents.

1.8 Purpose and importance of the investigation

Despite reports of the high numbers of care home residents with dysphagia and the existence of research evidencing the negative QOL impact of dysphagia, minimal research has explored the health-related quality of life (HRQOL) impact of dysphagia upon care home residents. Without such data, SLTs are likely to be ill-equipped to meet the needs of this client group.

Ultimately, it is proposed that by gaining insight into the HRQOL issues for care home residents with acquired neurological oropharyngeal dysphagia, these data can be used to inform the practice of SLTs and care home staff, thus ensuring that approaches to management are holistic, focused on enhancing HRQOL and minimising the negative impact of oropharyngeal dysphagia as much as possible.

Thus, the purpose of this study was to explore the HRQOL impact of oropharyngeal dysphagia caused by acquired neurological disorders among care home residents.

1.9 Study method

A qualitative methodology, based on the principles of descriptive phenomenology, was used to gain insight into the experiences of the participants. Methodological triangulation was employed to enhance the validity of the study and to obtain a greater depth of understanding of the phenomenon under investigation. Structured/semi-structured interviews, mealtime observations and reflexive discussions were used to collect data from participants. A pilot study informed on the feasibility of a larger study with this population and provided a basis for refinement of materials and procedures.

In addition to collecting data from participants with oropharyngeal dysphagia, data relating to the eating and mealtime experience within the care home were collected from care home residents without dysphagia of any type. Collection of these data served to strengthen the findings of the research, given that data relating to the HRQOL impact of acquired neurological oropharyngeal dysphagia could be considered against the backdrop of additional eating and mealtime-related issues experienced by care home residents.

1.10 Outline of the thesis structure

As previously mentioned, Chapters 2 and 3 provide a review of the literature relevant to this investigation. The study method is described fully in Chapter 4 (page 73) and a detailed account of the analytical framework used in data analysis is provided in Chapter 5 (page 116). The results obtained from the control participants are presented in Chapter 6 (page 128) and the results obtained from the participants with dysphagia are presented in Chapter 7 (page 153). Chapter 8 (page 207) concludes the thesis with a discussion of the findings of this investigation, a critique of both the pilot and main studies and a presentation of the implications of the study findings for clinical practice and future research.

1.11 Summary

This chapter has introduced the topic of investigation and has provided background information considered relevant to the field of enquiry. The purpose and importance of this study has been clearly stated and an outline of the study method has been provided. The content of the subsequent chapters contained within this thesis has been outlined. The following two chapters provide a review of the literature relevant to this investigation.

CHAPTER 2

LITERATURE REVIEW: THE IMPACT OF DYSPHAGIA UPON QUALITY OF LIFE

2.1 Introduction

Having introduced the disorder under investigation (acquired neurological oropharyngeal dysphagia) in the previous chapter, this chapter gives consideration to the impact that dysphagia exerts upon quality of life. As a means of providing appropriate background and contextual information, consideration is given to the place of quality of life measurement within the healthcare context, the terms ‘Quality of Life’ and ‘Health-related Quality of Life’ are defined and discussed (2.2) and an overview of the measurement of health-related quality of life is provided (2.3). Subsequently, the central component of this chapter ensues in the form of a review of previous research which has investigated the quality of life impact of dysphagia (2.4).

2.2 ‘Quality of Life’ and ‘Health-related Quality of Life’: Conceptualisation and application in healthcare

The term ‘Quality of Life’ (QOL) has been in common use since after the end of the Second World War, and in America was at first associated with material wealth (Farquhar, 1995a). However, gradually the use of this term expanded and “then served to indicate that the ‘good life’ represented more than simple material affluence” (Farquhar, 1995a, p.1439). The use of the term ‘QOL’ became more prevalent within the field of healthcare during the 1970s (Farquhar, 1995a). Gradually medicine has been moving away from its dependence on only “clinical and laboratory indicators of illness” to measures which include the perspective of service-users (Wood-Dauphinee, 1999, p.355). Moreover, awareness of the fact that longevity does not necessarily correlate with quality has increased (Farquhar, 1995a). As well as its use within healthcare, the term ‘QOL’ is in use within many research fields including the spheres of economics, geography, psychology and sociology and this provides an indication of the multidisciplinary use of this concept (Farquhar, 1995a).

The World Health Organisation’s (WHO) (1946) definition of health recognises that health cannot simply be defined as “the absence of disease or infirmity” and is considered “a state of complete physical, mental and social well-being” (WHO, 1946, p.2). This perspective, although utopic in nature (Bowling, 2005), views health in a holistic manner and proposes that health cannot be determined based purely on physiological status (Anderson and Burckhardt, 1999). The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) encapsulates this notion of holistic consideration of individuals. The ICF framework is based on a biopsychosocial model of disability, which was formed by integrating the medical and social models of disability. Within this framework, functioning and disability are seen as outcomes of interactions between health conditions and contextual factors. Individuals are considered at three different levels of functioning: Body functions and structure, activity and participation. Disability is considered to involve dysfunctioning at one or more of these levels of functioning and is the umbrella term used to refer to impairments, activity limitations and participation restrictions. Ultimately, the ICF framework enforces the point that a diagnosis is not enough, stating the need for more broad-ranging information, relating to levels of functioning and disability, to be obtained. All of this information explaining the ICF framework has been extracted from a document produced by the WHO (2002).

It is deemed that a holistic consideration of individuals beyond their physiological status as advocated within the WHO ICF (2001) is also incorporated within the exploration of patient QOL. Costa Bandeira et al (2008) advocate the collection of QOL data within the healthcare context, stating that, “evaluations based on the patient’s point of view could improve the knowledge on the real impact of the disease on the patient's daily life" (p.183). Plowman-Prine et al (2009) comment on the importance of measures from the patient's perspective, given that the viewpoints of patients and professionals frequently differ, the fact that such measures frequently provide insight into how a condition impacts the individual in daily life and patient management can be guided by this information. Additionally, Bowling (2001) refers to the use of QOL assessment in measuring treatment outcome.

Despite the importance which has been attributed to QOL measurement within healthcare, the term has not been well-defined and QOL research as a whole is plagued by the lack of a universal definition (Bowling and Brazier, 1995; Frytak, 2000; Bowling, 2005). Farquhar (1995b) reports that one reason for the lack of agreement on a definition of 'QOL' is the multi-disciplinary use of this term. An abundance of definitions of QOL exist (Farquhar, 1995a) and according to Anderson and Burckhardt (1999), when considered in relation to other outcome variables in healthcare (e.g. symptoms, functional status), "no concept or variable generates as much confusion and controversy as does quality of life" (p. 299). Probably the most widely recognised definition of QOL is provided by the WHO (1997) who have defined QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p.1). The WHO (1997) definition goes on to state that QOL "is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" (p.1).

Thus, it is evident that QOL is a multidimensional concept (WHOQOL Group, 1995). QOL is also conceptualised as subjective and individualised (WHOQOL Group, 1995; Davis, 2007). It should also be acknowledged that perceptions of positive and negative aspects must be addressed in an investigation into QOL (WHOQOL Group, 1995). Anderson and Burckhardt

(1999) state that “It seems…that quality of life has the same basic constituents for all people, although the relative importance of individual dimensions may vary over the life span or during illness episodes” (p. 301).

The term ‘Health-related Quality of Life’ (HRQOL) is favoured by many who have the job of evaluating “the impact of disease and treatment on the lives of patients” (Wood-Dauphinee, 1999, p. 356). The concept of HRQOL is one aspect of broader QOL (Bowling, 2005) and does not consider non-health aspects (e.g. housing, income) (Kamphuis et al, 2002). Ebrahim (1995) proposes that HRQOL refers to “those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment” (p.1384). Kamphuis et al (2002) propose that HRQOL is the most relevant concept for health professionals.

Unfortunately the term ‘HRQOL’ is burdened with the same lack of conceptual clarity that pervades the broader concept of QOL and a single definition does not exist (Wood-Dauphinee, 1999). The use of the term HRQOL is controversial and Anderson and Burckhardt (1999) challenge the use of this term, stating that it suggests that individuals differentiate between a component of life which is affected by health and components which are less affected. Moreover, Hunt (1997) expresses the standpoint that “the measurement of the so-called ‘quality of life’ of individuals within medical settings has isolated them from the social and material conditions within which they exist” (p.207). HRQOL has been envisaged as being synonymous with health status (Leplege and Hunt, 1997; Frytak, 2000), although other authors have conceptualised HRQOL and health status as distinct concepts (Kamphuis et al, 2002).

Despite these criticisms, it is proposed that narrowing the concept of QOL to HRQOL within a healthcare context is essential in order to help health professionals gain insight into the issues specifically related to their remit. It is also proposed that the use of the term HRQOL does not imply that health is the most important aspect of QOL, nor does it reflect a short sightedness that there are no other factors contributing to QOL. It simply provides a means for health professionals to gain insights into the specific effects of their patients' conditions upon their lives and to gauge the impact of their interventions.

2.3 The measurement of health-related quality of life

The complexities associated with defining QOL and HRQOL have been acknowledged (2.2). The measurement of these concepts is also complicated and, as Seed and Lloyd (1997) comment, measurement of quantity is less complex than measurement of quality. Given the lack of conceptual clarity regarding the concepts of QOL/HRQOL, it seems logical to assume that the methods used to measure these concepts will be equally chaotic.

2.3.1 Rating health-related quality of life: Who should do it?

An important query regarding the measurement of HRQOL relates to who should rate HRQOL (Bowling, 2001). Self-report is the method most often used to measure QOL, for instance by means of questionnaires or scaling devices (Sarno, 1997), and has been advocated by some authors as an essential component of QOL/HRQOL assessment (Bowling, 2001; Morton and Izzard, 2003). However, self-report may be problematic when, for instance, patients' cognitive or communicative abilities are inadequate (Sneeuw, Sprangers and Aaronson, 2002). In such instances, it is relevant to consider obtaining QOL ratings from proxies or surrogates (family members or health professionals) (Addington-Hall and Kalra, 2001). In a review of 23 studies examining patient-proxy agreement for HRQOL measures, Sneeuw et al (2002) found that ratings provided by proxies relating to various aspects of patients' HRQOL were "reasonably accurate" (p.1141). Proxies do however have a tendency to report more HRQOL issues than their patient partners and greater agreement between patients and proxies tends to occur for physical HRQOL domains in comparison to psychosocial domains (Sneeuw et al, 2002). Given that data obtained from proxies do not agree exactly with patient perceptions, it is proposed that the individual's subjective perspective is essential to the exploration of HRQOL, although it is recognised that this is not always possible.

2.3.2 Generic measures of health-related quality of life

Measures of HRQOL can be generic (2.3.2), disease-specific (2.3.3) or domain-specific (2.3.4) (Bowling, 2001).

Generic HRQOL measures are wide-ranging in terms of the QOL domains which they include and they permit QOL comparisons between different disease populations (Schrag et al, 2003). However, they have a significant limitation in that "they are unable to identify the condition-specific aspects of a disease" (Bowling, 2001, p. 18). One of the most commonly used generic measures of HRQOL is the Medical Outcomes Study (MOS) 36-Item Short-Form Health Survey (SF-36) (Ware and Sherbourne, 1992). The SF-36 is a measure of health status, incorporating domains of physical functioning, role limitations due to physical and emotional problems, social functioning, bodily pain, mental health, vitality and general health perceptions. It has previously been used to examine the HRQOL impact of dysphagia (Chen, Golub and Hapner and Johns, 2009; Brandao, Nascimento and Vianna, 2010), although Brandao et al (2010) use the Brazilian version and Chen et al (2009) use a shortened version. However, the SF-36 is a measure of health status rather than a measure of HRQOL and this raises the issue regarding the seemingly synonymous use of HRQOL and health status in many instances. Although measures of broader health status, such as the SF-36, are considered to contain the principal areas in which health can affect an individual's life and which are of relevance in the field of healthcare, the use of these measures as measures of HRQOL results in a lack of conceptual clarity (Bowling, 2005). It is proposed that the concept of HRQOL is broader than that of health status and researchers must exhibit care when selecting a HRQOL measure, ensuring that they accurately establish and define exactly what they are measuring.

The WHOQOL-100 (WHOQOL Group, 1998a) is often used as a generic measure of HRQOL, although Bowling (2005) classifies it as a measure of broader QOL, given that it considers aspects which affect QOL beyond health. The WHOQOL-100 consists of 100 items, divided into four broad QOL domains (physical, psychological, social relationships, environment) and 24 facets of QOL (e.g. bodily image and appearance; working capacity). Four items address subjective overall QOL and overall health (WHOQOL Group, 1998a; Bowling, 2005). A shortened version of the WHOQOL-100, the WHOQOL-BREF (WHOQOL Group, 1998b) has also been developed. The WHOQOL-Bref has previously been used to investigate the HRQOL impact of oropharyngeal dysphagia (Maclean, Cotton and Perry, 2009b).

2.3.3 Disease-specific measures of health-related quality of life

In contrast to generic HRQOL measures, disease-specific measures of HRQOL are designed to be relevant only to individuals with a specific illness (Schrag et al, 2003), and a disease-specific HRQOL measure should be used when “disease or condition-related attributes need to be assessed, and greater sensitivity to the clinical condition under consideration is required” (Bowling, 2001, p. 16). It is proposed that utilisation of a disease-specific measure of HRQOL can help in the identification of disease-specific HRQOL issues which need to be addressed during intervention, thus facilitating the provision of holistic intervention which progresses beyond consideration of physiological status and considers the clients’ perspective.

Four key dysphagia-specific HRQOL measures are known to exist, although none of the authors of these measures use the term ‘HRQOL’. The M.D. Anderson Dysphagia Inventory (MDADI) (Chen et al, 2001) was developed to explore the HRQOL impact of oropharyngeal dysphagia caused by head and neck cancer. Importantly individuals with dysphagia caused by head and neck cancer were consulted during questionnaire development. The MDADI is a validated and reliable questionnaire, consisting of 20 items divided into four subscales (global, emotional, functional and physical) and respondents are required to provide a response using five-point Likert Scales (Chen et al, 2001). The SWAL-QOL Outcomes Tool for Oropharyngeal Dysphagia in Adults (McHorney et al, 2002) was developed for use with a wider dysphagic population than the MDADI. Individuals with oropharyngeal dysphagia caused by a range of disorders including vascular disorders, neurological disorders and cancer were included within the patient samples used for SWAL-QOL development (McHorney et al, 2000a; McHorney et al, 2000b; McHorney et al, 2002). Given that a modified version of this tool has been utilised within this study, further information relating to the SWAL-QOL is provided in Chapter 4 (page 73). McHorney et al (2002) also developed the SWAL-CARE which assesses quality of care and clients' satisfaction with care provision. It was not the intention of this study to assess quality of care/client satisfaction with care and thus no further mention is made of the SWAL-CARE.

The two other key measures are not as yet as widely used as the MDADI and the SWAL-QOL. The Deglutition Handicap Index (Woisard, Andrieux and Puech, 2006) consists of 30 items divided into three domains (physical, functional and emotional). Respondents use a five-point rating scale to provide their responses. The Dysphagia Handicap Index (Silbergleit, Schultz, Jacobson, Beardsley and Johnson, 2012) consists of 25 items divided into three sub-scales (physical, emotional and functional) and responses are provided using a three-point scale. Respondents are also asked to rate the severity of their swallowing difficulty using a seven-point scale.

2.3.4 Domain-specific measures of health-related quality of life

Bowling (2001) states that a domain-specific measure is necessary “when the area covered is of particular relevance to the study and its hypotheses, and where generic and disease-specific scales neglect that area” (p.16). For example, a measure of an individual’s psychological well-being may be employed, such as the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) or functional ability could be measured by using The Barthel Index (Mahoney and Barthel, 1965). It is proposed that the use of domain-specific scales can be abused when the multidimensional nature of HRQOL is forgotten and data obtained from these measures are used to make inferences about an individual’s HRQOL in its entirety.

Thus, it is evident that the exploration of HRQOL within healthcare has become an important means of obtaining the patient’s perspective on how disease and its treatment impacts upon their life. However, the lack of agreement and conceptual clarity which dominates this field of research makes this a complex and foreboding area. It is therefore of no surprise that scepticism surrounds the use of the term ‘QOL’ and QOL measurement within healthcare (Leplege and Hunt, 1997). Whilst it is acknowledged that conceptual clarity is much needed within this area, it is considered that the concept of HRQOL is of vital importance in encouraging healthcare professionals to consider how a disease or disorder impacts the ‘whole person’.

The following section (2.4) is concerned with reviewing previous research which has explored the QOL impact of dysphagia.

2.4 Quality of life and dysphagia

Early research within the field of dysphagia concentrated on the impairment, although research in this area has now broadened to consider both the complications and consequences of experiencing dysphagia (Langmore, 2000). Such research is of extensive clinical relevance (Langmore, 2000).

The remaining sections of this chapter are concerned with reviewing previous research which has investigated the QOL impact of dysphagia. These studies were obtained as a result of conducting a search of the following databases: Ingenta Connect; Science Direct; ISI Web of Knowledge and Medline ProQuest. A specific search was also conducted of the ‘Dysphagia’ journal. In all cases, the search terms used were, ‘dysphagia, Quality of Life’. A search of the ISI Web of Knowledge and the Medline ProQuest databases was also conducted using the search terms, ‘Impact of dysphagia on Quality of Life’. The reference list at the end of each study included within this chapter was also examined for studies of relevance.

Given the relevance of acquired neurological oropharyngeal dysphagia to this study, this literature review commences with research which has specifically investigated the QOL impact of oropharyngeal dysphagia caused by acquired neurological disorders (2.4.1). The acquired neurological disorders for which such research is available are stroke, Parkinson’s Disease (PD), Multiple Sclerosis (MS) and Motor Neurone Disease (MND). There are some differences between the acquired neurological disorders presented here and those relevant to the present investigation. Given the relatively small volume of research in this area, studies which have investigated the QOL impact of dysphagia caused by cancer (head and neck and non-head and neck cancer) (2.4.2) or which have not been disease-specific (2.4.3) will also be reviewed as a means of providing further insight into the impact of dysphagia upon QOL. Furthermore, given that care home residents are the target population for the present investigation, where the studies include individuals residing within a care home setting, this is clearly stated.

It must be acknowledged that QOL research in the field of dysphagia is plagued with the same lack of conceptual clarity that dominates the field of QOL research as a whole. The majority of authors report that they are measuring QOL, rather than HRQOL, a more appropriate construct when exploring the impact of a disease. In the review which follows, the QOL terminology used by the authors has been employed when discussing each study.

2.4.1 The quality of life impact of dysphagia caused by acquired neurological disorders

There are relatively few studies which have specifically investigated the QOL impact of dysphagia caused by acquired neurological disorders and those which have been located are summarised in Table 2.1. Given the minimal research which exists in this area, several nursing studies which have explored the post-stroke eating experiences of individuals at different stages of the illness trajectory have been included in the review. However, whilst the qualitative designs employed in these studies facilitate detailed exploration of the participants' experiences, these studies explore the entire eating process and although dysphagia is one aspect considered, they do not focus exclusively on dysphagia. A total of ten studies are included in Table 2.1. Furthermore, there are several studies which have not been included in Table 2.1, given that their focus was not the QOL impact of dysphagia/experiences of eating post-stroke, but which are considered important to mention and have been included in the analysis of the literature below.

Acquired neurological disorders are associated with oropharyngeal dysphagia (Cook and Kahrilas, 1999). Thus, although the majority of studies reviewed in this section do not use the term 'oropharyngeal dysphagia' when referring to their participant sample it can be reliably assumed that this is the type of dysphagia under investigation. 'Dysphagia' rather than 'oropharyngeal dysphagia' is used below for the sake of conciseness.

Ultimately, it is apparent that dysphagia exerts a negative impact upon QOL/HRQOL regardless of the acquired neurological disorder causing the dysphagia. This previous research clearly illustrates the physical, social and psychological impact of acquired neurological dysphagia.

Eight of the ten studies presented in Table 2.1 indicate the negative physical impact of acquired neurological dysphagia (Jacobsson et al, 2000; Klugman and Ross, 2002; Perry and McLaren, 2003; Carlsson, Ehrenberg and Ehnfors, 2004; Miller, Noble, Jones and Burn, 2006; Brandao et al, 2010; Leow, Huckabee, Anderson and Beckert, 2010; Medin, Larson, Von Arbin, Wredling and Tham, 2010; Paris et al, 2013). Dysphagia-related physical issues identified by participants included, choking, coughing, an increased eating duration and leakage of food/liquid from the mouth. The studies by Leow et al (2010) and Paris et al (2013) used the SWAL-QOL to elicit information from participants concerning the frequency of various symptoms of dysphagia. It is interesting to note that whilst Leow et al (2010) and Paris et al (2013) found statistically significant differences between the dysphagic and non-dysphagic groups on the symptom frequency domain of the SWAL-QOL, no statistically significant difference was identified between these groups for this domain in the study by Plowman-Prine et al (2009). This may have been due to the fact that only nine dysphagic participants were included in this study.

Brandao et al (2010) found that participants without dysphagia post-stroke had better general health, according to the SF-36, than participants with dysphagia. The authors propose that this finding may be due to the fact that dysphagia can lead to pneumonia caused by aspiration or the fact that severe dysphagia can result in insufficient nutrient intake leading to the need for non-oral feeding. The more general physical impact of dysphagia caused by stroke has also been evidenced by Kwok et al (2006), who found that consumption of a soft diet or tube feeding was a factor associated with poorer physical HRQOL. At the three month post-stroke period in this study, 19% of participants were resident in a care home setting.

The negative psychological impact of dysphagia caused by acquired neurological disorders was identified in seven of the ten studies presented in

Table 2.1 (Jacobsson et al, 2000; Klugman and Ross, 2002; Carlsson et al, 2004; Miller et al, 2006; Plowman-Prine et al, 2009; Leow et al, 2010; Paris et al, 2013). Psychological issues pertaining to dysphagia included, a fear of choking, stressful emotions and a loss of eating enjoyment. Moreover, all three of the studies which used the SWAL-QOL to determine the QOL impact of dysphagia found statistically significant differences between dysphagic and non-dysphagic participants on the mental health domain (Plowman-Prine et al, 2009; Leow et al, 2010; Paris et al, 2013). Plowman-Prine et al (2009) also found a statistically significant relationship between swallowing-specific QOL and depression, indicating that the worse the swallowing-specific QOL the worse the depression.

The social impact of acquired neurological dysphagia was also evident in eight of the ten studies included in Table 2.1 (Jacobsson et al, 2000; Klugman and Ross, 2002; Carlsson et al, 2004; Miller et al, 2006; Plowman-Prine et al, 2009; Leow et al, 2010; Medin et al, 2010; Paris et al, 2013). Social issues included, embarrassment, self-consciousness and changes in social habits. As with the psychological impact of dysphagia, the three studies which utilised the SWAL-QOL found statistically significant differences between dysphagic and non-dysphagic participants on the social domain.

With regards to overall QOL, Kim et al (2005) demonstrated a relationship between the presence of dysphagia caused by stroke and reduced QOL. They compared the factors affecting QOL post-ischemic stroke between young and old stroke patients. The findings of a univariate analysis indicated that dysphagia was a factor related to low QOL in both young-onset and old-onset stroke patients.

However, two studies in the field of PD were located which conflict with the findings of the studies referred to above. In their investigation to identify which factors determine QOL in PD patients, Schrag, Jahanshahi and Quinn (2000) reported that a history of speech or swallowing impairment had no statistically significant impact on QOL scores. Furthermore, Perez-Lloret et al (2012) reported that following adjustment for PD characteristics and concomitant medications, dysphagia did not have any impact on HRQOL according to the Parkinson's Disease Questionnaire-39 (PDQ-39) (Peto, Jenkinson, Fitzpatrick and Greenhall, 1995). Perez-Lloret et al (2012) do acknowledge that the participant cohort in this study did not include individuals at the most severe stages of PD. Furthermore, both of these investigations used the PDQ-39 as a measure of QOL/HRQOL and given that this instrument is not a dysphagia-specific measure, nor does it contain any swallowing-specific items, it is not surprising that a relationship between reduced QOL/HRQOL and dysphagia was not identified. Perez-Lloret et al (2012) did however find that dysphagia was associated with the presence of depressive symptoms, supporting the findings of other studies which have reported the relationship between dysphagia and poor mental health (e.g. Leow, Huckabee, Anderson and Beckert, 2010; Plowman-Prine et al, 2009).

Whilst Plowman-Prine et al (2009), Leow et al (2010) and Paris et al (2013) used a dysphagia-specific measure of HRQOL to gain insight into the QOL issues experienced by individuals with acquired neurological dysphagia, Brandao et al (2010) used the SF-36 to investigate the QOL impact of dysphagia caused by stroke. The use of this generic measure of HRQOL means that little insight is gained into the specific HRQOL issues associated with dysphagia post-stroke. The qualitative design utilised by five studies presented in Table 2.1 facilitated a detailed exploration of dysphagia-related QOL issues/experiences of eating post-stroke. Although three of the studies reviewed in this section included care home residents (Perry and McLaren, 2003; Kwok et al, 2006; Medin et al, 2010), they were not exclusive to the care home population, meaning that a clear picture of the HRQOL impact of acquired neurological dysphagia upon care home residents cannot be obtained.

Table 2.1: Overview of studies which have explored the QOL impact of dysphagia caused by acquired neurological disorders

Study	Participants	Method	Main findings	Critical Appraisal
Stroke studies				
Brandao et al (2010)	30 elderly dysphagic stroke patients and 30 elderly non-dysphagic stroke patients.	Deglutition was assessed by means of a clinical examination. The Brazilian version of the SF-36 was used to measure QOL.	Brandao et al (2010) investigated both the functional capacity and QOL of the participants. Although the functional capacity of both participant groups was similar, the SF-36 indicated that the non-dysphagic participants had better general health but more pain than those with dysphagia and these findings were statistically significant. There were no statistically significant differences between the dysphagic and non-dysphagic groups on the other domains.	The exclusion of individuals with cognitive impairment and aphasia raises the question of whether this sample is representative of the typical stroke population. The appropriateness of the SF-36 to measure HRQOL is questioned, given that it is a measure of health status and it is considered that utilisation of a dysphagia-specific HRQOL measure would have been a more effective means of gaining insight into the specific HRQOL issues associated with the presence of dysphagia.
Jacobsson et al (2000)	30 acute stroke patients and 15 healthy older people.	In addition to conducting assessments of eating, swallowing and oral function, the researchers interviewed the participants regarding their	Seven categories were identified from the qualitative analysis. A fear of choking and feelings of discomfort in the mouth and throat were reported by both the stroke and control groups. Stroke participants who had difficulty	The sample of stroke participants consisted largely of more highly functioning individuals (60% were independent in activities of daily living) and such a sample may

		eating experiences, although four stroke participants declined the interview. Any comments made by stroke patients during the eating/swallowing assessment were also incorporated within the qualitative analysis.	drinking from a glass expressed thirst as a concern. The stroke participants also reported experiencing discomfort from food, feeling shame about their changed appearance, feeling humiliated because of their dependence in eating and experiencing feelings of hopelessness.	not be representative of the typical stroke population. This issue may have resulted from the procedure adopted for participant identification (stroke patients were asked to participate if the nurse responsible for their care judged that they would be able to participate).
Perry and McLaren (2003)	Participants were individuals six months post-stroke. Where communicative and/or cognitive impairments prevented participation, it was possible for a live-in carer to be interviewed. 113 interviews were subjected to thematic analysis. 15 participants in this study resided in institutions.	Semi-structured interviews were used to gain insight into the participants' perceptions of eating difficulties. An assessment of eating abilities was also conducted.	Six main categories were identified. Participants referred to physical eating impairments, some of which were dysphagia-related (e.g. dribbling/food leakage; coughing or choking); consequences of eating-related impairments (e.g. dislike of thickened fluids leading to limited fluid intake in two participants); appetite and weight; practical factors, namely shopping, cooking and food (the food sub-theme included reference to participants' perceptions of thickened fluids and texture modified food); psychological factors (e.g. mood state affecting eating following discharge) and social eating (e.g. importance of maintaining normal appearances if possible, to hide disability in public). Only one specific reference was made to the sub-group of institutionalised	It has previously been acknowledged that the evaluations of proxies are not identical to those of the patients (2.3.1).

			participants and it was not dysphagia-related.	
Medin et al (2010)	Participants were 13 individuals six months post-stroke. One participant was transferred to a nursing home after her stroke.	Semi-structured interviews were used to explore participants' experience and management of eating situations.	Analysis of the interviews using a constant comparative approach revealed a single common theme: Desire to master eating situations. The results indicated that participants' experience and management of their new eating situation varied and was connected to their values and previous habits relating to eating. The majority of participants found it difficult to master eating situations post-stroke. It was apparent that other people could either be experienced as facilitators or hurdles to mastering eating situations according to the values and previous habits of the participant. When participants were unable to maintain previous eating habits, they attempted to discover new ways of mastering eating situations. Some of the participants had got used to and accepted their changed eating situation. Reference was made to a dysphagia-specific issue experienced by the participant who resided in a nursing home (embarrassment when coughing in front of others).	It is considered a strength that individuals with communication difficulties were included in this study, thus ensuring a more representative sample of the target population.

Carlsson et al (2004)	Three individuals who were around one and a half years post-stroke, at the time of the first interview.	Two interviews and participant observation of a light meal were used to explore how participants experienced living with eating difficulties. The second interview was conducted three months after the initial interview and on this occasion, participant observation of a light meal also occurred.	Data analysis inspired by the phenomenological tradition revealed the overall theme of 'Striving to live a normal life', which was divided into three sub-themes. Participants expressed a sense of abandonment after their stroke, reporting that they felt predominantly left on their own to deal with their eating difficulties. The participants also reported experiencing losses relating to both functional eating ability and the ability to perform activities relating to food and meals. Feelings of dependency at mealtimes also emerged from the data, due in part to the existence of hemi-paresis and in part due to lack of environmental adjustment and the social roles of participants changed post-stroke.	Individuals with communication difficulties were not excluded and all participants had dysarthria. The use of two interviews per participant and incorporation of participant observation into the research design is likely to have increased the validity of the findings (the second interview provided an opportunity for respondent validation) and provided a greater depth of understanding regarding the phenomenon under investigation. The very small sample size prevents generalisation to a wider eating-impaired stroke population.
Parkinson's Disease studies				
Leow et al (2010)	16 participants with early PD, 16 with later PD, 16 healthy elders and 16 healthy young adults.	The impact of dysphagia upon QOL in ageing and PD was investigated using the SWAL-QOL.	The healthy elders experienced a greater frequency of physical symptoms of swallowing difficulties in comparison to the healthy young adults and the difference between the groups was statistically significant. However, no other statistically	Inclusion of the healthy young adults and healthy elders and the use of a dysphagia-specific measure of HRQOL enable identification of the issues specifically associated with dysphagia caused by PD.

			significant differences existed between these groups for the other SWAL-QOL domains. Conversely, statistically significant differences were found between the scores of the PD participants and the healthy elders for all of the SWAL-QOL domains, with the exception of the Sleep domain, indicating a dysphagia-related QOL impairment. There were statistically significant differences between the group with early PD and the group with late PD for the domains of Food Selection, Eating Duration and Eating Desire.	It is not clearly established whether the PD participants had dysphagia diagnoses, whether they self-reported the existence of dysphagia or whether the assumption was made that dysphagia was present since PD was present.
Plowman-Prine et al (2009)	36 individuals with PD.	Identification of dysphagia occurred through self-report, with 27 participants reporting no restrictions in food and liquid intake and nine participants reporting being on a restricted diet. However, a Speech-Language Pathologist (SLP) verified a clinical diagnosis of dysphagia. The SWAL-QOL was utilised to examine swallowing-related QOL. Data were also collected using the PDQ-39 and the	There was a statistically significant difference between the total SWAL-QOL score for the dysphagic and the non-dysphagic participants. Lower scores across all SWAL-QOL domains existed for the dysphagic participants, with the exception of the Sleep domain and both groups had equivalent mean scores on the Eating Desire domain. However, statistically significant differences existed between the groups only for the Mental Health and Social domains. Furthermore, there was a statistically significant negative correlation between the total SWAL-QOL and the	Although the detrimental impact of dysphagia upon QOL was evidenced, the small number of dysphagic participants in this quantitative study does limit the extent to which generalisations to the wider dysphagic PD population can be made.

		Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock and Erbaugh, 1961).	PDQ-39 scores, with better swallowing-specific QOL associated with better HRQOL. A statistically significant negative correlation was also evident between the total SWAL-QOL score and BDI (i.e. the worse the swallowing-related QOL, the worse the depression).	
Miller et al (2006)	37 individuals with PD. Carers were allowed to be present, but initially the views of the individuals with PD were given priority.	Semi-structured interviews were conducted to explore the impact of swallowing changes upon the participants' lives.	Qualitative analysis revealed two broad themes: effects on swallowing of underlying physical changes and psychosocial impact, which were both further divided into sub-themes. Participants commented on difficulties with lengthy or hard chewing due to diminished strength and endurance; managing saliva and the perceived stigma surrounding this; increased eating duration for various reasons; problems swallowing medication; choking and fear of choking. Various strategies were adopted to cope with swallowing changes, such as taking smaller bites or sips or having someone modify the consistency of food prior to consumption. However, despite the adoption of strategies, loss of mealtime enjoyment due to increased eating duration, altered diet and dependence on others to cut food existed for some. The strategies	The qualitative design of this study facilitated detailed examination of the issues of relevance for the participants.

			could also negatively impact carers. Social habits surrounding eating were altered. Not all participants experienced all or any of the problems identified. There were also individuals who faced changes but who had made adjustments (e.g. avoiding certain foods, eating little and often) which enabled them to maintain mealtime enjoyment. It was apparent that swallowing impairment does not need to be severe to considerably impact the lives of individuals with PD and their carers.	
Multiple Sclerosis studies				
Klugman and Ross (2002)	30 individuals with a clinically definite diagnosis of MS.	A self-administered questionnaire was used to collect data concerning speech-language difficulties, swallowing problems and hearing difficulties. Participants were also asked to provide demographic information, information relating to therapy and any additional comments.	50% of the participants reported experiencing swallowing difficulties and participants described the difficulties they experienced. Eight of these individuals felt that their difficulties with swallowing were insignificant in comparison to other MS-related issues. However, 34% perceived their swallowing difficulties as significant problems and eight participants felt that their swallowing difficulties impacted upon their QOL. Stressful emotions, fear, the need for	Use of a validated dysphagia-specific HRQOL measure would have provided further insight into the issues experienced by participants and utilisation of face-to-face interviews would have provided participants with the opportunity to express their perceptions in a less restricted manner. Participants were asked to self-report the presence of swallowing difficulties, raising

			careful planning concerning eating, an impact on interpersonal relationships and a lack of eating enjoyment were reported within the sample of participants whose QOL was affected by dysphagia.	the question of whether the participants' reporting was accurate and the number of participants who would actually receive a clinical diagnosis of dysphagia.
Motor Neurone Disease studies				
Paris et al (2013)	30 patients with a diagnosis of MND.	Evaluation of swallowing function occurred by means of a standardised videofluroscopic barium swallow. The SWAL-QOL was used to investigate the QOL impact of dysphagia.	There was a statistically significant difference between the participants with dysphagia and the participants with normal swallowing on the burden, eating duration, eating desire, fear, food selection, communication, social functioning and mental health domains of the SWAL-QOL, with the participants with dysphagia scoring significantly lower on these domains. The dysphagic participants also complained of more physical symptoms of swallowing difficulties compared with the non-dysphagic participants and the differences between the groups were statistically significant.	Instrumental evaluation of swallowing function is considered a strength of this study, given that it could be clinically established which participants had dysphagia. A nurse assisted participants with completion of the SWAL-QOL and the authors acknowledge the potential bias which could result from this, although it is reported that the nurse did try to be neutral. There is a possibility of the existence of unreliable responses within the data set due to decreased cognitive functioning.

2.4.2 The quality of life impact of dysphagia caused by head and neck cancer/non-head and neck cancer

There is a comparatively large volume of research investigating the QOL impact of dysphagia caused by head and neck cancer. Head and neck cancer is diagnosed when a primary tumour is present in the oral cavity, pharynx, larynx, salivary glands or paranasal sinuses (Maclean et al, 2009b). Dysphagia in head and neck cancer can occur due to the presence of a tumour (Platteaux, Dirix, Dejaeger and Nuyts, 2010), or as a result of the treatment used to eradicate the tumour (Manikantan et al, 2009).

Oropharyngeal dysphagia is the type of dysphagia associated with head and neck cancer (World Gastroenterology Organisation, 2007). Thus, although none of the head and neck cancer studies reviewed use the term ‘oropharyngeal dysphagia’ when referring to their participant sample, it can be reliably assumed that this is the type of dysphagia under investigation. ‘Dysphagia’ rather than ‘oropharyngeal dysphagia’ is used below for the sake of conciseness.

Oropharyngeal dysphagia may also occur as a result of non-head and neck cancers, such as lung cancer, due to the tumour, the treatment, cancer-related weakness and fatigue or co-morbidities (Roe, Leslie and Drinnan, 2007). Non-head and neck cancers, such as oesophageal cancer, can also give rise to oesophageal dysphagia (World Gastroenterology Organisation, 2007).

Much research within the field of head and neck cancer and non-head and neck cancer indicates that dysphagia caused by cancer negatively impacts QOL. Studies which have explored the QOL impact of dysphagia caused by head and neck cancer and non-head and neck cancer are summarised in Table 2.2. Eleven studies are included in Table 2.2. It should be noted that the Watt and Whyte (2003) study in Table 2.2 is concerned with oesophageal dysphagia rather than oropharyngeal dysphagia.

The negative impact that dysphagia exerts upon mental health is extremely apparent within this body of research. Seven studies in Table 2.2 clearly indicate the detrimental impact of dysphagia caused by head and neck cancer/non-head and neck cancer on psychological well-being. Distress as a result of dysphagia was identified in three studies. Ward, Bishop, Frisby and Stevens (2002) found higher levels of distress among individuals post-laryngectomy with dysphagia than those without dysphagia and the difference between the groups was statistically significant. Furthermore, 57.5% of individuals with dysphagia post-laryngectomy in Maclean et al's (2009a) study reported either moderate or severe distress as a result of their swallowing difficulty, while 70% of the post-irradiation nasopharyngeal carcinoma patients in a study by Tong, Lee, Yuen and Lo (2011) indicated that dysphagia caused them distress. Queija, Portas, Dedivitis, Lehn and Barros (2009) used the SWAL-QOL to determine the QOL impact of dysphagia following laryngectomy or pharyngolarynectomy. They found that there was a statistically significant difference between the participants who reported dysphagia and those who did not on the mental health domain, with participants reporting dysphagia scoring significantly lower. Negative psychological issues reported by participants in the two qualitative studies reviewed in this section included depression and low mood, a loss of eating enjoyment and fear, insecurity and anxiety about eating (Watt and Whyte, 2003; Tong et al, 2011).

Two studies used clinical assessments to determine the impact of dysphagia upon mental health. Nguyen et al (2005) found that individuals with moderate to severe dysphagia had greater levels of anxiety and depression on the Hospital Anxiety and Depression Scale (HADS) when compared with individuals with no or mild dysphagia. Additionally, Maclean et al (2009b) found that individuals with dysphagia post-laryngectomy had higher levels of stress, anxiety and depression on the Depression Anxiety Stress Scale (Lovibond and Lovibond, 1995) compared with the non-dysphagic participants. All of these findings were statistically significant.

Six of the eleven studies included in Table 2.2 also clearly evidenced the negative impact of dysphagia caused by head and neck cancer/non-head and neck cancer on social well-being. Negative social issues pertaining to dysphagia that were identified within these studies included, embarrassment at mealtimes, avoidance of eating with others and changes to lifestyle (Ward et al, 2002; Watt and Whyte, 2003; Garcia-Peris et al, 2007; Maclean et al, 2009a; Tong et al, 2011). Furthermore, in Maclean et al's (2009b) study of individuals post-laryngectomy, participants with dysphagia had a lower mean social score on the University of Washington QOL assessment (UWQOL) (Hassan and Weymuller, 1993), a head and neck cancer-specific HRQOL measure, compared with the non-dysphagic participants and the difference between the groups was statistically significant. It is questioned whether the existence of negative dysphagia-related social issues could exert an impact upon participants' perceptions of their psychological well-being.

It is of concern that seven of the eleven studies presented in Table 2.2 relied on participants' self-diagnosis of dysphagia and thus for these studies it remains unclear how many participants had a true dysphagia diagnosis, calling into question the accuracy of the reported findings. Furthermore, it was unclear whether the participants in the study by Costa-Bandeira et al (2008) had clinical dysphagia diagnoses. In contrast, Nguyen et al (2005) and Queija et al (2009) report the use of an instrumental assessment to diagnose dysphagia and this is considered a more rigorous approach than reliance upon self-diagosis. Additionally, four of the seven studies which used a validated measure of HRQOL to determine the QOL impact of dysphagia caused by head and neck cancer/non-head and neck cancer, utilised a dysphagia-specific measure of HRQOL, namely the SWAL-QOL. It is argued that using a dysphagia-specific HRQOL measure is a more suitable means of gauging the HRQOL impact of dysphagia, given that such measures only address issues of relevance to individuals with dysphagia.

Table 2.2: Overview of studies which have explored the QOL impact of dysphagia caused by head and neck cancer and non-head and neck cancers

Study	Participants	Method	Main findings	Critical Appraisal
Head and neck cancer studies				
Ward et al (2002)	55 patients who had undergone a total laryngectomy and 37 patients who had undergone a pharyngolaryngectomy.	In addition to a retrospective review of medical records, participants were interviewed regarding their long-term swallowing outcomes (this phase involved 36 laryngectomy and 14 pharyngolaryngectomy participants). At the point of interview, participants were at least one year post-surgery. This involved participants identifying their current dietary status and their levels of perceived swallowing disability, handicap and well-being/distress on the Therapy Outcome Measure (TOM) Dysphagia Scale (Enderby and John, 1997).	At the follow-up interview, 42% of the laryngectomy and 50% of the pharyngolaryngectomy participants had dysphagia (defined as the inability to consume a normal diet). With regard to the TOM scores, participants with dysphagia in the laryngectomy group perceived higher levels of disability, handicap and distress than non-dysphagic participants and the differences between the groups were statistically significant. Although small group numbers in the pharyngolaryngectomy group invalidated inferential statistical testing, examination of the group mean TOM scores indicated consistently higher levels of perceived disability, handicap and distress in the dysphagic participants compared with the non-dysphagic participants. Some	The follow-up phase of this investigation relied upon participants self-reporting the presence of dysphagia. The TOM resource has been developed for use by clinicians and therefore it is unclear whether it is suitable for use by patients. Ward et al (2002) infer from participants' TOM ratings that dysphagia impacts negatively upon QOL. However, the degree to which inferences regarding the QOL impact of dysphagia can be made from these ratings is unclear, as the TOM resource is not a validated HRQOL measure.

			of the participants who were consuming a normal diet, perceived a slight level of swallowing handicap and distress due to for instance, increased duration to eat a meal of normal consistency.	
Lovell, Wong, Loh, Ngo and Wilson (2005)	51 patients who had been treated for a nasopharyngeal carcinoma (now disease-free).	The UWQOL and the SWAL-QOL were used to assess the QOL impact of dysphagia. The questionnaires were translated into Mandarin and modified slightly. Only participants who self-reported dysphagia were required to complete the SWAL-QOL (although those without dysphagia were asked to read through the SWAL-QOL to ensure that none of the issues applied to them).	84% of participants reported experiencing dysphagia and these individuals had a lower UW-QOL composite score, HRQOL score and a lower overall QOL than those without dysphagia, and the differences between the groups were statistically significant. 59% of respondents selected dysphagia as the most important issue to them during the previous seven days.	Participants self-reported the presence of dysphagia. It is positive that the authors incorporated a dysphagia-specific measure of HRQOL within the investigation.
Nguyen et al (2005)	104 patients who had received treatment for various cancers of the head and neck.	73 participants (suspected of having dysphagia) underwent a Modified Barium swallow (MBS) as a means of assessing dysphagia severity. The 31 participants with no or minimal dysphagia formed the control group (no MBS). The QOL impact of dysphagia was assessed using the UWQOL	Participants with moderate to severe dysphagia (49) perceived a lower QOL than those with no or mild dysphagia (control group and those assessed via MBS as having mild dysphagia), and the difference between the groups was statistically significant. These participants also had greater levels of anxiety and depression	Use of an instrumental assessment to grade dysphagia severity is deemed more rigorous than reliance on self-report of severity. Incorporation of a dysphagia-specific HRQOL measure would have provided more insight into the specific QOL issues associated with dysphagia.

		and the HADS.	compared to those with no or mild dysphagia and the differences between the groups were statistically significant.	
Garcia-Peris et al (2007)	87 patients who had received treatment for various cancers of the head and neck.	In addition to a nutritional assessment, the QOL impact of dysphagia was assessed using a sub-section of a questionnaire utilised by Ekberg, Hamdy, Woisard, Wuttge-Hannig and Ortega (2002).	The prevalence of dysphagia was 50.6%. 51.7% of participants reported that dysphagia negatively affected their QOL. Nearly 62% avoided eating with others and approximately 37% reported experiencing embarrassment at mealtimes. The dysphagic participants had a more impaired QOL than the non-dysphagic participants and the difference between the groups was statistically significant.	The approach of self-diagnosis was adopted in this study. It is unclear how the questionnaire data were extrapolated to reach the conclusion of QOL impact/no QOL impact i.e. whether the conclusion was based on participants' responses to one question. It is also unclear whether the QOL data relates only to those who reported swallowing difficulties or whether it relates to the entire sample.
Costa Bandeira et al (2008)	29 patients who had received treatment for tongue cancer.	The QOL impact of dysphagia was assessed using the SWAL-QOL (which was translated and culturally adapted for Brazilian Portuguese).	Overall, participants experienced a good swallowing-related QOL. However, QOL issues related to swallowing were still evident. The eating duration domain presented the worst mean score. The worst possible score was noted in, for example, 17.2% of participants for the statement 'dealing with my swallowing problem is very difficult'; in 34.5% for the eating	It is unclear whether the participants had clinical dysphagia diagnoses. Utilisation of a dysphagia-specific HRQOL measure means that the study focuses on issues specific to swallowing. The small sample size impacts upon the generalisability of the findings.

			duration domain statements; in 27.6% for problems chewing and in 20.7% for food sticking in the mouth. Participants at an advanced stage of the disease had poorer scores of statistical significance on the following domains: eating duration, eating desire, symptom frequency, communication and fear. The authors provide various explanations for the positive findings, such as the fact that most participants had no dietary restrictions and the majority had early stage tumours ultimately meaning less impact on swallowing function and more concern with the cancer itself.	
Maclean et al (2009a)	110 individuals who had undergone a total laryngectomy (All members of the Laryngectomee Association of New South Wales, Australia).	A postal questionnaire battery was used to obtain demographic information, details regarding the laryngectomy surgery, additional treatment received and changes to swallowing ability post-surgery. The questionnaire also obtained data concerning changes to social life post-surgery and swallowing-related distress. Data regarding alcohol and tobacco use were also	71.8% of participants reported difficulty in swallowing, 71% of whom had altered the consistency of their diet. 61% of the dysphagic participants reported having made lifestyle changes (e.g. no longer eating out) due to dysphagia. In constrast, none of the participants without dysphagia reported having made significant lifestyle changes. In addition, 73 of the 79 dysphagic participants provided a rating of the	The approach of self-diagnosis was adopted in this study. Inclusion of participants from a large geographical area increases the generalisability of this study to a wider laryngectomy population.

		collected.	amount of distress caused by their dysphagia. 20.5% reported no distress; 22% mild distress; 17.8% moderate distress and 39.7% severe distress. Participants also provided written comments concerning consistency of food, regurgitation/reflux, time taken to swallow and social consequences of dysphagia (embarrassment as a result of dysphagia).	
Maclean et al (2009b)	Same participant sample as the 2009a study.	In addition to completing the questionnaire described above, participants completed measures of QOL (WHOQOL-Bref), functioning (UWQOL) and psychological well-being (Depression Anxiety Stress Scale), in order to gauge the consequences of dysphagia post-laryngectomy.	There were no statistically significant differences between the participants with dysphagia and the participants without dysphagia on the WHOQOL-Bref scores. However, the UWQOL indicated that the dysphagic participants had lower mean physical and social scores compared to the non-dysphagic participants, with the differences between the groups being statistically significant. Maclean et al (2009b) question whether major components of the UWQOL are more measures of functioning than of QOL. The participants with dysphagia also reported higher levels of stress, anxiety and depression than those without dysphagia and the	In addition to the points raised above in relation to the 2009a study, incorporation of a dysphagia-specific HRQOL measure would have provided more insight into the specific QOL issues relating to dysphagia. Furthermore, the group sizes of the dysphagic and non-dysphagic groups were unequal, with 71.8% of participants reporting having swallowing difficulties.

			differences between the groups were statistically significant.	
Queija et al (2009)	28 patients who had undergone a total laryngectomy or pharyngolaryngectomy.	The swallowing of all participants was assessed using videofluroscopy. The QOL impact of dysphagia was assessed using the SWAL-QOL (which was translated and culturally adapted for Brazilian Portuguese).	Although only six participants self-reported swallowing difficulties, dysphagia was diagnosed in 18 participants based on the videofluroscopy examinations. Good QOL was evident based on the SWAL-QOL scores, with lower scores existing for the communication, eating duration and social domains. The individuals who reported dysphagia perceived a greater swallowing-related QOL impact, with statistically significant differences between those not reporting dysphagia achieved in the burden and mental health domains. Impact on the mental health domain existed for participants with moderate/severe dysphagia. The authors justify these generally positive findings based on the likelihood of participants' prioritisation of disease cure. Additionally, participants were on average, 31.9 months post-treatment.	Use of an instrumental assessment in dysphagia diagnosis is deemed more rigorous than reliance on self-diagnosis. Utilisation of a dysphagia-specific HRQOL measure means that the study focuses on issues specific to swallowing. The small sample size impacts upon the generalisability of the findings.

Tong et al (2011)	60 post-irradiation nasopharyngeal carcinoma patients (all were at least one year post-irradiation).	Participants completed a self-administered questionnaire relating to diet, impact of swallowing difficulties on daily living, oropharyngeal well-being and a self-assessment of swallowing function. Following this, participants were engaged in a semi-structured interview which utilised a phenomenological approach. Although all participants were initially asked the same questions, they were then asked to further elaborate on their responses to the questions in the questionnaire.	Based on the questionnaire data, 85% of participants perceived some degree of swallowing difficulty, with 50% reporting either moderate, severe or profound difficulties. 70% perceived distress as a result of dysphagia; 31.7% avoided eating out; 36.7% reported that dysphagia affected their normal work and 21.7% perceived that dysphagia impacted upon relationships. Four themes were identified from the interview transcripts: Patient judgement of swallowing difficulties; Patients' definition of normal diet; The perceptions of 'no difficulties' in swallowing; Little attention paid to dysphagia symptoms. These themes provided insight into how the participants perceived swallowing difficulties and their own experiences. Misconceptions/lack of understanding/knowledge about swallowing difficulties existed. In addition to physical swallowing-related issues, the broader impact of dysphagia was apparent with for instance, comments regarding how dysphagia led to reduced socialisation, depression,	The approach of self-diagnosis was adopted in this study. The adoption of a qualitative methodology for this study permitted an in-depth exploration of participants' perceptions of swallowing difficulties.

			negatively impacted family and working life and affected diet. The authors did find that the threat of cancer recurrence was the main concern for many participants.	
Non-head and neck cancer studies				
Watt and Whyte (2003)	Six individuals with oesophageal dysphagia eligible only for palliative treatment of oesophageal cancer.	Between-method triangulation was adopted in this study and the experience and QOL impact of dysphagia was investigated using two cancer-specific HRQOL measures (one of which was specific to individuals with oesophageal cancer), and semi-structured interviews using a descriptive phenomenological approach.	Physical, emotional and social issues related to dysphagia were identified by the participants during the interviews e.g. the need for dietary restrictions/modifications; increased eating duration; problems with secretions; weight loss; longing for food that couldn't be eaten; loss of eating enjoyment; low mood; fear, insecurity and anxiety about eating; embarrassment; reluctance to eat with others, including close family members in some cases. Questionnaire data were able to corroborate interview data.	The use of between-method triangulation increases the depth of information obtained and enhances the validity of the findings. The process of bracketing (a principle of descriptive phenomenology) was adopted to reduce researcher bias. The small sample size prevents generalisation of the findings. The QOL impact of oesophageal dysphagia is explored rather than oropharyngeal dysphagia.
Roe et al (2007)	11 patients receiving specialist palliative care for non-head and neck cancer (e.g. lung, breast,	A modified version of the SWAL-QOL (administered in interview format) was used to collect data on the participants' experience of	Seven participants reported experiencing symptoms of dysphagia in the month prior to participation and two others	The approach of self-diagnosis was adopted in this study. The small sample size prevents the generalisation of these

	pancreatic). Six participants had metastatic disease.	dysphagia and QOL issues pertaining to dysphagia.	reported having experienced dysphagic symptoms since disease onset. Regarding the QOL impact of dysphagia, six participants reported one to two domains affected and three perceived a substantial QOL impact, given that four to seven domains were affected. A domain was considered problematic for a participant if the score was worse than the mean value for existing dysphagic data.	findings (many issues associated with recruiting terminally ill patients). The use of a dysphagia-specific HRQOL measure provides insight into the specific QOL issues pertaining to dysphagia.

2.4.3 Non-disease-specific studies

Some studies in this field of research have not confined investigation of the QOL impact of dysphagia to one specific aetiological group and in many cases, dysphagia aetiologies have not been (fully) established/it is not possible to be certain regarding dysphagia aetiologies. As a result, the question is raised regarding whether many of the non-disease-specific studies have considered cases of presbyphagia. Nevertheless, these studies provide an indication of the issues of concern for individuals with swallowing difficulties and they are summarised in Table 2.3. A total of nine studies are included in Table 2.3. Furthermore, there are several studies which have not been included in Table 2.3, given that their focus was not the QOL impact of dysphagia, but which are considered important to mention as they were concerned with institutionalised individuals. The issue raised above concerning dysphagia aetiology also relates to these studies.

Some of the studies discussed below clearly indicate that their focus is orpharyngeal dysphagia, oesophageal dysphagia or both types of dysphagia. However, in other studies, the focus is less clear and whilst in most cases it is likely that it is oropharyngeal dysphagia which is being studied, it is acknowledged that it is not possible to be certain.

It is noteworthy that all nine of the studies in Table 2.3 evidence the negative impact that dysphagia exerts upon mental health. Psychological issues pertaining to dysphagia which emerged from these studies included, feelings of hopelessness and panic, anxiety, a loss of eating enjoyment, a less enjoyable life as a result of dysphagia, fear of choking and depression (Gustafsson and Tibbling, 1991; Tibbling and Gustafsson, 1991; Ekberg et al, 2002; Farri, Accornero and Burdese, 2007; Martino, Beaton and Diamant, 2010). Two studies (Roy, Stemple, Merrill and Thomas, 2007; Chen et al, 2009) used a dysphagia-specific measure of HRQOL, namely the MDADI, and found that participants reporting dysphagia scored significantly lower on the Emotional domain than participants without dysphagia and these findings were statistically significant.

Two studies (Eslick and Talley, 2008; Turley and Cohen, 2009) used clinical measures of psychological well-being to investigate the impact of dysphagia upon mental health. Eslick and Talley (2008) found intermittent dysphagia to be independently associated with anxiety and progressive dysphagia to be independently associated with depression. However, Turley and Cohen (2009) reported that individuals with both dysphagia and dysphonia had higher levels of depression than individuals with neither disorder and the extent to which dysphagia contributed to depression in comparison with dysphonia is unclear. Interestingly, Martino, Beaton and Diamant (2010) suggest that dysphagia-specific QOL issues, specifically perceptions of psychological issues, vary across the recovery trajectory. The qualitative design adopted by Martino et al (2010) facilitated detailed insight into the psychological issues which exist for individuals living with oropharyngeal dysphagia.

Additionally, there are two studies which are specific to institutional settings which further indicate the negative impact of dysphagia upon mental health. Chow et al (2004) and Lin, Wang, Chen, Wu and Portwood (2005) found that swallowing difficulties were independently associated with depressive symptoms amongst elderly individuals residing in institutional settings in Hong Kong and Taiwan respectively. It should be noted that individuals undergoing tube-feeding were excluded from Lin et al’s (2005) study and Chow et al (2004) made no reference to how they handled any tube-fed participants. The causes of swallowing difficulties were not established in either of these studies, both of which utilised the same validated screening test for depression. Whilst participants in Lin et al’s (2005) study underwent a thorough swallowing examination incorporating both subjective and objective components, Chow et al (2004), on the other hand, reported that they obtained information relating to physical aspects by asking the resident or consulting the resident record if available and it is unclear how the authors defined ‘swallowing problems’.

Seven of the nine studies presented in Table 2.3 indicate the negative impact of dysphagia on social well-being (Gustafsson and Tibbling, 1991; Tibbling and Gustafsson, 1991; Ekberg et al, 2002; Farri et al, 2007; Roy et al, 2007; Chen et al, 2009; Martino et al, 2010). Dysphagia-related social issues identified in these studies included, a desire to eat alone and embarrassment at mealtimes. The two studies which used the MDADI (Roy et al, 2007; Chen et al, 2009) found that participants who reported dysphagia scored significantly lower on the Functional domain than participants without dysphagia and these findings were statistically significant. The Functional domain of the MDADI seeks to capture the impact of swallowing difficulties upon daily activities.

With regards to the negative social impact of dysphagia within the institutional setting, Wang, Chen and Li (2012) found in their study of long-term care facilities in Taiwan that there was a statistically significant relationship between problems with chewing and swallowing and difficulties with social engagement. There is however, a lack of terminological clarity in this study and it is unclear what ‘problems with chewing and swallowing’ encompassed and how they were identified and ‘oral health’ in this study seems, in many cases, to incorporate chewing and swallowing problems. Furthermore, it is not possible to be certain regarding the causes of the chewing and swallowing problems.

Self-diagnosis of dysphagia was an approach clearly adopted in six of the nine studies presented in Table 2.3 and it is considered that such an approach impacts upon the reliability of the findings. Moreover, it is unclear whether the participants in Farri et al’s (2007) study had clinical dysphagia diagnoses. Furthermore, only two of the studies reported in Table 2.3 utilised a validated dysphagia-specific HRQOL measure (Roy et al, 2007; Chen et al, 2009). However, these studies used the MDADI, a measure validated for use with head and neck cancer patients, with a non-head and neck cancer-specific population. Eslick and Talley (2008) used the SF-36 to investigate the QOL impact of dysphagia and it is argued that a generic measure of

HRQOL provides minimal insight into the issues which are specific to individuals with dysphagia.

Table 2.3: Overview of non-disease-specific studies which have explored the QOL impact of dysphagia

Study	**Participants**	**Method**	**Main findings**	**Critical Appraisal**
Gustafsson and Tibbling (1991)	19 individuals with some kind of non-malignant oesophageal disease that could cause dysphagia, although the diagnosis was unknown in four participants. The participants had experience of dysphagia.	Data were collected using a questionnaire administered in interview format.	According to a Disability-Goal-Handicap (DGH) scale developed for this study, it was found that all participants considered their dysphagia as a handicap. Physical, social and psychological disabilities as a result of dysphagia were reported during the interview. For instance, nine participants reported some degree of lack of satiation following meals, all of the participants experienced some degree of eating insecurity (e.g. feelings of panic when eating, feelings of hopelessness at mealtimes) and all participants experienced some degree of reluctance to share meals (e.g. feeling embarrassed at being in the presence of others at a meal). Moreover, 12 participants reported that they were restricted in one or more activities (e.g. participating in leisure activities) and all of the participants had some degree of reduced self-esteem (e.g. poor self-confidence as a result of dysphagia).	Oesophageal rather than oropharyngeal dysphagia was the focus of this study. Although not all participants were experiencing dysphagia at the time of interview, the accuracy of these participants' evaluations did not appear to be compromised despite the fact that they occurred retrospectively.

Ekberg et al (2002)	360 individuals from clinics/hospitals/nursing homes across Europe, although the total number of participants from these respective facilities is not provided.	A modified version of the questionnaire developed by Gustafsson and Tibbling (1991) was used to collect data (via interviews).	55% of participants found that particular foods were too difficult to eat unless their consistency was altered. Over 50% reported eating less due to discomfort, one third reported still feeling hungry or thirsty after a meal and 44% reported weight loss during the previous twelve months. Although 84% of participants felt that eating should be an enjoyable experience, only 45% perceived it to be so. Of the participants who were bothered by swallowing at mealtimes, 36% avoided eating with others, 37% felt embarrassed at mealtimes, 41% experienced anxiety or panic during mealtimes and 55% of all participants indicated that dysphagia made life less enjoyable.	Participants were included on the basis of a subjective dysphagia complaint, with only 40% acknowledging receipt of a confirmed diagnosis. Whilst it was reported that 67% of the participants had coexisting medical conditions (e.g. MS, throat cancer, PD), which were likely the cause of dysphagia in all of these individuals, the dysphagia aetiology of 33% of the participants was not reported. It is likely that oropharyngeal dysphagia is the focus of this study.
Farri et al (2007)	Four different client groups were surveyed: eight patients who had been admitted to the Neurology Department at the study hospital (in the previous two years); 33 who had undergone maxillofacial surgery (in the previous five years);	A modified version of the questionnaire utilised by Ekberg et al (2002) was used to survey the participants.	All of the participants had some eating restrictions, 75% of the neurological participants consumed smaller quantities of food and 63% of this participant group experienced hunger/thirst after meals. Avoidance of eating with others (with the exception of close family members) and feelings of embarrassment, anxiety and panic	A key limitation of this study concerns the fact that insufficient detail is provided relating to the procedure of participant selection and it is unclear whether the participants had clinical dysphagia diagnoses. It is likely that oropharyngeal dysphagia is the focus of this

	12 who had undergone ENT surgery (in the previous two years) and 20 who resided in a long-term care facility and who were reported as being presbyphagic.		during meals were issues apparent among the participants. Only 25% of the neurological participants derived pleasure from eating, 75% perceived swallowing as a bother and 63% reported that their lives were less enjoyable as a result of dysphagia.	study.
Tibbling and Gustafsson (1991)	796 elderly individuals who responded to a postal questionnaire.	A postal questionnaire was used to collect data concerning dysphagia and other chest symptoms (e.g. heartburn, regurgitation).	8% of the respondents had symptoms of dysphagia. 50% of the participants with dysphagia reported anxiety at mealtimes due to dysphagia. Eight participants with oesophageal dysphagia wished to eat alone, suggesting a negative social impact.	The approach of self-diagnosis is adopted in this study. This study did not focus solely upon oropharyngeal dysphagia. Participants had oropharyngeal (the authors use the term 'hypopharyngeal'), oesophageal or both types of dysphagia.
Eslick and Talley (2008)	A random population-based sample of 1000 adults were mailed a questionnaire. 672 individuals returned the completed questionnaire.	The validated Chest Pain Questionnaire (CPQ) (Eslick and Talley, 2004) was mailed to participants. Included within the questionnaire was a measure of QOL, the SF-36, and two measures of psychological well-being.	16% of the participant sample reported having ever had dysphagia. Intermittent dysphagia was found to be independently associated with anxiety and progressive dysphagia was independently associated with depression. With regards to the broader QOL impact of dysphagia, progressive dysphagia was found to be independently associated with reduced 'general health' on the SF-36, and intermittent	The authors relied on the participants to self-report the existence of swallowing difficulties. The utilisation of the SF-36 as a measure of HRQOL has previously been questioned (page 29) and a dysphagia-specific HRQOL measure would have been more appropriate for eliciting dysphagia-specific QOL issues. It is likely that both types of

			dysphagia was independently associated with a reduction in the 'role physical' component of the SF-36.	dysphagia were considered in this investigation.
Turley and Cohen (2009)	248 elderly individuals living independently in two retirement communities.	A survey was used to collect data relating to voice and swallowing problems in the elderly and their treatment. Data concerning the QOL impact of voice and swallowing problems were obtained via a seven-point Likert dysphagia severity scale, the Voice-Related QOL scale (VRQOL) (Hogikyan and Sethuraman, 1999) and the Center for Epidemiology Studies Depression Scale (CES-D) (Radloff, 1977).	Those with both dysphonia and dysphagia (6%) had statistically significantly higher depression scores than those who had neither symptom. Among participants with both disorders, more severe problems with swallowing were associated with lower scores on the VRQOL.	The approach of self-diagnosis is adopted and the authors do not provide a definition of a 'swallowing problem' within the survey, potentially generating ambiguity for the participants and reducing the reliability of the findings. Although Turley and Cohen (2009) report that voice and swallowing problems exert a significant impact on QOL, the lack of a dysphagia-specific HRQOL measure and use of the VRQOL calls into question the accuracy of this statement. By considering two disorders within the investigation, the specific QOL impact of dysphagia is obscured. It is likely that oropharyngeal dysphagia is the focus of this study.
Chen et al (2009)	107 elderly individuals residing in an independent-living	A questionnaire was used to collect data and this included two QOL	15% of participants reported experiencing swallowing difficulties. Of these individuals, nine scored in	The authors relied on the participants to self-report the existence of swallowing

	facility.	measures, the dysphagia-specific HRQOL measure, the MDADI, and the SF-12v2 (Ware, Kosinski and Keller, 1996), a shortened version of the SF-36.	the worst three quintiles on the Emotional, Functional or Physical sections of the MDADI. Overall, the individuals who reported swallowing problems scored lower in every domain of the MDADI than those without dysphagia, with the differences between the groups being statistically significant, evidencing a dysphagia-related QOL impact.	difficulties. The use of the MDADI with a non-head-and-neck-cancer-specific population must be questioned. The scores of the MDADI and the SF-12v2 were only weakly correlated, indicating the inadequacy of a generic measure of health status in investigating dysphagia-specific QOL. It is likely that oropharyngeal dysphagia was the focus of this study.
Roy et al (2007)	117 elderly individuals living independently.	Data were collected by means of a questionnaire delivered in interview format. The MDADI was used to assess the QOL impact of dysphagia. Data were also collected regarding the lifetime and current prevalence of swallowing disorders, signs and symptoms of dysphagia and risk and protective factors.	Those participants with a current swallowing disorder perceived a lower QOL related to swallowing than those participants with no current swallowing disorder, with statistically significant differences between the groups on each item of the MDADI. Additionally, Roy et al (2007) found that various medical conditions were observed more frequently among the participants with a history of dysphagia (stroke, arthritis, chronic pain, oesophageal reflux, COPD and severe neck, back or head injury).	The authors adopted the approach of self-diagnosis. The use of the MDADI with a non-head-and-neck-cancer-specific population must be questioned. It is possible that both types of dysphagia were considered in this investigation.

Martino et al (2010)	Three individuals with acute (onset of three months or less) oropharyngeal dysphagia and five individuals with chronic (onset of greater than three months) oropharyngeal dysphagia, with a range of dysphagia aetiologies.	Two focus groups were conducted, one with the acute participants and one with the chronic participants.	The two groups highlighted different psychological issues. For the acute patients, fear of choking was the predominant issue, while the chronic patients expressed 'worry' of choking. These individuals had acquired the strategies needed to manage their episodes of choking. Acute patients were overwhelmed by their dysphagia and thus felt vulnerable, while chronic patients, on the other hand, had learned strategies which enabled them to better manage their symptoms and thus felt less vulnerable. The main issue for chronic patients was that of depression. These individuals felt deprived at being unable to eat foods they liked, nostalgic towards the ease with which they used to eat and hopeless in relation to swallow recovery. Frustration and embarrassment, especially embarrassment about choking in public, were also issues expressed by the chronic patients.	A key strength of this study concerns the fact that participants were required to have a clinical diagnosis of oropharyngeal dysphagia. The qualitative design permits detailed exploration of the psychological issues perceived by individuals with oropharyngeal dysphagia. The small sample size limits generalisation to a wider dysphagic population, indicating the need for further research in this area. The authors acknowledge that variables other than recovery trajectory, such as disease type, may have impacted upon participants' perceptions of psychological issues.

2.5 Summary

This chapter has given consideration to the impact that dysphagia exerts upon QOL.

By means of introduction, consideration was given to the importance of QOL, specifically HRQOL, measurement within the field of healthcare as a means of considering the patient holistically beyond their physiological status and obtaining their perspective regarding the impact of the disease upon their life. The lack of conceptual clarity and resulting controversy surrounding the conceptualisation and measurement of QOL/HRQOL has been acknowledged.

The central component of this chapter comprised a review of previous research which has investigated the QOL impact of dysphagia and it is clear that dysphagia exerts a negative impact upon QOL, regardless of aetiology. It is apparent that the negative consequences of dysphagia extend beyond the physical, impacting upon psychological and social well-being and overall, individuals with dysphagia have been found to have a lower QOL than individuals without dysphagia.

Many previous studies exploring the QOL impact of dysphagia have been quantitative, have relied on patient self-reports of dysphagia and have used generic or non-dysphagia-specific measures of HRQOL. Although there are limitations regarding the extent to which qualitative data can be generalised to members of the same population, such data provide detailed information about participant experiences which may be similar for other members of the same population. Given the importance of self-report within QOL research, it is proposed that a qualitative methodology would facilitate the expression of individual experiences. Additionally, it is considered that the use of a dysphagia-specific measure of HRQOL will provide more insight into the HRQOL issues specific to dysphagia than if a generic or non-dysphagia-specific measure was used.

It is proposed that an understanding of the impact of dysphagia upon HRQOL is essential to the holistic management of clients. However, despite reports of the high numbers of care home residents with dysphagia and the existence of research evidencing the negative QOL impact of dysphagia, minimal research has explored the HRQOL impact of dysphagia upon care home residents. Thus, there is a clear need to gain insight into the experiences of these individuals in order to identify the dysphagia-specific HRQOL issues unique to these individuals.

The following chapter discusses the target population for the current study, the care home population, focusing on the issues which may impact upon the mealtime experience in the care home, other than dysphagia.

CHAPTER 3

LITERATURE REVIEW: THE MEALTIME EXPERIENCE IN THE CARE HOME

3.1 Introduction

This chapter gives consideration to the target population for this study, the care home population, a group of individuals of clinical relevance to the Speech and Language Therapist (SLT) due to the high prevalence of dysphagia amongst residents. This chapter gives consideration to one specific aspect of care home living, namely mealtimes, given that dysphagia is most likely to impact individuals at mealtimes and is likely to exert a considerable impact upon the mealtime experience. The purpose of this chapter is to highlight additional issues, beyond that of dysphagia, which contribute to the mealtime experience within the care home setting and on the basis of these confounding factors, justify the need for inclusion of a ‘control group’ of care home residents without dysphagia within the present investigation.

3.2 The mealtime experience in the care home

According to Kane et al (2003), an important aim of long-term care should be to “preserve and promote quality of life” (p.240). However, Kane et al (2003) go on to boldly state that life in a nursing facility can be “sterile, regimented, devoid of both privacy and meaningful association, and deadening to the human spirit” (p.240). According to Evans and Crogan (2001), “the mealtime experience can dramatically enhance the quality of life for residents in nursing homes” (p.131), and Kayser-Jones and Schell (1997) go as far as to say that “Food is one of the residents’ few remaining pleasures” (p.70). Food and mealtimes are considered a high priority by older individuals and influence their QOL (Social Care Institute for Excellence, SCIE, 2009). In addition to being crucial to individuals' physiological well-being, food contributes to cultural, social and psychological QOL (American Dietetic Association, 2005). Mealtimes within care home settings provide residents with the opportunity for socialising, making choices and relaxation (Nijs, de Graaf, Kok and van Staveren, 2006). Mealtimes in care home settings also bring structure to the lengthy day (Gastmans, 1998).

However, despite these positive attributes of mealtimes, the results of a recent survey carried out by the British Association for Parenteral and Enteral Nutrition (BAPEN, 2012) indicated that the prevalence of malnutrition among care home residents was 41%. This survey was carried out within 78 care homes in the UK. There are many causes of malnutrition among older people, some of which relate to the individual, such as, visual, speech and hearing impairments, depression, chewing and swallowing difficulties and institutionalisation (Cowan, Roberts, Fitzpatrick, While and Baldwin, 2004). Other causes are organisational, such as shortage of staff, inadequate staff training and education and a monotonous, unappetising diet (Cowan et al, 2004).

Given that dysphagia impacts upon an individual's ability to consume food and liquid (McHorney et al, 2002), it is likely that the presence of a swallowing disorder will exert a considerable impact upon an individual's mealtime experience. A loss of eating/mealtime enjoyment has been reported by individuals with dysphagia in previous research (Ekberg et al, 2002; Miller et al, 2006). However, there are many other factors which contribute to the mealtime experience within the care home setting, beyond the issue of dysphagia, impacting upon nutritional intake and QOL. It is important to acknowledge these contributing factors in order that the impact of dysphagia upon the mealtime experience can be differentiated from other aspects known to impact upon mealtimes. The following sub-sections that ensue (3.2.1 - 3.2.6) discuss these additional issues.

3.2.1 Dietary provision

According to Speroff, Davis, Dehr and Larkins (2005), a positive dining experience should, amongst other things, involve the provision of a “nourishing, pleasant meal” (p.292). The national care standards on care homes for older people (Scottish Government, 2007) state that care home residents can expect their meals to be “varied and nutritious”, to reflect their “food preferences and any special dietary needs” and to be “well prepared and cooked and attractively presented” (p.39). Unfortunately, there is often an expectation that the food served in institutional settings will be of a lower quality than food cooked in the home environment (Chisholm, Jensen and Field, 2011).

In their 2003 publication, Evans, Crogan and Shultz report on a pattern identified within interview data obtained from 20 residents of a large nursing facility in America (five of whom were under the age of 60), namely ‘Fostering a Quality Dining Experience’, which consisted of five themes. One of the negative issues reported by many participants concerning dining in the nursing home was a lack of variety of food. Additionally, some residents needed to feel that they could ask for and receive appropriate amounts and type of food: not too little and not too much. Given that all of the participants for this study were recruited from a single nursing facility, the extent to which the findings can be generalised to other care home settings is limited. Perry and McLaren (2003) investigated the eating-related experiences of individuals six months post-stroke, 15 of whom resided in institutions. Of the institutionalised participants who commented on the quality of their meals, only two individuals were very satisfied and participants more commonly reported negative experiences.

West, Ouellet and Ouellette (2003) collected data from random samples of staff and residents in nine Canadian long-term care facilities. Participants were asked to rank the perceived importance of 31 items relating to food service and then their satisfaction with these items. Three items ranked in the top ten of the importance rating measure by residents were, ‘Menu is varied', 'Meals are appetizing' and 'Respect food preferences', indicating the importance which these individuals placed upon being satisfied with the care home food. However, none of these items were ranked in the top ten on the satisfaction measure, indicating that residents were not satisfied with these aspects, given the importance they attributed to them. Interestingly, like the residents, the staff surveyed did not rank any of these items in the top ten on the satisfaction measure.

A particular issue of concern relates to the consumption of texture-modified diets, which is prevalent amongst the care home population. Steele et al (1997) reported that 48% of the individuals assessed in their study, who resided in a home for the aged, were consuming a soft, minced or puréed diet. Texture-modified diets may be prescribed to individuals with dysphagia (1.5) or individuals with poor dentition (Wright, Cotter, Hickson and Frost, 2005). In addition to the negative impact that texture-modified diets have been found to exert upon nutritional status (Wright et al, 2005), the QOL impact of dietary alterations must also be acknowledged (Langmore, 1999).

3.2.2 Choice at mealtimes

Promoting independence and choice is another means of enhancing the dining experience of care home residents (Speroff et al, 2005). Individuals residing in institutions do not have direct control over many events each day (Hotaling, 1990), and when individuals enter a care home, they become dependent upon other people for their nutritional provision (Winterburn, 2009). Winterburn (2009) states that there is a relationship between low nutritional risk and greater independence in relation to food choice, more autonomy and active involvement in food provision. The national care standards on care homes for older people (Scottish Government, 2007) state that care home residents should receive a choice of cooked breakfast as well as choices in courses at both lunch and dinner. Taking the notion of provision of choice further are 'buffet-style' or 'family-style' approaches to dining, which have been advocated as ways of promoting choice and independence at mealtimes (Speroff et al, 2005). It is advocated that the provision of choice at mealtimes should not stop at food choice and should extend to eating location, position in the dining room and portion size.

3.2.3 The dining environment

Hotaling (1990) makes the point that the provision of a meal which has been well-prepared and is appealing and tasty will not automatically result in good meal consumption. She states that, “The environment has a subtle but ultimately strong influence on providing the incentive for eating” (p.78). Speroff et al (2005) report that the dining experience in the care home setting can be improved if a “home-like environment” (p.292) is presented. Creation of a pleasant dining environment can be achieved by such things as the use of tablecloths, cloth napkins, centre pieces, name cards, appropriate lighting and temperature and age-appropriate background music (Hotaling, 1990; Speroff et al, 2005). Additionally, Yen (2003) states that noise created by such things as loud televisions and noisy staff conversations divert attention from eating, and Bourgeois and Hickey (2009) suggest that lessening distractions in the environment is one way of maximising both nutrition and QOL. In their study of staff and resident ratings of food services in long-term care, West et al (2003) reported that the residents ranked ‘Feel at home here’ as second in their importance ratings. However, this item was ranked twentieth in their satisfaction ratings, clearly indicating a lack of satisfaction with this aspect of dining in long-term care. Additionally, the item ‘Calm mealtime atmosphere’ was ranked eighth in the importance ratings and thirteenth in the satisfaction ratings, again indicating a discrepancy between the level of perceived importance and satisfaction.

3.2.4 Socialising at mealtimes

Dining is seen as a "social process" (Hotaling, 1990, p. 79) and Speroff et al (2005) advocate that a positive dining experience can be attained through enhancing the social facet of dining. Whilst minimal research has investigated the mealtime experience of care home residents in the UK, a study conducted by Philpin, Merrell, Warring, Gregory and Hobby (2011) in Wales provided valuable insight into mealtimes as social occasions. This multi-method study, conducted in two care homes and involving care home and catering staff, managers, residents and informal carers, indicated, amongst other things, that social interaction enhanced mealtime enjoyment and this in turn, encouraged eating. Some residents did comment that conversation at their table was restricted as a result of having dining companions who had hearing difficulties, who were quiet or who did not have anything to converse about. Mealtimes were however, basically pleasant social occasions. Hotaling (1990) suggests that socialising at mealtimes can be improved through such strategies as having residents sit at tables of no more than four to six, switching off the television during mealtimes and making sure that residents are not brought to the dining room too far ahead of mealtimes, as having to wait for a long time may make some residents weary and reduce their interest in socialising. Hotaling (1990) also advocates that assigned seating based on social compatibility helps residents to feel secure at mealtimes, although it is questioned whether this robs residents of an opportunity to exert choice and control over an aspect relating to mealtime.

3.2.5 Age and disease-related changes

Physiological changes as a result of ageing can impact upon nutritional status (Curran, 1990). For instance, the gastrointestinal and renal systems are less efficient which may affect adequate ingestion, digestion, absorption, utilisation and excretion of nutrients (Curran, 1990). Additionally, a lack of appetite can result from poor nutrition and a lack of physical activity (Amarantos et al, 2001). Furthermore, changes in vision, smell and taste can result in reduced enjoyment of food (Amarantos et al, 2001), while hearing impairments may impede socialisation at mealtimes (Curran, 1990). The effects of aging on the swallowing mechanism have previously been considered (1.6). Additionally, with age, the prevalence of disease increases (Ney et al, 2009) and the presence of disease may also have implications for the mealtime experience. For example, in addition to the potential existence of dysphagia, individuals who have had a stroke may also experience difficulty with the manipulation of food on the plate and transportation of food to the mouth (Jacobsson et al, 2000). Individuals with PD may experience trouble executing the motor acts associated with eating (Berry and Marcus, 2000).

3.2.6 Care home staff

Care home staff can also exert an influence upon the mealtime experience of care home residents. Significantly, residents participating in West et al's (2003) study ranked the item "Employees respect you" as the most important aspect of food services in long-term care. This item was ranked as third on the satisfaction scale, indicating that residents in this study were relatively satisfied with this component of food service. Furthermore, participants in Evans et al's (2003) study referred to staff characteristics which promoted a quality dining experience. For instance, it was important to be served by courteous staff and staff who were truthful.

Kayser-Jones and Schell (1997) investigated the influence of staffing upon the mealtime experience and quality of care of care home residents. The study was conducted in two nursing homes and data collection consisted of participant observation and in-depth interviews with doctors, nursing staff, residents and families of residents. Additionally, event analysis was used to collect data on 100 residents who were eating poorly and each resident also had an examination by a dentist and a speech pathologist. Data were collected over a period of 23 months and this longitudinal design strengthens the study findings as it provides a more representative picture of the mealtime situation in these settings than if the data had been collected within a short space of time. Kayser-Jones and Schell (1997) reported that inadequate staffing majorly influenced nutritional care and that the nursing assistants did not have the knowledge required to feed residents safely and with dignity and were inadequately supervised by professional staff. Negative issues reported included such things as, a lack of personal care (e.g. oral hygiene neglected, dentures not inserted); many residents consumed most meals in bed and residents fed in bed were poorly positioned for eating; sometimes staff fed residents who could eat independently but ate slowly, fostering dependence; residents were fed quickly and forcefully; dysphagia was undiagnosed and unrecognised and some residents received little or no food.

Based on the findings of their study, Kayser-Jones and Schell (1997) enforced the need to increase the staff/resident ratio at mealtime, to educate staff regarding how to feed care home residents and to ensure that nursing assistants are supervised at mealtime. With regards to the issue of positioning at mealtimes, the importance of proper positioning has been emphasised elsewhere, and it is recommended that where possible, staff transfer residents from wheelchairs and ensure that they are properly positioned in dining chairs (Yen, 2003).

3.3 Enhancing the mealtime experience in the care home setting

Dining programmes have been developed which have sought to enhance the mealtime experience of care home residents. Three examples of these dining programmes (their characteristics and outcomes) are provided below in order to illustrate the effects of enhancing the dining experience upon nutritional intake and QOL.

Nijs et al (2006) investigated the effect of family-style mealtimes upon residents residing in five different Dutch nursing homes. Each participating nursing home had an intervention ward and a control ward (allocated blindly) within which the typical pre-plated service was maintained. 178 residents completed the study which lasted for a period of six months. Characteristics of the family-style mealtimes included many of the aspects described in the preceding sections (3.2.1 - 3.2.6). For example, amendments were made to the table dressing (e.g. use of tablecloths, drinking glasses instead of plastic cups, normal plates, napkins); food services (e.g. cooked meal served in dishes on the table, residents had some choice of food at the mealtime rather than having to choose meals in advance); staff protocol (e.g. staff sat at tables and conversed with residents, drugs handed out prior to start of meal); residents' protocol (e.g. most residents served themselves, with some assistance from nurse or dining companion, mealtimes commenced when everyone was seated); mealtime protocol (e.g. no other activities; dining room generally closed to visitors and healthcare providers). Nijs et al (2006) found that the overall QOL of the intervention group remained stable, while the QOL of the control group declined and the difference in changes in QOL between the groups was statistically significant. There was also a statistically significant difference in changes in fine motor function between the groups, with fine motor function remaining stable in the intervention group and significantly declining in the control group. Mean body weight remained relatively stable in the intervention group, but significantly decreased in the control group and the difference in changes in body weight between the groups was statistically significant. Finally, mean energy intake significantly increased in the intervention group, yet decreased significantly in the control group. Again the difference in changes between the groups was statistically significant.

Ruigrok and Sheridan (2006) reported on a pilot project undertaken in a community- nursing unit in Ireland. The unit's dedicated smoking room was transformed into a dining room which could accommodate up to four residents at any one sitting and the idea was to offer a home-style dining experience. Within the enhanced dining room, there was a more leisurely pace of dining and a home-like dining environment existed, with features such as table linen, flowers, attractive tableware and appropriate background music. The main differences between this dining experience and the usual routine included aspects such as, provision of a menu card which also listed alternate choices, provision of discrete assistance, encouragement and promotion of reminiscence, socialisation and independence in dining, no provision of 'minced' meals in the enhanced dining room. Over a three month period, there were eight dining sessions and 23 residents had the opportunity to enjoy the enhanced dining experience. Whilst the feedback received from the residents who participated was very positive, it considered that use of more formal outcome measures, including assessments of nutritional intake and QOL would have provided a more accurate indication of the program's effectiveness.

Remsburg et al (2001) conducted a pilot study to ascertain the feasibility of implementing a buffet-style dining programme and to establish the impact of the programme upon care home residents. Forty residents from three long-term care units of a long-term care facility participated and were randomised to either the intervention group or to the control group which meant continuing to receive the conventional tray service. The buffet-style dining programme was implemented during the evening meal only for a period of three months. The components of this programme included an enhanced dining room environment (e.g. china, tablecloths, optimal positioning of residents for eating and social engagement); supervision of dining procedures by nursing staff; assistance by nursing assistants, dedicated to mealtime assistance and trained to provide the appropriate type and amount of assistance. Furthermore, food was served on a steam table, which allowed residents to choose from a variety of foods and obtain second helpings and enabled the maintenance of ideal food temperatures. In contrast to the positive findings reported in relation to the programmes discussed above, Remsburg et al (2001) reported inconclusive findings, with no statistically significant differences in weight or biochemical indicators of nutritional status between the intervention and control groups at three months. Remsburg et al (2001) speculated that the programme enhanced resident QOL, although no formal measure was used and thus conclusions cannot be drawn.

3.4 Summary

This chapter has identified the care home population as a population of clinical relevance to the SLT due to the high prevalence of dysphagia amongst these individuals. This chapter has specifically focused on mealtimes within the care home setting and it is apparent that in addition to the negative consequences of dysphagia, there are many factors which contribute to the mealtime experience in the care home, affecting nutritional intake and QOL. Although some of these factors, including dysphagia, are associated with the ageing process and the onset of disease, many factors are attributable to institutional living. The existence of these confounding factors indicates the need to include a ‘control group’ of care home residents without dysphagia within this investigation in order that the HRQOL impact of acquired neurological oropharyngeal dysphagia can be distinguished from other issues which impact upon the mealtime experience of care home residents.

The aims of the pilot study and the main study are presented in the subsequent sections (3.5; 3.6), and the following chapter discusses the methods used to achieve the aims of this investigation.

3.5 Pilot study aim

1. To pilot the study materials and procedures (with care home residents with oropharyngeal dysphagia caused by stroke) for the purpose of refinement and to inform on the feasibility of a larger study.

3.6 Main study aims

1. To gain insight into the HRQOL issues for care home residents with oropharyngeal dysphagia caused by an acquired neurological disorder, from the perspective of the residents.

2. To gain insight into the eating and mealtime experiences of care home residents without dysphagia of any type, in order that the HRQOL impact of acquired neurological oropharyngeal dysphagia can be distinguished from other issues which impact upon the mealtime experience of care home residents.

CHAPTER 4

METHOD

4.1 Introduction

This chapter details the design and methods used to address the aims of this investigation. Initially, the methodological approach is outlined and this investigation is placed within the field of qualitative research, specifically the domain of descriptive phenomenology (4.2). Following this, information is provided pertaining to the participant sample for both the pilot study and the main study (4.3). Subsequently, insight is provided into the researcher's theoretical and personal beliefs surrounding the investigation and information relating to the suspension of the researcher's presuppositions concerning the study is presented (4.4). The methods of data collection are then described, along with an outline of the procedures adopted for data collection (4.5). This chapter concludes with a discussion of the ethical issues which have been considered in relation to this investigation (4.6).

4.2 The methodological approach

4.2.1 A qualitative approach to research

The exploration of participant quality of life (QOL), specifically health-related quality of life (HRQOL), is central to this study. Given the subjective and individualised nature of QOL (WHOQOL Group, 1995; Davis, 2007), it was considered appropriate to adopt a qualitative approach for this investigation in order to gain insight into the perceptions of individual participants. Qualitative approaches to research are used "to explore the behaviour, feelings and experiences of people and what lies at the core of their lives" (Holloway and Wheeler, 2010, p.3). Within qualitative research there is a concern with the 'emic perspective', that is, the 'insiders' view' (Holloway and Wheeler, 2010).

Qualitative approaches to research have their basis in interpretivism (Snape and Spencer, 2003), while quantitative research has historically been associated with positivism (Robson, 2011). Positivism is an epistemiological stance which maintains that the methods of the natural sciences are appropriate to use when studying social phenomena (Snape and Spencer, 2003). Those who advocate qualitative approaches have argued that a very different approach to research is required when undertaking social research, given that the focus is on human beings in social situations (Robson, 2011). Within the field of healthcare, adoption of a qualitative approach to research enables service-users' 'voices' to be heard and their experiences and feelings to be understood (Holloway and Wheeler, 2010).

Various approaches to qualitative research exist, although the aim of many of these approaches is the same, that is, "to understand, describe and interpret social phenomena as perceived by individuals, groups and cultures" (Holloway and Wheeler, 2010, p.3). Creswell (2007) advocates that using a known approach to qualitative research "enhances the rigour and sophistication of the research design" (p.45). Thus, for this study, a phenomenological approach, specifically a descriptive phenomenological approach, was adopted.

4.2.2 Phenomenology

Phenomenology is both a philosophy and a research method (Dowling, 2007). The German philosopher, Edmund Husserl, is referred to as the 'father' of phenomenology (Ray, 1994). Husserl believed that humans' perceptions of their experiences have "value and should be an object of scientific study" (Lopez and Willis, 2004, p. 727). Given that humans rarely reflect upon their experiences, Husserl thought that a "scientific approach was needed to bring out the essential components of the lived experiences specific to a group of people" (Lopez and Willis, 2004, p.727). Thus, a phenomenological study "describes the meaning for several individuals of their lived experiences of a concept or a phenomenon" (Creswell, 2007, p.

57). Data are obtained from individuals with experience of the phenomenon under investigation and a description detailing the “essence of the experience” for all of the participants is developed (Creswell, 2007, p. 58).

Within health research, one of the topics which has been suggested as being appropriate for a phenomenological approach is that of exploring the QOL of individuals with a chronic illness (Polit and Hungler, 1999) and thus it is proposed that this study is suited to a phenomenological approach. It is considered essential that the experiences of care home residents living with acquired neurological oropharyngeal dysphagia are elicited in order that this information can be used to guide the practice of both SLTs and care home staff. Additionally, by eliciting the experiences of care home residents without dysphagia, specifically in relation to eating and mealtimes, insight can be gained into the eating and mealtime-related issues which exist for care home residents, other than dysphagia.

Two commonly used phenomenological approaches are descriptive or eidetic phenomenology and interpretive or hermeneutic phenomenology (Lopez and Willis, 2004; Holloway and Wheeler, 2010). It is considered important to outline the philosophical assumptions upon which this study is based (Norlyk and Harder, 2010). Given that a descriptive phenomenological approach was adopted for this study, the key philosophical underpinnings of descriptive phenomenology are provided below (4.2.3). Following this, the underlying philosophies of descriptive and interpretive phenomenology are compared (4.2.4) and the rationale for adopting a descriptive phenomenological approach is provided (4.2.5).

4.2.3 Descriptive phenomenology

The descriptive or eidetic phenomenological approach is deemed to have originated from Husserl (Wojnar and Swanson, 2007). The main objective of a descriptive phenomenological approach is “to generate a description of a phenomenon of everyday experience to achieve an understanding of its essential structure” (Holloway and Wheeler, 2010, p. 213). Key components of Husserl’s philosophy of phenomenology have been delineated by Lopez and Willis (2004) and these are detailed below:

1. Husserl desired scientific rigour and advocated achievement of ‘transcendental subjectivity’ (Lopez and Willis, 2004), a concept which Wojnar and Swanson (2007) define as “a condition of consciousness wherein the researcher is able to successfully abandon his or her own lived reality and describe the phenomenon in its pure, universal sense” (p.173). Attainment of transcendental subjectivity can be achieved by means of ‘bracketing’ (Lopez and Willis, 2004), the term used to refer to the process of “suspending beliefs and prior assumptions about a phenomenon” (Holloway and Wheeler, 2010, p. 216).

2. The concept of ‘universal essences’ was coined to describe the assumption that there are aspects of each experience which are common to everyone who has the experience (Lopez and Willis, 2004). These essences “are considered to represent the true nature of the phenomenon being studied” (Lopez and Willis, 2004, p. 728).

3. The concept of ‘radical autonomy’ was used to refer to the belief that people are “free agents who bear responsibility for influencing their environment and culture” (Lopez and Willis, 2004, p. 728).

4.2.4 Descriptive phenomenology and Interpretive phenomenology: A comparison

Heidegger, altering and building on Husserl’s work, developed an interpretive or hermeneutic phenomenology (Lopez and Willis, 2004). Heidegger was critical of Husserl’s emphasis upon description (Cohen and Omery, 1994) and thus placed an emphasis upon the concept of hermeneutics, which is concerned with progressing beyond description to search for meanings (Lopez and Willis, 2004). An interpretive phenomenological approach to research “explores the meaning of being a person in the world” (Holloway and Wheeler, 2010, p. 217). The key philosophical underpinnings of interpretive phenomenology, as outlined by Lopez and Willis (2004), are documented below, and these central tenets of Heidegger’s philosophy are compared with Husserl’s descriptive phenomenology:

1. Within an interpretive phenomenological approach, the researcher’s knowledge or presuppositions are “valuable guides to inquiry and, in fact, make the inquiry a meaningful undertaking” (Lopez and Willis, 2004, p. 729). Thus, bracketing is not compatible with an interpretive phenomenological approach (Lopez and Willis, 2004). Ray (1994) envisages this antithetical standpoint regarding the suspension of beliefs as being the fundamental difference between descriptive and interpretive phenomenology. The term ‘co-constitutionality’ was coined by Heidegger to refer to the fact that “the meanings that the researcher arrives at in interpretive research are a blend of the meanings articulated by both participant and researcher within the focus of the study” (Lopez and Willis, 2004, p. 730).

2. Whilst the description of universal essences is stressed in descriptive phenomenology, interpretive phenomenology is more concerned with “understanding the phenomena in context” (Wojnar and Swanson, 2007, p.175) and Heidegger used the term ‘lifeworld’ to convey the notion that “individuals’ realities are invariably influenced by the world in which they live” (Lopez and Willis, 2004, p. 729).

3. In contrast to the concept of ‘radical autonomy’ postulated by Husserl, the term ‘situated freedom’ refers to the notion that “individuals are free to make choices, but their freedom is not absolute; it is circumscribed by the specific conditions of their daily lives” (Lopez and Willis, 2004, p. 729).

4.2.5 Application of a descriptive phenomenological approach

A descriptive phenomenological approach was adopted for this study. This approach has been adopted in previous research which has explored the QOL impact of oesophageal dysphagia caused by oesophageal cancer (Watt and Whyte, 2003) and in other QOL health research (Roberts et al, 2006; Moi and Gjengedal, 2008). A descriptive phenomenological approach is "useful in uncovering essences of phenomena that have been incompletely conceptualised by prior research" (Lopez and Willis, 2004, p. 734). Given that minimal research has explored the HRQOL impact of acquired neurological oropharyngeal dysphagia upon care home residents, the application of this approach is justified. Furthermore, when the aim of the study is to obtain the perspectives of the participants themselves, providing a description of their experiences is considered more appropriate than progressing beyond description to interpretation. Additionally, it is considered that the use of bracketing, central to descriptive phenomenology and inconsistent with interpretive phenomenology, enables the researcher "to take a fresh perspective toward the phenomenon under examination" (Creswell, 2007, p. 59-60).

4.3 Participants

For the pilot study, data were collected from a care home resident with oropharyngeal dysphagia caused by stroke. Data collection with this individual provided an opportunity to pilot the study materials and procedures with an individual with acquired neurological oropharyngeal dysphagia and enabled the researcher to gain experience in conducting a research interview and discussion with an individual with brain damage. The data obtained from this participant are not incorporated within the thesis as the researcher was not satisfied with her approach to interviewing and was concerned that she may have been 'leading' in some of the questions asked. Given the existence of this concern relating to misrepresentation of the participant, the decision was made to focus on the lessons learned from data collection with this individual. This rich learning experience equipped the researcher for data collection with the other participants with oropharyngeal dysphagia who were involved in the main study. A reflection on the learning experiences afforded through data collection with this individual is provided in Chapter 8 (8.4). It should be noted that the same procedures and methods of data collection were utilised within the pilot study.

Within the main study, data were collected from six care home residents without dysphagia of any type, herein referred to as the ‘Control participants’ (CP), and from seven care home residents with acquired neurological oropharyngeal dysphagia, herein referred to as the ‘Participants with dysphagia’ (PWD). Data collection with the CP and analysis of these data occurred prior to data collection with the PWD.

4.3.1 Sampling strategy

A purposeful sampling strategy was used to select participants for this investigation. Purposeful sampling is utilised within qualitative research and means that people (and sites) are selected for investigation because “they can purposefully inform an understanding of the research problem and central phenomenon in the study” (Creswell, 2007, p. 125). Thus, the focus of purposeful sampling lies in the selection of “information-rich cases whose study will illuminate the questions under study” (Patton, 2002, p. 230).

Patton (2002) identifies various strategies for purposeful sampling and as suggested by Creswell (2007), a criterion sampling strategy was selected for this phenomenological investigation. In a phenomenological study, all participants must have experienced the phenomenon under investigation (Creswell, 2007) and the purpose of criterion sampling is to pick “all cases that meet some criterion” (Patton, 2002, p. 243). Thus, potential PWD were selected based on their experience of living with acquired neurological oropharyngeal dysphagia, while potential CP were selected based on their lack of experience with the phenomenon under investigation. The specific study inclusion criteria are listed in the following section (4.3.2).

4.3.2 Participant inclusion criteria

Table 4.1 outlines the criteria which individuals were required to meet before they could be considered for inclusion within the investigation. Criterion 4 was narrower during the pilot study, as only care home residents with oropharyngeal dysphagia caused by stroke were suitable for inclusion. This criterion was broadened for the main study to include residents with oropharyngeal dysphagia caused by any acquired neurological disorder, excluding dementia, in order to increase the available pool of participants. Consumption of thickened liquids had originally been a requirement for participants with oropharyngeal dysphagia caused by stroke within the pilot study. However, this requirement was removed approximately two months after participant recruitment commenced, based on feedback from the SLT involved in participant identification and recruitment in the pilot. This criterion was not reinstated for the main study. For the duration of the pilot and the beginning of the main study, the diet texture modification criterion had excluded individuals consuming a Texture E diet (Appendix 2). However, early on in participant identification and recruitment for the main study, the decision was made to include individuals consuming a Texture E diet in order to increase the available pool of participants.

Table 4.1: Overview of the participant inclusion criteria for the main study

	Criterion	**Rationale**	**How fulfilment of the criterion was established**
All participants must:	1. Have a sufficient understanding of the English language.	To enable easeful participation in the interview and reflexive discussion, given the extensive researcher/participant discussion involved within these components of data collection.	PWD: The SLT (responsible for identification and recruitment of PWD). CP: The care home manager/staff nurse (responsible for identification and recruitment of CP).
	2. Be cognitively and linguistically able to provide their informed consent and participate in an interview and reflexive discussion.	To minimise the risk that individuals incapable of providing informed consent would be approached regarding participation and to enable easeful participation in the research interview and discussion.	PWD: The SLT, using professional opinion/clinical records. CP: The care home manager/staff nurse, using professional opinion/care home records. The researcher also informally verified participants' capacity to provide informed consent during the informed consent process.
	3. Have adequate vision and hearing.	To enable active participation in the interview and reflexive discussion.	PWD: The SLT, using professional opinion/clinical records. CP: The care home manager/staff nurse, using professional opinion/care

			home records.
PWD must:	4. Have oropharyngeal dysphagia caused by any acquired neurological disorder, excluding dementia. Participants with oropharyngeal dysphagia caused by stroke must be at least two months post-stroke. Participants were not excluded on the basis of having had more than one stroke.	To ensure the selection of individuals with experience of living with acquired neurological oropharyngeal dysphagia.	The SLT, using their knowledge of the client/clinical records.
	5. Consume a diet consisting of texture modified foods (Texture B-E of the Dysphagia Diet Food Texture Descriptors, NPSA, 2012) (Appendix 2) and have been consuming this diet for at least one month. Consumption of thickened fluids was not a requirement for participation, although individuals consuming fluids thickened using a commercial thickener were suitable for inclusion.	In order that insight into the experiences of individuals consuming a texture modified diet could be obtained.	The SLT, using their knowledge of the client/clinical records.

	6. Obtain their nutrition via oral means.	Some of the statements/items contained within the SWAL-QOL (McHorney et al, 2002) (the dysphagia-specific HRQOL measure used in a modified form within the interviews), may not be relevant to individuals receiving non-oral feeding, especially those individuals who require complete tube feeding (Rinkel et al, 2009).	The SLT, using their knowledge of the client/clinical records.
	7. Have an activity level of 2, 3, 4 or 5 on the Therapy Outcome Measure (TOM) for dysarthria (Enderby, John and Petheram, 2006) (Appendix 3).	It was considered important to increase the likelihood that participants with dysarthria would be able to successfully convey their experiences, with support from the researcher if required.	The SLT, using clinical records/rating the potential participant's level of activity on the dysarthria TOM.
CP must:	8. Have no dysphagia of any type or neurological/cognitive deficits that could cause dysphagia.	It was considered important to include a group of care home residents with no experience of the phenomenon under investigation, in order that insight could be gained into the eating and mealtime-related issues which exist for care home residents, other than dysphagia.	The care home manager/staff nurse, using their knowledge of the resident/care home records.

4.3.3 Participant identification and recruitment

SLTs were responsible for the identification and recruitment of PWD. Initially, one SLT working for a large health board was involved in the study. However, in order to increase the available pool of participants, permission was sought from Speech and Language Therapy managers in two other Scottish health boards, who agreed that SLTs working in their region could be involved in participant identification and recruitment. Although information on the participant inclusion criteria and research procedure was circulated among groups of SLTs working for both of these health boards, only one additional SLT was successful in identifying and recruiting PWD for the study. Additionally, an attempt at participant recruitment was made by emailing members of the Scottish Dysphagia Special Interest Group (SIG), although this yielded no further participants.

The SLTs identified potential PWD by drawing on their knowledge of suitable clients on their caseload/by referring to Speech and Language Therapy clinical records. They recruited participants by means of provision of a participant information sheet (Appendix 4) and a verbal explanation regarding the study. If individuals agreed to participate, the researcher made arrangements to visit them at the care home in which they resided. The SLTs obtained agreement from the relevant care home managers that the research could be conducted within their care home and prior to visiting, the researcher also spoke to the managers to confirm that they were happy for her to visit the resident and conduct the research procedures.

The initial visits by the researcher to the PWD occurred between one and ten days after participants had indicated to the SLT their agreement to participate. At this initial visit, the researcher introduced herself to the participant, discussed the participant information sheet with the individual, gave them an opportunity to ask any questions and obtained verbal and written consent (Appendix 5). One participant was unable to sign the consent form himself due to severe visual difficulties and mobility problems, although he verbally consented to participate and consented to a member of care staff signing the form on his behalf. One individual who originally agreed to take part, did not appear comfortable with participating when the researcher made her initial visit and written consent was not obtained. Following discussion with the SLT who had obtained verbal agreement from the individual and with care home staff, the decision was made to rearrange the visit for a time when the resident was feeling better (according to care staff she had not been well on the day of the initial visit) and for a time when her key worker, with whom she had a good relationship, could be present. However, although written consent was obtained on this occasion, it quickly became apparent during the interview that participation in the research was not a positive experience for this individual and thus the participant was withdrawn from the research.

It was considered appropriate to involve SLTs in the identification and recruitment of PWD, given their knowledge of potentially appropriate participants. Furthermore, through involvement of SLTs in this process, it could be established that the participants recruited had a diagnosis of oropharyngeal dysphagia, avoiding the risk of participants being included based on a self-diagnosis of dysphagia.

Given that potential CP were not to have a diagnosis of dysphagia of any type or any neurological/cognitive deficits that could affect swallowing function, they would not have been known to the Speech and Language Therapy service, invalidating replication of the identification procedure described above. Therefore, care home managers/staff nurses identified potential participants for the control group by drawing on their knowledge of residents residing in their home/by referring to individuals' care home records. Potential CP were provided with a participant information sheet and a verbal explanation of the study. The information sheet for the CP differed sightly in content from that provided to the PWD and did not include illustrations. The SLT who was involved in the research from the beginning established and coordinated the procedure for the identification and recruitment of CP and informed the researcher when a resident had agreed to be involved in the control group. The researcher liaised directly with the care home to arrange the visits. During the first visit, the researcher discussed the information sheet with participants and obtained verbal and written consent. The consent form for the CP differed slightly in content from that used with the PWD. One participant was unable to provide written consent due to a severe visual impairment, although she verbally consented to participate and gave permission for her consent form to be signed by a staff member on her behalf.

4.3.4 Sample size

Qualitative research studies usually include a small sample (Holloway and Wheeler, 2010) and Polit and Hungler (1999) report that frequently less than ten participants are involved in a phenomenological study. A sample size of six CP was considered appropriate and the decision was made that no further control data would be collected unless considerably younger PWD emerged. The difficulties associated with sourcing care home residents with oropharyngeal dysphagia caused by stroke who met the study inclusion criteria within the pilot study (8.4.2), clearly signalled the need to broaden the inclusion criteria for the main study to incorporate care home residents with any acquired neurological disorder, excluding dementia. Seven PWD were involved in the main study and although appropriate for a qualitative study, this small participant sample reflects the difficulties associated with identifying suitable care home residents with acquired neurological oropharyngeal dysphagia (8.5.2). Personal information relating to the CP summarised in Table 4.2 and personal information relating to the PWD is summarised in Tables 4.3.1 and 4.3.2. Within these tables a rating is provided for each of the CP and PWD on the Functional Oral Intake Scale (FOIS) (Crary, Carnaby Mann and Groher, 2005) (Appendix 6). The functional oral intake ratings were based on the food which the participants were served during the mealtime observations (4.5.2). It should be noted that information relating to the duration of care home residency and visitors was not available for the CP.

Table 4.2: Demographic/Personal information relating to the CP (N=6)

Control participant (CP) number and care home letter	**Gender**	**Age (years)**	**Mobility**	**Visual/hearing/communication needs**	**Feeding status**	**Status on the FOIS**
CP1 (A)	Female	92	Wheelchair	Severe visual impairment	Feeds independently but some assistance required due to visual impairment	Level 7
CP2 (A)	Male	76	Zimmer frame to aid walking	Has glasses for reading, but doesn't use all the time.	Feeds independently	Level 7
CP3 (B)	Female	94	Wheelchair	Wears glasses for reading. Severe hearing impairment.	Feeds independently	Level 7
CP4 (B)	Female	87	Stick to aid walking	Visual impairment	Feeds independently	Level 7

CP5 (C)	Female	76	Wheelchair		Feeds independently	Level 7
CP6 (C)	Female	79	Zimmer frame to aid walking	Wears glasses for reading	Feeds independently	Level 7

Table 4.3.1: Demographic/Personal information relating to the PWD (N=7) (Part one)

Participant (P) number and care home letter	Gender	Age (years)	Dysphagia aetiology	Information relating to the neurological disorder, including effects on mobility	TOM activity level for dysarthria (Appendix 3), if present	Visual/hearing/ communication needs
P1 (D)	Male	76	Progressive supranuclear palsy (PSP)	PSP diagnosis in May 2010. Wheelchair bound. Potential episodes of emotional lability. 1 previous stroke (2006).	Had been rated 4 by SLT, but upon meeting P1 the rating was more akin to 2.	Poor vision- unable to read. Requires time to process information and respond to questions.
P2 (E)	Male	66	Stroke	2 years post-onset. Right-sided stroke. Moderate dysarthria and aphasia. Wheelchair bound.	3	
P3 (F)	Male	84	Parkinson's Disease	Diagnosed 5 years ago. Mobility poor- walks with a stick and requires wheelchair at times. Mild dysarthria/ dysphonia.	4	Requires extra time to respond and careful listening due to low volume of voice.

P4 (G)	Male	87	Stroke	1 year post onset. Right infarct. Left-sided weakness. Severe dysarthria. Walks with a stick.	4	Regularly uses writing to communicate.
P5 (H)	Male	84	Unspecified progressive neurological disorder. Query Myasthenia Gravis.	Muscle weakness and fatigue. Walks with a stick.	5	Eyesight compromised by muscle weakness in eyelids.
P6 (I)	Female	80	Stroke	Stroke in April 2003 resulting in dense left sided hemiplegia. Wheelchair bound.	4	Visual difficulties.
P7 (G)	Male	91	Stroke	Stroke in December 2010 (Left hemiparesis)- No dysphagia reported. Following reports of dysphagia, investigation indicated further vascular event (Summer 2012). Wheelchair bound.	3	

Table 4.3.2: Demographic/Personal information relating to the PWD (N=7) (Part two)

Participant (P) number and care home letter	Food texture recommended (B-E) and length of time participant has been consuming this diet	Fluid texture recommended (1-3), if required	Feeding status	Status on the FOIS	Duration of care home residency	Visitors
P1 (D)	D, 17 months	Stage 1	Requires total feeding assistance but drinks independently	Level 5	17 months	Regular visits from wife and son.
P2 (E)	C, 2 years	Stage 1	Feeds independently, but with left hand due to right-sided weakness	Level 5 (However, if P2 had been consuming the diet recommended by the SLT, his status would have been Level 4).	18 months	No regular visitors.

P3 (F)	E, 5 weeks (Had videofluroscopy in March 2007 when still living at home- soft/normal diet recommended but had been taking normal more recently)	Normal	Requires total feeding assistance	Level 5	18 months	Daily visit from wife and regular visits from other family and friends.
P4 (G)	E, Approx 8/9 months (was initially Nil-by-mouth and PEG fed post-stroke).	Normal	Feeds independently, but with right hand due to left-sided weakness	Level 5	6 months	Daily visits from partner/children.
P5 (H)	To have most foods at C, but can manage some foods at D. Started with D just over 2 years ago and has had to have items at C for approx 1 year.	Naturally thicker liquids	Feeds independently	Level 5	Approx 4 months	Wife also lives in care home.

P6 (I)	C, 3 months	PEG for majority of fluids. Can have Stage 2 fluids but to be taken only during mealtimes and quantity restricted to approx 150 mls each time.	Feeds independently, but with right hand due to left hemiplegia	Level 3	9 years	Daughter visits, usually at weekend.
P7 (G)	E. On dysphagia diets for 2 months (has progressed from Texture C and D).	Stage 1	Feeds independently, but with right hand due to left-sided hemiparesis	Level 5	1 year	

4.4 The researcher

In order to make the researcher’s stance regarding this investigation explicit, the beliefs of the researcher pertaining to this study, both theoretical and personal, are stated below. Furthermore, in keeping with a descriptive phenomenological approach, the researcher’s pre-suppositions relating to the phenomenon under investigation are also listed.

The researcher is a firm advocate of qualitative approaches to research when the aim of the study is to gain insight into the perceptions and experiences of individuals. A descriptive phenomenological approach is considered ideal for eliciting individuals’ descriptions of their experiences regarding a specific phenomenon. The researcher feels strongly about the need for the voices of healthcare service-users to be heard and for healthcare professionals to do what they can to address issues which are of importance and concern to their clients. Healthcare service-users should be viewed holistically and not simply as a ‘patient’ with a specific diagnosis which needs to be treated. These individuals should also be viewed as ‘experts’ in their health condition and empowered to share their experiences of living with that condition.

In addition to the clear gap which exists in the literature concerning the topic under investigation in this study, this research also has personal significance to the researcher. Firstly, the researcher worked as a care assistant in a care home for three years during her undergraduate summer holidays, an experience which was greatly enjoyed. As a result of this experience, the researcher became aware of the importance of ensuring that care home residents have as good a QOL as possible, given that they will most likely spend the remainder of their lives in the care home. Secondly, as an individual who derives much pleasure from food, the researcher took time to reflect on what life would be like if her diet was restricted or required to be modified in some way. By placing herself ‘in the shoes’ of an individual with dysphagia consuming a modified diet, the researcher became aware of the detrimental impact that this issue would exert upon her QOL. Food has such extensive social significance in human life. It is a central part of celebrations, social time with family and friends and times of rest and relaxation. Thus, it is considered that food contributes significantly to psychological well-being and an individual's identify as a social being. Losing the ability to consume food and drink freely without restriction would be an incredible loss and source of disempowerment to the researcher.

Prior to data collection within this investigation, the researcher engaged in the process of 'bracketing' by suspending her beliefs and presuppositions relating to the phenomenon under investigation, in order that she could "properly examine what is present" (Holloway and Wheeler, 2010, p.215). The researcher listed her presuppositions relating to the phenomenon under investigation after taking time to reflect on her expectations of what the study would uncover. These presuppositions are listed below:

1. Acquired neurological oropharyngeal dysphagia would negatively impact the HRQOL of care home residents.

2. Oropharyngeal dysphagia would exert a negative impact upon the mealtime experience of care home residents.

3. Consumption of a modified diet would negatively impact the mealtime experience and HRQOL.

4. Eating and mealtime-related issues, other than oropharyngeal dysphagia, would exist for care home residents.

4.5 Methods of data collection

For this investigation, methodological triangulation, specifically between-method triangulation, was employed, whereby three different methods were used to assess the same phenomenon (Arksey and Knight, 1999), although two methods were interview-based. Triangulation can be used as a means of validation (Lewis and Ritchie, 2003), that is, to determine the extent to which the findings generated by the different methods corroborate with one another (Denscombe, 2010). Furthermore, triangulation can provide a “fuller picture” of the topic of investigation (Ritchie, 2003, p.44). Additionally, by using between-method triangulation, weaknesses inherent in one method are counterbalanced by strengths inherent in the other methods (Arksey and Knight, 1999). Watt and Whyte (2003) used between-method triangulation in their study which sought to gain insight into the effect of oesophageal dysphagia caused by oesophageal cancer upon the QOL of individuals.

Within this investigation, data were collected using: (1) Structured/Semi-structured Interviews; (2) Observations, and (3) Reflexive Discussions. Detailed descriptions of and justifications for using these methods are provided below in sections 4.5.1, 4.5.2 and 4.5.3 respectively.

4.5.1 Structured/Semi-structured interviews

At the first visit to participants (during which informed consent was obtained), the researcher engaged participants in an interview, which used a combined structured/semi-structured approach.

Interviews are the main means of data collection within phenomenological studies (Creswell, 2007). In-depth interviews are an appropriate method of collecting data concerning participants’ experiences, feelings, emotions and opinions (Denscombe, 2010). Additionally, research interviews can have a cathartic and healing effect on individuals; can validate an individual’s self-worth; can provide participants with a sense of purpose; can increase participants’ self-awareness; can enable individuals to feel empowered and importantly, “can give a voice to the voiceless” (Hutchinson, Wilson and Wilson, 1994, p. 164).

4.5.1.1 Structured component of the interviews with the PWD: The modified-SWAL-QOL and ranking item

The interviews with the PWD (Appendix 7) commenced with a brief explanation of what the interview would involve and an opportunity was provided for participants to ask any questions about the procedure. This was followed by the structured component of the interview, which involved administration of a dysphagia-specific HRQOL measure and a ranking item.

Although structured interviews are generally not employed in qualitative research (Holloway and Wheeler, 2010), it was considered appropriate that a dysphagia-specific HRQOL measure be used in order to focus participants' thinking and to provide an indication of key HRQOL issues requiring further discussion within the subsequent semi-structured component of the interview. In Watt and Whyte's (2003) study exploring participants' experience of oesophageal dysphagia caused by oesophageal cancer, two HRQOL questionnaires (one of which was specific to individuals with oesophageal cancer) were administered prior to a semi-structured interview. In this instance, the purpose of questionnaire administration was for triangulation, rather than to inform the content of the interviews. However, the authors did comment that in the case of some participants, questions contained within the QOL measures helped to draw out concerns and arouse discussion regarding these during completion of the questionnaire. Furthermore, in Tong et al's (2011) study exploring perceptions and experiences of post-irradiation swallowing difficulties in survivors of nasopharyngeal cancer, participants' responses to a self-administered questionnaire (a swallowing-specific questionnaire devised by the authors) formed the basis of the interview guide.

The SWAL-QOL (McHorney et al, 2000a; McHorney et al, 2000b; McHorney et al, 2002) (Appendix 8) is a dysphagia-specific HRQOL measure. The SWAL-QOL can be used within both clinical practice and clinical research (McHorney et al, 2002) and is a respected tool in dysphagia research (Bogaardt, Speyer, Baijens and Fokkens, 2009). The SWAL-QOL has been used in many previous research studies (e.g. Lovell et al, 2005; Robbins et al, 2007; Greenblatt et al, 2009; McKinstry, Tranter and Sweeney, 2010; Barikroo and Lam, 2011; Heijnen, Speyer, Baijens and Bogaardt, 2012). The validity of the SWAL-QOL has been documented (McHorney et al, 2002), and the inclusion of individuals with acquired neurological disorders within the patient samples used for SWAL-QOL development (McHorney et al, 2000a; McHorney et al, 2000b; McHorney et al, 2002) further supports the use of the SWAL-QOL within the present study.

The SWAL-QOL consists of 44 statements/items relating to swallowing which are divided into 11 domains. Given the purpose of the SWAL-QOL within the present investigation, the formal scoring system was not required. Care home residents were not included within the patient samples used for SWAL-QOL development (McHorney et al, 2000a) and thus for this study, modifications were made to the SWAL-QOL to enhance its suitability for use with individuals residing in a care home (Table 4.4). Additionally, the questions at the end of the questionnaire (regarding oral/non-oral nutrition; diet texture; liquid viscosity; general health and demographic information) were omitted. Any relevant data about participants required by the researcher were provided by the SLTs. The version of the SWAL-QOL utilised within this study is herein referred to as the ‘modified SWAL-QOL’.
It was considered that oral administration of the modified-SWAL-QOL eliminated the risk of participants being unable to complete the questionnaire due to difficulties with reading and/or writing.

Table 4.4: The modifications made to the SWAL-QOL prior to use with care home residents

Statement/Domain omitted	**Rationale**
Food selection domain	Care home residents are not involved in food selection- it is expected that they are provided with food which is appropriate for their modified diet.
Communication domain	Whilst it is recognised that communication difficulties may also exist in individuals with acquired neurological disorders, this study sought to specifically explore the impact of oropharyngeal dysphagia on HRQOL.
'I worry about getting pneumonia' (statement from the Fear domain)	It was considered that many participants may not be aware of pneumonia as a potential consequence of dysphagia and may therefore become anxious if the researcher imparted this information during an explanation.
Sleep domain	The connection between problems with sleeping and the presence of oropharyngeal dysphagia was unclear. Rinkel et al (2009) found that the 'Sleep' domain did not clearly distinguish between individuals who had been treated for oral or pharyngeal cancer and a group of healthy controls.

Responses to the SWAL-QOL statements/items are typically made using a five-point Likert Scale, although the response options are not the same for every domain. For this study, the mid-point option was omitted and a four-point Likert Scale employed (for example, Strongly Agree, Agree, Disagree, Strongly Disagree). Omission of the mid-point option occurred as it was considered important that participants did not maintain neutrality (Arksey and Knight, 1999), given that the researcher wished to gain insight into their perceptions. To aid the clarity of the task and to reduce output requirements for participants with dysarthria, visual Likert Scales were developed and an example has been appended (Appendix 9). A vertical presentation of these scales was used to help reduce unreliability in the presence of a visual field deficit. Visual impairment prevented use of the scales with four PWD and reading difficulties hindered use of the scales with another participant, although at the time of the interview, it was believed that the participant had a visual impairment.

There were notable instances of ambiguity/uncertainty surrounding some of P1 and P2's responses to statements/items within the modified-SWAL-QOL and ranking item, which were identified during transcription of the interviews. For example, it was necessary for the researcher to establish a system for eliciting P2's responses to the modified-SWAL-QOL and ranking item given that he was only willing to provide yes/no/non-verbal responses. As a result of this, there were instances where, upon viewing the recording, there was some confusion regarding which response the participant was actually indicating. All of the instances of ambiguity/uncertainty were carefully documented and discussed with the first supervisor who viewed relevant sections of the video recordings with the researcher and final decisions about these issues were made during this discussion. There were however five instances relating to modified-SWAL-QOL responses where the ambiguities were unresolved. Although ambiguous, these responses were retained within the data set, given that the modified-SWAL-QOL data were not being formally scored.

A ranking item was added at the end of the modified-SWAL-QOL as a means of examining the extent to which acquired neurological oropharyngeal dysphagia impacted QOL compared with other issues associated with ageing/disease/life in a care home. The options included within the ranking item and the rationale for their inclusion are documented in Table 4.5. Participants were required to indicate whether or not they perceived the issues within the ranking item as problematic. They were then asked to identify which issue they felt affected their life the most/which one would be the biggest problem and the one which they would rank in second place. Visual aids were developed for each option within the ranking item as a means of aiding the clarity of the task for those for whom they would be useful (Appendix 10).

Table 4.5: Overview of the options included within the ranking item and the rationale for their inclusion

Option	Rationale for inclusion
1. My joint/back pain	A common impairment amongst elderly individuals (Harwood, Prince, Mann and Ebrahim, 1998).
2. There are not enough opportunities to talk to people	Loneliness is common among individuals in care home-like settings (Drageset, Kirkevold and Espehaug, 2011).
3. My swallowing difficulty	Relevance to this study (the phenomenon under investigation).
4. Having less independence	Many residents of care home-like settings are dependent on others for care and management of their affairs (Maas, Kelley, Park and Specht, 2002).
5. My mobility problems- I'm not as able to get around by myself as easily or at all	Individuals entering care home-like settings are more likely to have serious functional limitations e.g. limitations in mobility (Maas et al, 2002).
6. Other?	Inclusion of this option provided participants with an opportunity to comment on other issues which they perceived as problematic.

4.5.1.2 Semi-structured component of the interviews with the PWD

Following completion of the structured component of the interview, the researcher engaged the PWD in a semi-structured interview. Semi-structured interviews provide the interviewee with greater freedom in discussion compared with structured interviews (Denscombe, 2010). Watt and Whyte (2003) employed semi-structured interviews using a descriptive phenomenological approach to gain insight into the participants' experience of oesophageal dysphagia caused by oesophageal cancer.

Initially, the PWD were asked if there was anything that they wished to share with the researcher about their swallowing problem/about what it is like to have a swallowing problem and appropriate repetition/paraphrasing was added. This was intended to provide the participants with the opportunity to comment on their dysphagia. Following this, prompts based on the participants' responses to the modified-SWAL-QOL statements/items were used to guide the direction of the remainder of the interview. Participants' responses within each modified-SWAL-QOL domain were examined and participants were questioned about their responses to specific statements/items or domains which the researcher considered would provide valuable insight into their perceptions of acquired neurological oropharyngeal dysphagia. For example, P3 responded with 'Agree' to all of the statements within the Social domain and thus the researcher asked him to comment on how his swallowing problem affected his social life. As another example, P1 responded with 'Often true' to two items within the Symptom Frequency domain and with 'Hardly ever' or 'Never' to the other items. The researcher asked him how he felt about experiencing these two physical symptoms in turn.

The interviews with the PWD lasted between approximately 29 minutes and 57 minutes. P1's interview was conducted over two days due to apparent fatigue and the two parts of the interview lasted for approximately 49 minutes and 51 minutes. A transcript of an interview conducted with one of the PWD is appended (Appendix 13).

4.5.1.3 Structured/Semi-structured interviews with the CP

The interviews with the CP differed slightly from the interviews with the PWD, given that the CP did not have dysphagia of any type. The differences between the interviews conducted with the CP and those conducted with the PWD are detailed in Table 4.6. It should also be noted that the published version of the SWAL-QOL tool was not available to the researcher at the time of data collection with the CP, and therefore there were minor differences between the modified-SWAL-QOL used with the CP and that used with the

PWD. The version of the tool used with the CP was the same as the version used within the pilot study. The interviews with the CP lasted between approximately 10 minutes and 31 minutes.

Table 4.6: Overview of the differences between the interviews conducted with the CP and those conducted with the PWD

Difference	**Rationale**
All statements containing the words "swallowing problem" were omitted from the modified-SWAL-QOL, leading to deletion of the 'Burden' 'Mental health' and 'Social' domains.	These domains were irrelevant to the CP.
Omission of the statement, "My swallowing difficulty" from the ranking item (visual aids adapted accordingly).	This item was not relevant to the CP.
The semi-structured interview focused on gaining insight into participants' eating and mealtime experiences, rather than the HRQOL impact of acquired neurological oropharyngeal dysphagia.	Obtaining data relating to the eating and mealtime experiences of the CP enables insight to be gained into the eating and mealtime-related issues which exist for care home residents, other than dysphagia.

4.5.1.4 Interview procedure

Privacy during data collection has been reported as an issue when conducting research within a care home setting (Hall, Longhurst and Higginson, 2009). To maximise privacy for participants, the interviews were conducted in a private room, either the participant's bedroom or a sitting room with no one else present. However, despite the private location of the interviews, interruptions did occur and these were predominantly by members of staff, although P5's wife briefly interrupted his interview. These interruptions, the majority of which were very brief, did not appear to make the participants feel less at ease in terms of their willingness to express their views, although it is possible that they may have had an effect on participants. The only interview not conducted in a private room was that of the participant who was withdrawn from the study. Her interview was commenced in a sitting room in which other residents were present.

The researcher recorded participants' responses to the modified-SWAL-QOL and ranking item on the interview schedule. In agreeing to participate in the study, participants provided consent for the interviews to be audio and video recorded. Audio recording provides an accurate record of the interview and enables the researcher to focus on the participant (Holloway and Wheeler, 2010). Furthermore, taking notes during an interview may be disruptive for a participant (Holloway and Wheeler, 2010). Video recordings enable non-verbal communication to be captured, in addition to verbal communication (Denscombe, 2010). A Roland Edirol MP3 recorder was used for the audio recordings and was positioned on a flat surface near the participant. A Sanyo Xacti Full HD Dual Camera was used to make the video recordings and was positioned on a tripod on a flat surface facing the participant.

When conducting interviews with elderly individuals, visual and auditory impairments can be problematic (Domarad and Buschmann, 1995). Although individuals were required to have adequate vision and hearing to be able to participate, it was acknowledged that some degree of sensory deficit may exist. Therefore, the writing on the visual aids for use within the modified-SWAL-QOL and the ranking item was presented in large bold font (size 24 and 36 respectively) and speaking volume was adjusted to a level appropriate for each participant. The researcher also tried to ensure that the interviews did not last for more than 45 minutes, as advised by Weed (2010), given that older individuals may lose focus after this point. The researcher monitored the length of the interviews using the timer on the audio recorder. The interviews with P1, P4 and P5 lasted for longer than 45 minutes (both of P1's interviews exceeded this time). In the case of P1, this was due to the extensive processing time which he required and his poor intelligibility which meant that frequent repetition was requested. In the case of P4, this was due to the fact that he responded to the questions in written form due to severe dysarthria and his interview was interrupted for medication administration. P5 was a very verbose individual and in addition to providing extensive information concerning dysphagia, digressed to unrelated topics at times and on two occasions, these digressions were lengthy.

4.5.2 Mealtime observations

Following the interview, all of the CP and PWD were observed during two mealtimes (lunchtime and dinnertime on different days). In the majority of cases, both observations took place within one week of the interview. In the case of two PWD, the second observation took place just over a week after the interview. Furthermore, for the majority of the PWD, the first observation took place on the same day as the interview and the second observation took place on the same day as the reflexive discussion. It was considered important to gain insight into the mealtime experiences of the PWD, given that dysphagia is most likely to impact individuals at mealtimes. Additionally, by conducting mealtime observations of the CP, insight could be gained into the additional mealtime-related issues which exist in the care home, other than dysphagia.

Although interviews are the primary means of data collection within phenomenological studies, data may also be gathered in other forms, including observations (Creswell, 2007). It is recognised that within an interview, the accounts of participants are not necessarily truthful (Denscombe, 2010). Holloway and Wheeler (2010) explain that participants may produce responses which present themselves favourably or which aim to please the researcher. Observation, on the other hand, “draws on the direct evidence of the eye to witness events at first hand” (Denscombe, 2010, p.196).

Within this investigation, the researcher adopted the role of ‘complete observer’ as opposed to the opposite extreme of ‘complete participant’ (Creswell, 2007). It was considered that researcher participation during the mealtimes would have altered the typical mealtime experiences of participants and therefore hindered the collection of representative data. Additionally, the approach of ‘overt observation’ was adopted over that of ‘covert observation’. In overt observations, participants are aware that they are being observed, while covert observation conceals this fact from participants (Patton, 2002). Although the known presence of the observer may alter the behaviour of participants (Patton, 2002), it is deemed unethical to engage in covert observation. To try and preserve the naturalness of the observational setting as much as possible, the researcher avoided interaction with participants when possible and tried to sit in as unobtrusive a position as possible (Denscombe, 2010). There were however some instances where the researcher needed to sit at the participants’ table as there was no alternative seating option. In these situations, the researcher tried to be as unobtrusive and undisruptive as possible.

For this study, a structured observation schedule consisting of pre-determined categories was developed for conducting the mealtime observations of the participants. The same observational schedule was used for both the CP and the PWD. Two examples of completed mealtime observation schedules are appended (Appendix 11), one from data collection with one of the CP and the other from data collection with one of the PWD. The content of the schedule was derived in part from a mealtime screening tool designed to explore mealtime difficulties, including oropharyngeal dysphagia, among the institutionalised elderly (Steele et al, 1997) and also from literature which is concerned with the mealtime experience in the care home setting. The literature indicates that there are many factors other than dysphagia which can impact upon the mealtime experience in the care home.

Although the observational schedule for this investigation utilised a different design to Steele et al’s (1997) mealtime screening tool, many of Steele et al’s

(1997) categories and their constituent items were used to inform the content of the observational schedule (e.g. Provision of mealtime assistance; Type of assistance provided; Specific positioning problems). Additional categories were included as a result of gaining familiarity with the literature relating to mealtimes in the care home: Menu; provision of food choice; dining environment; assistance with positioning; the categories relating to social status/social interaction; participant's physical status; length of time the participant is seated before meal is served; disruptions of the meal.

The observation schedule consisted of three main components: a pre-meal component, a during-meal component and a post-meal component.

1. Completion of the pre-meal component occurred prior to the participant receiving their meal. Observation commenced approximately 30 minutes prior to the beginning of the mealtime, where possible. Verbal consent was obtained from participants prior to commencing the observations. Within this component, descriptive data were obtained relating to the menu; the provision of food choice; the dining environment; the participant's social status pre-meal; the type of seating occupied by the participant; assistance with positioning prior to meal provision; specific problems with positioning; the participant's dental and general physical status and the length of time the participant was seated before receiving their meal. Where appropriate, prompts were included to minimise the risk of omission of important data.

2. Completion of the during-meal component commenced when the participant received their meal. An interval coding approach to observation was adopted for this component, which involved dividing the period of observation into specified intervals of time and recording information regarding what occurred during each interval (Robson, 2011). This approach was considered to provide a detailed account of various aspects considered relevant to participants' mealtime experiences. The mealtimes were divided into one minute intervals and each category was coded during each minute, beginning when the participant received their meal and typically ending when the participant finished eating and/or drinking, although some observations

extended beyond this. A stop watch was used to ensure the accuracy of the interval timings. Both the categories and their constituent items (where appropriate) were pre-coded to facilitate ease in relation to data collection. The aspects under investigation within this component were: assistance and problems with positioning; provision and type of mealtime assistance; participants' attitude towards eating and drinking; challenging behaviours; social status and social interaction; mealtime disruptions by staff and other residents. The researcher also recorded any additional information which was considered relevant (e.g. specific information regarding the nature of mealtime assistance; the occurrence of coughing or loss of food/liquid from the mouth).

3. The post-meal component was completed once the participant had finished their meal. The amount of food and drink consumed by the participant was recorded by estimating the proportion consumed (all, more than ¾, ½, less than ¼, none) and their eating duration was recorded using the data obtained from the interval coding component.

Although video recording the mealtime observations would have provided a permanent record of the observations which could have been used to obtain measures of intra and inter-rater reliability, this was not considered appropriate, given that a video camera could be threatening or disruptive for participants and cause them to alter their behaviour (Holloway and Wheeler, 2010). Moreover, individuals who had not provided informed consent would be captured on the recording, rendering this approach unethical.

4.5.3 Reflexive discussions

Subsequent to the mealtime observations, the participants were engaged in a Reflexive discussion (RD). The majority of the RDs were either conducted on the day after the final observation or on the same day as the final observation, following a short interval to enable the researcher to finalise preparations for the discussion. Verbal consent was sought from participants prior to commencing the RD.

The data obtained from the mealtime observations were used to inform the content of the RDs. Thus, the RD schedules for both the CP and the PWD were only templates which were developed subsequent to the mealtime observations, making them individualised and relevant to the experiences of each participant. The RD schedule for the PWD is appended (Appendix 12). The RD schedule for the CP differed only in terms of omission of the dysphagia-specific content. All participants were also given the opportunity to openly share about eating and/or mealtimes (the PWD were asked how they felt about mealtimes and the CP were asked if there was anything they wished to share about eating and mealtimes/how they felt about eating and/or mealtimes) and all were asked if there was anything they would change about mealtimes. The PWD were also asked whether there was anything they would like to share about their swallowing difficulty and how it affects mealtimes/affects them at mealtimes/affects them. The RDs with the CP provided an opportunity to gain further insight into the experience of eating and mealtimes for care home residents without dysphagia of any type. The RDs with the PWD provided an opportunity to evaluate the extent to which acquired neurological oropharyngeal dysphagia impacted upon the mealtime experience compared with other eating and mealtime-related issues.

The same procedures for privacy and recording that were adopted for conducting the interviews were implemented when conducting the RDs. As with the interviews, several of the RDs were interrupted by staff and another resident caused some disruption to P2's RD. At one point, this resident sat briefly in the same room as P2 and the researcher before leaving. As with the interviews, the researcher tried to ensure that the RDs did not exceed 45 minutes in duration and the timer on the audio recorder was used to monitor the length. Three of the RDs with the PWD extended marginally beyond this time. In the case of P3 this was due to an interruption for medication administration and a lengthy digression at the beginning of the RD. P4's RD was slightly longer than 45 minutes because he produced responses in written form and P5's RD extended beyond 45 minutes because of a lengthy digression. The RDs with the CP lasted between 9 minutes and 32 minutes. The RDs with the PWD lasted between 10 minutes and 50 minutes. A transcript of a RD conducted with one of the PWD is appended (Appendix 14).

Participants' involvement in the investigation did not exceed beyond a period of two weeks from their first contact with the researcher to their last, and the majority of participants had completed their involvement within one week of their initial contact with the researcher.

4.5.4 Piloting the data collection materials

Prior to data collection within the pilot study, the materials were studied on multiple occasions in order to increase familiarity with the content and procedure. The researcher also became acquainted with the use of the audio and video recording equipment to be used to record the interviews and RDs. Additionally, the researcher trialled the format of the structured/semi-structured interview and RD with two colleagues, both trained SLTs familiar with the field of dysphagia and one who was familiar with the care home environment. These experiences reminded the researcher of the importance of using prompts to gain further information, where appropriate and also to ask for clarification if required in order to confirm that participants' insights have been correctly understood. Furthermore, the format of the structured/semi-structured interview and RD were also trialled with a relative, in addition to a trial of the mealtime observation schedule. This process reminded the researcher of the need to explain the procedures for the interview and RD slowly and to allow time for the participants to ask any questions in order to ensure that participants obtain a full understanding of the procedure. Piloting of the mealtime observation schedule enforced the importance of ensuring complete familiarity with the codes contained within the interval coding component, given that important observational data could be missed when searching for an appropriate code.

4.6 Ethical considerations

4.6.1 Ethical approval

Ethical approval for the pilot study and the main study was obtained from the NHS West of Scotland Research Ethics Service (WoSRES) and from the University of Strathclyde.

4.6.2 Informed consent

There are various concerns relating to informed consent when conducting research with elderly individuals, including those residing in care home settings. For instance, elderly individuals residing in institutional settings may be pressured/feel pressured to participate in research (High and Doole 1995). Impairments of hearing or vision may affect the ability of an elderly individual to perceive information presented orally or in written form (Alt-White, 1995). Furthermore, the fact that cognitive impairment is increasingly likely among older individuals poses a challenge in relation to obtaining informed consent (Hall et al, 2009). However, in this study only individuals who were considered by the SLTs/care home managers/staff nurses as capable of providing informed consent were referred to the researcher. The researcher had no concerns about the capacity of referred participants to provide their informed consent.

Within the present investigation, various steps were taken in an attempt to ensure that participants provided their fully informed consent. Firstly, it was considered that recruitment of participants by individuals not directly involved in the research minimised the risk of residents being coerced into participating. Furthermore, the participant information sheets and consent forms were specially developed in order to make them appropriate for elderly care home residents, including individuals with acquired neurological disorders. As recommended by the National Research Ethics Service (NRES, 2011) size 16 font was used to increase the likelihood that potential participants would be able to read the text. The researcher also tried to ensure that all information was presented clearly and concisely. Furthermore, in order to maximise clarity, sections of text within the information sheet developed for the PWD were supplemented with visual aids and in both participant information sheets and consent forms, key words were highlighted in bold font. These strategies were utilised within an adapted information sheet and consent form developed by Parr (2004).

Upon first meeting the potential participants, time was spent explaining the research by reading through the information sheet and allowing time for any questions/expression of concerns. The researcher adjusted her speaking volume to a level appropriate for each participant. Participants were then asked to provide written consent by initialling and signing the consent form. Two participants were unable to provide written consent but gave verbal consent and their permission for a member of staff to sign the form on their behalf. The researcher also obtained verbal consent from participants prior to conducting each aspect of data collection. In their qualitative study exploring the experience of oesophageal dysphagia, Watt and Whyte (2003) regarded informed consent as a “dynamic and ongoing process” (p.186).

4.6.3 Confidentiality

The confidentiality of participants and the care homes in which they resided was respected throughout this investigation. Participants were assigned a number and care homes a letter in place of their name as a means of ensuring anonymity. All data were stored in a locked filing cabinet in a room that was locked when no one was present. Data stored on a university computer were password protected. All data obtained, including the audio and video recordings, will be stored for no longer than six years.

4.6.4 Risks and burdens associated with research participation

In planning this investigation, consideration was given to the potential risks and burdens associated with research participation and solutions for minimising these were developed.

It was recognised that research participation would take up some of the participants' time. As a result, all arrangements relating to the research activities were made with the participants' convenience in mind, with visits only occurring at a time considered suitable by the care home staff.

Additionally, it was recognised that the PWD may find it difficult to talk about their dysphagia and the impact that it has upon their lives. Thus, the researcher carefully attended to participants' comments and endeavoured to create as supportive an environment as possible for information disclosure. P1 displayed several episodes of emotional lability during administration of the modified-SWAL-QOL, although he quickly recovered from these episodes. Upon viewing the video recording of P4's interview, it seemed that he became slightly emotional upon being asked how he felt about the risk of aspiration, an issue which he identified himself. The researcher did not notice this possible display of emotion at the time of the interview and P4 recovered quickly and displayed no other signs of distress.

4.7 Summary

This chapter has detailed the design and methods used to address the aims of this investigation. The methodological approach for this investigation was outlined, with a discussion ensuing regarding the appropriateness of adopting a qualitative approach, specifically a descriptive phenomenological approach. An overview of the participant sample for both the pilot study and the main study was then provided. Subsequently, insight into the researcher's theoretical and personal beliefs surrounding the investigation was provided, in addition to information relating to the suspension of the researcher's presuppositions concerning the study. The methods of and procedures for data collection were outlined and consideration has also been given to the ethical issues relating to this investigation.

The following chapter provides an account of the procedures which were adopted for data analysis within this investigation.

CHAPTER 5

DATA ANALYSIS

5.1 Introduction

This chapter provides an account of the procedures which were adopted for data analysis within this investigation. Differences in the process of analysis between the CP and the PWD are reported below, although the same analytical framework was used for both participant groups.

5.2 Generation of quantitative data

Although this was a qualitative investigation, based on the principles of descriptive phenomenology, quantitative data were generated from the structured component of the interviews (the modified-SWAL-QOL and to some extent, the ranking item) and from components of the mealtime observations. The modified-SWAL-QOL data were used to inform the content of the semi-structured component of the interviews, especially with the PWD, and the observational data were used to inform the content of the RDs. The responses of the PWD to the statements/items within some of the modified-SWAL-QOL domains are presented in bar charts in Chapter 7 (7.4.2.1; 7.4.2.2; 7.4.2.3) to provide support to the participants' accounts. The observational data obtained from both the CP and PWD were also examined for corroborations and contradictions with participants' accounts and reference has been made to both corroborations and contradictions within Chapters 6 (6.4) and 7 (7.4). These data have also been used to produce descriptive summaries of the mealtime experiences of all participants and some data have been presented in tables or charts within Chapters 6 (6.2; 6.3) and 7 (7.2; 7.3). The responses of the PWD to the ranking item are presented in table format in Chapter 7 (7.4.2.5) and these data illuminate the extent to which oropharyngeal dysphagia is perceived as a problem in the context of other issues associated with old age/disease and life in a care home.

5.3 Qualitative data analysis

5.3.1 Transcription

The interviews and RDs were transcribed verbatim from the audio and video recordings by the researcher using Microsoft Office Word 2007. The researcher relied more heavily on the video recordings than the audio recordings during transcription of the data obtained from the PWD due to two participants' high level of dependence on non-verbal communication and also because the researcher found it easier to accurately transcribe using the video recordings, due to higher volume, being able to see participants' lip movements and being able to record verbal and non-verbal communication simultaneously. Transcription by the researcher facilitated immersion in the data and enabled the researcher to become aware of the key issues (Holloway and Wheeler, 2010). The time consuming nature of transcription has been emphasised (Holloway and Wheeler, 2010) and approximately two to four days per participant were spent transcribing the interviews and RDs, checking the transcripts against the recordings and making modifications as required. Recordings were listened through/viewed as many times as needed until the researcher was satisfied with the accuracy of the transcriptions. When transcribing the data obtained from the PWD, the first supervisor's opinion was sought regarding some extracts where intelligibility was particularly poor. Two transcripts have been appended as examples, one interview and one RD, both from different PWD (Appendices 13 and 14 respectively).

A sample of transcripts from both participant groups were checked by the second supervisor in order to verify the accuracy of the transcripts. In the case of the CP, the second supervisor checked the longest and shortest transcripts against the respective audio recordings. The majority of changes made to the transcripts related to words/interjections which had been omitted by the researcher, words which had been unintelligible to the researcher or words which had been transcribed in a formal manner and did not represent the dialect of the participant, none of which significantly altered the meaning of the text. In the case of the PWD, the second supervisor randomly selected two transcripts to review (one interview and one RD with different participants) and was provided with the respective audio and video recordings. Very few changes were made to the transcripts, none of which significantly altered the meaning of the text and the majority of changes related to words/phrases which had been unintelligible to the researcher.

5.3.2 Phenomenological data analysis

An approach to data analysis in line with the principles of descriptive phenomenology was adopted for this investigation. Phenomenological analysis “seeks to grasp and elucidate the meaning, structure and essence of the lived experience of a phenomenon for a person or group of people” (Patton, 2002, p. 482). For this study, the procedural steps outlined by Colaizzi (1978), an advocate of the descriptive phenomenological approach, have been used as a framework for phenomenological analysis. When searching for an analytical framework to use within this investigation, it was deemed important that the chosen framework should be clear and easy to follow in order to minimise ambiguity and thus enhance the consistency of the analytical procedure between participants. Use of the framework was trialled during the pilot study and deemed to be suited to the needs of the researcher. Furthermore, Colaizzi’s (1978) framework for phenomenological analysis has been utilised in previous research which has explored the QOL impact of oesophageal dysphagia caused by oesophageal cancer (Watt and Whyte, 2003), and in research which has explored participants’ perceptions and experiences of oropharyngeal dysphagia following radiation therapy for nasopharyngeal carcinoma (Tong et al, 2011). Thus, this framework is known and used within this field of research.

The decision was made not to use computer aided qualitative data analysis software (CAQDAS) to assist with analysis of the data obtained from the CP. Webb (1999) recommends that individuals new to qualitative research initially conduct analysis manually in order to gain an understanding of the process of qualitative data analysis. Sanders (2003) provides a detailed account of her application of Colaizzi's (1978) analytical framework within her descriptive phenomenological study in the field of nursing, and she reports adopting a manual approach to analysis. However, given that experience was gained in qualitative data analysis with the CP, NVivo 8 (QSR International, 2008) was used to aid analysis of the data obtained from the PWD. Some of the uses of CAQDAS include, storing, sorting and organising data and developing diagrams (Holloway and Wheeler, 2010) and the researcher found these functions to be very helpful when utilising NVivo 8. The memo function within NVivo 8 was found to be a useful means of recording thoughts and ideas about the data and documenting decisions made during the process of analysis. The importance of memoing in aiding qualitative data analysis has been acknowledged (Holloway and Wheeler, 2010). Although the benefits of CAQDAS are recognised, Barbour (2008) warns that use of a computer programme to aid qualitative data analysis does not mean that the analysis is more rigorous, rather it is the researcher who ensures analytical rigour.

Colaizzi (1978) outlines seven steps in his analytical framework which are detailed below, along with a description of their application within the investigation.

1. "Read all of the subject's descriptions, conventionally termed protocols, in order to acquire a feeling for them, a making sense out of them" (Colaizzi, 1978, p.59).

All of the transcripts were read through a number of times in order to become familiar with the data. This reading of the transcripts in their entirety occurred during the transcription process. Sole involvement of the researcher in data collection initiated this process of familiarisation.

2. “Return to each protocol and extract from them phrases or sentences that directly pertain to the investigated phenomenon; this is known as extracting significant statements” (Colaizzi, 1978, p.59).

The researcher carefully examined each transcript and identified statements/extracts which directly related to the phenomenon under investigation. When conducting the analysis of the data obtained from the CP, the researcher clearly indicated each significant statement on a copy of the transcripts. Within the control group, a statement was considered to be significant if it was considered to provide insight into the participants’ perceptions of eating and mealtimes in the care home. In the case of the PWD, a statement was deemed significant if it was considered to provide insight into the participants’ perceptions of the HRQOL impact of acquired neurological oropharyngeal dysphagia or given the inclusion of a control group, was considered to provide insight into the participants’ perceptions of eating and mealtimes in the care home. Significant statements identified within the transcripts of the PWD were highlighted and organised into themes within NVivo 8, although further organisation of these data occurred manually and this is detailed below.

It should be noted that the majority of P4’s responses within the interview and RD were written due to his extremely poor intelligibility. With one exception, only P4’s written utterances were extracted for analysis, given that any of his verbal utterances which were interpreted during transcription had the same meaning as his verbal responses. The exception to this related to P4’s response to the swallowing component of the ranking item because no written account of this statement was provided, although the utterance was intelligible to the researcher. Additionally, many of P7’s utterances within the interview related to his perceptions of his shyness and problems with socialisation. The decision was made to exclude these statements from the analysis as they were not dysphagia-related and did not appear to be specific to mealtimes. Another statement uttered by P7 was omitted because it was in complete contradiction with other comments he made.

Colaizzi (1978) states that repetitions can be eradicated. Within this investigation, statements considered to be identical or nearly identical to statements already uttered by the same participant were not included within the analysis, unless the repetition formed part of a more extended exchange. In relation to the PWD, there were four occasions when the original statement contained an unintelligible segment and thus the subsequent version of the statement was incorporated within the analysis. In one of these instances, the participant omitted the unintelligible segment from the repetition. A total of 268 significant statements were extracted from the transcripts of the CP and, following adjustments to the analysis based on feedback from the first supervisor (page 126), a total of 355 significant statements obtained from the transcripts of the PWD were included within the analysis.

3. “Try to spell out the meaning of each significant statement, known as formulating meanings” (Colaizzi, 1978, p.59).

Within this stage of analysis, Colaizzi (1978) suggests that the researcher “attempts to formulate more general restatements or meanings for each significant statement distilled from the text” (Sanders, 2003, p. 296). Thus, each significant statement was thoroughly examined and a more general meaning articulated. The formulated meanings were repeatedly checked against the significant statement from which they were derived to ensure as accurate a formulation of meaning as possible. Sanders (2003) notes the importance of attending to context when formulating meanings and the researcher found that examining the context in which a statement was uttered aided interpretation of the meaning of statements and reduced the risk of misinterpretation. Colaizzi (1978) describes the process of formulating meanings as a “precarious leap” (p.59), because at the same time as progressing beyond the statements contained within the transcripts, the researcher still needs to retain a connection between the transcripts and the formulated meanings.

The significant statements identified within the transcripts of the CP and the PWD were transferred to word documents and tabulated. The statements were organised within the tables in order of their extraction from the transcripts (which in all cases occurred methodically from the beginning to the end of the transcript) and were numbered. The formulated meanings corresponding to each significant statement were displayed in an adjacent column in the tables and thus assumed the same number. Examples of the meanings formulated from significant statements identified within the transcripts of the CP and the PWD are displayed in Tables 5.1 and 5.2 respectively.

Table 5.1: Examples of significant statements extracted from the transcripts of the CP and their corresponding formulated meanings

Significant statement	**Formulated meaning**
(7) What I’m trying to say is I enjoyed eating while I had my eyesight but I don’t enjoy it now because I go down XXX and I cannae see what I’m getting for the eating, you know…But there’s somebody there cutting it up for me and trying to guide me to it, you know (CP1, Interview, 056; 058).	The participant’s enjoyment of eating has been taken away by the visual impairment, as it is not possible to see the food that has been provided. Assistance is provided to try and compensate for this difficulty.
(96) It’s [the food] alright. It’s alright…There’s certain things that you don’t like…but you take…Because of eating purposes, you know…And eh…it’s not like you’re in your own home where you can make what you feel like…(You gotta)They have a menu…you’ve gotta take it, you know (CP2,	The food which is served in the care home is satisfactory. The nature of care home living means that the participant is unable to make the kind of food that he feels like and it is therefore necessary for him to eat what food is available, even if he doesn’t like some of the food.

Reflexive discussion, 060; 062; 064; 066; 068; 070; 072).	
(117) I’ve seen it with other people, not with me, eh they’ve left their dinner. Come on, you must eat something…but they don’t need to do that with me cus I sometimes clear my whole plate. The only plate, thing I don’t do is if I’ve got an awful lot of vegetables…I don’t usually eat an awful lot of vegetables. And chips I don’t eat an awful lot…But I like the meals, I like my food (CP3, Interview, 102; 104; 106; 108).	The participant has observed other residents not eating much and having to be encouraged to eat by the care staff. However, she does not require such encouragement as she generally eats all of the food with which she is provided, with the exception of foods which are not of personal preference. She likes eating and is positive about the meals which are served in the care home.
(151) I wouldn’t say it’s the best of food…I wouldn’t say it’s, well what I’m thinking about is the best of food. Maybe I’m out of order (Laughs). It’s not all that bad, but I don’t think it’s all that great (CP4, Interview, 188; 190).	The food that is provided at the care home is not viewed in a positive light.
(190) Eh well I mean I quite enjoy the mealtimes, they do it, they vary it (Gestures)…You know you don’t get the one thing all the time (Gestures)…They vary what’s on the menu like, you know (Gestures) (CP5, Interview, 216; 218; 220).	The participant enjoys mealtimes. The menu is varied, meaning that the same food is not served all the time.
(249) So I don’t have, I can’t say that I’ve any problems of my own, you know, obviously you don’t get exactly everything that you want and cooked and that cus it’s em, maybe the word, institutional food…is the description that’s, you’ve obviously got to cater like that…I think so (CP6, Reflexive discussion, 094; 096; 098).	Although no major mealtime issues exist, the participant recognises that it is not possible for her to have whatever she wants to eat because large numbers of people are being catered for.

Table 5.2: Examples of significant statements extracted from the transcripts of the PWD and their corresponding formulated meanings

Significant statement	Formulated meaning
(10) Mmm (purses lips) indifferent (Closes eyes)…Eh aye indifferent…Indifferent…to the meals…(Closes eyes) (P1, Reflexive discussion, 030; 032).	The participant is uninterested in the meals which are served in the care home.
(28) XXX I like alone (P2, Reflexive discussion, 122).	The participant likes to eat at a table alone.
(30) XXX…I'm dribbling now…And it goes on (/t/) to lunchtime…And (these, the) the doctors have tried so many different remedies…and they haven't been able to help…So it's a major issue (P3, Interview, 062; 064; 066; 068; 070).	Drooling is experienced by the participant and all medical interventions to alleviate this issue have been unsuccessful. Thus, drooling is perceived to be a major issue.
(110) The waiting time is sometimes frustrating…The food arriving from the kitchen…Especially in the morning (P4, Reflexive discussion, 120; 122; 130).	It can take a while for food to arrive in the dining room from the kitchen, particularly in the mornings, and this waiting time can be frustrating.
(136) I've trouble Almost always, aye, chewing, aye…XXX Making a decision when to swallow, you know that…(that is) that is the problem (Nods head)…You're chewing away and then will I or won't I (Shakes head) (P5, Interview, 184; 186; 188; 190).	The participant experiences indecision regarding when it is safe to swallow.
(254) My mouth's all dry (Points to mouth)… (Nods head) And my lips (Points to lips)…And my tongue (Protrudes tongue)...I usually drink what they give me (Gestures) (P6, Interview, 488; 490; 492; 494).	The participant has dry lips, a dry mouth and a dry tongue. She usually drinks what liquid she is given.
(327) I'm not very sociable…I'd rather eat on my own (P7, Reflexive discussion, 072; 074).	The participant is not a sociable person and would rather eat his meals on his own. He seems to have the option of eating at least some of his meals in his room if he wishes, as

	was the case for the observed dinnertime.

4. "Repeat the above for each protocol, and organise the aggregate formulated meanings into clusters of themes" (Colaizzi, 1978, p.59).

Throughout the process of analysis, the researcher had been identifying themes which represented commonalities in the participants' experiences. Within this stage, each formulated meaning was organised into a theme or themes and within each theme, the formulated meanings were further organised into theme clusters, or sub-themes. This process was carried out within word documents. The fact that the data obtained from the PWD had already been organised into themes within NVivo 8, aided this component of the analysis. Documents listing the significant statements assigned to each theme were exported from NVivo 8 and used to help assign the formulated meaning of each significant statement to the appropriate word document(s). Within the data obtained from the CP, four emergent themes were identified, each of which contained at least two theme clusters. Within the data obtained from the PWD, nine emergent themes were identified, each of which contained at least two theme clusters. One emergent theme from the data obtained from the CP and one from the data obtained from the PWD, with their associated theme clusters and formulated meanings, are appended as examples of the end result of this stage of analysis (Appendices 15 and 16 respectively).

In terms of verifying the accuracy of the analysis, different steps were taken with regards to the CP and the PWD. In the case of the CP, the researcher discussed eight of the transcripts produced from data collection with this participant group with the first supervisor, who agreed with the emergent themes which had been identified. Throughout analysis of the data obtained from the PWD, the researcher had many discussions with the first supervisor predominantly concerning interpretation of statements, assignment of statements and the labelling of a theme and sub-theme. When the analysis was complete, the first supervisor then reviewed all of the data and some revisions were made to the analysis based on the feedback received from this review. The second supervisor, who also reviewed the data, was in agreement with the feedback provided by the first supervisor. These revisions largely related to:

- Eliminating statements originally extracted for being irrelevant to the topic under investigation or for not contributing much to the topic under investigation;
- Combining two or more significant statements and their formulated meanings to ensure that all formulated meanings are clearly aligned with the heading of the theme cluster;
- Making some formulated meanings clearer in terms of explaining their significance/relevance to the theme cluster;
- Including only the extract relevant to a specific theme/theme cluster in the case of a lengthy formulated meaning;
- Amending the title of a theme and several theme clusters;
- Addition, elimination and merging of theme clusters;
- Reassignment of formulated meanings to different theme clusters.

5. “The results of everything so far are integrated into an exhaustive description of the investigated topic” (Colaizzi, 1978, p. 61).

The exhaustive description of the topic under investigation is derived from integrating the ideas which have emerged from the analytical process (Sanders, 2003). For both participant groups, the emergent themes, theme clusters and formulated meanings, supplemented with verbatim quotations from participants, were used to construct the exhaustive description. The exhaustive description pertaining to the data collected from the CP is presented in Chapter 6 (6.4) and the exhaustive description pertaining to the data collected from the PWD is presented in Chapter 7 (7.4).

6. “An effort is made to formulate the exhaustive description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible” (Colaizzi, 1978, p.61).

This statement can also be referred to as an “essential structure of the phenomenon” (Holloway and Wheeler, 2010, p.224). Condensing the exhaustive description to an ‘essential structure’ occurs as a result of the lengthy nature of the exhaustive description (Sanders, 2003). An essential structure for each group of participants is presented within the conclusion of the respective results chapters (6.5; 7.5) and concisely summaries the key findings.

7. “A final validating step can be achieved by returning to each subject, and, in either a single interview session or a series of interviews, asking the subject about the findings thus far…Any relevant new data that emerges from these interviews must be worked into the final product of the research” (Colaizzi, 1978, pp.61-62).

The decision was made to omit this stage of analysis because the researcher had already engaged the participants in two sessions which focused on eliciting their experiences and perceptions and it was deemed inappropriate to place further demands on these frail, elderly individuals. During analysis, the researcher maintained a close connection with the original transcripts to ensure as accurate a portrayal of the participants’ experiences as possible.

5.4 Summary

This chapter has provided an account of the procedure for analysis adopted within this investigation. The following chapter presents the findings of the data obtained from the CP, while the findings of the data obtained from the PWD are documented in Chapter 7.

CHAPTER 6

CONTROL PARTICIPANT FINDINGS

6.1 Introduction

The aim of data collection with the CP was to gain insight into the eating and mealtime experiences of care home residents without dysphagia of any type. This chapter presents the findings of the data obtained from the CP. Initially, insight is provided into the mealtime experiences of each of the participants based on the observational data (6.2). Subsequently, group summaries of some of the observational data are provided (6.3). This is followed by a presentation of the participants' accounts concerning their experience of eating and mealtimes in the care home and these accounts are considered in relation to the observational data (6.4). It is recognised that the order in which the results are reported in this chapter deviates from the order in which the data were collected. Whilst the mealtime observations were conducted between the interviews and reflexive discussions, it is considered that the observational data provide a context for the participants' accounts of their experiences. Thus, the decision was made to present these data prior to the interview and reflexive discussion data, which collectively represent participants' self-reports of their experiences.

6.2 Summary of the mealtime experiences of each participant

The data obtained from the mealtime observations have been used to provide insight into each of the participants' mealtime experiences and provide a suitable backdrop for the presentation of their own accounts. Most of the observational data are presented below in descriptive summaries, although the data most conducive to tabulation are summarised in Table 6.1.

The CP were resident in three different care homes (two participants per care home). Unless stated otherwise, participants received a starter and main course at lunchtime and a main course and dessert at dinnertime. Portion sizes appeared similar between care homes. None of the participants displayed challenging behaviours and only one instance of rejection of food was observed (CP4 complained about the taste of the soup and pushed her bowl of soup away after consuming only half at dinnertime). In other instances where food/drink was left unfinished, it was deemed too much of an assumption to interpret this as a sign of disinterest or rejection, as participants could simply have consumed sufficient. It should be acknowledged that CP4 was also heard complaining about the care home food during her main course at dinnertime and consumed only half. However, at the time of the observation she was not documented as rejecting the food, likely because the researcher felt that there may also have been a possibility that she was full.

CP1 had a choice of two main courses at both mealtimes and at lunchtime there was also a choice of two potato options. She ate both meals in one of the dining rooms and was seated with three other residents at lunch and two at dinner. She sat in her wheelchair at both mealtimes, although she was given the choice to move to a dining chair at dinnertime. At both mealtimes, care staff positioned her at an angle to the table in an attempt to help her see her food more clearly, and described the location of the foods, served as part of her main course, on her plate. At dinnertime, her food was also chopped up and she received some assistance with the preparation of her dessert. Although she had a brief conversation with another resident prior to the provision of lunch, she did not interact with other residents during either meal. Also prior to lunch, a resident with dementia created noise. CP1 had some of her own teeth.

CP2 resided in the same care home as CP1 and therefore also received a choice of two main courses at both mealtimes. At lunch, he was offered a choice of main course following completion of his starter. He ate both meals in the same dining room as CP1. He sat in a dining chair at the same table on both occasions and was seated with three other residents at lunch and two at dinner. He did not engage in social interaction with any of the residents at his table prior to or during the meals and prior to dinner and during both meals, a resident with dementia created noise.

CP3 received a main course and dessert at lunchtime and a starter and main course at dinnertime. She received a choice of two main courses at dinnertime, however received no choice at lunchtime. She ate lunch in the dining room, seated in a wheelchair at a table with two other residents, and dinner in her room, seated in an armchair with a cushion behind her for support. Prior to the provision of lunch, she had a cushion placed under her feet. She did not engage in any social interaction with the residents at her table prior to or during lunch. CP3 had some of her own teeth.

CP4 resided in the same care home as CP3 and thus the same course arrangements existed, although a choice of two main courses was available at both mealtimes. She ate both meals in the same dining room in which CP3 consumed lunch. CP4 sat at the same table on a dining chair on both occasions and with three other residents at lunch and one at dinner. Prior to and during both meals, she conversed with one of the female residents sitting at her table and during dinner complained to this resident about the food. During lunch, medication was administered to some residents.

CP5 received a choice of two main courses at both mealtimes (her order for dinner was taken prior to the mealtime). She ate both meals in one of the dining rooms and sat in her wheelchair at the same table with the same residents on both occasions. Prior to and during both meals, CP5 engaged in some conversation with one of the female residents sitting at her table who had dementia, and she interacted with staff during both meals. Medication was administered during both meals and during dinner, two members of staff conversed across the dining room while providing feeding assistance. Both residents at CP5's table left before she had finished her dessert. During lunch, the resident with whom CP5 conversed uttered jargon and CP5 ignored this. CP5 had dentures, although did not wear them for eating her meals.

CP6 resided in the same care home as CP5 and therefore also received a choice of main course, although her order was taken prior to both mealtimes. She ate lunch in one of the dining rooms seated on a dining chair, and her dinner seated in an armchair in a sitting room, a Friday evening tradition where residents were served fish and chips in front of the television. She was seated with three other female residents at lunch. She did not interact with any residents prior to or during both meals. She was provided with medication during lunch and other residents received medication during dinner. A resident with dementia created noise prior to and during dinner.

Table 6.1: Summary of various aspects related to control participants' mealtime experiences

	Approx waiting time prior to meal provision (minutes)		**Clothing protection provided**		**Provision of liquid prior to meal (Some drinks not provided until food had been served/further drinks provided during some meals)**		**Vision/Hearing**	**Mobility**	**Feeding status**
	Lunch	*Dinner*	*Lunch*	*Dinner*	*Lunch*	*Dinner*			
CP1	5	10	No	No	Choice of juice or milk	Choice of juice or milk	Severe visual impairment	Wheelchair	Fed independently but some assistance required due to visual impairment (page 129).
CP2	Arrived 45 mins prior to start of meal-time	Arrived 45 mins prior to start of mealtime	No	No	Choice of juice or milk	Choice of juice or milk	Sometimes wore glasses to read	Zimmer frame to aid walking	Fed independently

CP3	10	N/A	Yes	No	No	No	Wore glasses when reading. Severe hearing impairment.	Wheelchair	Fed independently
CP4	10 (no main course eaten as had eaten at café so further waited until dessert served)	15	No	No	Choice of juice or milk	Choice of juice or milk	Visual impairment	Stick to aid walking	Fed independently
CP5	10	Not available	No	No	Glass of milk	Glass of milk	N/A	Wheelchair	Fed independently (appeared to have some difficulty manipulating the cutlery)
CP6	5	5	No	No	Choice of juice or milk	No	Wore glasses for reading	Zimmer frame to aid walking	Fed independently

6.3 Group summaries of the observational data

Having summarised the data collected from individual participants during the mealtime observations (6.2), this section presents group summaries of some of the data collected within the interval coding component of the observations and key findings are discussed. Data relating to mealtime and eating duration and quantities of food and liquid consumed are also presented.

6.3.1 Mealtime assistance

CP1 was the only participant who received any form of mealtime assistance and this was provided due to her severe visual impairment. Assistance was provided during both mealtimes and the nature of this assistance is outlined in CP1's descriptive summary on page 129.

6.3.2 Social status and interaction at the mealtimes

Eating in the presence of other residents was the most common social state in which participants were observed. With only one exception, participants consumed their meals sitting at a table with at least one other resident in a dining room or, as was the case with CP6's dinnertime meal, eating in a lounge along with other residents. The exception related to CP3's dinnertime observation, during which she ate alone in her room, the typical arrangement for her dinnertime meals. It should be noted that both of the residents seated with CP5 at dinnertime left before she had finished her dessert and she completed this course alone.

With regards to interactions with other residents, it was interesting to find that CP4 and CP5 were the only participants documented as interacting with other residents during the meals.

6.3.3 Disruptions of the meal by staff and other residents

The disruptions of the meals by staff related to staff conversation and drug administration. Staff conversation was noted during one minute of CP5's dinnertime, while drug administration was documented as occuring during CP4's lunch and both of CP5 and CP6's meals. The only disruption caused by other residents was that of noise. Noise produced by other residents was noted during both of CP2's meals, CP5's lunch and CP6's dinner. The noise documented at CP5's lunch related to a resident with dementia sitting at CP5's table who uttered jargon during two minutes of the lunchtime. This was the same resident with whom CP5 had some interaction with during both meals. On the occasions when this resident uttered jargon, CP5 ignored her.

6.3.4 Mealtime and eating duration and amount of food/liquid consumed

Mealtime duration, as displayed in Figure 6.1, has been measured from the point the participant received their meal to the point at which they stopped eating and/or drinking. The time spent not eating refers to the time between courses, and/or the time between food being served and the participant starting to eat, and/or the time after both courses during which drinking occurred. It should be noted that the time taken for CP4 to finish drinking a cup of tea following the completion of her dessert was not recorded. There was great variation in the mealtime durations, and CP5's mealtimes were the longest, due to the fact that she took longer to eat overall than the other participants. In general, participants spent little or no time not eating indicating that, on the whole, they did not have to wait at all or for long between courses and spent either little or no time drinking at the end of a meal.

It is apparent from Table 6.2 that, in general, the CP ate the majority of the food served, although none of the participants consumed all of both courses at any of the mealtimes. It can be seen from Table 6.3 that most participants consumed all of the liquid with which they were provided and there were only two mealtimes where at least one glass/cup of liquid was not consumed in its entirety.

Figure 6.1: The duration of the observed mealtimes (CP) (in minutes)

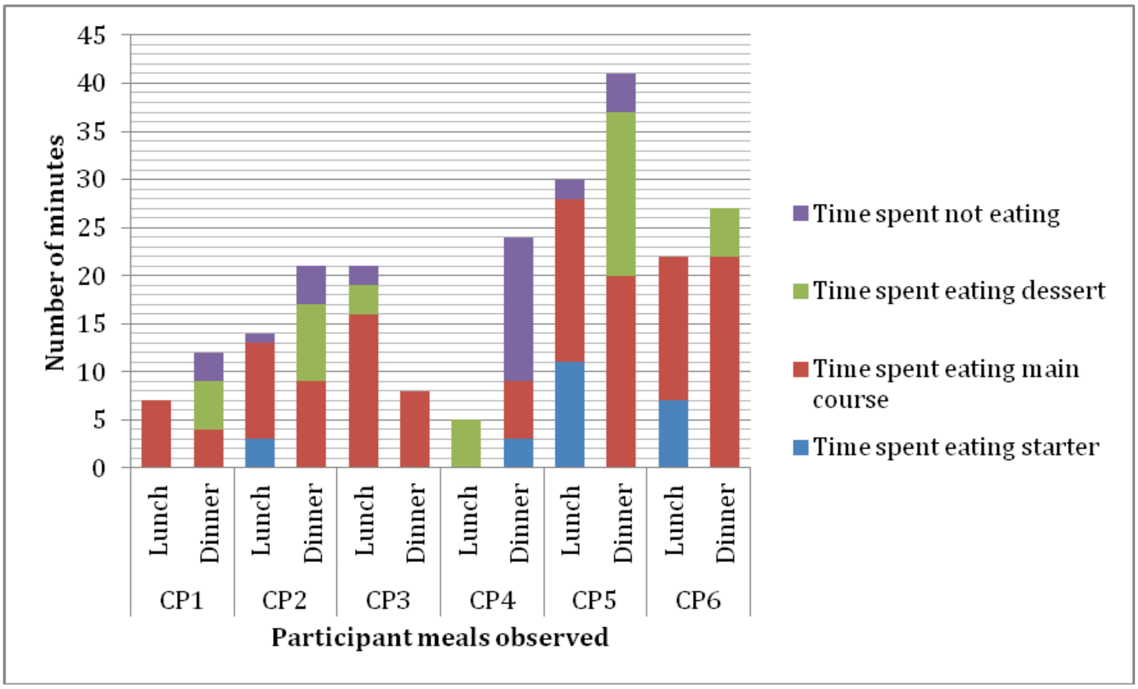


Table 6.2: The approximate quantity of food consumed at each observed mealtime (CP)

Participant	**OBSERVED LUNCHTIME**			**OBSERVED DINNERTIME**		
	Starter	**Main course**	**Dessert**	**Starter**	**Main course**	**Dessert**
CP1	Refused	> 3/4	_____	_____	1/2	All
CP2	All	> 3/4	_____	_____	> 3/4	> 3/4
CP3	_____	1/2	All	Refused	> 3/4	_____
CP4	_____	Had eaten at cafe	All	1/2	1/2	_____
CP5	> 3/4	> 3/4	_____	_____	3/4	All
CP6	All	3/4	_____	_____	> 3/4	All

Table 6.3: The approximate quantity of liquid consumed at each observed mealtime (CP)

Participant	**OBSERVED LUNCHTIME**			**OBSERVED DINNERTIME**		
	Drink 1	**Drink 2**	**Drink 3**	**Drink 1**	**Drink 2**	**Drink 3**
CP1	> 3/4	_____	_____	All	_____	_____
CP2	All	_____	_____	All	_____	_____
CP3	All	_____	_____	All	_____	_____
CP4	All	All	All	All	All	All
CP5	All	1/2	_____	> 3/4	_____	_____
CP6	All	3/4	_____	All	_____	_____

6.4 Control participants' accounts of their experiences

The preceeding sections (6.2; 6.3) have presented the data collected during the mealtime observations and these data have provided important contextual information prior to the presentation of the participants' accounts. Four themes, which represented commonalities in the participants' experiences of eating and mealtimes, were identified from the interview and reflexive discussion (RD) data using Colaizzi's (1978) framework for data analysis: Enjoyment of eating and mealtimes in the care home (6.4.1); Barriers to mealtime enjoyment (6.4.2); Choice at mealtimes (6.4.3); Quantity of food (6.4.4). These themes are presented in turn below and quotations which clearly illustrate the themes are provided. For the most part, the observational data corroborated/did not conflict with the participants' accounts and reference is made to both corroborations and contradictions below.

6.4.1 Enjoyment of eating and mealtimes in the care home

Attitude to eating and mealtimes

All of the CP expressed a positive attitude towards eating and/or mealtimes in the care home and extracts from the interviews with two participants illustrate this:

"O aye I enjoy eating. I cannae say I'm (Laughs) going to sit and starve you know" (CP1, Interview, 066, transcript line number).

"Eh well I mean I quite enjoy the mealtimes" (CP5, Interview, 216).

CP2 also shared his opinion that mealtimes were straightforward events. Furthermore, whilst CP3 would usually clear her plate, she would leave food that was not of personal preference or when she had already consumed sufficient. She also indicated that she was not fussy and enjoyed many different foods, a sentiment shared by CP5, although she did list foods she didn’t like as well as those she did. She explained that she would generally eat anything served to her, unless it was not to her taste. She didn’t think she had ever refused a meal and was positive about the variation in the menu. CP5 ate most of her food at both mealtimes. Additionally, although CP4 expressed an enjoyment of eating, she conveyed a more tempered attitude towards mealtimes, reporting that she didn’t mind them and describing them as “not bad” (CP4, RD, 194). She also commented that she did not enjoy meals as much as she used to.

Positive perceptions of the food which is provided

Differing views existed regarding the food that was provided. CP1, CP2, CP3 and CP5 were positive about the food served in their respective care homes. CP1 felt the food was “alright” and felt that was a “good variety” (CP1, Interview, 236). Elsewhere, she commented on her enjoyment of the food, particularly the puddings. She felt that all of the residents also enjoyed their meals. CP2 felt that the food was satisfactory and conveyed a sense of contentment towards it:

“I’m quite happy with the choice, you know” (CP2, Interview, 145).

Lunchtime was his favourite mealtime, as he enjoyed the soup served at lunch. Furthermore, CP3 and CP5 repeatedly complimented the food served at their respective care homes. For example:

“Well actually, to be quite honest with you, I enjoy every meal” (CP5, RD, 016).

CP3 did however comment that she had not finished her main course at lunchtime because some of the food had been overcooked.

Negative perceptions of the food which is provided

CP4 and CP6 expressed more negative views towards the food served in their respective care homes. CP4 appeared unimpressed by the food and on one occasion, described the meals as “eatable but not great” (CP4, RD, 026). Although she couldn’t remember why she hadn’t finished her starter at dinnertime, she acknowledged that it might have been because it was not very appetising. She was overheard criticising both courses during this mealtime and it is possible that her dislike of the food had also been why she had not finished her main course. Moreover, although she did refer positively to the food and felt that in general it was satisfactory, CP6 explained that she did not like all of the food, as she preferred “plain food” (CP6, interview, 316). She expressed concern regarding the impact of budgetary constraints upon the standard of food provided:

“I don’t know if the credit crunch, it must be hitting everywhere, yes I wondered, you know, since I came in, no we didn’t have luxury meals but I can’t help feeling maybe it’s sort of gone down a wee bit” (CP6, Interview, 352).

Furthermore, she alluded to the fact that the food was not the same as the food she had eaten at home, although she seemed to accept this. She felt she had been better fed during the war, at a time of food rationing. However, CP6 was observed to eat most of her food at both mealtimes. Furthermore, she commented on her enjoyment of breakfast, given that the same plain food could be eaten everyday at this mealtime.

Aspects which facilitate/do not hinder participants’ enjoyment of mealtimes

Furthermore, all of the participants referred to specific aspects which either facilitated or did not hinder their enjoyment of mealtimes. CP1, who had a severe visual impairment, explained that she enjoyed breakfast and the fish and chips that were served on Friday evenings and were eaten without cutlery, because she knew what she was eating at these mealtimes. Fish and chips was a meal she had always enjoyed, however. She also found it entertaining to see the other residents eating without cutlery. Furthermore, CP6 referred to an enjoyable eating-related activity, which involved eating biscuits in her room at night, and found this a relaxing time of day.

Four participants (CP1, CP2, CP4, CP5) expressed satisfaction in relation to their respective dining rooms. For example:

“Well it feels alright to me. I don’t see so well…But it feels alright” (CP4, RD, 078; 080).

CP4 was also content with the arrangement that she ate in the dining room. CP2 commented specifically on the round tables in the dining room which he felt were more accessible than long tables. Moreover, although he acknowledged that some of the residents could create noise at mealtimes, he was not really bothered by this. CP5 commended the care home for its cleanliness and felt that she did not spend a lot of time in the dining room. She was positive about the other residents who ate there, although she acknowledged that fellow diners could be argumentative. CP5 also reported that the staff contributed to her enjoyment of mealtimes.

For CP3 and CP4, it appeared that having the opportunity to have contact/interact with other residents was a positive aspect of their mealtime experience. Both participants attended the care home café for lunch at times each week and both indicated that this was an opportunity for them to meet other residents. For example:

“It’s the same when you go up the stairs to…the thingme, you meet all the different people there, you know…Some of them sit and talk to you and others are very quiet, they’re just enjoying their meal, you know” (CP3, RD, 242; 244).

Moreover, CP3 liked going to the dining room for lunch as it gave her an opportunity to see the other residents. CP4 interacted with the same resident prior to and during both meals and commented that she was happy with the amount of conversation she was involved in at mealtimes. Although CP5 had some interaction with a resident at her table prior to and during both meals, she reported that conversation with other residents at mealtimes rarely happened. She was content with minimal conversation, as exchanges tended to revolve around illness.

CP3 was observed eating lunch in the dining room and dinner in her room and confirmed that these were the usual arrangements for her mealtimes. She was content with these arrangements. She was also happy sitting in her wheelchair during meals in the dining room and although she reported that the wheelchair was comfortable, she stated that the armchair in which she sat when eating in her room was more comfortable. CP4 and CP5 did not appear to have any problems with their mealtime seating arrangements, which generally involved sitting at the same table with the same resident(s), and CP4 stated that she liked sitting with the same resident. They were observed to occupy the same table at both mealtimes in their respective care homes and sat with at least one of the same residents. CP5 also reported that she was comfortable sitting in her wheelchair to eat.

6.4.2 Barriers to mealtime enjoyment

All of the CP identified negative aspects of their mealtime experience. Some of these barriers had arisen as a result of physical difficulties, which were mainly attributable to the ageing process, while others were as a result of institutional living.

Physical barriers

Visual impairment was an issue identified by both CP1 and CP4. CP1 repeatedly commented on how her visual impairment had detracted from her enjoyment of eating, as it had left her unable to see the food served to her at mealtimes:

“What I’m trying to say is I enjoyed eating while I had my eyesight but I don’t enjoy it now because I go down…and I cannae see what I’m getting for the eating, you know” (CP1, Interview, 056).

Being unable to see her food had resulted in her experiencing various emotions, including worry and fear. She even considered herself to be in a worse position than someone with cancer. Her inability to see her food meant that sometimes, larger pieces of food than anticipated were ingested. She reported an increased eating duration as a result of her visual impairment, however she did remark that her eating duration was not lengthy. Furthermore, she explained that she found it difficult to see how much food she had consumed and had to ask whomever she was sitting with. However, she acknowledged that being unable to see who was sitting next to her did not make it more difficult to have a conversation, as she knew the residents. Various strategies had been implemented by the care home staff as a means of compensating for her visual impairment and whilst CP1 was grateful for these efforts, she did acknowledge that some strategies were not always helpful. One of the strategies mentioned by CP1, which involved serving food on a blue plate, was not utilised at either mealtime. CP1 did, however, try and eat as much as she could to avoid creating concern for the care home staff. She explained that even if she was eating something she didn’t like, she felt that she was “better taking something” (CP1, RD, 155). She had not experienced any mealtime-related issues prior to the onset of her visual impairment.

CP4 also stated that her visual impairment affected her ability to see her food, with the exception of breakfast items, and she asked what she was being served. She appeared less concerned about this than CP1 and when asked whether being unable to see her food affected her enjoyment of mealtimes, indicated that it did not:

“I mean I always was a good eater…I’m still eating so I don’t really know if it makes much difference (Laughs)…I’ve got to eat (Laughs)…I always had an appetite” (CP4, RD, 120; 122; 124; 126).

However, when asked if there was anything she would like to change about mealtimes to make them more enjoyable, she referred to her visual impairment:

“This not seeing things doesn’t help, you know” (CP4, RD, 196).

CP4 also explained that she no longer looked forward to meals as much as she used to, due to a reduced appetite.

CP3 commented on how her hearing impairment affected her ability to interact with other residents at mealtimes and she hoped that receiving a hearing aid would resolve this issue:

“They’ve been here for years and years and they know what they’re talking about…But I can’t hear, understand what they’re saying, you know…It’s a shame, you know…But…maybe once I get my hearing…it’ll maybe help a wee bit, you know” (CP3, Interview, 483; 485; 487; 489; 491).

Being unable to hear what others were saying at mealtimes was unpleasant for her. CP3 also reported having previously experienced leg pain which had detracted from her enjoyment of eating, although she acknowledged that this issue had been resolved. It was noted that a cushion was placed under her feet for support at lunchtime.

CP5 reported a difficulty with chewing as a result of not wearing dentures at mealtimes (she seemed to still have some of her own teeth). She explained that she did not enjoy meals when wearing her dentures. CP5 reported feeling afraid of choking and when asked to confirm this, explained that there had been times when she had been chewing meat and had to remove it from her mouth. It seems likely that not wearing dentures would have led to difficulties in chewing meat to a consistency considered safe to swallow. However, when asked within the RD how not wearing dentures affected her at mealtimes, CP5 reported that it did not affect her in any way. A swallowing-related issue was also identified by CP2, who reported experiencing the sensation of food sticking in his throat at times, which he attributed to a bone condition.

Institutional barriers

Unlike CP3 and CP4, three CP did not welcome socialising at mealtimes. CP1 recounted an experience where another resident had attempted to engage her in conversation during a meal and shared her disapproval of this:

“But it’s annoying when somebody’s eh, this woman’s telling me something and I’m trying to eat or else…she’s eating. I says I never talk to her while she’s eating, you know” (CP1, RD, 318; 320).

She explained that there were plenty of opportunities to converse in the lounge and felt that her views about socialising during meals were shared by many other residents. Whilst she had a brief conversation with another resident prior to lunch, she did not interact with other residents during either mealtime. Although CP2 acknowledged that mealtimes were an opportunity to chat with other residents, he viewed conversation at mealtimes to be impolite, a view that he had acquired from his upbringing:

“I was brought up in a house where we were taught that eh eating and speaking were…bad manners” (CP2, RD, 159).

He did not interact with other residents at either mealtime. CP2 reported that in general, very little conversation occurred at mealtimes, although arguments were a common occurrence. Additionally, CP2 remarked that mealtimes were lengthy, as less mobile residents required assistance with positioning at tables and this process commenced some time prior to the beginning of the mealtime.

CP6 explained that she did not get particularly involved in socialising at mealtimes. She reported that she did not initiate much conversation with other residents at mealtimes and refrained from becoming involved in any topics which she viewed to be “controversial” (CP6, RD, 412). She remarked that the mood of other residents could vary. She was not observed interacting with any residents at either mealtime. Additionally, it was noted that no conversation occurred at CP3’s table at lunch and she explained that this was because many residents fall asleep. She stated that she would love to chat to the other residents.

For CP6 the dining environment was also an issue of concern, a view contrary to the perceptions of CP1, CP2, CP4 and CP5. On various occasions, she reported witnessing challenging behaviours exhibited by residents with dementia and found observing such behaviour sad at times. For example, she reported witnessing residents eating from the tablecloth and commented on the mess of the dining room floor due to spillages. Furthermore, that morning, she had observed a resident eat from the sugar bowl and drink from the milk jug on the table. It seemed that sometimes such behaviour could be off-putting, but generally this was not the case.

Although CP6 reported that she had become used to these challenging behaviours, her repeated descriptions of these encounters would suggest otherwise. A resident with dementia was heard making noise during dinner and CP6 acknowledged that such disruptions were not uncommon. She explained that the disruptive behaviour of other residents at mealtimes did not bother her “excessively” (CP6, RD, 322) and appeared to have adopted an attitude of acceptance towards this noise:

“it’s there and if I’m not used to it by now, you know, I think it’s reasonable to say I’m eh I’ve left it too late” (Laughs) (CP6, RD, 344).

She did however contrast this noise with that heard in an eating establishment:

“But it’s, you know, a different kind of noise than being in a eh noisy cafeteria, that sort of thing” (CP6, RD, 346).

6.4.3 Choice at mealtimes

Provision of choice at mealtimes

All of the CP reported that some choice of food was available to them. For example:

“A choice eh…at lunchtime and a choice at night” (CP1, Interview, 238).

Furthermore, it was documented that a choice of main course was available in each care home. CP1 explained that whilst there was usually something available that she liked, in instances where she did not like what was available, the care staff would provide alternative options, which seemed to simply be the main course potato choices. CP2 reported that on occasions when he did not like the main course at lunchtime, he would opt for two servings of the soup starter. As well as receiving a choice of food, CP5 reported that she could choose what she would like off the menu, that is, she could opt for one or two courses, or could decline a meal altogether. Furthermore, CP6 explained that in addition to the existing food choice, residents could obtain alternatives to the items on the menu, although these appeared to be readily available foods. She also reported that she had the choice of eating in her room if she wished and indicated that she could choose where to sit at mealtimes. CP1 and CP5 were explicitly positive about being able to exercise their right to choose at mealtimes. For example:

“O aye, it’s eh, it’s really very helpful” (CP5, RD, 226).

It should be noted that CP3 was not offered a choice of main course at lunchtime.

Desire to exercise the right to choose at mealtimes

Although some choice of food was available to all participants, five alluded to their desire to further exercise their right to choose in relation to food provision and/or to exercise their right to choose concerning other aspects of mealtimes. CP1 remarked that she was unable to choose where she sat at mealtimes, explaining that it was necessary for her to occupy any available space. She expressed her annoyance when another resident was sitting in ‘her place’:

“But sometimes I get annoyed if there’s somebody sitting at it. If you say there’s somebody sitting with a chair they don’t like that, they say naebody belongs to the chairs here, you know…Just sit there. Wherever there’s a place eh when…the meal’s nearly ready, you know” (CP1, RD, 294; 296).

She also commented that whilst the nurse in charge wanted residents to sit in regular chairs at mealtimes, she liked to sit in her wheelchair to eat in order that she could choose when to leave the dining room after her meal. She appeared grateful for the fact that whilst she was in a wheelchair, she was able to move it herself, facilitating greater freedom of choice and indeed, she sat in her wheelchair for both mealtimes. Furthermore, she explained that there were foods which she liked but which were not served at the care home. However, she had requested two of these foods and one of these items had started to be served.

CP2 was also keen to obtain his position of choice in the dining room in order that he could exit swiftly at the end of mealtimes and arrived early in order to do so:

“I do that so I get a seat where I want…that time they’d probably put people in my chairs…So you’re better going a bit early…It’s a nuisance being early but it’s better being early…and get where you want to be, you know” (CP2, RD, 123; 125; 127; 129).

He did however acknowledge that arriving early took up quite a bit of his time each day. He usually sat at the same table for each mealtime. CP2 arrived early for both mealtimes and occupied the same table on both occasions. He explained that the nature of care home living meant that he could not make the kind of food he felt like and therefore had to eat what was available, even if he didn’t like some of it. CP6 echoed this sentiment on several occasions, referring to the reduced freedom of choice within the care home setting:

“obviously you don’t get exactly everything that you want and cooked and that cus it’s em, maybe the word, institutional food…is the description that’s, you’ve obviously got to cater like that…I think so” (CP6, RD, 094; 096; 098).

Ultimately, it was not possible for her to have whatever she wanted to eat, whenever she wanted.

CP4 and CP5 referred to situations where they actively exercised their right to choose at mealtimes. CP4, who waited for 15 minutes before receiving dinner, commented on her dislike of waiting in the dining room prior to meal provision and explained that she resultantly tried to time her entry to the dining room to coincide with the arrival of the meals. CP5 frequently commented on her willingness to refuse food if it was not to her taste or she didn’t want it:

“Eh well if it was something I didnae like…food or that then I would refuse it, I wouldnae take it” (CP5, Interview, 256; 258).

She also stated that she would not be afraid to tell care staff not to give her something that she didn’t like again. Furthermore, she indicated that attending meals in her motorised wheelchair provided her with a degree of independence as it enabled her to choose when to come and go.

6.4.4 Quantity of food

All of the CP commented that they received sufficient amounts of food and three reported receiving too much food.

Provision of too much food

CP1 repeatedly commented on the provision of too much food, explaining that she was a “small eater” (CP1, Interview, 052):

“what I think is I’m getting too much too eat…You know the way we get with lunch and eh there’s always potatoes and things like that and meat eh for your lunch and then maybe we’re down at half past four and there seems to be meat and something else some maybe eh mashed potatoes, it’s…we seem to be getting potatoes twice a day you know…At the lunch and the night time. And I’m a small eater, you know” (CP1, Interview, 048; 050; 052).

She remarked that she was not hungry for her evening meal as she had already consumed a sufficient amount of food and had avoided this mealtime on occasion. She refused the soup starter at lunchtime and reported that whilst sometimes the starter was omitted because she was late in arriving for the meal, she often refused the soup in order that she could eat her main course. She also did not attend suppertime. CP1 did not finish her main course at one observed mealtime because she had had sufficient, and it is likely that this was her reason for leaving some main course at the other mealtime. It seemed that the care staff were keen to ensure that residents did not go hungry and encouraged CP1 to eat. CP1 felt that some of the other residents were “good eaters” (CP1, Interview, 242), although she was of the opinion that other residents also felt that they received a lot of food.

CP2 and CP3 also reported receiving too much food and both acknowledged the existence of a reduced appetite. Although CP2 described his appetite as “normal” (CP2, Interview, 137), he indicated elsewhere that his appetite had become smaller due to reduced energy expenditure, and explained that whilst he would normally finish his food, he was not always able to do so:

“Sometimes you leave portions, you know…You don’t eat so much…When you’re not hungry…You’re stuck in here all the time. You’re not working…You’re hungry when you go home…You’ve been out and pulling your energy…You don’t use as much energy here” (CP2, RD, 197; 199; 201; 203; 205; 207; 209).

It was observed that CP2 left some food at both mealtimes.

CP3 commented on the abundance of food provided at the care home:

“Well as long as I’m in this place, I’ll never lose any fat…I’ll never get slim again” (CP3, Interview, 076; 078).

Furthermore, she reported that she never felt hungry. She did not snack much between mealtimes, although she sometimes ate crisps provided by a family member. She attended a café upstairs in the care home for lunch twice a week and on these days she would sometimes just have soup for dinner, as this was sufficient. CP3 recounted that at one point she had been a “big big eater” (CP3, Interview, 090) but acknowledged that this was no longer the case. She did not have a starter at dinnertime, commenting that she was still full from her toastie at lunch.

Provision of a sufficient quantity of food

CP4 and CP5 both commented on receiving sufficient amounts of food, and like CP2 and CP3, felt that their appetites had become smaller. CP4 essentially attributed her reduced appetite to old age, while CP5 felt that her appetite had reduced following a surgical accident which had resulted in damage to her left leg. CP6 also indicated on several occasions that she received sufficient amounts of food:

“I’ve never gone hungry or without” (CP6, RD, 396).

She reported that she only experienced feelings of hunger “Very occasionally” (CP6, Interview, 072) and did not do a lot of snacking. CP6 described her appetite as “alright” (CP6, Interview, 332).

6.5 Summary

This chapter has presented the findings of the data obtained from the CP and these data provide insight into the eating and mealtime experiences of six elderly care home residents without dysphagia of any type. Whilst positive aspects of eating and mealtimes were apparent, there were also less positive aspects, namely negative perceptions of the care home food; physical and institutional barriers to mealtime enjoyment and a desire for greater freedom of choice at mealtimes. Provision of excessive quantities of food was also an issue for some participants. These findings are discussed in relation to existing literature in this area in Chapter 8 (8.3). The following chapter presents the findings of the data obtained from the PWD.

CHAPTER 7

PWD FINDINGS

7.1 Introduction

The aim of data collection with the PWD was to gain insight into the HRQOL issues for care home residents with oropharyngeal dysphagia caused by an acquired neurological disorder. This chapter presents the findings of the data collected from the PWD. Initially, the mealtime experiences of each participant have been summarised using the data from the observational schedules (7.2). Following this, group summaries of some of the observational data are displayed and key findings discussed (7.3). Subsequently, the data obtained from the participants' accounts of their experiences are presented and are considered in relation to the observational data (7.4). It is recognised that the order in which the results are reported in this chapter deviates from the order in which the data were collected. The findings of the data obtained from the CP were also presented in this order and the rationale for doing so is detailed in section 6.1.

7.2 Summary of the mealtime experiences of each participant

The data obtained from the mealtime observations have been summarised to provide an overview of the experiences of each participant at the observed mealtimes. These summaries serve to provide a context for the exploration of the participants' perceived experiences. They describe the researcher's observations from the point at which data collection commenced prior to food being served, to the point at which the participant stopped eating and/or drinking. The data most conducive to tabulation are summarised in Table 7.1. Seven of the observations continued beyond this point, although for the sake of consistency, these data have not been incorporated within the accounts.

Unless stated otherwise, participants received a starter and main course at lunchtime, and a main course and dessert at dinnertime. The served portions appeared roughly equivalent between participants. None of the participants displayed challenging behaviours or a negative attitude towards eating/drinking. Whilst failure to finish food/drink could be seen as a sign of disinterest or rejection, this seemed too great an assumption to make, as the participant could simply have been satiated.

P1 ate both meals in the dining room and a care assistant (CA) positioned him at the table in his wheelchair. He was seated with three other residents at lunchtime and at dinnertime, was seated at the same table with two of the same residents. He did not interact with any of the residents at his table. A resident at P1's table repeatedly uttered monosyllabic vocalisations during both meals and prior to the lunchtime meal, although these noises were not particularly loud. P1 received a starter and main course at both mealtimes. Three courses were served at dinnertime as it was a Burn's Night supper. However, P1 did not receive a dessert, as he was removed from the table shortly after his main course because he was choking. Although a choice of main course was available at both mealtimes, P1 did not receive a choice of food on either occasion. He had brief interactions with staff during both meals, although these exchanges were initiated by staff and tended to relate to the mealtime. A member of staff entered briefly to administer medication during lunch. P1 experienced coughing/choking during both meals and such episodes seemed to prevent completion of some courses.

P2 ate both meals in the dining room and a CA positioned him at the table in his wheelchair. He was seated alone at lunchtime and with one other resident at dinnertime and did not engage in any social interaction with this resident. P2 was hunched over at both mealtimes, although this appeared to be his 'normal' position, rather than being a specific positioning problem. At dinnertime however, he was observed to be leaning to the right. P2 did not receive a choice of food at either mealtime. At lunchtime, he drank his soup from the bowl instead of using a spoon. During both meals, he had some brief exchanges with staff concerning the mealtime. Members of staff engaged heavily in conversation unrelated to the mealtime during lunch, and during dinner, a CA spilled P2's milk when serving his dessert. A member of staff provided him with positioning assistance by pushing his wheelchair closer to the table just after he had started his dessert, as he had pushed himself away from the table when he had eaten what he wanted of his main course. The researcher noted that P2 was 'gurgly' during both meals and he lost food from his spoon and mouth, which he tried to retrieve with his hand. Drooling was noted during lunch and some coughing/choking during dinner. P2 was taken from the table at dinnertime without being asked if he wanted to finish his milk, despite having previously indicated that he wanted to drink more.

P3 ate both meals in his room. His wife joined him for dinner and, in addition to reading the paper, conversed with her husband prior to meal provision. On both occasions, P3 sat in an armchair on a support cushion with a table in front of him. He had another cushion behind his back at lunchtime and had a neck cushion at dinnertime, although he later asked for this to be removed. He was observed to be leaning to the left at lunchtime. P3 received a main course and dessert at lunchtime and a starter and main course at dinnertime. He was not observed being offered a choice of food at either mealtime. During both meals, he had brief exchanges with the CA providing feeding assistance, all of which related to meal consumption. At lunchtime, he had a brief exchange with a member of staff returning laundry who entered when the CA had gone to fetch dessert. P3 had some exchanges with his wife during dinner and when the CA left to fetch the main course, she provided him with a drink. P3's wife and the CA also conversed during this meal. Coughing occurred during both meals, although it was noted to be minor at dinnertime and throat clearing was evident during dinner. During the reflexive discussion (RD), P3 confirmed that the usual arrangements for his mealtimes were the same as those observed (lunch eaten in the company of a member of staff who provided assistance and wife present at dinnertime).

P4 ate lunch in the dining room and at dinnertime, indicated that he wished to eat in his room. Within the RD, he explained that he typically consumed meals in the dining room. At lunchtime, he sat on a dining chair at a table with two other residents, one of whom was talking and singing. P4 laughed at this resident and appeared entertained and they had a few brief interactions prior to the meal and one brief exchange during the meal. He explained in the RD that he sat at the same table with the same residents when in the dining room. At lunchtime, a nurse provided P4 with positioning assistance by pulling out a chair for him to sit on and pushing him into the table. At dinnertime, P4’s partner was present prior to the meal, although she left before the meal was served. They conversed with one another (P4 largely communicated using the written word) and, in addition to tidying his room, she positioned a table in front of him in preparation for meal provision. He was seated in an armchair for this mealtime. P4 did not receive a choice of food at either mealtime. He had brief exchanges with staff concerning the mealtime during both meals and at dinnertime, watched television throughout the meal. Staff conversation, unrelated to the mealtime, occurred during lunch. By the time he had waited for 28 minutes following completion of the main course at dinnertime, the researcher felt it was necessary to ask the staff whether P4 was to receive a dessert. P4 lost food from his mouth during both mealtimes and minor coughing/throat clearing was noted during dinnertime.

P5 opted to eat both meals separately from other residents, indicating that he wanted privacy, although he indicated within the RD that he usually ate in the dining room. He was observed in a study/reading room at lunchtime and in a sitting room at dinnertime. He was seated in an armchair at a table at both mealtimes. At lunchtime, he adjusted his armchair before starting his soup in order to be closer to the table and was assisted in doing this by the researcher. He did not receive a choice of food at either mealtime. During lunch, a nurse provided him with his medication, which he took following the completion of his main course. He interacted briefly with staff during lunch and these interactions related to the mealtime/medication administration. During dinner, he had a discussion with a member of staff regarding the suitability of his food texture. Coughing and throat clearing occurred during both meals.

P6 ate both meals in the dining room and sat alone on both occasions. A CA positioned her wheelchair at the table and she interacted very briefly with staff prior to both meals. One resident was provided with medication prior to lunch being served. P6 did not receive a choice of food at either mealtime. She had brief interactions with staff during both meals and these exchanges generally related to the mealtime. At lunchtime, she was offered feeding assistance when she was nearing completion of her main course, which she accepted. Following the completion of this course, a nurse decanted fluids into her Percutaneous Endoscopic Gastrostomy (PEG) tube and conversed with her while doing this, although P6 did not contribute much. During both meals, medication was administered to residents, including P6 at dinnertime and staff conversations unrelated to the mealtime occurred during dinner. At lunchtime, one resident entered the dining room late and at dinnertime, two residents entered late and one exited early. While P6 was drinking her tea at lunchtime, staff commenced the process of assisting residents out of the dining room. During both meals, instances of coughing were noted and P6 lost some food from her spoon when feeding, which spilt on her.

P7 ate lunch in the dining room and dinner alone in his room. He reported within the RD that he usually consumed meals in his room. At lunchtime, a CA positioned his wheelchair at the table and he was seated with two other residents, although he did not interact with these individuals. During the RD, he indicated that he did not always sit with the same residents when in the dining room. P7 was seated in an armchair at dinnertime and prior to meal provision a CA placed a pillow behind his back and positioned a table in front of him. He did not receive a choice of food at either mealtime, although other residents in the dining room at lunchtime were offered a choice. He had brief exchanges with staff prior to the lunchtime meal and during both meals and these generally related to the mealtime. The CA serving his main course at dinner adjusted the pillow behind his back and cut up his baked potato. At lunchtime, one of the residents at his table left while he was still eating his main course and upon finishing his cup of tea, P7 tried to remove his apron without success. During both meals, he spilt food on himself when eating.

Table 7.1: Summary of various aspects related to the mealtime experiences of the PWD

	Approx waiting time prior to meal provision (minutes)		**Clothing protection provided**		**Provision of liquid prior to meal (Some drinks not provided until food had been served/further drinks provided during some meals)**		**Vision**	**Mobility**	**Dentition (dentures; own teeth; combination)**	**Feeding status**
	Lunch	*Dinner*	*Lunch*	*Dinner*	*Lunch*	*Dinner*	[redacted]	[redacted]	[redacted]	[redacted]
P1	29	10	Yes	Yes	Thickened milk	Thickened milk (brief choking episode)	Severe visual impairment- wore glasses	Wheelchair	Combination	Total feeding assistance. Drank independently
P2	14	0.23	Yes	No	Milk	No	No glasses	Wheelchair	Own teeth	Right-sided weakness- fed independently with left hand
P3	N/A	N/A	No	Yes	No	No	Visual impairment- wore glasses	Only seen seated in armchair	Own teeth	Total feeding assistance

P4	34 (chose to arrive early, despite advice from nurse)	N/A	Yes	Used kitchen roll	Milk and juice	No	Wore glasses	Walked with a stick	Dentures	Left-sided weakness- fed independently with right hand
P5	N/A	N/A	Yes	No	No	No	Compromised vision due to drooping eyelids- wore glasses	Walked with a stick	Own teeth	Fed independently
P6	5-10	14	Yes (also used a napkin)	Yes	No	Thickened water	Visual impairment- glasses not worn	Wheelchair	Own teeth	Left hemiplegia- fed independently with right hand
P7	21	N/A	Yes	Yes	Thickened orange	No	Some visual impairment- not observed wearing glasses	Wheelchair	Combination	Left-sided hemiparesis- fed independently with right hand

7.3 Group summaries of the observational data

Having summarised the data collected from individual participants during the mealtime observations (7.2), this section presents group summaries of some of the data collected within the interval coding component of the observations and key findings are discussed. Bar/pie charts have been used to display the categories most conducive to graphical display. Categories not discussed below have been accounted for above. The data presented below are those collected from the point the participant received their meal to the point at which they stopped eating and/or drinking. Data relating to mealtime and eating duration and quantities of food and liquid consumed are also presented.

7.3.1 Mealtime assistance

Four participants received some form of assistance during either one or both mealtimes. Only two participants (P1, P3) required assistance for the duration of both courses at both meals and for both participants, this took the form of total feeding. There was one instance of total feeding assistance noted during P6's main course at lunchtime. A CA mashed the food on her plate and gave P6 one spoonful. She then accumulated the remaining food together and P6 took this final spoonful independently. The assistance received by P7 concerned the preparation of his food before eating and prior to starting his main course at dinnertime, the CA serving his meal cut up his baked potato. P3 was the only participant who required assistance to drink and a nurse decanted fluids into P6's PEG tube at lunchtime.

7.3.2 Social status and interaction at the mealtimes

It is evident from Figure 7.1 that eating at a table with another resident/other residents and eating in a room alone were equally the most common social states in which participants were observed. Eating at a table alone was the next most common social state. P3 was the only participant observed eating a meal with a family member present. The social status of all of the participants remained constant throughout the mealtime, at least until the participant had stopped eating and/or drinking, although one of the residents at P7's table left while P7 was eating his main course. Three participants maintained the same social status for both mealtimes, while the social status of the other four participants differed between mealtimes. Whilst not reflected in the chart below, a member of staff was also present with the participants when they were receiving mealtime assistance.

Figure 7.1: % of mealtimes spent by participants alone or with others (PWD)

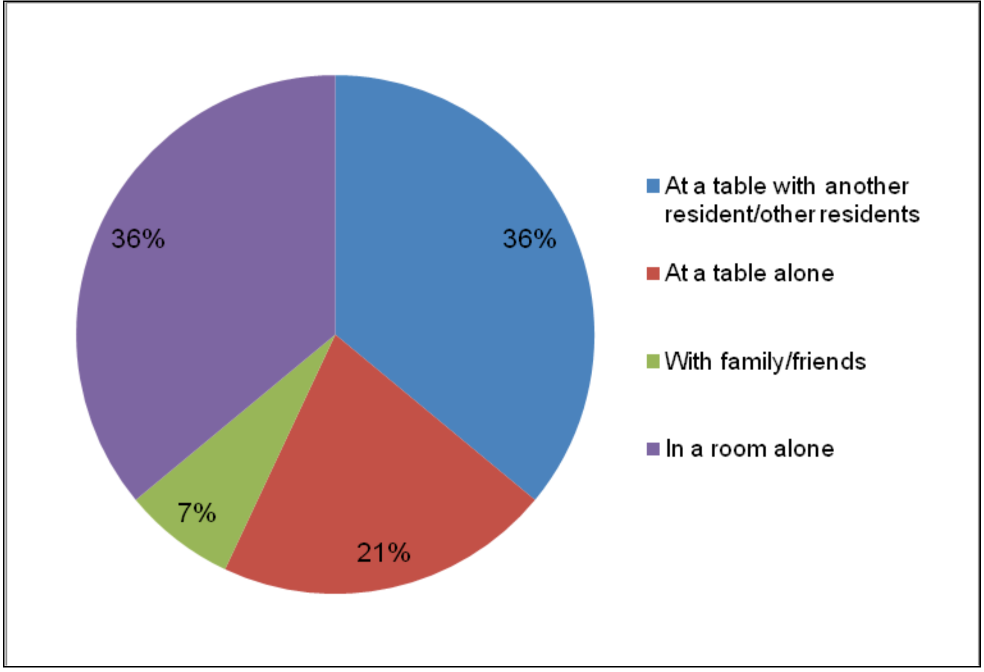
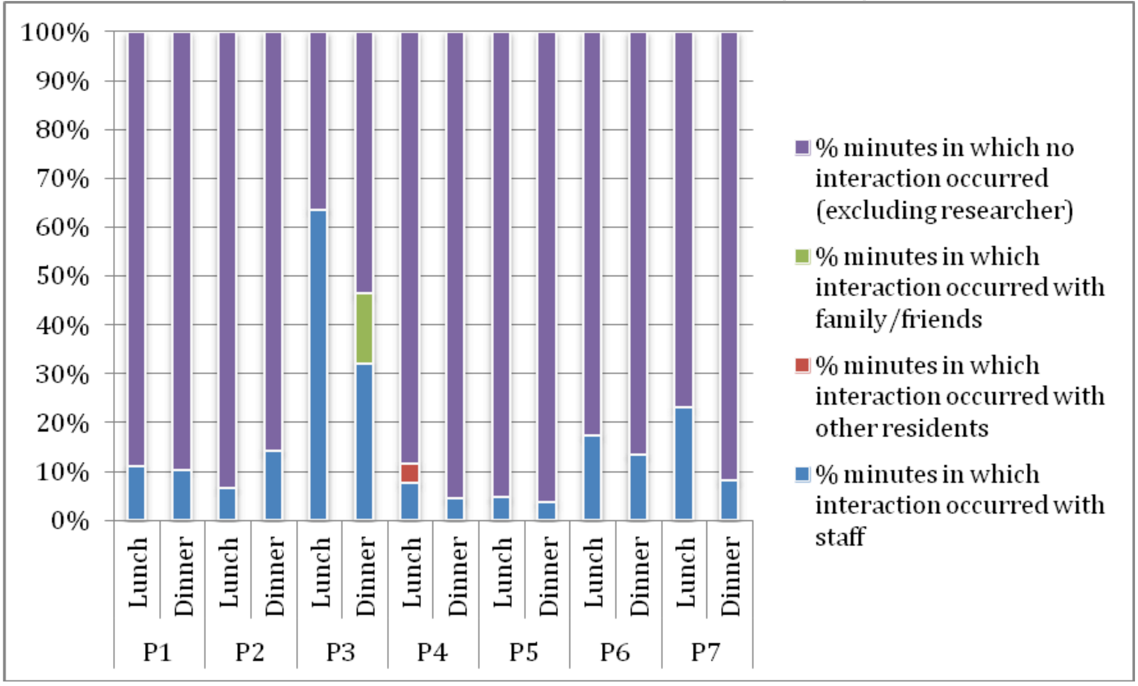


Figure 7.2 indicates that for nearly all of the mealtimes, minimal interaction occurred. Staff were the most common people with whom the participants interacted and the majority of these interactions were brief and mealtime-related. Many consisted of the participants responding to a question asked by a member of staff, or acknowledging receipt of food/drink or a comment

made by a staff member. Interactions with staff were most prevalent during P3's mealtimes. This was largely due to the CAs providing feeding assistance making comments concerning meal consumption and P3 acknowledging these comments. Interactions with other residents were almost non-existent. P4 was the only participant to interact with another resident, although the other resident initiated this exchange. Whilst other comments may have been made to participants, these would not have been recorded because the participant did not acknowledge/respond to them, and they were not therefore viewed as interactions.

Figure 7.2: % of minutes in which interaction did and did not occur and with whom the interaction occurred (PWD)



7.3.3 Disruptions of the meal by staff and other residents

Staff generally did not disrupt the meals. However, drug administration occurred during four mealtimes and staff conversation unrelated to the mealtime during three. There was also an incident involving the spillage of

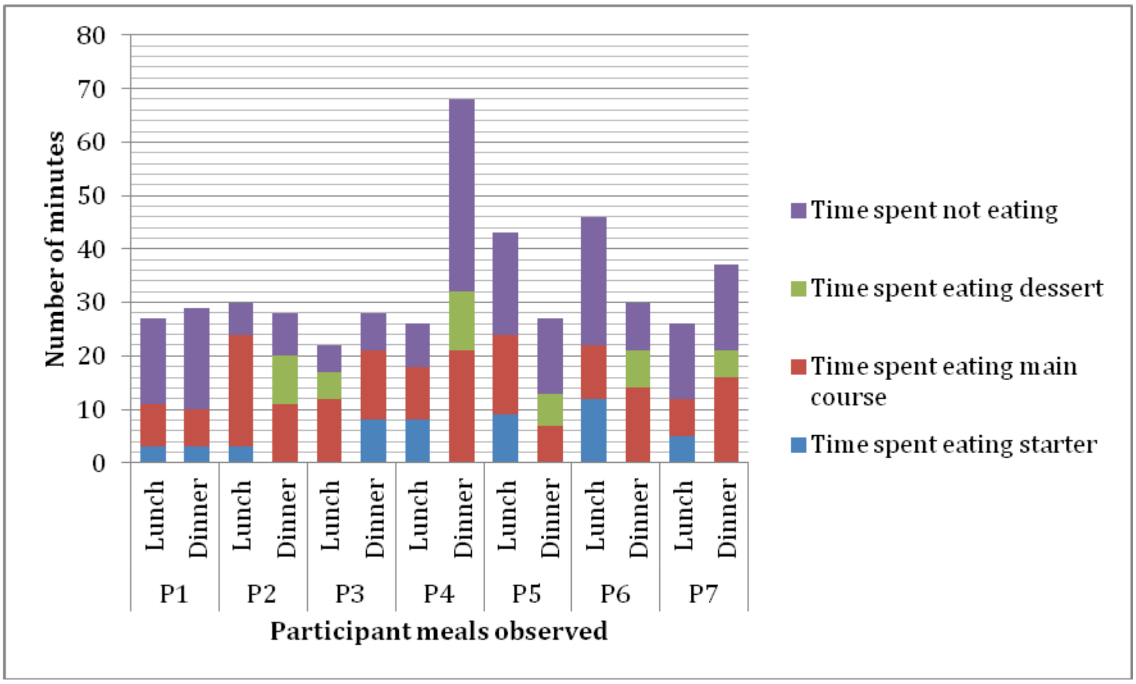
P2’s drink by a member of staff at dinnertime, which required cleaning up. Staff conversation unrelated to the mealtime was most prevalent during P2’s lunchtime, while drug administration was most prevalent during P6’s dinnertime.

The only disruption caused by other residents was that of noise. This was only apparent at both of P1’s mealtimes and related to a resident at his table uttering monosyllabic vocalisations, although these noises were not particularly loud. It is possible that so few resident disruptions were recorded because six of the fourteen observations took place in separate rooms from other residents.

7.3.4 Mealtime and eating duration and amount of food/liquid consumed

Mealtime duration and eating duration is displayed in Figure 7.3. The time spent not eating refers to the time between courses during which drinking may have occurred, and/or the time between food being served and the participant starting to eat, and/or the time after courses during which drinking occurred. The majority of meals lasted for 30 minutes or less, with only four being longer. P4’s dinnertime was the longest of the mealtimes, due to the fact that this mealtime had the longest period of time spent not eating (36 minute wait between main course and dessert) and also because P4 had the greatest combined course duration at this mealtime. Interestingly, the participants who received total feeding assistance (P1, P3) had the greatest level of consistency between their two main course durations, compared with the other participants. Furthermore, P1, who received a starter at both mealtimes, had identical durations for consumption of his starter. There was considerable variation in the time spent not eating and this was generally more marked between participants. This finding predominantly suggests variation in the time between courses and also in the time participants spent sitting at the end of a meal, during which drinking occurred.

Figure 7.3: The duration of the observed mealtimes (PWD) (in minutes)



It is apparent from Table 7.2 that most of the participants consumed all or most of their food. Consumption of only ½ of a course was noted at four mealtimes, two of which were P7's mealtimes. P3 and P6 consumed all of both courses at both mealtimes. There was no obvious relationship between eating duration and amount of food consumed. It can be seen from Table 7.3 that the fluid intake of participants varied. Four participants consumed only ½ or less than a ¼ of a drink served to them at one or both mealtimes. Conversely, P6 consumed all of two drinks at both mealtimes, while P7 consumed all of two drinks and more than ¾ of a third at lunchtime.

Table 7.2: The approximate quantity of food consumed at each mealtime (PWD)

Participant	OBSERVED LUNCHTIME			OBSERVED DINNERTIME		
	Starter	Main course	Dessert	Starter	Main course	Dessert
P1	> 3/4	> 3/4	_____	All	> 3/4	_____
P2	All	All	_____	_____	1/2	All
P3	_____	All	All	All	All	_____
P4	All	> 3/4	_____	_____	All	> 3/4
P5	All	> 3/4	_____	_____	1/2	> 3/4
P6	All	All	_____	_____	All	All
P7	All	1/2	_____	_____	> 3/4	1/2

Table 7.3: The approximate quantity of liquid consumed at each mealtime (PWD)

Participant	OBSERVED LUNCHTIME			OBSERVED DINNERTIME		
	Drink 1	Drink 2	Drink 3	Drink 1	Drink 2	Drink 3
P1	< 1/4	_____	_____	< 1/4	_____	_____
P2	1/2	_____	_____	1/2	_____	_____
P3	< 1/4	_____	_____	1/2	_____	_____
P4	1/2	> 3/4	_____	1/2	_____	_____
P5	> 3/4	_____	_____	All	_____	_____
P6	All	All	_____	All	All	_____
P7	All	All	> 3/4	> 3/4	1/2	_____

7.4 Participants' accounts of their experiences

The observational data presented in the preceeding sections (7.2; 7.3) have provided important context prior to the presentation of the participants' experiences. Identified from the interview and RD data using Colaizzi's (1978) framework for data analysis were nine themes, which represented commonalities in the participants' experiences. Five relate to the HRQOL impact of acquired neurological oropharyngeal dysphagia (7.4.2.1 - 7.2.4.5), while four are concerned with additional mealtime-related issues (7.4.3.1 - 7.4.3.4). Figures 7.4.1 and 7.4.2 illustrate the emergent themes which have been placed under these respective umbrella headings, as well as the theme clusters, or sub-themes, belonging to each theme. These emergent themes are presented in turn below and quotations considered to clearly illustrate each theme are provided. P4's responses (with one exception) were written. Only one utterance was extracted from the data obtained from P2. The observational data largely corroborated/did not conflict with the participants' accounts of their experiences and reference is made below to both corroborations and contradictions.

Figure 7.4.1: Thematic model for the emergent themes relating to the HRQOL impact of acquired neurological oropharyngeal dysphagia

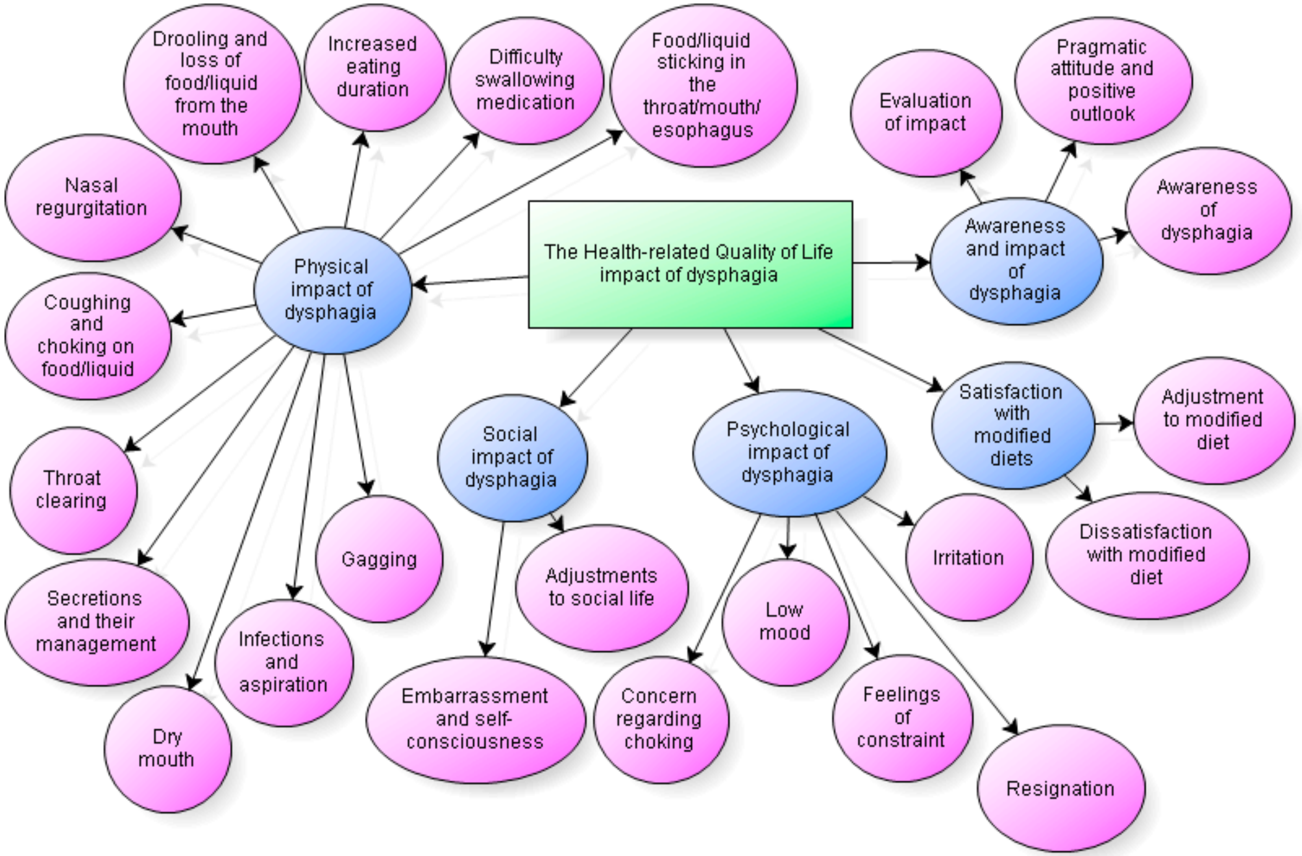
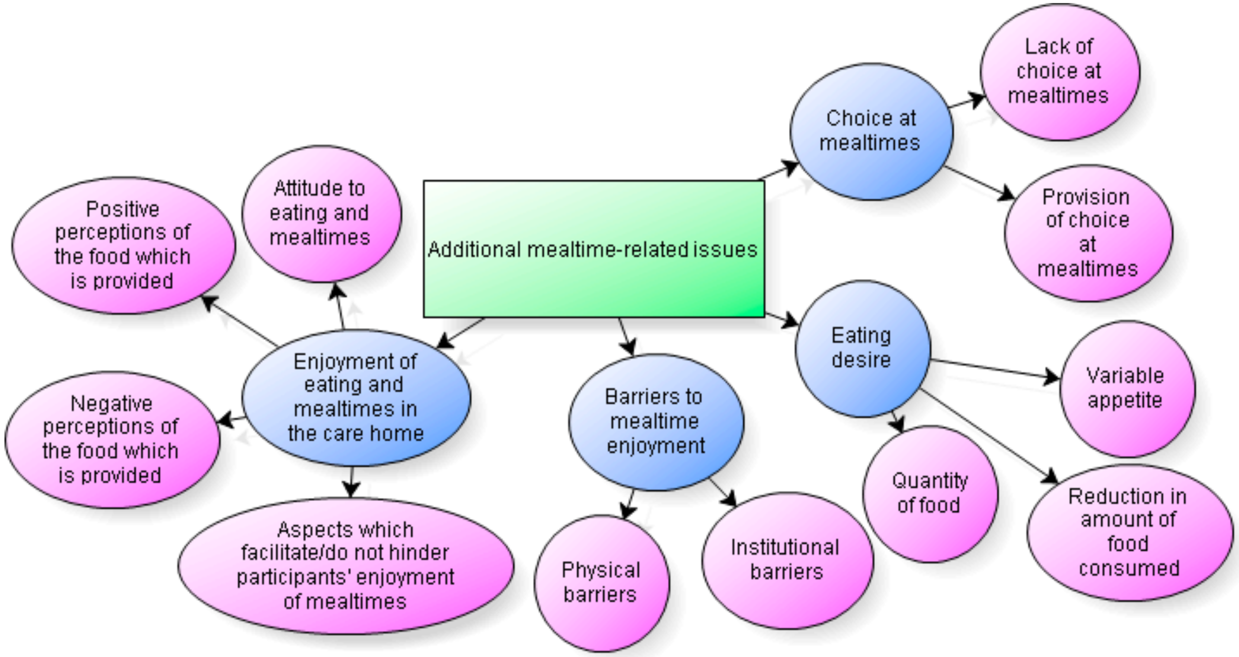


Figure 7.4.2: Thematic model for the emergent themes relating to additional mealtime-related issues



7.4.1 Modified-SWAL-QOL data

The data collected via administration of the modified-SWAL-QOL were used to inform the content and direction of the semi-structured component of the interviews. Bar charts displaying data from four modified-SWAL-QOL domains are located within the presentation of the themes below to provide support to the participants' accounts. Five different Likert Scales, each with four response options, were used within the SWAL-QOL which had been modified to contain 37 items. The response options which indicated that the modified-SWAL-QOL item was a concern for the participant were: Very much true/Quite a bit true; Almost always/Often; Always true/Often true; Strongly agree/Agree; All of the time/Most of the time. The response options which indicated that the modified-SWAL-QOL item was less of a concern/not a concern for the participant were: A little true/Not at all true; Hardly ever/Never; Hardly ever true/Never true; Disagree/Strongly disagree; A little of the time/None of the time. Three participants (P2, P3, P5) responded to over half of the modified-SWAL-QOL statements/items (35, 27 and 27 responses respectively) in a way which indicated that these aspects were a concern. Four participants (P1, P4, P6, P7) responded to over half of the modified-SWAL-QOL statements/items (27, 29, 31 and 20 responses respectively) in a way which indicated that these aspects were less of a concern/not a concern.

7.4.2 The HRQOL impact of acquired neurological oropharyngeal dysphagia

7.4.2.1 Physical impact of oropharyngeal dysphagia

All participants (with the exception of P2) commented on the physical impact of acquired neurological oropharyngeal dysphagia, with various dysphagia-related physical problems reported.

Difficulty swallowing medication

Three participants remarked on the difficulty they experienced when swallowing medication. P4's interview was temporarily halted for medication administration and P4, who largely used the written word to communicate, verbally indicated to the CA that a tablet was stuck in his throat. The CA remarked that it was just a small tablet and advised him to take a drink to wash it down. When alone with the researcher, P4 verbally indicated that tablets stuck in his throat. During the interview, he referred to the difficulty he experienced with swallowing the small tablets which he took:

"The small pill is inclined to stick in m I* (sp error: participant most likely means 'my') throat whilst trying to wash it down with a drink of liquid…results in the liquid by passing the pill- ie. the drink goes down but the pill is still there" (P4, Interview, 396; 398, transcript line numbers).

This problem appeared to resolve by itself when the tablets dissolved. He felt that a bigger tablet would most likely be washed down with liquid, further enforcing his point that drinking did not dislodge the small tablets.

P5's RD was also halted for medication administration and before the recordings were switched off to allow P5 privacy to take his medication, he commented, "You see the problem with getting these down", alluding to the difficulty he believed he would experience when swallowing medication. P5 referred to his difficulty swallowing medication elsewhere:

"Taking tablet, paracetemol tablets regular and other tablets if they're no out of their capsules, I've difficulty getting them doon" (Gestures)…(P5, Interview, 152).

Furthermore, he acknowledged the possibility of resorting to medication in liquid form. He also explained that because of dysphagia, he waited to take his medication after meals and whilst he had got used to this, if no swallowing difficulties were experienced, he would choose to take his medication during meals. P5 did not take the medication delivered during lunch until he had finished eating.

Whilst not reported in the interview or RD, P3 also seemed to have difficulty swallowing medication. His RD was interrupted for medication administration and during this period, he explained that it had taken him three attempts to swallow a tablet. Furthermore, when swallowing his final tablet, he indicated to the researcher that it had got stuck and was provided with a drink to wash it down.

Coughing and choking on food/liquid

Five participants reported coughing/choking on food and/or liquid. P1 acknowledged that he had been choking on his food during both mealtimes, dinnertime in particular. He blamed his ‘cold’, actually a chest infection (which may have been dysphagia-related), for the occurrence of choking. His chest infection may have further compromised his swallowing ability, leading to choking. P3 explained that choking would occur if he ate quickly and indicated that he generally knew when he was going to choke. P3 was heard coughing during both mealtimes and explained that he didn’t panic when coughing occurred. For P4, the difficulties he experienced in swallowing medication increased the likelihood that coughing would occur. He also needed to cough in order to clear food which had become stuck in his throat. Minor coughing was noted during P4’s dinnertime.

P5 frequently referred to experiencing coughing and choking at mealtimes and stated that he knew when he was going to choke. Coughing was noted during both of his mealtimes. He commented on how coughing was necessary to release food/liquid which had become stuck and explained that choking would occur if he took too much food at once/ate too quickly. Elsewhere he alluded to the fact that choking episodes were serious when they occurred:

“I’m actually upset about it because I know for a fact that if I can always tell…if I swallow that I'm gonnae choke…and I choke" (P5, Interview, 1102; 1104).

The care home did not always provide P5 with suitable food and he had previously choked on unsuitable food. In addition to being satiated at lunchtime, P5 had not finished his main course because he felt he would choke if he ate anymore, possibly due to pharyngeal residue which could become problematic if he continued. It appeared however that he "seldom" (P5, RD, 452) experienced a coughing episode that was so severe that he had to leave his meal. Furthermore, he reported no longer coughing as much as he used to as he exercised a lot of care when eating.

P6 explained that she was prone to eat too much food at once, something which the care staff had pointed out to her and she usually experienced choking when too much food was consumed at once. She also appeared to indicate that care staff were more concerned about her choking episodes than she was, suggesting that this had become normal for her:

"Aye, they think I'm choking…The carers think I'm choking…(Nods head)…But I'm no (Shakes head)…It's just normal" (P6, Interview, 154; 156; 158; 160; 162).

P6 also reported that coughing occurred after meals, although she was unsure why. Conversely, within the RD, she stated that she didn't cough much at mealtimes. P6 was heard coughing during both mealtimes.

Drooling and loss of food/liquid from the mouth

Drooling was reported by two participants. P3 explained that whilst various medical interventions had been trialled, none had been successful in managing his drooling, rendering it "a major issue" (P3, Interview, 070). P4 reported that saliva escaped from the left-hand side of his mouth and he seemed to feel that his left-sided hemiparesis was, amongst other things, responsible for detrimentally affecting his oral control. This also impacted upon the management of food and liquid in the oral phase. P4 lost food from the side of his mouth during both mealtimes and reported that he managed the loss with a tissue. P5 "occasionally" (P5, Interview, 248) experienced food/liquid dribbling out of his mouth.

Secretions and their management

Four participants reported the existence of problematic secretions and three of these referred to their management of/their problems managing these secretions. P4 explained that he was unable to cough up any phlegm, blaming a weak cough reflex. P1 blamed his 'cold' for the existence of thick saliva/phlegm. P6 explained that she removed thick saliva/phlegm from her mouth using a serviette. P5 reported experiencing excess saliva/phlegm, in addition to thick saliva/phlegm. He explained that his secretions stuck in his throat and could cause him to choke:

"I get a lot of catarrh (Gestures at throat/chest)…And eh rubbish coming up my throat like (Gestures at throat/chest)…you know…off my chest or…off my lungs or what, I don't know. And…that combined…with the swallowing, I can choke easy wi that (Gestures at throat/chest)…you know (Gestures at throat/chest)…a bit of rubbish stuck in, stuck down there noo at the moment" (Gestures at throat) (P5, RD, 730; 732; 734; 736; 738).

P5 seemed to be almost constantly troubled by his secretions. A build-up of secretions in his throat usually occurred after meals. During the interview and RD, P5 was observed to manage his secretions by means of effortful swallows and in one instance, also gave a minor cough. P5 explained that if he were to experience any dysphagia-related trouble between mealtimes, it would be due to the presence of catarrh, although he then remarked that he no longer had any trouble between mealtimes.

Throat clearing

P5 also reported having to clear his throat on a regular basis and referred to throat clearing on several occasions. This was also noted during both mealtimes. It seemed that the predominant reason for throat clearing was to manage his secretions. P1 also reported frequent throat clearing, which may have been due to his thick saliva/phlegm.

Food/liquid sticking in the throat/mouth/oesophagus

Five participants reported experiencing food and/or liquid sticking in their throat. P1 remarked that food got stuck in his throat “A bit” (P1, Interview, Part 1, 388), while P4 explained that small pieces of food could stick in his throat and cause a tickling sensation, although he did not appear bothered by this. P3 explained the strategy he adopted when he felt food sticking:

“Fortunately, I’ve never got to total blockage on any occasion, but…when I feel it…sticking, I say right, sit back, take it easily (Gestures and points to throat)…drink plenty of fluid…and eh the thing will pass…And eh, it does” (P3, RD, 578; 580; 582; 584).

P5 reported that food frequently stuck in his throat, particularly when he had been eating too quickly and like P3, he drank water to dislodge the stuck food. He exercised caution when eating and reported that he would not carry on eating something that he felt would stick in his throat. The froth on a pint of Guinness could also stick in his throat. P5 had not finished his main course at lunchtime because, in addition to being satiated, he was aware of food and liquid sticking in his throat (possibly pharyngeal residue) and was therefore reluctant to eat anymore. Pharyngeal residue also seemed to be an issue for P5 during the RD, which followed the observed dinnertime. P7 reported a previous negative experience where food became stuck in his throat, although this had not occurred recently:

“had a bad experience once. A bad experience once…A bad experience once…Couldn't clear my throat, I couldn't get it out of my throat (Gestures)…I couldn't clear my throat" (P7, Interview, 500; 502; 506; 508).

Additionally, food/liquid appeared to stick in P6's mouth, as she explained that care staff removed anything which had become stuck in her mouth. Moreover, in addition to oropharyngeal swallowing difficulties, P3 indicated the existence of difficulties pertaining to the oesophageal phase:

"When you're seized up in your mid oesophagus…it's terribly difficult to get it going (Points to chest)…And you just learn to have to be patient (Gestures)…my lesson for today…Be patient" (P3, Interview, 458; 460; 462; 464).

Increased eating duration

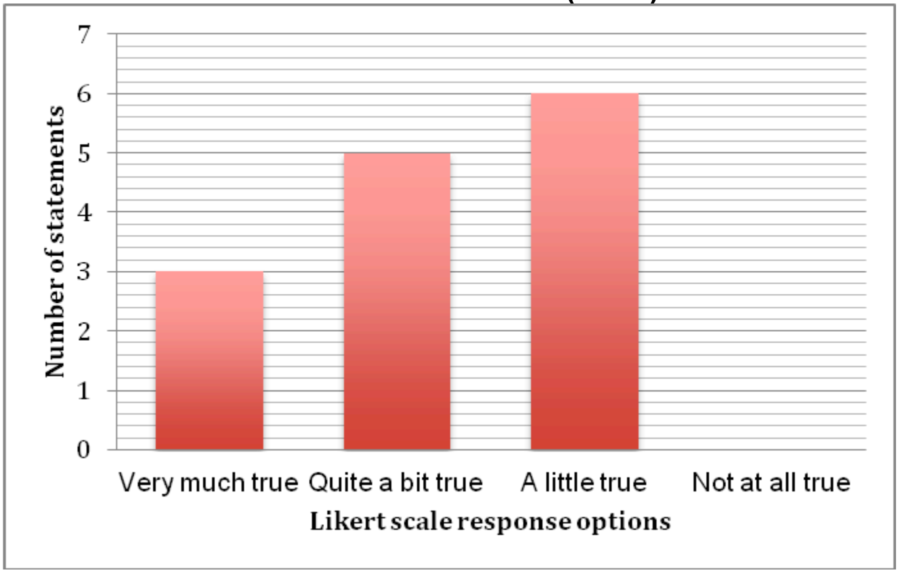
Three participants reported an increased eating duration as a result of dysphagia. P3 stated that dysphagia resulted in a slow eating process, while P4 explained that an increased eating duration could result from the need to ensure that certain foods (like steak) were well chewed prior to swallowing. P5 repeatedly commented that he was always last to finish his meals. This seemed to be because he took small amounts of food at a time/took his time when eating to avoid choking:

"Even with the soup (Gestures)…they're sitting at the table with their soup, they're all coming collecting the plates and I'm…sitting carrying on wi mine for a wee bit. Otherwise…I go too fast…(Gestures)… and then they'll all hear the choking" (P5, RD, 192; 194; 196).

It also seemed to be partly due to indecision regarding whether or not something was safe to swallow. Foods which were easier to swallow took less time to eat than foods which posed more difficulty. P5 explained that he had always been a slow eater, as had two members of his family, causing him to question whether this issue was the precursor to his current issues and whether his difficulties had been inherited. It was unclear whether the increased eating durations which appeared to exist, to some extent, for P6 and P7 were dysphagia-related.

Figure 7.5 displays the responses of all of the participants (including P2) to the Eating Duration domain of the modified-SWAL-QOL and indicates that all participants perceived at least some increase in their eating duration.

Figure 7.5: Participants' responses to the Eating Duration domain of the modified-SWAL-QOL (PWD)



Nasal regurgitation

P5 was the only participant to report nasal regurgitation, occurring when he drank too much liquid at once. He explained that he found it difficult to remember to take small amounts of liquid at a time, as he had not been used to doing so.

Gagging

P5 also reported that he experienced gagging "all the time" (P5, Interview, 112).

Dry mouth

Only P6 reported having a dry mouth, likely due to the fact that her oral intake of fluids was limited as she received the majority of fluids via a PEG tube:

“My mouth’s all dry (Points to mouth)…(Nods head) And my lips (Points to lips)…And my tongue (Protrudes tongue)…I usually drink what they give me” (Gestures) (P6, Interview, 488; 490; 492; 494).

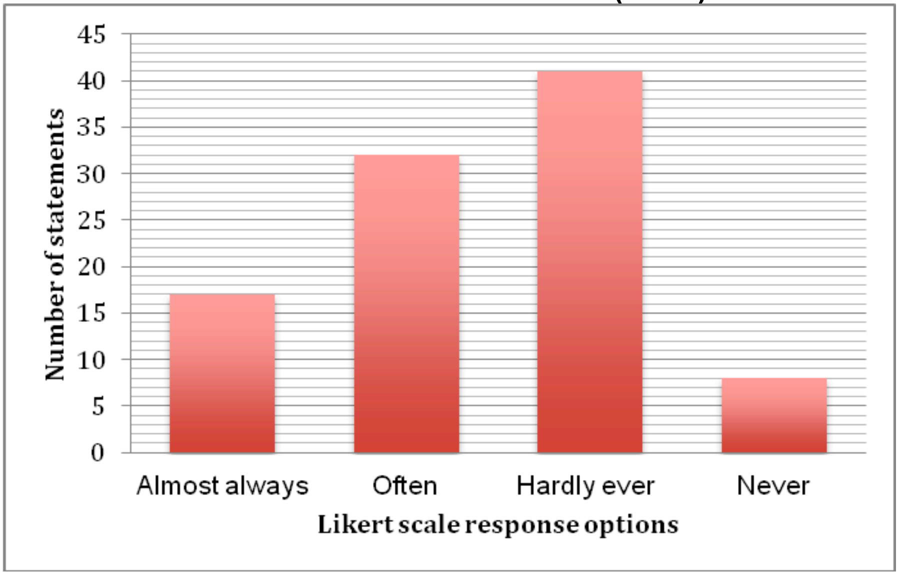
Infections and aspiration

P6 seemed to have recently recovered from a chest infection, which may have been dysphagia-related, although she felt it had returned. P4 demonstrated an awareness of aspiration as a potential consequences of dysphagia and seemed to understand that it could occur silently:

“I know that the danger is although it might be easy enoughh* (sp error: participant means ‘enough’) to swallow some things there is a danger of the food or whatever going into the lungs” (P4, Interview, 428).

Figure 7.6 displays the participants’ responses (including P2) to the Symptom Frequency domain of the modified-SWAL-QOL and serves to further provide an indication of the physical impact of acquired neurological oropharyngeal dysphagia upon the participants. Half of the total 98 responses were either ‘Almost always’ or ‘Often’, while the other half were either ‘Hardly ever’ or ‘Never’. Thus, while there were dysphagia-related physical problems that participants experienced all the time or frequently, there were also issues which were experienced rarely or not at all.

Figure 7.6: Participants' responses to the Symptom Frequency domain of the modified-SWAL-QOL (PWD)



7.4.2.2 Social impact of oropharyngeal dysphagia

All participants (with the exception of P2) commented on the social impact of acquired neurological oropharyngeal dysphagia.

Embarrassment and self-consciousness

Four participants reported feelings of embarrassment/self-consciousness as a result of dysphagia. P1 stated that he felt "Embarrassed" (P1, RD, 172) when he choked on his food at mealtimes, while P7 reported that dysphagia detrimentally impacted his enjoyment of social gatherings because of the potential for choking to occur. He explained that he would feel "Terrible" (P7, Interview, 636) if choking did occur. It seemed that he was concerned about the potential ramifications if choking occurred in a social setting. P7 also stated that he felt "Awkward" (P7, Interview, 520) during an incident when food became stuck in his throat, suggesting that this event had occurred with others present and had been an uncomfortable experience.

P5 indicated that embarrassment was the main issue he experienced as a result of dysphagia. He reported experiencing embarrassment when eating with others as a result of the occurrence of various dysphagia-related physical problems:

“I’m always coughing and eh…maybe with the, as you say with…the liquid coming back my nose, my hanky, my hanky’s never oot my hand, you know (Points at nose and Gestures)…and choking a bit and clearing my throat and that happens all the time…at meals…And em that is embarrassing” (P5, Interview, 842; 846; 848; 850).

He was also embarrassed about always being last to finish his meals and would stop eating a short time after the other residents had finished, suggesting that he was self-conscious about his eating duration. Eating with his family was less embarrassing for him than eating with non-family members. Other than these negative social experiences at mealtimes, P5 appeared to be very socially at ease and had good relationships with the other residents. Moreover, he reported that he continued to get involved in various activities, despite the existence of dysphagia. Elsewhere however, P5 indicated that embarrassment was not much of an issue for him at mealtimes. He reported that he did not feel a need to eat alone at the care home because, although he was always last, the other residents were also a bit slower at eating. Moreover, he explained that other residents also experienced coughing episodes and remarked that he would feel more embarrassed in front of a younger person.

P3 reported experiencing feelings of “tension” (P3, Interview, 406) at mealtimes because he didn’t want to embarrass himself or his wife when eating. He was also extremely self-conscious about his drooling. It was evident that he felt demeaned by the occurrence of drooling in the presence of competent family members and was concerned with how his drooling would be perceived by his family:

“we’ve got a son who’s a doctor…who’s a, what do you call it…a lawyer…in town…And we've got…a grandson who's in medicine and does very well…And I try not to appear an old, drooling…has-been" (P3, Interview, 422; 424; 426; 428; 430).

"I keep telling my wife that…it's not infected…It's just pure water, dripping" (Gestures) (P3, Interview, 442).

Adjustments to social life

Three participants referred to changes in their social lives as a result of dysphagia. Although P4 indicated on the modified-SWAL-QOL that dysphagia did not affect him socially and confirmed this later in the interview, he did explain that he had been advised against going out for certain types of food and stated that he could not tolerate such restrictions forever:

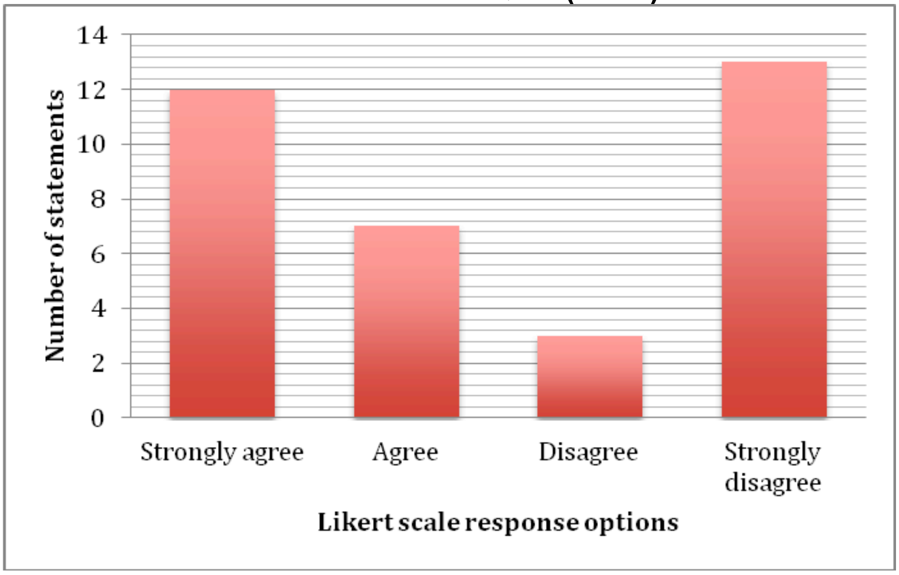
"Going out for a Chinese or Indian curry…which I find is no problem I am still advised not to risk it…I couldn't do that for the rest of my life" (P4, Interview, 572; 576; 584).

P5 explained that he used to drink Guinness in the pub, but was no longer able to drink Guinness (page 175) and drank sherry instead. He acknowledged however that whilst dysphagia was partly responsible for the fact that he no longer went to the pub to have a pint with friends, other factors also contributed to his reduced levels of social activity, namely the weather, his age and health. Although P5 explained that he was no longer able to go out, he did refer to a recent occasion where he had gone out for a meal with family. As he knew the staff in the restaurant, he was confident that they would liquidise his soup for him, which they did, and he was also able to select a suitable pudding. Dysphagia made it hard for P7 to have a social life because he was afraid of choking. P7 also felt that his role with family and friends had maybe changed slightly because of dysphagia, but was unsure why.

Only P6 perceived no dysphagia-related social impact. Despite indicating on the modified-SWAL-QOL that social gatherings were not enjoyable because of dysphagia, she later refuted this and explained that she was able to enjoy musical social events which took place (although such events are unlikely to involve eating). She subsequently confirmed that she did not feel dysphagia affected her socially.

Figure 7.7 displays the participants' responses (including P2) to the Social domain of the modified-SWAL-QOL. The majority of responses were either 'Strongly Agree' or 'Agree', further demonstrating the negative impact of dysphagia upon social functioning. However, many responses were also 'Disagree' or 'Strongly Disagree', indicating that participants perceived that some aspects of social functioning were not affected by acquired neurological oropharyngeal dysphagia.

Figure 7.7: Participants' responses to the Social domain of the modified-SWAL-QOL (PWD)



7.4.2.3 Psychological impact of oropharyngeal dysphagia

All participants (with the exception of P2) commented on how acquired neurological oropharyngeal dysphagia affected them psychologically and all perceived the existence of negative emotional issues relating to dysphagia.

Irritation

Irritation was an emotion experienced by six participants as a result of dysphagia. P1 indicated that infrequently, he could become annoyed by having to be careful when eating/drinking and stated that experiencing thick saliva/phlegm was “Inconvenient” (P1, Interview Part 2, 436). P4 was frustrated at experiencing various dysphagia-related physical problems. P7 was also frustrated by dysphagia, although was unsure why. He was also unsure why he got impatient dealing with dysphagia. For P6, coughing was a source of irritation:

“O…I don’t like it (Shakes head)” (P6, Interview, 640).

P3 explained that he had chosen to eat in his room because of the behaviour of other residents in the dining room. Although there was evidence of a more general issue concerning the behaviour of residents with dementia at mealtimes, there was also a sense of P3’s annoyance at these residents who swallowed their food without difficulty, having complained about it prior to consumption.

P4 appeared irritated that he had been advised against consuming foods which he felt capable of eating. He had been advised not to go out for certain types of food (page 181) although he did not feel these foods were problematic in relation to swallowing, and had also been advised against consuming a fish supper due to the batter on the fish. However, he had occasionally ordered this meal outside the care home and had experienced no difficulty. His irritation concerning dietary restrictions was also evident within the care home setting and P4 stated that he was “A bit peeved” (P4, RD, 064) at this situation:

“Some of the food, I feel I am quite capables* (sp error: participant means ‘capable’) of eating it and yet lle* (sp error: participant means ‘the’) carers tells* (sp error: participant means ‘tell’) me that it is banned due to my swallowing trouble” (P4, RD, 054).

Ultimately, P4 could not understand why certain foods were deemed to be a choking risk when he could swallow them successfully and provided pieces of meat as an example of food he could swallow without difficulty.

P5 was also frustrated by the restrictions which resulted from dysphagia, as he was unable to drink Guinness (page 175). A further frustration was the fact that he was not consistently served food which was appropriate for his modified diet and bore responsibility for flagging up concerns relating to the suitability of his diet:

“But…always the beans and they even gave me them and I’ve been told them half a dozen times, no beans any description (Gestures)…And eh, I still got them last night (Gestures)…So I passed them back so I said to them, I says you know about the beans, I says I’m not taking the beans (Gestures and shakes head)” (P5, Interview, 370; 372; 374).

During dinner, P5 had a conversation with a member of staff regarding the suitability of his food texture. However, P5 did explain that he understood the difficulties for care staff in catering for large numbers and held no ill feeling about these occurrences, which he felt were occasional. P5 also remarked that dysphagia was “mair annoying than depressing” (P5, Interview, 1112) and commented on how he got annoyed with himself when nasal regurgitation resulted from taking too much liquid at once.

Low mood

There was evidence of a low mood in four participants which related to the presence of dysphagia. P3 felt depressed by drooling, while P5 reported feeling a bit depressed and discouraged by dysphagia and conveyed a sense of hopelessness in relation to the permanence of his condition:

“Because there’s no em, no light at the end of the tunnel…I try and deal wi it as best I can and it never gets any better (Shakes head)…And em and I’ve told this eh, it’s…difficult it’s something that there’s no cure for (Shakes head)…And eh…I’ve had the experience that there’s no cure for it…And eh I try my best to cope” (P5, Interview, 880; 882; 884; 886; 888).

P7 indicated that he found it difficult to cope emotionally with dysphagia and found experiencing various dysphagia-related physical problems “A bit difficult” (P7, Interview, 478), suggesting a potential negative impact upon his mood. Whilst P1 did not report a low mood due to dysphagia, he did display distress upon hearing four of the modified-SWAL-QOL statements, two of which were explicitly dysphagia-specific. Although these were episodes of emotional lability, it is possible that these reactions represented P1’s true feelings on these issues to some extent. Finally, although P6 had responded with ‘Often true’ to the modified-SWAL-QOL statement ‘My swallowing problem depresses me’, when asked for confirmation she stated “No much” (P6, Interview, 664), suggesting that she perhaps felt just a little depressed as a result of dysphagia.

Concern regarding choking

Four participants expressed their concern regarding choking. P3 stated that he experienced feelings of fear of choking on food and liquid “Fairly often” (P3, Interview, 398), while P7 appeared to feel afraid of choking due to a previous negative experience where food had become stuck in his throat. P6 reported that she was “glad” (P6, Interview, 556) when a choking episode had ended. P5 reported experiencing indecision regarding whether or not something was safe to swallow and when it was safe to swallow, and remarked on the care he exercised to avoid choking:

“I’m trying to be as careful as I can (Nods head)…when I’m eating…And em…the food I'm eating…if I think myself…it's gonnae choke me I won't eat it (Shakes head and gestures)" (P5, Interview, 284; 286; 288).

He was "upset" (P5, Interview, 1102) that there were certain foods, which, if swallowed, would cause him to choke. Furthermore, he described feeling relieved when, through coughing he managed to release food/liquid which had become stuck, although elsewhere described the occurrence of coughing as "terrible" (P5, RD, 598). At times, P5 received food which was unsuitable for his dysphagia diet and referred to two occasions where he had been frightened of choking on food he had been served, one of which was the observed dinnertime. This fear had been one of the reasons for his failure to finish his main course. P5 also experienced feelings of fear because he was aware that if he drank too much liquid at once, nasal regurgitation would occur.

Resignation

P4 and P5 exhibited a sense of resignation about aspects of dysphagia. P4 was resigned to the fact that he lost food from the side of his mouth:

"Nothing I can do about it except wipe my mouth with a tissue" (P4, RD, 222).

When prompted further on this, he stated, "Whatever will be, will be" (P4, RD, 224).

P4 and P5 appeared resigned to accept circumstances about which they had also expressed irritation. P4 appeared to feel powerless to challenge dietary restrictions:

"Nothing one can do about it" (P4, RD, 308).

P5 appeared to have accepted or else felt powerless to stop the cycle of (seemingly frequently) being served food unsuitable for his dysphagia diet and then requesting a readily available alternative:

“if the puddings got a big crusty pudding they gi yae something, you know, hard crust and that, they come round and give me that I say no just…give me a bit of ice cream and custard” (Gestures)…(P5, Interview, 392).

However, he acknowledged that he had gone along with eating part of what he had been given at dinnertime. He felt that whether or not he was provided with suitable food was determined by which cook was on duty.

Feelings of constraint

Four participants appeared to experience feelings of constraint as a result of dysphagia. P1 explained that having a swallowing difficulty was “A wee bit…restrictive” (P1, Interview, Part 1, 478) and P5 expressed a desire for the freedom which he used to enjoy in relation to eating and drinking. He also remarked on how he was no longer able to do the things he used to do like sitting for a meal with others, seemingly due to embarrassment at his eating duration. For three participants, feelings of constraint resulted from dietary restrictions. For example:

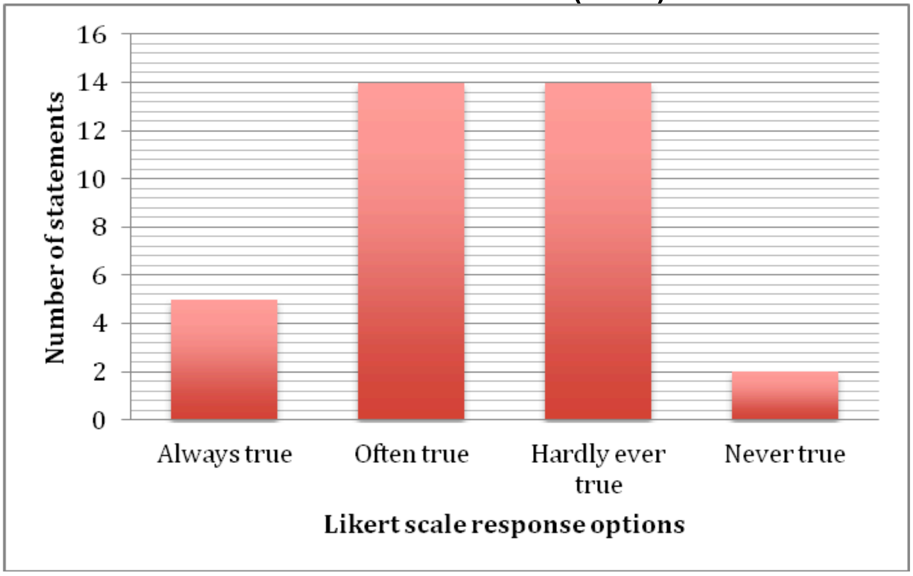
“I dare say that I occasionally feel a longing for food that I am warned to risk eating…Lettuce…Tomatoes…Link sausges* (sp error: participant means ‘sausages’)…due to having a skin on them…I just have to do with other alternatives” (P4, Interview, 468; 476; 478; 480; 482; 492).

“I mean likes of a steak and that years ago, O I was great on the steaks and that and…different meals eh…liked eh pork fillet and stuff like that...pork links and…couldnae eat sausages noo like, you know…Different things like that with the skin on them. But eh I used to have a varied diet and…used to eat quite well like but eh, I had a bigger selection” (Gestures) (P5, RD, 130; 132; 134).

Moreover, P6, whose oral intake of fluids was limited, reported that she only received a cup of tea twice a day.

Figure 7.8 displays the participants' responses (including P2) to the Mental Health domain of the modified-SWAL-QOL. The majority of responses were either 'Always true' or 'Often true', further emphasising the negative impact which acquired neurological oropharyngeal dysphagia exerts upon psychological well-being. However, fourteen of the responses were 'Hardly ever true', indicating that there were some dysphagia-related emotional issues which were rarely experienced.

Figure 7.8: Participants' responses to the Mental Health domain of the modified-SWAL-QOL (PWD)



7.4.2.4 Satisfaction with modified diets

All participants (with the exception of P2) commented on the extent to which they were satisfied with consuming a texture modified diet.

Adjustment to modified diet

Four participants indicated that they had adjusted to consuming a texture modified diet. P1 stated that he felt "Not bad" (P1, RD, 198) about receiving softer food and thickened fluids. P7 had also adjusted to thickened fluids and his fluid consumption at both mealtimes supported this:

“It’s alright, I’m used to it” (P7, RD, 162).

Furthermore, P3, P4 and P7 appeared to have adjusted to their Texture E diets. P3 explained that the care staff ensured his food was suitably prepared to meet his dietary requirements:

“Em…before it was a matter of cutting it up for yourself (Gestures)…Now…one of the wee lassies…cuts it up (Gestures)…and if she doesn’t get it right then she’ll go back to the kitchen (Gestures)…Whether she gets the machinery, I don’t know…” (P3, RD, 278; 280; 282; 284).

He also felt that his dysphagia diet did not cause him any digestive problems. Prior to feeding P3 his main course at dinnertime, the CA fork mashed the potatoes on the plate. However, although P3 remarked on the staffs’ efforts to prepare his food appropriately, he commented to the CA that the fish was “lumpy”, and the CA then further fork mashed the fish. P3 then pulled a piece of potato skin out of his mouth. These observations suggest that the food had not been fully prepared appropriately. Both P4 and P7 felt that consuming a softer diet was “Alright” (P4, RD, 078; P7, RD, 146), although P7 also seemed to feel that he did not have much of an option. By outlining the typical breakfast menu, P4 provided an overview of the kinds of foods he consumed as part of his dysphagia diet, not all of which were appropriate. When the subject of a softer diet was broached with P7, he commented that he had been served a softer diet in hospital, suggesting that he had been consuming a texture modified diet ever since his admittance to hospital.

P6 was not bothered about receiving fluids (that is, the majority of fluids) via a PEG tube although she reported having a dry mouth (page 178), suggesting that she may not have made the connection between her reduced oral intake of fluids and her PEG. She was “getting used” (P6, RD, 126) to consuming thickened fluids, although initially, drinking these had been like consuming wallpaper paste. It seemed that because her oral intake of fluids was restricted, she was grateful for moisture in her mouth, regardless of the texture:

“It’s wet” (Gestures to her mouth) (P6, RD, 142).

She consumed all of two thickened drinks at both mealtimes.

Dissatisfaction with modified diet

P6 however, expressed a strong dislike of her texture modified food and referred to this issue on four separate occasions. It was apparent that she did not find the appearance of her Texture C diet appealing:

“When they put it into purée (Gestures)…and splish, splash on your plate, I don’t like that” (Gestures and shakes head) (P6, Interview, 288; 290).

However, she ate all of both courses at both mealtimes.

P5 also expressed dissatisfaction, explaining that he could become bored of his softer diet, given that it was repetitive and because he had been used to having to chew his food. It seemed that he sometimes received similar food at both lunch and dinnertime which he found “off-putting” (P5, RD, 180). He would refuse food at dinnertime which was similar to what he had received at lunch and obtain an alternative.

7.4.2.5 Awareness and impact of oropharyngeal dysphagia

Evaluation of impact

All participants provided an evaluation of the impact which acquired neurological oropharyngeal dysphagia had upon their lives overall within the ranking item component of the interview. Interestingly, although all participants (with the obvious exception of P2) commented on the existence of various dysphagia-specific HRQOL issues, only two perceived dysphagia as a problem. However, neither P2 nor P5 identified dysphagia as being the issue which most affected their lives.

Of the remaining five participants, four stated that their swallowing difficulty was not a problem and P3 commented that his dysphagia was not a serious problem and confirmed this elsewhere. Furthermore, P6 remarked elsewhere that her swallowing difficulty did not bother her, while P7 stated that he now felt better about his dysphagia than he used to and indicated that he had got used to it:

"It used to be a problem but not now. Got used to it" (P7, Interview, 344).

He also remarked that he was "getting over" (P7, RD, 464) his dysphagia and indeed, his diet had been progressing.

Ultimately, it was apparent that the participants had other issues in their lives which they perceived to be more problematic than dysphagia (Table 7.4).

Table 7.4: Participants' responses to the ranking item (PWD)

P1	Identified 'Not enough opportunities to talk to people' as an issue
P2	1st- Joint/back pain; 2nd- Mobility problems; Also identified 'Not enough opportunities to talk to people' and 'Swallowing difficulty' as issues but not ranked 1st or 2nd
P3	1st- Joint/back pain (if back was left untreated); 2nd- Speech problems; Also identified 'Mobility problems' as an issue but not ranked 1st or 2nd
P4	1st- Bladder problems; 2nd- Joint/back pain
P5	1st- Wife in early stages of dementia and has a hearing impairment; 2nd- Mobility problems and Swallowing difficulty; Also identified back/leg pain and less independence as issues but not ranked 1st or 2nd
P6	1st- Visual impairment; 2nd- Back pain; Also identified mobility problems as an issue (sore back from sitting in wheelchair) but not ranked 1st or 2nd
P7	1st- Less independence; 2nd- Mobility problems; Also identified joint/back pain as an issue but not ranked 1st or 2nd

Pragmatic attitude and positive outlook

Three participants, one of whom perceived dysphagia as a problem, had adopted a pragmatic attitude and positive outlook in relation to dysphagia. P3 tried to maintain a positive outlook concerning the existence of various dysphagia-related physical problems:

“Well I am 84…I’m 84…So then you’ll say, well, so what. I’m 84. I’ll be 85 in November (Gestures)…So there’s no point in getting depressed about it (Gestures)…There’s always somebody worse than yourself” (P3, Interview, 330; 332; 334; 336; 338).

Here and elsewhere, he voiced his belief that there would always be someone in a worse position than himself. He also explained that he received good familial support, which he felt positively affected his situation. P5 was also determined to adopt a positive outlook in relation to his dysphagia and it seemed that this had always been the attitude he adopted when faced with a challenging situation. He also explained that he was getting used to handling his swallowing difficulty. Dysphagia was something that he had to live with and so he just had to get on with it and this had been the attitude he adopted when he had encountered other problems. P6’s pragmatic attitude towards dysphagia was also apparent:

(Shakes head) “I take it all in my stride” (P6, Interview, 522).

However, the extent to which she was aware of her difficulty swallowing was unclear.

Awareness of dysphagia

P6 did not appear to have much insight into her dysphagia, stating that she did not feel she had any difficulty:

“I don’t feel (Shakes head) that it’s any difference with swallowing” (Gestures at throat) (P6, RD, 024).

Furthermore, despite having indicated awareness that she received fluids via a PEG, P6 subsequently appeared unaware of this. Conversely, P3 appeared to have good awareness, commenting that the onset of dysphagia was a recent occurrence ("in the last three or four weeks", P3, RD, 206). He had only been consuming a modified diet for five weeks prior to data collection.

7.4.3 Additional mealtime-related issues

7.4.3.1 Enjoyment of eating and mealtimes in the care home

All participants discussed the extent to which eating and mealtimes in the care home were enjoyable. P2's only extracted utterance has been incorporated within this theme.

Attitude to eating and mealtimes

Five participants expressed a positive attitude towards eating and/or mealtimes. P3, P5 and P6 indicated an enjoyment of eating and expressed their satisfaction with/enjoyment of mealtimes. For example:

"Well I'm quite happy with them" [mealtimes] (P3, RD, 214).

P3 and P6 consumed all of both courses at both mealtimes. On one occasion, P5 stated that eating was enjoyable if he liked the food and P6 conveyed a more tempered attitude towards mealtimes in one instance, stating that they were "alright" (P6, RD, 046). P4 felt "OK" (P4, RD, 020) about mealtimes and when asked how he enjoyed mealtimes stated, "Quite good" (P4, RD, 028). P7 explained that eating was generally enjoyable and reported that he was ready for his breakfast when it arrived, further suggesting an enjoyment of eating. He enjoyed mealtimes at the care home "Alright" (P7, RD, 066).

Only P1 conveyed a negative attitude towards eating and mealtimes. He had indicated during modified-SWAL-QOL administration that eating was no longer enjoyable for him, although he was unsure why this was the case on the two occasions that this topic was broached. He expressed disinterest towards the meals he was served:

"Mmm (purses lips) indifferent (Closes eyes)…Eh aye indifferent…Indifferent…to the meals"…(Closes eyes) (P1, RD, 030; 032).

However, he ate most of his food at both mealtimes and reported that he usually consumed most of his food. He also did not identify anything he would change about mealtimes in the care home.

Positive perceptions of the food which is provided

All participants (with the exception of P2) perceived at least some of the food they were served in a positive light. P3, P5 and P6 were positive about the food served, for example:

"It's good food" (P6, RD, 090).

However, in one instance P3 acknowledged that the food was not first class:

"The food's, you know, it's not 5-star…but…it's nourishing…you get a good mixture" (P3, RD, 238; 240).

P5 reported that he tended to have no problem managing porridge and fish, and whilst the fish could be a bit chewy, it was generally served with a nice sauce. He explained that the kind of meals provided varied with the cook who was on duty, although P5 was understanding of this and did not seem to feel that the meals varied hugely between cooks. He did however indicate that some cooks did a better job than others. P5 listed various foods he enjoyed, poached fish in particular and it appeared that the staff were aware of the foods he enjoyed. P6 also specifically commented on her enjoyment of ice cream, which she took in small amounts using a spoon. P7 felt that the food he received was "Not bad" (P7, RD, 116).

Three participants (P1, P3, P7) indicated that breakfast was their favourite mealtime. For P3, this was because the food served could be swallowed without difficulty. P5 was also positive about breakfast, reporting that porridge was one of his favourite foods, with the soup served at lunchtime being another. These foods were his daily staples, the main foods which he consumed on a daily basis, and were foods he had been used to eating all his life. Whilst P4 did not have a favourite mealtime, he was explicitly positive about part of the breakfast menu.

Negative perceptions of the food which is provided

P1 and P4 possessed predominantly negative opinions of the food they were served. P1 described the food as “a bit monotonous” (P1, RD, 068) or “Plain” (P1, RD, 076), suggesting a lack of variation. P4 also expressed a negative opinion of the food he received:

“It leaves a lot to be desired” (P4, RD, 068).

Like P1, he referred to the repetition. P4 explained that he did not finish his main course at lunchtime because the fish was too dry. Finally, although P7 attributed his failure to finish his main course at lunchtime to a lack of appetite, he then indicated that he hadn’t liked one of the items.

Aspects which facilitate/do not hinder participants’ enjoyment of mealtimes

All participants referred to specific aspects which either facilitated or did not hinder mealtime enjoyment. Five participants (P1, P4, P5, P6, P7) appeared satisfied with the dining rooms of their respective care homes. For example:

“The dining room’s perfect” (P5, RD, 366).

“It’s [the dining room] alright” (P4, RD, 118).

P1 also indicated that he hadn’t heard the noise (not particularly loud) made by a resident at his table during both mealtimes.

Four participants indicated that they were content not to socialise at mealtimes. Socialising was not a concern for P1 at mealtimes, while P7 had not conversed with the residents at his table at lunchtime because he was "not a talker" (P7, RD, 216). Unsurprisingly, sitting alone for a while at this mealtime, once the others at the table had left, did not bother him. However, he also stated that he didn't mind eating with other residents when eating in the dining room. P2 and P6 were content to eat at a table alone/not bothered by this, for example:

"I like alone" (P2, RD, 122).

P2 was seated at a table alone at lunchtime and P6 at both mealtimes.

P3 was content with the arrangement that he ate meals in his room and being joined by his wife for some meals (usually teatime) was a positive aspect of his mealtime experience. It also appeared that P3 tried to maintain some mealtime etiquette when eating in his room and it is possible that this may not have been observed in the dining room.

Four participants commended the care staff for their service at mealtimes. P3 spoke positively about the care staff, including the chef, and referred to the encouragement offered by a member of staff providing feeding assistance:

"One of the nurses would take the whip and say, 'Come on, you've done that well, now take the next one' (Gestures)…You know…encouraging…without bullying…That's what I'm trying to say" (P3, RD, 534; 536; 538).

He was content eating his lunch in the presence of a member of staff, although he commented that some did a better job of providing feeding assistance than others. P5 indicated that he was comfortable when eating his meals and was well taken care of:

"Yea, very comfortable… Aye, make sure…I've got my bib on and all (Gestures)…for to protect my clothes…They always take care of you very nicely…No problem" (P5, RD, 382; 384; 386; 388; 390).

He also explained that the care staff were flexible and catered for residents as and when they arrived for their meal. P6 was positive about the feeding assistance she received at times and P7 “enjoyed” (P7, RD, 360) the mealtime assistance he received at dinnertime. P7 also described the care staff as “expert” (P7, RD, 420).

There were other miscellaneous aspects which facilitated/did not hinder participants’ mealtime enjoyment. P4 had become accustomed to only having the use of his right hand when eating/drinking and P5 felt that his visual impairment did not affect him at mealtimes. P6 appeared to indicate that medication administration during mealtimes was not disruptive to her. This had occurred during both mealtimes and P6 was provided with medication at dinnertime. Additionally, P3 described the care home kitchen as “very adequate” (P3, RD, 444).

7.4.3.2 Barriers to mealtime enjoyment

All participants (with the exception of P2) identified negative aspects of their mealtime experience. These barriers either related to physical issues, largely attributable to ageing and/or disease, or to aspects associated with care home living.

Physical barriers

Three participants reported a visual impairment which posed various problems for them at mealtimes. P1 explained that he required feeding assistance because he was “blind” (P1, RD, 136). P3 felt that his vision was further deteriorating and explained that he received coloured bowls at breakfast to help him see when he was near the end. Furthermore, he believed that he was able to choose cranberry juice to drink because of the colour, which helped him a little. P6 reported her visual impairment and the resultant food spillage as an additional issue within the ranking item:

“I cannae see. I spill all my food” (Gestures and gestures wiping food off her clothes) (P6, Interview, 442).

She lost food from her spoon which fell down her front at both mealtimes. However, within the RD, P6 indicated that this did not bother her and thus it was unclear to what extent food spillage as a result of her visual impairment was an issue for her. P6 also explained that her visual impairment meant that she could only manage to feed independently “up to a point” (P6, RD, 358), and she received some feeding assistance at lunchtime.

P7 was also observed to spill some food down his front at both mealtimes and he explained that this was because he was not taking enough care over eating. P7 did not appear to be a confident person and this lack of confidence also seemed to apply to eating. He reported that he was “a bit unsure” (P7, RD, 326) of himself and was “Not at ease” (P7, RD, 330) when eating, although it was unclear why he felt this way. He explained that his lack of confidence had been the reason he had appreciated the assistance with preparation of his food prior to eating at dinnertime. Conversely, P3 was less happy about receiving mealtime assistance as he was troubled by his inability to feed independently:

“Well…I feel terribly eh dependent…And it would be nice if, these hands…just get all jerky or (Gestures)…twitchy. If they would behave themselves…Then…I would be happy to do it myself” (P3, RD, 568; 570; 572; 574).

P3 also reported experiencing digestive problems which detracted from his enjoyment of mealtimes, namely acid reflux and a build-up of gas, issues which he associated with PD.

P4, who had not engaged in much conversation at lunchtime, explained that his dysarthria impacted upon his ability to converse at mealtimes. P6 reported that she felt sick after eating a meal, but was unsure why and when asked, confirmed that she sometimes felt this way. She also reported that her enjoyment of eating had been detrimentally affected by a cold and the medication used to treat the cold. It seemed that the cold and the antibiotics had affected her sense of taste, although this appeared to be returning.

Institutional barriers

Institutional barriers to mealtime enjoyment also existed. Four participants referred to the waiting time in the dining room prior to their meal being served. P1 and P7 waited for 29 and 21 minutes respectively before receiving their lunch. P1 felt that his waiting time was inappropriate:

“It’s too long” (tilts head back) (P1, RD, 132).

P7 stated that this situation could be annoying at times. However, he subsequently indicated that he was not too troubled by sometimes having to wait for a while before being served. P5 referred to the waiting time prior to being served in the dining room on two occasions and also explained that he would likely be served before the others at his table because of his dysphagia diet and then be eating his meal while his tablemates were still waiting to be served. He did however comment that “it works out alright” (P5, RD, 690).

P4 could get frustrated by the fact that the food took a while to arrive in the dining room from the kitchen, especially in the mornings, and referred to the late arrival of the porridge on several occasions. P4 chose to enter the dining room 30 minutes prior to lunch, although he explained that he generally only arrived early at breakfast time because as the porridge arrived late, arriving earlier gave him an opportunity to have his cereal first. P4 waited for 36 minutes at dinnertime before receiving his dessert and during this time the researcher enquired if a pudding was to be provided. However, he seemed to feel that he would probably have waited longer if he had been in the dining room and explained that the yoghurt was simply a substitute for a pudding because none had been prepared, something which P4 reported happened fairly often. Additionally, the spoon provided with the yoghurt was

too large for the container meaning that it could not be finished and the coffee at this mealtime was not finished because it had grown cold.
An issue for P3 and P5 concerned the behaviour of residents with dementia in the dining room. P3 did not like mealtimes when, due to staffing levels, he had to eat in the company of other residents. P5 felt nervous about attending breakfast due to the difficult behaviour exhibited by his wife (who was in the early stages of dementia) in the mornings, and he resultantly lost his appetite.

Uncomfortable seating was an issue for P7, who explained that he was not comfortable when seated in his armchair, the chair in which he seemed to sit when eating in his room. Additionally, P7 did not like teatime because he was not sociable and found the dining room too busy at teatime. P6 did not view staff conversation positively:

“Aye sometimes it’s noisy…And they should be taking me to my room but they’re talking away” (Gestures) (P6, RD, 334; 336).

However she subsequently indicated that she did not have an opinion on this matter, making it unclear to what extent she was troubled by staff conversation at mealtimes. P6 was not observed being assisted from the table at either mealtime and it is possible that engaging in conversation unrelated to the mealtime at dinnertime distracted staff from providing this assistance. However, given that no such conversations occurred at lunchtime, it is possible that staff were simply waiting for the researcher to finish before assisting P6 from the table.

7.4.3.3 Choice at mealtimes

All participants (with the exception of P2) commented on the provision of choice, or lack thereof, at mealtimes.

Lack of choice at mealtimes

Four participants were not observed to receive a choice of food and confirmed that this was typical. P1 and P7 were unconcerned about not receiving a choice of food, while P4 had become accustomed to it. P4 presumed that the care staff were told what he should be served and may have been alluding to the fact that his dysphagia diet was the reason for his lack of choice. P6 indicated that other residents usually received a choice of food and was indignant that she did not:

“Well I’m no different from anybody else” (Shakes head) (P6, RD, 170).

She was unsure why she did not receive a choice of food and referred to the injustice of not receiving a choice when other residents did. The extent to which consumption of a dysphagia diet was responsible for a lack of food choice was unclear. P6 also did not appear to have a choice of where she sat. She sat at a table alone at both mealtimes and confirmed that this was the typical arrangement and was a decision made by staff.

Provision of choice at mealtimes

Although P3 was not seen being offered a choice of food at either mealtime, he indicated that he often did receive a choice. He may have been required to make his choice some time prior to mealtimes. He also indicated that he was able to choose cranberry juice to drink. Furthermore, P5 was not offered a choice of food at the outset of either mealtime. However, he repeatedly commented on the availability of food choice, explaining that he was able to obtain an alternative option when he was served food which was inappropriate for his dysphagia diet and would likely cause him bother, or was already causing him bother:

“I’ll em, I’ll just leave…things that’s gonna bother me (Gestures)…I’ve got the choice because they’re good enough to give me a choice (Gestures)…to give me something else” (P5, Interview, 360; 362; 364).

The alternatives seemed to consist of readily available items which had not been specially prepared to meet his dietary requirements. P5 reported that sandwiches were, to some extent, problematic in relation to swallowing, an item which he seemed to request at times as an alternative to an unsuitable meal, though not recommended for a Texture C or D diet. P5 was served unsuitable food at dinnertime and in this instance, although he was given the option of obtaining alternative food, explained that he had carried on because he wasn't particularly hungry and wished to show the researcher how he managed the items he had been served. He also obtained an alternative meal when he refused food for being too similar to what he received at the previous mealtime. P5 also commented on other ways in which he was able to exercise his right to choose at mealtimes. He explained that tea, coffee and biscuits or alternatives of his choosing were served in the evening after dinner and reported that residents could choose how much food they wanted.

Additionally, P6 was given the choice as to whether or not she would like some assistance with feeding. Four participants (P3, P4, P5, P7) also seemed to be able to choose where they ate all or some of their meals, or rather had decided to exercise their right to choose concerning their desired eating location. These participants ate in their own room/a room separate from other residents for at least one observed mealtime. Initially, P3 explained that he had chosen to eat in his room because of the occurrence (almost always) of specific dysphagia-related physical issues. However, he then explained that it was due to the behaviour of other residents in the dining room, although his concern with their behaviour was partly dysphagia-related. P3 did acknowledge that this choice was a solitary one. His right to choose his eating location seemed to depend on staffing levels. P4 did not have a preference for where meals were consumed, while P7's preference was to eat alone, because he was not a sociable person. P5 explained that he had chosen to eat separately from the other residents for the observed mealtimes, because he preferred privacy on occasions like these.

7.4.3.4 Eating desire

Five participants (P3, P4, P5, P6, P7) made reference to their eating desire. The approximate quantity of food consumed by participants at each observed mealtime is presented in Table 7.2 (page 166).

Variable appetite

Two participants reported experiencing a variable appetite. P3 reported that his appetite was variable although he was unsure why this was:

“Comes and goes…Well I…might have…a…couple of days I’m really quite hungry…and then other days I (shakes head)…no interest” (P3, Interview, 032; 034; 036).

When P4 was asked whether he had a favourite mealtime, he explained that this depended on how hungry he was, suggesting that the more feelings of hunger were experienced, the more a meal was enjoyed.

Reduction in amount of food consumed

Four participants alluded to a reduction in the amount of food that they consumed. P3, who reported a variable appetite, commented that his appetite was no longer as good as it used to be. P6 had responded with ‘A little true’ to the modified-SWAL-QOL statement ‘I’m rarely hungry anymore’, however she was unsure why she sometimes didn’t feel hungry. However, she did refer to temporary issues which had resulted in a loss of appetite elsewhere. She reported that her appetite was coming back and seemed to attribute her reduced appetite to a diminished sense of taste, which was now returning. She also reported that a chest infection had detrimentally affected her appetite. P7 responded with ‘Quite a bit true’ to the modified-SWAL-QOL statement previously mentioned, and attributed his reduced appetite to decreased physical activity:

“Laziness” (P7, Interview, 452).

He also referred elsewhere to the fact that he did not have much of an appetite. He explained that he had only eaten about half of his main course at lunchtime because he had not been hungry, although he then went on to explain that he hadn’t liked one of the items served, making it unclear to what extent a lack of appetite had been responsible for failure to finish the main course. He also explained that he did not finish all of his main course and dessert at dinnertime because he was “full up” (P7, RD, 388).

P5 indicated that he did not have a big appetite:

“Don’t get too hungry at all” (P5, Interview, 078).

He repeatedly commented that he was unable to finish his meals, reporting that he was satiated before his meals were finished and was easily filled up. He explained that he would leave some food if he had been given too much, as he got full up quite easily. He also felt that he was more easily filled up by his softer diet than his previous, normal diet and reported that if he were still full from breakfast, he would leave some of his meals later in the day. P5 explained that he was not always ready for his meals, but would eat his staple foods (he included pudding here) to ensure he was consuming a sufficient quantity of food, even if he didn’t feel like it. Elsewhere, he remarked that there was no point in continuing to eat when he felt full up, as he had received a sufficient amount of food by consuming his daily staples, porridge and soup. He would eat what he could of the other meals/courses. P5 explained that he had not finished his main course at lunchtime because he had been given too much and felt full up and confirmed elsewhere that he had not finished this course because he felt full up. He also reported that he had felt food and liquid sticking in his throat, making him reluctant to eat anymore, although stated that the main reason was that he was satiated. At the end of this observation, he reported to the researcher that he felt full up. Additionally, P5 reported that he felt nervous about attending breakfast due to the difficult behaviour exhibited by his wife in the mornings and resultantly lost his appetite. He also reported that he felt less hungry because he was constantly trying to manage his secretions.

Quantity of food

P5 also referred to the quantity of food at his care home. He commented on the abundance of food available/provided on several occasions and seemed to feel that he received too much food. He reported that he had been eating on a regular basis since entering the care home, explaining that he was provided with three meals a day and tea/coffee between meals and referred to his weight gain on several occasions. He felt that he obtained a sufficient amount of food by eating his staples of porridge and soup and some of the other meals and explained that he did not finish these other meals because there was too much on his plate. Three meals a day was more than what P5 was used to and he stated that he would not eat three meals a day if he lived at home. Although he would stop eating a short time after the other residents had finished, he felt that he had consumed a sufficient amount of food to fill him up. He also reported that he did not feel the need to do much snacking, suggesting that he received plenty of food at mealtimes.

P5 reported that he had decided to carry on with the food he had been served at dinnertime, even though it was unsuitable, because he hadn’t felt particularly hungry and wished to show the researcher how the managed those items. When initially asked about his failure to finish his main course, P5 explained that he had been frightened of choking on it, but subsequently also remarked on the short duration between meals, meaning that he was not ready for his next meal. He remarked on the short duration between meals elsewhere. He consumed only half of his main course at this mealtime and more than three quarters of his dessert and reported to the researcher at the end of this mealtime that he felt full up.

7.5 Summary

This chapter has presented the findings of the data collected from the PWD. These data have provided insight into the HRQOL impact of acquired neurological oropharyngeal dysphagia upon seven care home residents. Participants described the physical, social and psychological impact of their swallowing disorder and expressed their adjustment to or dissatisfaction with modified diets. However, despite reports of various dysphagia-related HRQOL issues, none of the participants felt that acquired neurological oropharyngeal dysphagia was the issue which affected their lives most, ranking other age/disease-related issues above their swallowing disorder. These data have also provided insight into the additional eating and mealtime-related issues which exist for these individuals and strong similarities exist between these data and the data obtained from the CP. The following chapter discusses the findings obtained from the CP and the PWD, presents implications for clinical practice and future research and evaluates this investigation in its entirety.

CHAPTER 8
DISCUSSION AND CONCLUSIONS

8.1 Introduction

The previous chapter presented the findings of the data collected from the PWD. This chapter discusses these findings in the context of the existing literature base, giving consideration to how they corroborate with and differ from the results of previous research in this area (8.2). The themes which relate to additional mealtime-related issues are discussed together with the findings of the data obtained from the CP (Chapter 6), given their strong similarities (8.3). Together, these findings provide insight into the eating and mealtime-related issues which exist for care home residents, regardless of the presence of oropharyngeal dysphagia. Following this, consideration is given to the key learning experiences afforded by the pilot study and its role in informing the main study (8.4). Subsequently, an evaluation of the main study is provided, consisting of a discussion of the study strengths and limitations, the experience acquired and challenges encountered in the main study and the researcher's perceptions of the study findings (8.5). The implications of this study for clinical practice (8.6) and the recommendations for future research are then presented (8.7). This chapter concludes with a summary of the present investigation, bringing the thesis to a close (8.8).

It is acknowledged that a researcher adhering to a 'purist' descriptive phenomenological approach would not necessarily offer interpretation of the data by relating it to existing literature. However, healthcare research requires a level of interpretation to be able to make clinical recommendations.

8.2 The HRQOL impact of acquired neurological oropharyngeal dysphagia

The data obtained from the PWD provide insight into the impact of acquired neurological oropharyngeal dysphagia upon the HRQOL of a small sample of care home residents. Due to the relatively small volume of research which has previously explored the impact of dysphagia upon the QOL of care home residents/the QOL impact of acquired neurological oropharyngeal dysphagia, reference will also be made to studies which have described the experience of eating as a whole post-stroke, relevant research within the field of head and neck cancer/non-head and neck cancer, as well as pertinent non-disease-specific studies. Each theme is discussed in turn below in relation to the existing literature (8.2.1 - 8.2.5).

8.2.1 Physical impact of oropharyngeal dysphagia

Various dysphagia-related physical problems were reported by the PWD, such as difficulty swallowing medication, drooling and loss of food/liquid from the mouth and coughing and choking on food/liquid (7.4.2.1). Dysphagia-related physical problems have also been self-reported by participants in studies which have explored the eating/swallowing experiences of individuals with acquired neurological disorders, and they mirror many of the issues reported by the PWD. Problems reported by participants in these studies include, coughing and choking on food/liquid; dribbling/food/liquid leakage; food sticking in the mouth and throat; increased eating duration; difficulty swallowing medication; dry mouth (Jacobsson et al, 2000; Klugman and Ross, 2002; Perry and McLaren, 2003; Carlsson et al, 2004; Miller et al, 2006; Medin et al, 2010). Some of the other physical issues reported by the PWD, namely nasal regurgitation and problems with secretions, are evident in the reports of individuals with dysphagia caused by some form of cancer (Watt and Whyte, 2003; Tong et al, 2011). Additionally, P3, who had a diagnosis of PD, indicated difficulties relating to the oesophageal phase of swallowing and Cichero (2006) reports that oesophageal difficulties may also be present in individuals with PD.

For three PWD (P3, P4, P5), it was clear that they had made some changes to their eating habits in order to try and minimise the occurrence of certain dysphagia-related physical problems. P3 reported the need to eat slowly to avoid choking, while P4 commented on the importance of ensuring that certain foods were well chewed prior to swallowing. P5 needed to eat slowly/take small amounts of food at a time to avoid choking and tried to remember to take small sips of liquid to avoid nasal regurgitation. He demonstrated caution when deciding what to eat and generally exercised care when eating. It was unclear whether the participants' SLTs had advised the implementation of any of these strategies. Participants in other studies have also reported making changes to their eating habits in order to ease their difficulties (Ekberg et al, 2002; Miller et al, 2006; Farri et al, 2007; Medin et al, 2010). For instance, Ekberg et al (2002), whose participant sample included care home residents, reported that 59% of participants had adopted various strategies including, chewing food for longer before swallowing, taking sips of liquid between mouthfuls and eating and swallowing more slowly.

8.2.2 Social impact of oropharyngeal dysphagia

Five participants reported negative dysphagia-related social issues. Four participants reported feelings of embarrassment/self-consciousness as a result of oropharyngeal dysphagia (7.4.2.2). For example, P1 stated that he felt embarrassed when he choked on his food at mealtimes, while it was apparent that P3 felt self-conscious about the drooling he experienced. Furthermore, three participants referred to changes in their social lives due to the presence of oropharyngeal dysphagia (7.4.2.2). For instance, P4 had been advised against going out for Chinese or Indian food and stated that he could not tolerate such restrictions forever.

Previous research has indicated that dysphagia negatively impacts social well-being. Research conducted amongst a large sample of long-term care residents in Taiwan, reported a statistically significant relationship between chewing and swallowing problems and difficulties with social engagement (Wang et al, 2012), although it was unclear how chewing and swallowing problems were defined. Within community-dwelling populations, individuals with oropharyngeal dysphagia have been found to score significantly lower on scales of social functioning than individuals without dysphagia (Maclean et al, 2009b; Plowman-Prine et al, 2009). Maclean et al (2009b) found that laryngectomees with oropharyngeal dysphagia had a lower mean social score on a head and neck cancer-specific HRQOL measure (UW-QOL) than laryngectomees without dysphagia, with a statistically significant difference between the groups. However, there was no statistically significant difference between the mean social scores of these groups on a generic QOL measure (WHOQOL-Bref). Similarly, Brandao et al (2010) found no statistically significant difference between the social functioning of individuals post-stroke with and without oropharyngeal dysphagia on a version of the generic health status questionnaire, the SF-36. These findings suggest that generic measures of QOL/HRQOL may be less likely to pick up on specific issues of relevance to individuals with dysphagia.

Feelings of embarrassment due to dysphagia have been reported by participants in many previous studies (e.g. Ekberg et al, 2002; Watt and Whyte, 2003; Farri et al, 2007; Garcia-Peris et al, 2007; Martino et al, 2010; Medin et al, 2010). Specific examples of embarrassing situations have been reported in some studies and are akin to experiences reported in the present investigation. For example, participants with chronic oropharyngeal dysphagia in a study by Martino et al (2010) were especially embarrassed about choking in public settings. Moreover, Medin et al (2010) referred to an account provided by a participant who resided in a care home following her stroke and who reported feeling embarrassed when coughing occurred in the presence of others. References to self-consciousness as a result of oropharyngeal dysphagia are also evident within the literature. For example, a psychosocial issue identified by participants with PD in a study by Miller et al (2006) was that of managing saliva and the stigma which participants perceived was associated with having to repeatedly wipe the mouth and be ready to wipe the mouth. Similarly, Jacobsson et al (2000) found that individuals post-stroke reported feeling shame about their altered appearance. They seemed self-conscious about issues like loss of saliva from the mouth and endeavoured to conceal their lack of control, for example by controlling saliva leakage.

The detrimental impact of dysphagia upon the social lives of individuals has also been documented in the literature (e.g. Miller et al, 2006; Maclean et al, 2009a; Tong et al, 2011). For instance, Maclean et al (2009a) found that 61% of laryngectomees with oropharyngeal dysphagia had made lifestyle changes as a result of their swallowing difficulty, while no participants without dysphagia reported having made significant lifestyle changes. Moreover, Tong et al (2011) reported that 31.7% of their participants, who had received treatment for a nasopharyngeal carcinoma, avoided eating out because of oropharyngeal dysphagia and 21.7% reported that oropharyngeal dysphagia affected their friendships/family relationships. Reduced socialisation was evident amongst the PD participants in Miller et al’s (2006) study, and one participant indicated that he no longer went out for meals due to a fear of choking. Similarly, P7 reported that oropharyngeal dysphagia made it hard for him to have a social life because he was afraid of choking. P5 acknowledged that factors other than oropharyngeal dysphagia also contributed to his less active social life, referring to the weather as well as his age and health. Although not mentioned by the other participants, it seems likely that such aspects would impact upon the social functioning of any elderly care home resident with an acquired neurological disorder.

8.2.3 Psychological impact of oropharyngeal dysphagia

Negative emotional issues relating to oropharyngeal dysphagia were reported by the PWD and these psychological issues encompassed five broad domains, namely feelings of irritation, resignation and constraint, as well as low mood and concerns regarding choking (7.4.2.3).

The negative impact of dysphagia upon mental health has been well documented within the literature. Swallowing difficulties have been found to be independently associated with depressive symptoms among residents within institutional settings in Hong-Kong and Taiwan (Chow et al, 2004; Lin et al, 2005). However, whilst these studies used a clinical assessment to detect the presence of depression, the present study utilised a self-report dysphagia-specific HRQOL questionnaire, in a modified form, and participants' reports of their experiences to ascertain the impact of acquired neurological oropharyngeal dysphagia upon mental health. Additionally, Ekberg et al (2002) reported that of the participants (some of whom resided in care homes) who were bothered by swallowing at mealtimes, 41% experienced anxiety or panic at mealtimes because of dysphagia and 55% of all participants felt that swallowing problems made life less enjoyable. All of these findings provide support to the present investigation, which indicates that oropharyngeal dysphagia can have deleterious consequences upon the psychological well-being of care home residents.

Within the community-dwelling population, Plowman-Prine et al (2009), who explored swallowing-related QOL among a sample of individuals with PD, reported a statistically significant negative correlation between the SWAL-QOL and Beck Depression Inventory (BDI) scores, indicating that the worse the swallowing-related QOL, the greater the depression. Furthermore, Nguyen et al (2005) reported that participants with moderate to severe oropharyngeal dysphagia following treatment for head and neck cancer had higher levels of anxiety and depression than participants with no or mild oropharyngeal dysphagia, and the differences between the groups were statistically significant. In contrast to these findings, Brandao et al (2010) found no statistically significant difference between the mental health of individuals post-stroke with and without oropharyngeal dysphagia using a version of the SF-36. Similarly, Maclean et al (2009b) reported no statistically significant difference between the mean scores of laryngectomees with and without oropharyngeal dysphagia on the psychological domain of the WHOQOL-Bref. However, they found that participants with oropharyngeal dysphagia had higher levels of stress, anxiety and depression than those without dysphagia using a measure of psychological well-being, and the differences between the groups were statistically significant. As above (page 210) these findings call into question the use of generic QOL/HRQOL measures and point to the need to utilise measures which will explore in sufficient detail aspects of potential relevance to individuals with dysphagia.

Within qualitative research in this area, some of the dysphagia-related psychological issues previously reported include, fear (including fear of choking), panic, anxiety, hopelessness, frustration, stress, impatience, low mood and longing for food that could no longer be eaten (Jacobsson et al, 2000; Klugman and Ross, 2002; Watt and Whyte, 2003; Martino et al, 2010). Participants in some studies have indicated that fear of choking lessens or fades with increasing time post-onset (Jacobsson et al, 2000; Carlsson et al, 2004; Martino et al, 2010). For example, Martino et al (2010) found that whilst a fear of choking was a concern among a sample of participants with acute oropharyngeal dysphagia (onset less than three months), those with chronic oropharyngeal dysphagia (onset greater than three months) expressed ‘worry’ of choking rather than fear. These participants felt equipped to control choking. However, in the present investigation, P5 remained fearful of choking despite the fact that he had been consuming texture modified diets for approximately two years. However, his fear of choking seemed to exist largely because he was served food which was unsuitable for his dysphagia diet. Moreover, P2, who was two years post-stroke, responded with ‘Almost always’ and ‘Often’ respectively to the modified-SWAL-QOL statements regarding fear of choking on food and liquids. These findings suggest that fear of choking may not always fade or lessen with increasing time post-onset.

8.2.4 Satisfaction with modified diets

Four participants indicated that they had adjusted to their various dysphagia diets, while two were dissatisfied with consuming texture modified food (7.4.2.4). Whilst P6 disliked her Texture C diet, she had adjusted to consuming thickened fluids and receiving the majority of fluids via a PEG tube. With regards to the management of oropharyngeal dysphagia, dietary modification is the most frequently used compensatory approach (Ney et al, 2009). However, the RCSLT (2009) reports that there is limited evidence to support the efficacy of dietary modification. Langmore (1999) states that "Clinicians may readily turn to this 'easy' way to fix the problem without appreciating the major impact a diet change has on a person's functional status and quality of life" (p. 222). She expresses particular concern about imposing dietary restrictions upon care home residents, who may have to consume such a diet permanently. Unfortunately, very little attention has been devoted to eliciting the perceptions of individuals with oropharyngeal dysphagia concerning texture modified diets and much further research in this area is required.

Perry and McLaren (2003) gained some insight into the experiences of individuals consuming modified diets post-stroke. All of the participants who required thickened liquids disliked them, while attitudes of acceptance and dissatisfaction towards texture modified food were expressed an equal number of times, although it was not clear how many participants were consuming texture modified food. Within the current investigation, all of the PWD who consumed thickened liquids had adjusted to these, although one had initially been dissatisfied. The differing opinions between individuals concerning texture modified food in Perry and McLaren's (2003) study reflect the findings of the current investigation, with evidence of both adjustment and dissatisfaction among the participant sample.

It is interesting that the two PWD who were dissatisfied with their texture modified food, were consuming the most modified consistency of all the participants. Both had been recommended a Texture C diet (thick purée), although P5 could tolerate some items at Texture D. Moreover, although P2 had been recommended a Texture C diet and thickened fluids, the main courses which he was observed eating did not constitute a thick purée (e.g. scrambled egg, mashed potato, haggis in a softer form) and his milk was not thickened at either mealtime. He was also observed eating ice cream, which is not recommended for individuals consuming thickened liquids. Liaison with the SLT involved in his dysphagia management revealed that he refused to comply with his dysphagia diet, thus indicating that he was also dissatisfied with his modified diet.

The reasons given by P5 and P6 for their dissatisfaction with texture modified food were lack of variation and unappealing appearance respectively. P5 also indicated that he had been used to having to chew his food a bit. This dissatisfaction did not appear to have reduced their intake of food (P6 consumed everything at both mealtimes, while P5 provided other reasons for failure to finish three of the four courses which he was observed eating). However, their opinions signal a need for further consideration of how to increase variety and improve the appearance of texture modified food. This implication is also applicable to P2, who could be vulnerable to medical complications as a result of non-compliance (Davis, 2007), such as aspiration pneumonia.

Some research has sought to ascertain the success of moulds/re-shaping of minced/puréed textures in enhancing the appearance and appeal of texture modified food (Cassens, Johnson and Keelan, 1996; Stahlman, Garcia, Hakel and Chambers, 2000; Stahlman et al, 2001; Germain, Dufresne and Gray-Donald, 2006). However, the findings have been inconclusive. For instance, Cassens et al (1996) reported that the percentage intake of residents in a skilled nursing facility who were consuming food presented in 3-D form, which was nutritionally enhanced and was designed to look and taste better, increased by an average of 15%, compared with the intake of the same residents when consuming regular puréed food. Additionally, their calorie intake increased by 41% and protein intake by 36%. However, the extent to which improved appearance was responsible for the increased average percentage intake compared to improved taste or additional attention from care staff was not established. No evidence of the use of moulds was noted during the mealtime observations, although it appeared that each of the food items served as part of P5's main course at lunchtime had been piped onto his plate.

It was concerning that all of the PWD were observed to receive at least some food which was not appropriate for their recommended dysphagia diet. Care homes are required to provide residents with food which meets their dietary requirements (The national care standards on care homes for older people, Scottish Government, 2007). Someone like P5, who was clearly aware of his limitations and was prepared to refuse food which would be problematic, is likely to be less at risk of serious and potentially life threatening medical consequences than an individual with less awareness of their difficulties and/or with less understanding of the potential consequences of consuming unsuitable food. For instance, P6 demonstrated some degree of unawareness of her swallowing difficulty and she was observed receiving items which were unsuitable for a Texture C diet. When an individual lacks awareness of their difficulty, it is their carer(s) who must assume responsibility for adhering to the recommendations made by the SLT and SLTs need to educate carers to guarantee conformity to safety recommendations (RCSLT, 2009).

8.2.5 Awareness and impact of oropharyngeal dysphagia

An unexpected finding of this study was that, despite reports of various HRQOL issues related to acquired neurological oropharyngeal dysphagia, only two participants indicated that oropharyngeal dysphagia was a problem on the ranking item (the task within the interview where participants were asked to identify the problem which affected their lives most and the issue which they would place second) and neither of these individuals ranked it as the issue which affected their lives most (7.4.2.5). This finding clearly illustrates that the ranking item served its purpose, as it provided insight into how the participants perceived oropharyngeal dysphagia in the context of other problems faced. Klugman and Ross (2002) found that just over half of their participants with MS who reported the existence of oropharyngeal swallowing difficulties, felt that their swallowing problems were insignificant in comparison to other issues associated with MS. However, with the exception of participants' reports of the difficulties experienced, there was no indication of dysphagia severity and whether there was a relationship between dysphagia severity and whether or not swallowing problems were considered significant in relation to other MS-related problems.

In the present investigation, two of the participants with more severe oropharyngeal dysphagia (that is, they had been recommended a Texture C diet) were the participants who perceived dysphagia as a problem. However, P6 was also advised to consume a Texture C diet and did not perceive dysphagia as a problem, although the extent to which she was aware of her difficulty was unclear. Thus, definitive conclusions cannot be drawn from this small study regarding whether there is a relationship between oropharyngeal dysphagia severity and whether or not oropharyngeal dysphagia is perceived as a problem when considered in the context of other difficulties experienced.

Despite reporting the existence of negative issues pertaining to oropharyngeal dysphagia, three participants were pragmatic about their swallowing disorder and were keen to maintain a positive outlook, including P6 whose level of awareness has been questioned. A positive attitudinal stance was also adopted by two individuals with oesophageal dysphagia caused by oesophageal cancer in the Watt and Whyte (2003) study, who felt that they were better off than individuals with other health conditions, such as Alzheimer's disease.

Thus, whilst clinicians should be holistic in their consideration of oropharyngeal dysphagia and its impact on an individual's life, there is also a need to remember that a care home resident with oropharyngeal dysphagia will likely also be dealing with other issues e.g. visual impairment, bodily pain, bladder problems. Whilst they may perceive problems pertaining to oropharyngeal dysphagia, they may be preoccupied with issues which they deem more of a priority.

8.3 Additional mealtime-related issues

In addition to reporting the negative HRQOL impact of acquired neurological oropharyngeal dysphagia, the PWD commented on other aspects of their mealtime experience within the care home (7.4.3). These data concerning additional mealtime-related issues are very similar to the data collected from the CP (6.4). The strong similarities between these data sets suggest that there are aspects of the mealtime experience within the care home which are similar for residents with and without dysphagia. The themes identified from the data of both participant groups are discussed below (8.3.1 - 8.3.4).

8.3.1 Enjoyment of eating and mealtimes in the care home

The SCIE (2009) states that food and mealtimes are considered a high priority by older persons and influence their QOL. An encouraging finding of this investigation was that the majority of all participants were positive about eating and/or mealtimes in the care home and were satisfied overall with the food which they were served (6.4.1; 7.4.3.1). However, negative views of the care home food also existed. For example, CP6 reported that she didn't like everything she was served and felt that budgetary constraints had exerted a detrimental effect upon the standard of the food, while P1 and P4 commented on the lack of variation in their diets. However, it was unclear whether their perceptions of repetition were reflective of the care home food in general or were attributable to their dysphagia diets.

Negative perceptions of food served within care home settings have been reported in other studies. For instance, a lack of variety of food was a negative issue reported by participating residents in a study by Evans et al (2003). Moreover, Perry and McLaren (2003) found that those post-stroke participants who resided in institutions and who commented on the quality of the meals served, more commonly reported negative experiences. Furthermore, West et al (2003) found that a varied menu, appetising meals and respect for food preferences were among the top ten most important aspects of food service for residents in long-term care facilities. However, none of their satisfaction ratings of these aspects appeared in the top ten, suggesting low satisfaction with these components of mealtimes considering their perceived importance.

Another point of interest is that although the PWD reported negative HRQOL issues relating to acquired neurological oropharyngeal dysphagia, most expressed a positive attitude towards eating and/or mealtimes in the care home, suggesting that the presence of oropharyngeal dysphagia does not necessarily detract from eating/mealtime enjoyment. These findings can be contrasted with those reported by Ekberg et al (2002) who found that whilst 84% of participants with dysphagia (including care home residents) felt that eating should be an enjoyable experience, only 45% felt that it was. Yet the extent to which dysphagia was responsible for reduced eating enjoyment was unclear and other factors may have contributed. The small participant sample within the present study must be acknowledged however and generalisations regarding the eating and mealtime enjoyment of care home residents with acquired neurological oropharyngeal dysphagia cannot be made.

8.3.2 Barriers to mealtime enjoyment

Negative aspects of the mealtime experience were identified by both the CP and the PWD (6.4.2; 7.4.3.2). Some of these barriers concerned physical difficulties, which were largely attributable to ageing and/or disease. Sensory impairment was the most prevalent physical issue identified by participants, with five reporting that their mealtimes were affected by visual impairment and one commenting that her hearing impairment had implications for socialising at mealtimes. Referring to nursing facilities in North Carolina, Speroff et al (2005) commented on the fact that there are a large number of residents who are unable to see the food they have been served or are unable to hear conversations at the dining table. They make two suggestions for how to reduce noise in the dining room in order to help residents with hearing impairment hear conversations, namely restricting needless staff conversations and incorporating sound-absorbing materials within the dining room. Four participants received some form of mealtime assistance due to their visual impairment and/or utilised strategies implemented by the care staff to compensate for their visual impairment. One of these participants, who had PD, also required total feeding assistance due to involuntary movements and was concerned about his dependence for feeding. Difficulties with self-feeding in PD due to reduced strength, tremor and dyskinesias have been reported in another study (Miller et al, 2006). In addition to hearing impairment, dysarthria was another physical issue impacting upon socialising at mealtimes, and the psychosocial impact of motor speech disorders upon individuals has been acknowledged (Walshe, 2011).

It was interesting that two CP reported difficulties related to swallowing. CP5 reported difficulty chewing as a result of not wearing dentures at mealtimes, while CP2 reported that food could stick in his throat at times, an issue which he attributed to a bone condition. The existence of swallowing-related difficulties among the elderly population has been reported by Leow et al (2010), who found a statistically significant difference between healthy young and older adults on the symptom frequency domain of the SWAL-QOL. Thus, swallowing-related difficulties can also exist amongst elderly individuals without dysphagia as a result of age-related changes or, in the case of CP2, individuals who experience intermittent difficulties with swallowing as a result of a medical condition but do not have a dysphagia diagnosis.

Other barriers identified by participants were attributable to care home living. Whilst the importance of mealtimes in the care home setting as social occasions has been emphasised within the literature (Nijs et al, 2006; Philpin et al, 2011), an interesting finding of this study was that three CP did not welcome socialising at mealtimes and CP5 was content with minimal conversation at mealtimes. These perspectives differed from those of CP3 and CP4, who seemed to enjoy contact/interaction with other residents. Furthermore, five PWD were content not to socialise with other residents, one of whom was P7, who was not a sociable person, and who also reported that he did not like teatime because the dining room was too busy at this mealtime. These findings suggest that it cannot be assumed that socialising will contribute to mealtime enjoyment and may even detract from the mealtime experience. In their study exploring the eating experiences of individuals post-stroke, Medin et al (2010) refer to an account of an individual residing in a care home, who was not sociable, but felt she had to eat in the company of other residents.

The dining environment or more specifically, the behaviour of other residents with dementia was a concern for three participants. P5’s concern actually related to the difficult behaviour exhibited by his wife in the mornings, who was in the early stages of dementia. Conversely, nine other participants expressed contentment in relation to their respective dining environments. Hotaling (1990) emphasises that even when food is served which has been well-prepared and is appealing and delicious, the existence of negative environmental or psychosocial factors could result in poor food intake. Thus, it is important that all care home residents are able to consume their meals in a pleasant environment.

Four PWD remarked on the waiting time in the dining room prior to being served. Two were wheelchair bound and dependent on care staff to assist them to the dining room. It is possible that these situations were a direct result of a shortage of staff. Inadequate staffing at mealtimes was a key issue reported by Kayser-Jones and Schell (1997) in their longitudinal study of mealtimes in two long-term care facilities in America. CP2 also had to wait for a while before he was served as a result of his decision to arrive in the dining room 45 minutes prior to the beginning of the mealtime. Perhaps care staff could have helped him to avoid such an early arrival by ascertaining his motive for doing so and assuring him that they would ‘reserve’ his desired position.

8.3.3 Choice at mealtimes

Whilst all CP received some choice of food, only two PWD reported receiving a choice of food, although neither were offered a choice at the outset of their observed mealtimes. For P5, the availability of food choice at lunch and dinner seemed to exist mainly when he refused food which was unsuitable for his dysphagia diet and even then, the alternatives appeared to consist of readily available items. It is worth noting that three PWD were either unconcerned by or had become accustomed to not receiving a choice of food. Although generalisations cannot be made due to the small sample size, these findings suggest that care home residents who are consuming a dysphagia diet are less likely to receive a choice of food than residents consuming a normal diet. The national care standards on care homes for older people (Scottish Government, 2007) state that care home residents should expect to have, “a choice of cooked breakfast and choices in courses in [their] midday and evening meals” (p.39). These findings indicate that further investigation of care home practices regarding the provision of choice for care home residents consuming dysphagia diets is warranted.

Some participants reported being able to exercise their right to choose in relation to other aspects of mealtimes, for example, where they sat or ate their meals, while others did not have such freedom of choice. Moreover, although they received a choice of food, two CP referred to the restricted freedom of choice in relation to food provision, explaining that it was not possible for them to have whatever they wanted to eat and CP6 also referred to being more restricted in terms of when she ate. Four CP referred to their desire to exercise their right to choose concerning mealtime-related aspects. For instance, CP2 expressed his desire to obtain his position of choice in the dining room and arrived early in order to do so.

It is recognised that upon entering a care home, individuals become dependent upon others for their nutritional provision and meals may vary from residents' previous experiences in terms of their timing, setting, frequency as well as the kind and quantity of food provided (Winterburn, 2009). Whilst it is not feasible for care homes to cater to each resident's preferences relating to eating (Bourgeois and Hickey, 2009), it is deemed important that residents are able to exert some control over their dining experience. Nijs et al (2006) have commented on how mealtimes make it possible for residents to make choices, and it is advocated that these choices should not be limited to food alone.

8.3.4 Quantity of food/Eating desire

Eight participants reported the existence of a reduced appetite or a reduction in the amount of food consumed, one participant described herself as a 'small eater' and two reported variable appetites. Four participants reported receiving too much food. It should be acknowledged that when analysing the data obtained from P5, it was difficult to ascertain whether some of his statements indicated a reduction in the amount of food consumed or were referring to the provision of too much food. Decisions regarding the placement of these statements within these two theme clusters were made carefully and with consideration to the context in which the utterances were made, although ambiguity still remains.

As people age, their appetite becomes smaller and they eat less (Ahmed and Haboubi, 2010). However, when individuals eat less food, there is a greater risk that they will not obtain sufficient amounts of some nutrients in their diet (Caroline Walker Trust, 2004). Furthermore, whilst it was encouraging that none of the participants reported not receiving enough food, it is argued that provision of too much food is not conducive to a positive mealtime experience. Residents participating in Evans et al's (2003) study reported that they needed to feel that they could ask for and receive appropriate amounts and type of food: not too little and not too much so that it was overwhelming.

8.4 Reflection on the pilot study and implications for the main study

For the pilot study, data were collected from one care home resident with oropharyngeal dysphagia caused by stroke. The pilot study provided an opportunity to pilot the study materials and procedures for the purpose of refinement and informed on the feasibility of a larger study.

8.4.1 Piloting the study materials and procedures

Collecting data from the care home resident with oropharyngeal dysphagia caused by stroke was a very useful exercise in piloting the study materials and procedures with an individual with acquired neurological dysphagia, and was the researcher's first opportunity to engage an individual with brain damage in a research interview and discussion. Conducting the interview and RD with this individual served as a very useful learning experience and taking time to reflect on these interactions enhanced the researcher's knowledge of good practice in these situations and also enabled identification of what should be avoided within the main study.

One of the main issues noted related to administration of the modified SWAL-QOL. Early on in modified-SWAL-QOL administration and in response to three different statements, the stroke participant selected Likert scale response options which contradicted his added contributions. In these instances, it was considered appropriate to reduce his choice of response options to two, based on his input. However, as a result of these experiences, there were other instances where the researcher may have too readily reduced the participant's response options to a choice of two. The researcher did however base her decision regarding which two response options to provide on the participant's initial reaction to the statement/the participant's response to the researcher's questioning which sought to establish whether or not the problem in the statement was an issue for the participant. Upon reflection, the researcher may have simplified things too readily, without initially persevering and providing the participant with further explanation concerning use of the Likert Scale. There were also instances where the researcher made an assumption about the participant's chosen response without providing him with response options/without seeking appropriate clarification. Moreover, there was an instance of ambiguity where the researcher did not persevere for long in order to obtain clarification. Rather than making assumptions, the researcher should have consistently provided the participant with response options/sought appropriate clarification when necessary.

A key issue relating to both the interview and RD with the stroke participant concerned the use of leading questions/prompts and the use of prompts too readily without giving the participant an opportunity to respond to the open question. However, this process provided an indication of the effectiveness of the SWAL-QOL in informing the content and direction of the semi-structured component of the interview, and the usefulness of the RD in further exploring dysphagia-related issues as well as providing insight into other aspects of the mealtime experience.

Overall, conducting the interview and RD with the stroke participant in the pilot study increased the researcher’s confidence in using these methods. Moreover, the piloting process provided insight into how to conduct modified-SWAL-QOL administration more appropriately and effectively and drew attention to the importance of monitoring the phrasing of questions within the main study, in order to increase the quality of the interviews and discussions. Experience was also gained in operating the audio and video recording equipment used to record the interview and RD, enhancing efficiency and reducing the risk of operator error resulting in loss of important data.

Utilisation of the mealtime observation schedule to collect data from the stroke participant helped assure the researcher that the schedule was an effective means of obtaining data relating to the mealtime experience in the care home. Using the schedule during data collection with the stroke participant helped to improve the researcher’s observational skills. Furthermore, using the data obtained from the mealtime observations of the stroke participant appeared to be an effective means of informing the content and direction of the RD and ensured that the topics for discussion were tailored to this individual participant.

The pilot study also provided the researcher with the opportunity to practise the transcription of audio and video recordings and acquire skills in qualitative data analysis, specifically analysis from a descriptive phenomenological perspective. Colaizzi’s (1978) framework for data analysis was considered to be an appropriate and feasible means of analysing the data obtained from the stroke participant.

8.4.2 Participant identification and recruitment

The pilot study clearly served its purpose in informing on the feasibility of a larger study. Only one care home resident with oropharyngeal dysphagia caused by stroke was successfully recruited to the pilot. The SLT, who was responsible for the identification and recruitment of stroke participants, documented the issues associated with participant identification and recruitment.

The SLT had not anticipated difficulty with sourcing an appropriate number of stroke participants. However, although 350 care home residents with a history of stroke were identified through a computer database search, the majority were cognitively unable to take part, due to multiple strokes which had resulted in vascular dementia. The Speech and Language Therapy clinical notes (going back four years) were then examined. However, residents who had oropharyngeal dysphagia post-stroke tended to fall into three categories:

- Those with severe oropharyngeal dysphagia resulting in PEG feeding (individuals receiving non-oral nutrition were unsuitable for this study);
- Those with mild oropharyngeal dysphagia meaning that their diet did not require to be modified beyond a Texture E (individuals could only be considered for inclusion in the pilot if their food was modified to at least a Texture D) and/or not requiring thickened fluids (the requirement for participants to consume thickened fluids was removed approximately two months into participant identification and recruitment, as the SLT had reported that many individuals consuming modified diets were taking normal fluids);
- Those who had a history of multiple strokes and as a result, cognitive impairment, excluding them from participation.

Twelve residents were found to meet the study criteria, however upon further investigation, one had died; one had an ‘Adults with Incapacity’ certificate in place (meaning that they had been deemed by a medical practitioner as unable to make a decision about medical treatment); two had a history of being very uncooperative and four no longer had oropharyngeal dysphagia. Of the remaining four residents, three declined to participate and one agreed. Additionally, the SLT made contact with SLT adult services on several occasions, however no responses were received. She also passed on the criteria to the NHS Care Home Liaison Nurses and the Dietician attached to Care Home Services and again no suitable participants were identified via this route, with the main issue encountered being cognitive impairment.

Thus, it became apparent that difficulties existed in sourcing stroke participants who were willing to participate and who met the study inclusion criteria, largely due to the high prevalence of cognitive impairment among this population, preventing participation in a study of this kind where interview is a main means of data collection. The existence of these issues relating to the identification and recruitment of stroke participants indicated that an adequate sample of care home residents with oropharyngeal dysphagia caused by stroke was unlikely to be obtained for the main study. Therefore, in order to increase the likelihood of obtaining a suitable number of participants and resultantly gain adequate insight into the HRQOL issues for care home residents with oropharyngeal dysphagia, it was deemed appropriate that the inclusion criteria be broadened to include individuals with oropharyngeal dysphagia caused by any acquired neurological disorder, excluding dementia. This proposal was discussed with the SLT, who indicated no concern with obtaining an adequate sample for the main study using these amended criteria.

8.5 Evaluation of the main study

This investigation sought to explore the impact of acquired neurological oropharyngeal dysphagia upon the HRQOL of care home residents and was much needed given the paucity of available data in this area for use by SLTs working with this client group. The key strengths (8.5.1) and limitations (8.5.2) of the study are detailed below and following this, consideration is given to the experience acquired and the challenges encountered in the main study (8.5.3). Subsequently, the researcher's perceptions of the results of this investigation are presented (8.5.4).

8.5.1 Key strengths of the investigation

(1) It is considered that a qualitative methodology was appropriate for achieving the aims of this investigation and some previous healthcare studies investigating QOL have adopted a qualitative approach (e.g. Watt and Whyte, 2003; Roberts et al, 2006; Moi and Gjengedal, 2008). The concept of QOL has been conceptualised as subjective and individualised (WHOQOL Group, 1995; Davis, 2007) and thus it is considered essential that individuals' perceptions of their QOL are elicited. The majority of previous studies examining the QOL impact of dysphagia have been quantitative and have relied upon structured HRQOL measures to provide an indication of dysphagia-related QOL impact (e.g. Nguyen et al, 2005; Roy et al, 2007; Plowman-Prine et al, 2009; Brandao et al, 2010; Leow et al, 2010). The value of these measures is acknowledged and indeed the SWAL-QOL (in a modified form) played an exceedingly important role within the present investigation. However, it was considered of utmost importance that this study did not solely rely upon a structured measure of HRQOL, as the researcher recognised the value in providing research participants with the opportunity to express their experiences in their words.

(2) It was deemed that having SLTs identify suitable PWD was a strength of this investigation, as it could be established that the participants had a clinical diagnosis of oropharyngeal dysphagia. Many previous studies exploring the QOL impact of dysphagia have relied upon participants self-reporting the existence of swallowing difficulties and the reliability of this approach is questioned (e.g. Ekberg et al, 2002; Lovell et al, 2005; Roy et al, 2007; Chen et al, 2009).

(3) The inclusion of a control group strengthened this investigation as it indicated a recognition that the HRQOL impact of acquired neurological oropharyngeal dysphagia could not be viewed in isolation, given the many additional factors known to influence the mealtime experience in the care home.

(4) The fact that residents of various care homes within the West of Scotland area were involved in this study strengthens the findings, as it is apparent that there are similarities in the dysphagia and/or mealtime-related experiences of individuals residing in different care homes.

(5) With regards to the methods of data collection, it is considered a positive aspect of the study design that methodological triangulation, specifically between-method triangulation was utilised. The use of three methods of data collection served to provide detailed insight into the HRQOL impact of acquired neurological oropharyngeal dysphagia and/or the mealtime experience in the care home. Moreover, between-method triangulation enables the weaknesses inherent in one method of data collection to be counterbalanced by the strengths inherent in the other methods (Arksey and Knight, 1999). The interviews and RDs with the CP and PWD relied on these individuals self-reporting their experiences, although the content of the RDs was largely informed by the observational data. Self-report is an essential means of obtaining data relating to QOL (Morton and Izzard, 2003). However, problems can arise when relying on self-report and Denscombe (2010) states that participants' accounts are not necessarily truthful. Holloway and Wheeler (2010) explain that participants may produce responses which aim to please the researcher or which presents them favourably. The mealtime observations on the other hand did not rely on self-report and provided direct access to the participants' mealtimes. This investigation is strengthened by the fact that the observational data largely corroborated with the participants' accounts.

(6) The use of the SWAL-QOL (in a modified form) to focus the thinking of the PWD and to highlight issues for further discussion within the semi-structured component of the interviews is considered a particularly positive aspect of the study design. It provided a means by which the researcher could gain further insight into the HRQOL impact of acquired neurological oropharyngeal dysphagia based on the participants' own evaluations of impact. Watt and Whyte (2003) administered two HRQOL questionnaires

(one of which was specific to individuals with oesophageal cancer) prior to conducting semi-structured interviews with individuals with oesophageal dysphagia caused by oesophageal cancer, although their purpose for doing this was for triangulation, rather than to inform the content of the interviews. Furthermore, in Tong et al's (2011) investigation of perceptions and experiences of post-irradiation swallowing difficulties in survivors of nasopharyngeal cancer, participants' responses to a self-administered questionnaire (a swallowing-specific questionnaire devised by the authors) formed the basis of the interview guide. Other research in this area has utilised generic or non-swallowing-specific measures of HRQOL (Nguyen et al, 2005; Eslick and Talley, 2008; Maclean et al, 2009b; Brandao et al, 2010) and it is proposed that the use of a dysphagia-specific measure of HRQOL provides more detailed insight into the HRQOL impact of dysphagia.

(7) It is considered that the mealtime observation schedule was an effective tool for collecting data concerning care home residents' mealtime experiences. It is acknowledged that producing video recordings of the observations for the purpose of checking them retrospectively would have been a good measure of intra-rater reliability. However, ethical issues precluded this as other residents and staff who had not given informed consent may also have been captured on the recording.

(8) With regards to data analysis, it is deemed that analytical rigour was demonstrated within this investigation. Use of Colaizzi's (1978) framework for phenomenological analysis served to provide a structured means for conducting analysis and thus enhanced the transparency of the analytical process. Moreover, it is considered that the use of a computer software programme to aid analysis of the data obtained from the PWD assisted with organisation of the data and helped to ensure that a systematic approach to analysis was adhered to. Checks of two transcripts from both participant groups provided assurance that transcription had been conducted accurately. Furthermore, eight of the transcripts produced from data collection with the CP were discussed with the first supervisor and many discussions between

the first supervisor and the researcher occurred during analysis of the data obtained from the PWD. The transcripts of the PWD and the analysis of these data were also subjected to a review by the first and second supervisors and amendments to the analysis were made based on feedback received.

(9) It should also be noted that engaging with the process of 'bracketing', an important component of a descriptive phenomenological approach to research, prior to data collection, served to make the researcher aware of her preconceptions about the topic of investigation. By bringing these preconceptions into conscious awareness, the researcher could try to minimise the influence of these preconceptions upon data collection and analysis as much as possible.

8.5.2 Limitations of the investigation

(1) The main limitation of this investigation is deemed to be the small number of PWD, which clearly limits the extent to which these findings can be generalised to the wider population of care home residents with acquired neurological oropharyngeal dysphagia. The small sample size did however afford detailed exploration of the data and thus enabled the researcher to gain a detailed understanding of the experiences of individuals with acquired neurological oropharyngeal dysphagia residing in a care home.

Despite the belief of the SLT involved in participant recruitment in the pilot study that inclusion of individuals with any acquired neurological disorder excluding dementia would make obtaining a good participant sample manageable, significant difficulties were experienced in identifying individuals who met the study inclusion criteria. Approximately fourteen months were allocated to participant identification and recruitment and within this period further steps were taken in an attempt to increase the available pool of participants. Two additional health boards were added to the study and their involvement yielded two participants (both from the same health board).

Furthermore, the inclusion criterion relating to dietary modification was broadened to include individuals consuming a Texture E diet and this was also successful in obtaining further participants. An attempt was also made to locate suitable participants by emailing members of the Scottish Dysphagia Special Interest Group (SIG). One SLT responded positively, however, upon further examination of the criteria realised that the individuals she had initially considered were not suitable. It was apparent from feedback and comments made by the SLTs involved in participant identification and recruitment, that the main issue in identifying individuals who met the inclusion criteria related to the high prevalence of cognitive impairment among this population. Whilst focusing on one specific dysphagia aetiology would have been preferable, the experiences of the pilot clearly indicated that this was not feasible. However, dysphagia aetiology has been confined to acquired neurological disorders and individuals with oropharyngeal dysphagia caused by structural abnormalities, such as head and neck cancer and/or its treatment, have been excluded.

(2) Given that care home managers/staff nurses were responsible for the identification and recruitment of CP, it is possible that selection bias may have existed, as residents who were positive about eating and mealtimes and tended not to complain about aspects of care home living may have been approached. However, no viable alternative existed and negative aspects of mealtimes which were attributable to the care homes themselves were reported within the participant sample.

(3) Although negative aspects of mealtimes which were attributable to the care homes themselves were reported within both participant samples, it is possible that participants may have with-held information/failed to be fully open with the researcher/'watered down' their opinions in relation to aspects which could come across as critical of the care home or staff for fear that these comments would be reported back to staff. Whilst all participants were assured of the confidential nature of the study, the researcher could have

taken a further step to offer specific assurance that no information would be reported to care staff.

(4) With regards to data analysis, the final step was omitted from Colaizzi's (1978) analytical framework (asking participants about the findings) on the basis that the researcher did not wish to place further demands upon these frail individuals as they had already been engaged in two sessions where the focus centred on expression of their experiences and perceptions. It is acknowledged that including respondent validation within the analytical procedure would provide a further assurance that the findings accurately represent the views of the participants.

8.5.3 Experience acquired and challenges encountered during the main study

8.5.3.1 Control participants

Critical appraisal of the interview and RD transcriptions produced from data collection with the CP led to important lessons being learned, which the researcher was able to carry forward into data collection with the PWD.

Failure of the researcher to be insistent that responses to the modified-SWAL-QOL were provided using the Likert Scales/to provide explanations and prompts to facilitate consistent use of the Likert Scales meant that for three CP minimal responses were provided using the Likert Scale options, leading to the researcher overtly or covertly making assumptions about chosen responses based on participants' contributions. Upon reflection, it was considered that for two of the other CP it would have been appropriate to offer them the four response options for each statement/item.

Furthermore, there were occasions where the wording of questions would have benefited from rephrasing in order to be more open. For example, questions such as, "Do you have a big appetite?" or "Is [the dining room] a pleasant place to eat your meals?" could be construed as leading. Although some questions were poorly phrased, it is deemed highly unlikely that the use of such questions would have amounted to misrepresentation of the CP. It is also recognised that elderly individuals may have difficulty in responding to very open questions.

8.5.3.2 Participants with acquired neurological oropharyngeal dysphagia

It is considered appropriate to provide a reflection on the interviews and discussions with the PWD from the researcher's perspective in order to provide an overview of the key challenges encountered and how these were handled.

Poor intelligibility was the most common problem encountered with the PWD and was most problematic in the interviews and RDs with P1, P3 and P7. Low volume was the issue for P3 and in order to at least make transcription of the RD less challenging, the researcher provided the participant with a headset containing a microphone which was connected to the audio recorder and he was content to wear this for the RD. Additionally, when P3's RD was halted for medication administration, the researcher asked the staff nurse if P3's pressure mattress could be switched off to reduce background noise. P1 and P7 were the participants from whom the most data were lost as a result of their poor intelligibility. P4 predominantly used the written word to communicate and this served to effectively compensate for his very poor intelligibility. The visual Likert Scales were very useful with this participant as he was able to point to his chosen modified-SWAL-QOL responses, thus eliminating any risk of misinterpretation due to poor intelligibility.

P3, P5 and P7 notably digressed during their interviews and RDs about aspects unrelated to the topic under investigation which they were clearly keen to share. Most of P3's tangential comments were relatively brief and in most cases when necessary, the researcher brought him back to the aspect under discussion once he had finished speaking. P3 also embarked on a lengthy digression about PD in general at the outset of the RD and in this instance, the researcher felt it was appropriate to allow him to share his knowledge and experiences of his condition. Three of P5's digressions were very lengthy and upon reflection, the researcher should have politely interrupted him sooner, although a digression was successfully avoided on another occasion. During his interview, P7 was less concerned about talking about his experiences of oropharyngeal dysphagia and more about his issues with socialising which did not appear to be specific to mealtimes. The researcher tried to keep P7 on topic as best as possible. On the two occasions where P6 clearly demonstrated a lack of awareness of her swallowing difficulty, the researcher considered that it was appropriate not to challenge P6 on her comments, in order to avoid causing her distress.

The interviews and RDs with P1 and P2 were considered the most challenging. Although P1 was able to cope with a choice of four response options to the modified-SWAL-QOL statements on some occasions, in other instances he struggled to provide a response from a choice of four options and thus it was considered necessary to reduce his choice of response options to two. The visual Likert scales could not have been used to aid this participant because he had a severe visual impairment. The interview was conducted over two days, as the researcher became aware that fatigue was a particular issue for this participant. He did not provide much insight into his perceptions of oropharyngeal dysphagia within the semi-structured component of the interview and any contributions were minimal. He seemed to handle the questions in the RD slightly better than those in the interview, although again his responses were short. P1 required extensive processing time and often required further prompting in order to obtain a response. P2 was unwilling to respond to open questions (seemingly due to his personality) and would only provide yes/no responses. This meant that the researcher had to quickly develop a strategy to collect data from the modified-SWAL-QOL and ranking item and the system was established that the participant would indicate verbally and/or non-verbally when his desired response had been read out. P2 only responded to one open question within the RD. Within P1's interview and P2's interview and RD, the researcher felt that it was necessary to persevere with questioning in case a topic arose that the participants were keen to discuss, and neither indicated an unwillingness to continue.

8.5.4 Researcher's perceptions of the results

Following completion of the study, it was interesting to compare the researcher's pre-suppositions (4.4) with the findings of the investigation. Acquired neurological oropharyngeal dysphagia was indeed found to negatively impact the HRQOL of care home residents. However, with regards to oropharyngeal dysphagia negatively affecting participants' mealtime experience, most expressed a positive attitude towards eating and/or mealtimes in the care home and this finding was surprising to the researcher. Dissatisfaction with texture-modified diets was a dysphagia-specific HRQOL issue reported by two participants, although this did not appear to negatively impact their overall enjoyment of eating and mealtimes, which was unexpected. Finally, eating and mealtime-related issues, other than oropharyngeal dysphagia, were found to exist for care home residents.

The most surprising finding which emerged from this investigation concerned the responses provided by the PWD to the ranking item. The researcher had expected the majority of participants to rank their swallowing difficulty as the issue which affected their life the most, given the centrality of food to QOL. However, none of the participants ranked their swallowing problem as the issue which affected them most, despite the fact that they had identified various HRQOL issues pertaining to their oropharyngeal dysphagia. This finding reminded the researcher that there is a need to bear in mind that there may well be other issues of greater importance to care home residents with acquired neurological oropharyngeal dysphagia.

8.6 Implications of the findings for clinical practice

This section clearly states the implications of this research for clinical practice. Given the small sample of PWD and CP included in this study, these recommendations are stated with caution.

8.6.1 Implications for clinical practice relating to care home residents with acquired neurological oropharyngeal dysphagia

The key recommendations for SLTs relating to the management of care home residents with acquired neurological oropharyngeal dysphagia are as follows:

1. Sensitive consultation with clients

This study has indicated that care home residents with acquired neurological oropharyngeal dysphagia experience negative physical (8.2.1), social (8.2.2) and psychological (8.2.3) issues as a result of this disorder. Negative perceptions of texture modified food were also evident within this participant sample (8.2.4). Thus, it is considered of utmost importance that SLTs use their counselling skills to elicit clients' perceptions of their dysphagia and any concerns which they have relating to this disorder and provide appropriate support based on this discussion. It is proposed that SLTs are best equipped to do this, given their key role in the management of oropharyngeal dysphagia and the knowledge of swallowing disorders which they possess. Klugman and Ross (2002) state that SLTs (although they use the term SLP-Speech-Language Pathologist) are qualified to provide counselling to individuals with dysphagia concerning the QOL impact of this disorder. It is however important that SLTs do not function beyond their level of competence and thus, if deemed appropriate, referral to another professional such as a clinical psychologist should occur (RCSLT, 2006).

In order to elicit client's perceptions of their oropharyngeal dysphagia and their concerns relating to this disorder, SLTs may find it helpful to use a dysphagia-specific HRQOL measure, such as the SWAL-QOL, which proved to be effective in the present investigation for focusing clients' thoughts and stimulating discussion. Such measures could not only provide an indication of areas to focus on in management, but they could also be used in the evaluation of treatment outcome.

Ultimately, by being informed of their clients' dysphagia-related concerns, SLTs will be better placed to provide the support required to eliminate or minimise HRQOL issues related to oropharyngeal dysphagia. Examples of the kind of support which could be provided to care home residents with acquired neurological oropharyngeal dysphagia, based on the present investigation, are provided below.

For instance, P3 was depressed by his drooling, which had not been alleviated by any medical interventions and in instances like this, it is proposed that giving the client an opportunity to share their concerns whilst being empathic, could help them to feel less isolated in their suffering.

Moreover, although he already appeared to understand that dysphagia could lead to choking and aspiration, if he had not previously been able to do so, P4's irritation concerning dietary restrictions could possibly be reduced by allowing him to question the restrictions which had been placed on foods he felt he was able to swallow safely. It is considered appropriate that every client be given the oppportunity to express their opinions on decisions relating to the management of their oropharyngeal dysphagia and to ask questions, if desired. It is also considered appropriate that SLTs ensure that they review the management recommendations for their clients on a regular basis to prevent clients from consuming a more restricted diet than is necessary. The SIGN guideline for dysphagia caused by stroke (SIGN 119, 2010) recommends that individuals with persistent dysphagia be subject to regular review.

A desire to eat alone, with the exception of close family members in some cases, due to the presence of dysphagia has been frequently reported within the literature (e.g. Ekberg et al, 2002; Watt and Whyte, 2003; Miller et al, 2006; Farri et al, 2007; Garcia-Peris et al, 2007). All care home residents have the right to eat their meals in a location of their choice (The national care standards on care homes for older people, Scottish Government, 2007). However, in the present investigation, it was unclear whether one of the PWD (P1) who reported experiencing embarrassment at mealtimes as a result of dysphagia and who usually ate in the dining room, was aware that he had such an option. The SCIE (2009) states that, “While socialising during mealtimes should be encouraged, offer privacy to those who have difficulties with eating, if they wish, to avoid embarrassment or loss of dignity” (p.3). However, the potential impact of social isolation upon mental health should also be taken into consideration.

2. Communication with care home staff

The RCSLT (2005) stress the importance of team working in the management of oropharyngeal dysphagia and acknowledges that the composition of the team may vary depending on the setting. Given that nursing and care staff will have the most frequent contact with care home residents with acquired neurological oropharyngeal dysphagia, it is argued that collaboration with these individuals is essential.

It is proposed that SLTs will need to work closely with care home staff in order to ensure that some of the support identified as necessary for their clients is consistently provided. However, SLTs should ensure that clients give their permission to information they provide being shared with care staff when this is necessary in order to ensure the consistent provision of care which seeks to minimise the HRQOL impact of oropharyngeal dysphagia. For example, if a client expresses embarrassment due to an increased eating duration, the SLT could liaise with the care staff in order to make arrangements for them to eat little and often, in an attempt to minimise embarrassment at mealtimes. Furthermore, if a client were to express concerns regarding the provision of unsuitable food, the SLT would need to sensitively liaise with the nursing staff to establish how this issue would be resolved, in order to increase physical safety and reduce the psychological burden placed on the individual. There may also be instances where three-way discussions between the SLT, care staff and client would be helpful to give the client an opportunity to voice any concerns regarding their dysphagia management in the presence of the individual responsible for making the recommendations and representatives of the individuals responsible for implementing the recommendations.

3. Care home staff training

With regards to the management of care home residents with acquired neurological oropharyngeal dysphagia, it is proposed that SLTs have an important role in providing education and training to care home staff, the individuals who are responsible for the daily care of residents.

Three participants in this study were dissatisfied with their texture-modified dysphagia diets and there is a clear need to improve the variety and appearance of texture modified food. It is proposed that care home catering staff should receive (further) training in how to retain variety in texture modified diets and how to increase their visual appeal and it is advocated that SLTs have a role in providing such training, in collaboration with dieticians and catering experts. The views of dysphagic individuals regarding how modified diets could be made more pleasing could also be used to inform the direction of such training.

The fact that all of the PWD in this study received at least some food which was not appropriate for their recommended dysphagia diet signals the need to training to be conducted with care staff, catering staff in particular. Within a care home setting, where residents do not have control over the food which they are served, it is considered essential that catering staff are aware of the reasons for dietary modification and the potential consequences if unsuitable food is provided. It would be considered helpful for such training to include guidance on using and interpreting the Dysphagia Diet Food Texture Descriptors (NPSA, 2012).

It is also considered that SLTs have a role in providing care home staff with insight into the negative HRQOL impact of acquired neurological oropharyngeal dysphagia, to enable them to understand the potential concerns which may exist for residents with oropharyngeal dysphagia and to provide them with suggestions for how to minimise the negative HRQOL impact. Equipped with this knowledge, care staff may be more sensitive to potential issues of concern for dysphagic residents and may be able to take action to alleviate these concerns, with advice and guidance from the SLT.

It is recognised that the provision of training for care home staff is complicated by the fact that care homes are likely to employ a large number of staff, some of whom may be agency staff, and that there may also be a high turnover of staff. To try and overcome these issues, it is suggested that training for both care staff and catering staff is provided at regular intervals. Furthermore, it is recommended that the information delivered during training also be presented in written form, not only to help staff present at the training remember the points, but also in order that the information can be disseminated by management to members of staff who have not yet attended training.

O'Loughlin and Shanley (1998) have reported on the success of a care home staff training programme in the domain of swallowing difficulties, indicating that change in the management of swallowing difficulties by care staff is possible. The 'Swallowing…on a Plate' or SOAP programme is a training programme which teaches nursing staff how to identify, assess and manage swallowing problems and learn more about making referrals. As part of their participation in the programme, the course participants were required to provide some form of inservice training to the other staff at their care home and devise a swallowing management plan for the home. In their evaluation of the training programme, O'Loughlin and Shanley (1998) found a statistically significant difference between the 'Knowledge of dysphagia' test scores at the beginning of the first session and at the three month follow-up. Importantly, the nurses reported that the nursing assistants in their care homes were clearer about the proper management of residents with swallowing problems at the three month follow-up and this finding was statistically significant. It is positive that the course material has been developed into a stand-alone training resource which can be used by experienced nurses to bring about change in their workplace, thus reducing the training workload for SLTs. However, this programme did not appear to provide information relating to the HRQOL impact of swallowing difficulties and it is recommended that it be adapted to include this information.

Steele, Rivera, Bernick and Mortensen (2007) elicited the experiences of non-nursing staff in a geriatric care facility who had been recruited to provide mealtime assistance in an emergency situation, where quarantine restrictions prevented volunteers and family members, who would typically have provided mealtime assistance, from entering. Their intention was to use the participants' experiences of mealtime assistance to inform the design and operation of future mealtime assistance programmes. In a similar vein, it may be appropriate to gain insight into the perceptions and experiences of care home staff with regards to working with residents with oropharyngeal dysphagia and use the findings to develop training materials which will meet the specific needs of care staff.

8.6.2 Implications for clinical practice relating to all care home residents, regardless of the presence of oropharyngeal dysphagia

This investigation has also indicated that negative mealtime-related issues exist for care home residents, regardless of whether or not oropharyngeal dysphagia is present. Some key recommendations can be made based on the accounts of care home residents with and without dysphagia concerning their eating and mealtime experiences:

1. Where necessary, resident satisfaction with the care home food should be enhanced.

The national care standards on care homes for older people (Scottish Government, 2007) state that the meals provided to care home residents should be “varied and nutritious”; should reflect residents’ “food preferences and any special dietary needs” and should be “well prepared and cooked and attractively presented” (p.39). The existence of negative reports about care home food within this study, suggest a need for staff to ensure that residents’ views are taken into consideration when developing and reviewing the catering system.

However, it is recognised that catering for large numbers will impose limitations on the extent to which individual preferences can be accommodated. Budgetary constraints are also likely to be a restricting factor. Evans, Crogan and Shultz (2005) do however suggest the implementation of a strategy which involves appointing the occupants of one table every week as ‘hosts’ and serving everybody a favourite food chosen by each ‘host’ at intervals in the week. It is considered that such a strategy would not have significant cost implications. Evans et al (2003) state that “Serving good food is essential for a quality dining experience, no matter what the setting” (p.2) and thus it is considered of utmost importance that residents are satisfied with the food they are served.

2. The impact of barriers to mealtime enjoyment (both physical and institutional) should be minimised as much as possible.

Given the existence of various physical issues impacting upon the mealtime experience of care home residents, it is clear that such issues need to be identified if they have not been already, and appropriate action taken to compensate for these and/or emotional support provided.

Three key institutional barriers identified in the present investigation concerned the desire of some residents not to socialise at mealtimes/their contentment with minimal socialisation; the behaviour of other residents with dementia in the dining room and lengthy waiting times in the dining room prior to food provision. Recommendations for how these issues could be addressed are presented below.

It is considered important that care home residents be consulted regarding their preferred social state at mealtimes, to avoid individuals being placed in circumstances which they find undesirable. For instance, if staff are aware that a resident does not wish to socialise, they may sensitively advise this individual that they may not wish to sit at a table where plenty of conversation usually occurs. A resident who does not desire any social contact at all may ideally choose to eat in their room and the rights of care home residents to eat in a location of their choice has previously been acknowledged (page 240).

Whilst all three of the participants in this study who expressed concerns relating to the behaviour of other residents in the dining room were aware that they could eat their meals in their own room, only one had chosen to consistently do so. For residents who still wish to eat in the dining room, it is deemed appropriate that sensitive consultation with these individuals occurs and staff should take time to observe the dining room dynamic. Decisions relating to seating arrangements should be made on a case-by-case basis and should not be made without careful monitoring of the situation.

With regards to reducing lengthy waiting times prior to meal provision, it is possible that by having more staff on duty at mealtimes, care staff would be under less pressure to assist more dependent residents to the dining room and may be able to wait to bring them to the dining room closer to the beginning of the mealtime. Increasing staffing levels may also serve to reduce any delay before getting served. Kayser-Jones and Schell (1997) enforce the need for adequate staffing within care home settings as one way of enhancing the quality of mealtime-related care of residents. It is recognised however, that this suggestion has financial implications for care home managers.

3. Care home residents should be enabled to maintain as much autonomy as possible at mealtimes.

It is proposed that care staff have an important role in helping care home residents to maintain their autonomy while residing in an institutional setting and it is considered that this can be done simply by consultation with individual residents. For instance, care staff could take time to elicit residents' preferences for their desired eating location and seating position should they choose to eat in the dining room. Moreover, Evans et al (2005) recommend that care staff consult residents and their families/friends concerning resident food preferences.

4. The nutritional status of residents should be monitored regularly.

It is expected that care homes regularly monitor the nutritional status and weight of residents and take appropriate action if a resident is identified as being at-risk of under-nutrition (Care Commission, 2009) (Now the Care Inspectorate).

5. Residents should be consulted concerning their desired portion size.

Addressing issues related to food quantity could involve consulting a resident concerning their desired quantity. Moreover, Evans et al (2005) support a food cart/buffet-style dining system, which allows residents to choose their desired portion size and also provides them with the opportunity to exert choice over food selection. It is acknowledged that the feasibility of such an approach is questionable when residents require dysphagia diets.

It is proposed that SLTs could use these recommendations to help improve the mealtime experience of their clients with acquired neurological oropharyngeal dysphagia. However, they could also disseminate this information to care staff during training concerning the HRQOL impact of acquired neurological oropharyngeal dysphagia. This could result in enhanced mealtime experiences for residents with and without dysphagia.

8.7 Recommendations for future research

(1) First and foremost, it is considered that future investigations should include a larger participant sample in order to gain a more representative picture of the HRQOL impact of acquired neurological oropharyngeal dysphagia upon care home residents. The experiences of this investigation clearly illustrate the difficulties associated with obtaining participants when conducting research with care home residents with acquired neurological disorders, largely due to the high prevalence of cognitive impairment within this population. This was despite the involvement of three large Scottish NHS health boards and advertisement of the study to members of the Scottish Dysphagia SIG. Therefore, researchers conducting future investigations in this area will need to collaborate with multiple health boards and may need to explore the involvement of other countries in the UK. The role of the SLT in participant identification and recruitment however is considered imperative.

(2) The inclusion of a control group of care home residents without dysphagia within the present study was highly beneficial and should be strongly considered for inclusion within future investigations in this area.

(3) Given that the majority of previous research which has explored the QOL impact of dysphagia has been quantitative, there is a great need for further qualitative research in this area, as a means of gaining further insight into the perceptions and experiences of participants. Interviews in future studies could also use the SWAL-QOL to focus thinking and inform the content of the semi-structured component as it provides a means by which further insight into participants' views can be sought based on their own evaluations of impact.

It is recognised that improvements to the semi-structured component of the interviews could be made for use in future research. Whilst the schedule for the RD was prepared in advance of the RDs, largely based on the observational data, the schedule for the semi-structured component of the interviews was not. Although identifying issues for discussion with the PWD based on their responses to the modified-SWAL-QOL statements necessitated flexibility and recognition of the individuality of participants, on hindsight it is considered that a slightly more structured framework could have been employed to avoid the researcher having to formulate questions from scratch during each interview. For future investigations, the researcher could prepare a schedule which contains several questions for each statement, covering the various response options, in order to enhance the consistency of questioning across the participant sample and thus ensure a more uniform approach.

(4) Future research should also incorporate a more in-depth exploration of participants' opinions regarding consumption of texture modified diets, with a view to further illuminating the impact of Speech and Language Therapy management decisions upon the lives of clients and resultantly leading to the development of clear recommendations concerning care home catering. Given that it was the two participants who consumed at least some puréed food who expressed dissatisfaction towards their texture modified diets, further research with individuals consuming puréed diets is justified and indeed necessary.

(5) The present investigation has indicated that between-method triangulation can provide detailed insight into participants' experiences, in addition to enhancing the validity of the research. Thus, it is considered that future research in this area should utilise more than one method of data collection and even the same combination of methods used within this investigation.

Investigators using the mealtime observation schedule within future studies might consider field-testing the schedule prior to data collection as a means of gauging the inter-rater reliability of this measure. This would involve two researchers who had familiarised themselves with the schedule observing the same individual in a similar setting to where the actual study would be conducted, and several of these trial observations could be conducted with different people. By evaluating the extent to which similar data were obtained during the observations, it could be established whether different researchers are likely to capture identical or nearly identical information during mealtime observations. If notable differences existed between the data collected, refinement of the schedule could take place to improve inter-rater reliability and thus increase confidence in the tool. For example, it may be concluded that additional prompts and explanations should be incorporated within the schedule in order to increase consistency between researchers.

(6) It is recognised that data collection with each participant in this investigation occurred over a very short period of time (data collection with all participants was completed within two weeks and the majority within less than a week). In future investigations, data collection could occur over a longer period of time, for instance a period of one month. In addition to an initial interview, a second interview could also be conducted with participants towards the end of the month as by this point, participants would have become more familiar and likely more comfortable with the researcher and may share perceptions and experiences that they may not have disclosed at the beginning of data collection. The second interview could be based on the

content discussed during the initial interview, with participants asked to elaborate on anything else they wished to share regarding these aspects. This interview session could also incorporate a formal measure of psychological well-being, such as the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983), which has been used in previous relevant research by Nguyen et al (2005). If such a measure was utilised, it would be appropriate to include a control group of care home residents without dysphagia in order to determine whether the presence of oropharyngeal dysphagia is associated with lower levels of psychological well-being, as has been reported in previous research.

During this more extended period of data collection, observations could occur at breakfast (where possible), lunch and dinner once a week and RDs could be conducted at the end of each week based on the data collected. This would provide a more representative picture of the mealtime experience, as opposed to the 'snap-shot' view gained in the present investigation. However, it must be acknowledged that data collection may well be disrupted by participant illness, which was one of the reasons for ensuring that data collection was not extended over a longer period in the present investigation.

(7) There is also scope for longitudinal research which evaluates change associated with the provision of the care staff education and training previously recommended (pages 241-243).

(8) Minimal research has explored the eating and mealtime experiences of individuals residing in care homes in the UK and further research with a larger participant sample is warranted to enable greater generalisation to the wider care home population.

8.8 Conclusions

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) clearly advocates the need to consider healthcare service-users beyond their physiological status. It is considered that exploration of an individual's QOL encapsulates holistic consideration of service-users, although the term HRQOL is deemed more appropriate within the health care domain. In addition to being crucial to individuals' physiological well-being, food contributes to cultural, social and psychological QOL (American Dietetic Association, 2005) and previous research has evidenced the negative impact of dysphagia upon QOL. However, despite the high numbers of care home residents who have dysphagia, minimal research has explored the HRQOL impact of dysphagia upon care home residents, meaning that SLTs lack sufficient knowledge regarding the QOL issues which exist for this client group.

This investigation has provided insight into the HRQOL issues experienced by care home residents with acquired neurological oropharyngeal dysphagia and their experiences of eating and mealtimes. The physical, social and psychological impact of acquired neurological oropharyngeal dysphagia upon the study participants is clearly apparent. Whilst the majority of participants had adjusted to their modified diets, dissatisfaction towards texture modified food was expressed by two individuals. Interestingly, despite the obvious HRQOL issues which existed as a result of acquired neurological oropharyngeal dysphagia, none of the PWD felt that dysphagia was the issue which affected their lives most, indicating that care home residents with acquired neurological disorders are dealing with other issues in their lives which they deem more of a priority.

The eating and mealtime experiences of the PWD were similar to those of the care home residents without dysphagia of any type who were involved in this study, and by collecting data from these individuals it was possible to distinguish the HRQOL impact of acquired neurological oropharyngeal dysphagia from other issues which impact upon the mealtime experience of care home residents. These findings indicate that there are aspects of the eating and mealtime experience which are similar for care home residents with and without dysphagia. Whilst the majority of all participants enjoyed eating and/or mealtimes and the care home food, negative views were expressed. Barriers to mealtime enjoyment were identified, some of which were physical and some of which were attributable to the care home situation. Consumption of a modified diet generally appeared to prevent provision of food choice and whilst choice relating to other aspects of mealtimes was evident in some cases, a lack of choice in relation to aspects of mealtimes other than food was also apparent. Amongst the CP, a desire for greater freedom of choice at mealtimes, in relation to both food and other aspects, was expressed. Participants from both groups reported variable/reduced appetites/a reduction in the amount of food consumed, in addition to the provision of too much food, in some cases.

These findings indicate that SLTs should ensure that they adopt a holistic approach to the management of care home residents with acquired neurological oropharyngeal dysphagia. This means that time should be spent eliciting any concerns possessed by clients relating to dysphagia and the resulting management decisions and providing emotional support/taking any appropriate action to alleviate these concerns, liaising with care staff where appropriate and also involving the resident in a three-way discussion when fitting. Furthermore, regular reviews of swallowing ability should occur to avoid individuals consuming more restricted diets than necessary. SLTs should also educate care home staff on the HRQOL impact of acquired neurological oropharyngeal dysphagia and should collaborate with other professionals to provide training to care home catering staff to encourage adherence to the Dysphagia Diet Food Texture Descriptors (NPSA, 2012) and the provision of texture modified food which is appealing, increasing resident satisfaction and compliance. It is proposed that by adhering to these recommendations, the negative impact of acquired neurological oropharyngeal dysphagia upon the HRQOL of care home residents can be minimised. The findings of this investigation also clearly indicate the existence of additional mealtime-related issues in the care home, other than dysphagia. Awareness of these aspects could enable SLTs to provide more holistic care to residents with acquired neurological oropharyngeal dysphagia and raise staff awareness of these aspects, resulting in enhanced mealtime experiences for residents with and without dysphagia.

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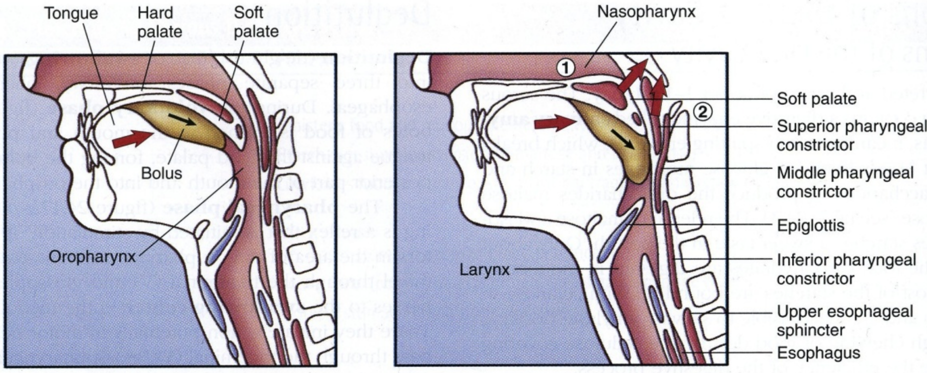
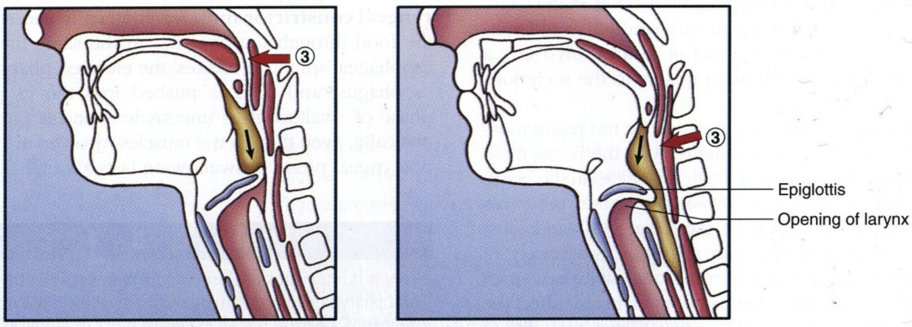
APPENDIX 1

Diagram illustrating the three phases of swallowing

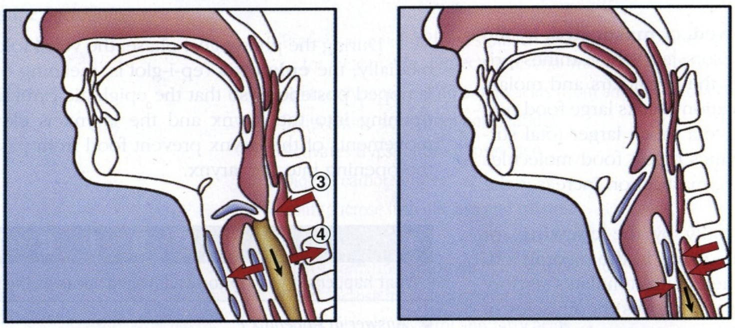


(a) During the voluntary phase, a bolus of food (*yellow*) is pushed by the tongue against the hard palate and posteriorly toward the oropharynx (*red arrow* indicates tongue movement; *black arrow* indicates movement of the bolus).

(b) During the pharyngeal phase, ① the soft palate is elevated, closing off the nasopharynx. ② The pharynx is elevated (*red arrows* indicate muscle movement).



(c) Successive constriction of the pharyngeal constrictors ③ from superior to inferior (*red arrows*) forces the bolus through the pharynx and into the esophagus. As this occurs, the epiglottis is bent down over the opening of the larynx largely by the force of the bolus pressing against it.



(d) As the inferior pharyngeal constrictor contracts ③, the upper esophageal sphincter relaxes ④ (*outwardly directed red arrows*), allowing the bolus to enter the esophagus.

(e) During the esophageal phase, the bolus is moved by peristaltic contractions of the esophagus toward the stomach (*inwardly directed red arrows*).

Figure 1.1: Three phases of swallowing (Deglutition)

Source: Seeley, R.R., Stephens, T.D., and Tate, P. (2000). *Anatomy and physiology* (5th ed.). Boston, Mass: McGraw-Hill Higher Education. This material is reproduced with permission of The McGraw-Hill Companies.

APPENDIX 2

The Dysphagia Diet Food Texture Descriptors

Dysphagia Diet Food Texture Descriptors

March 2012

NHS
National Patient Safety Agency

ROYAL COLLEGE OF
SPEECH & LANGUAGE
THERAPISTS

NACC
National Association of Care Catering

THE BRITISH DIETETIC ASSOCIATION

NNNG
National Nurses Nutrition Group
Registered Charity No: 295411

HOSPITAL CATERERS ASSOCIATION
CATERING FOR HEALTH CARE

Dysphagia Diet Food Texture Descriptors

What are these descriptors?

These descriptors detail the types and textures of foods needed by individuals who have oro-pharyngeal dysphagia (swallowing difficulties) and who are at risk of choking or aspiration (food or liquid going into their airway). The descriptors provide standard terminology to be used by **all health professionals and food providers** when communicating about an individual's requirements for a texture modified diet. The food textures are:

B = Thin Purée Dysphagia Diet
C = Thick Purée Dysphagia Diet
D = Pre-mashed Dysphagia Diet
E = Fork Mashable Dysphagia Diet

Fluids are not currently included in these descriptors. The following guidance is suggested for information on thickened fluids:

http://www.gcu.ac.uk/sndri/pdf/consistency/100505FluidThickening.pdf
and
http://www.speechpathologyaustralia.org.au/resources/terminology-for-modified-foods-and-fluids

Who developed the Descriptors?

The descriptors were developed by the National Patient Safety Agency (NPSA) Dysphagia Expert Reference Group in association with Cardiff and Vale University Health Board. This group included representatives from nursing, speech and language therapy, dietetics, hospital catering and industry. These descriptors **replace** previous versions that were developed by the British Dietetic Association (BDA) and Royal College of Speech and Language Therapists (RCSLT). These new 2011 descriptors have been endorsed by the BDA, RCSLT, Hospital Caterers Association (HCA) and the National Nurses Nutrition Group (NNNG).

Consultation has taken place with representatives from a wide range of manufacturers of dysphagia products throughout the development process.

Why were the descriptors developed?

The descriptors were developed in response to concerns relating to patient safety and a request from industry and in-house caterers for detailed guidance on categories of texture.

What is the rationale for the Descriptors?

The descriptors were developed from both the 2002 British Dietetic Association/Royal College of Speech and Language Therapists National Descriptors for Texture Modification in Adults and the Cardiff and Vale University Health Board's 2010 interpretation of these original descriptors. The scientific evidence in this field is limited. These descriptors are therefore based on the best available current evidence, on texture descriptors produced internationally, and a consensus of expert opinion. As new evidence emerges these descriptors will need to be amended.

Why might individuals need a texture modified diet?

Individuals may need to eat a texture modified diet because a) they are generally unwell and need a 'soft diet', or b) they have oro-pharyngeal dysphagia. The Dysphagia Diet Food Texture Descriptors are for individuals who have oro-pharyngeal dysphagia. Food for individuals who are generally unwell can usually be available from the 'soft food' options on a menu.

An individual who has oro-pharyngeal dysphagia may be at risk of choking and/or aspiration of food into the lungs. They may also be at risk of being unable to eat sufficient food to maintain their weight and unable to drink sufficient fluid to maintain hydration. Children may additionally be unable to eat sufficient food to grow.

How is a texture modified dysphagia diet recommended?

A texture modified dysphagia diet will be prescribed following assessment by a speech and language therapist or other appropriately trained healthcare professional, e.g. a professional trained to a specialist level on the Inter-professional Dysphagia Competency Framework. The prescribing practitioner will use their clinical judgement to prescribe any additional textures on a case-by-case basis.

How is a texture modified dysphagia diet provided to individuals?

This will depend on where the person is living or staying. For individuals who are in hospitals or residential care the food may be prepared by in-house caterers, or may be produced by industry. In other settings the modified diet may be produced by the individual's family or carers, or may be provided by industry.

Can these descriptors be used with children?

These new descriptors have been developed to include the needs of children. The only change is the size of the pieces of meat included in texture E, the Fork Mashable Dysphagia Diet. Following an individual child's assessment, a speech and language therapist may prescribe the Fork Mashable Dysphagia Diet, and will give specific guidance to parents and carers on the size of the meat particles based on the child's swallowing skills, their age and their development level. School caterers may also use these descriptors in conjunction with speech and language therapists and school staff.

What consistencies should all care settings provide?

It is envisaged that all care settings will have 2 available textures:

Texture C (Thick Purée Dysphagia Diet) and
Texture E (Fork Mashable Dysphagia Diet)

Texture D (Pre-mashed Dysphagia Diet) may be required routinely in some care settings: this should be agreed locally. Similarly some setting may routinely require Texture B (Thin Purée Dysphagia Diet).

Individual patients may require variation to one of these textures – this will be prescribed on an individual basis by a speech & language therapist following individual assessment.

What does this document include?

- Specific standards for each texture B, C, D and E.
- Audit checklists so that the food can be measured against the standards for each texture.

These sheets were designed for food producers, but may be useful for staff teaching and training.

Additional recommendations

The following recommendations are made by the NPSA Dysphagia Expert Reference Group:

- A review of the descriptors for thickened fluids should be undertaken
- Members of the Dysphagia Expert Reference Group should be involved in the review of the descriptors for thickened fluids
- Industry should be consulted with as part of the review of thickened fluids
- All professional organisations should encourage their members to comply with the terminology and language used within this document
- A pictorial training aid should be developed to support these Dysphagia Diet Food Texture Descriptors
- Industry is encouraged to review their packaging of texture modified foods to reflect the colour codes used for each texture descriptor within this document.

This document will be reviewed in two years from date of issue.

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HOSPITAL CATERERS ASSOCIATION
CATERING FOR HEALTH CARE

Dysphagia Diet Food Texture Descriptors

B Thin Purée Dysphagia Diet B

General description:

☑ Food has been puréed or has purée texture. It does not require chewing.

☑ It is a *thin* purée (*please see note below).

☑ It is smooth throughout with no 'bits' (no lumps, fibres, bits of shell/skins, bits of husk, particles of gristle/bone etc). It may need to be sieved to achieve this.

☑ It may have a *fine* 'textured' quality as long as the bolus remains cohesive in the mouth.

☑ It is moist.

☑ Any fluid in or on the food is as thick as the purée itself.

☒ There are no loose fluids that have separated off.

☒ The texture is not sticky in the mouth.

☒ No garnish.

Check before serving/eating:

☒ No hard pieces, crust or skin have formed during cooking/heating/standing.

☒ It has not thinned out and any liquid within the food has not separated off.

Note: No ice cream or jelly unless advised as suitable by speech & language therapist on an individual basis.

***Note – definition of '*thin*' purée**
Does not hold its shape on a plate or when scooped.
Cannot be eaten with a fork because it slowly drops through the prongs.
The prongs of a fork do not make a clear pattern on the surface.
It can not be piped, layered or moulded.
Can be poured.
'Spreads out' if spilled. A light, disposable plastic teaspoon must be able to stand upright when the head is fully covered.
If it does not do this, the texture is too thin.

Dysphagia Diet Food Texture Descriptors

C Thick Purée Dysphagia Diet C

General description:

☑ Food has been puréed or has purée texture. It does not require chewing.

☑ It is a *thick* purée (*please see note below).

☑ It is smooth throughout with no 'bits' *(no lumps, fibres, bits of shell/skin, bits of husk, particles of gristle/bone etc.)* It may need to be sieved to achieve this.

☑ It may have a <u>fine</u> 'textured' quality as long as the bolus remains cohesive in the mouth.

☑ It is moist.

☑ Any fluid in or on the food is as thick as the purée itself.

☒ There is no loose fluid that has separated off.

☒ The texture is not sticky in the mouth.

☒ It is not rubbery.

☒ No garnish.

Check before serving/eating:

☒ No hard pieces, crust or skin have formed during cooking/heating/standing.

☒ Fluid/gravy/sauce/custard in or on the food has not thinned out or separated off.

See overleaf for more details

***Note – definition of 'thick' purée**
Holds its shape on a plate or when scooped.
Can be eaten with a fork because it does <u>not</u> drop through the prongs.
The prongs of a fork make a clear pattern on the surface.
It can be piped, layered or moulded.
<u>Cannot</u> be poured. Does <u>not</u> 'spread out' if spilled.

Dysphagia Diet Food Texture Descriptors

C Thick Purée Dysphagia Diet C

Breakfasts and Desserts

☑ The texture of thick smooth porridge made from powder (purée porridge) with no loose fluids

☑ The texture of wheat-biscuit breakfast cereal fully softened with milk fully absorbed

☑ The texture of thick blancmange or mousse with no ‘bits’

☑ The texture of purée rice pudding

☒ There is no loose fluids

☒ There are no lumps

☒ Wheat-biscuit breakfast cereal has not fully softened

☒ Milk has not fully absorbed leaving loose fluid

Note: No ice cream or jelly unless advised as suitable by speech and language therapist on an individual basis.

Dysphagia Diet Food Texture Descriptors

D Pre-Mashed Dysphagia Diet D

General description:

☑ Food is soft, tender and moist. Needs very little chewing.

☑ It has been mashed up with a fork before serving (see overleaf for meat).

☑ It usually requires a very thick, smooth (non-pouring) sauce, gravy or custard (see next point).

☑ Any fluid, gravy, sauce or custard in or on the food is very thick (*please see note below).

☒ No mixed (thick-thin) textures. No loose fluid.

☒ No hard, tough, chewy, fibrous, stringy, dry, crispy, crunchy or crumbly bits.

☒ No pips, seeds, pith/inside skin. No skins or outer shells e.g. on peas, grapes. No husks.

☒ No skin, bone or gristle.

☒ No round or long-shaped foods e.g. sausages, grapes, sweets. No hard chunks e.g. pieces of apple.

☒ No sticky foods e.g. cheese chunks, marshmallows.

☒ No ‘floppy’ foods e.g. lettuce, cucumber, uncooked baby spinach leaves.

☒ No juicy food where juice separates off in the mouth to a mixed texture e.g. water melon.

Check before serving/eating:

☒ No hard pieces, crust or skin have formed during cooking/heating/standing.

☒ Fluid/gravy/sauce/custard in or on the food has not thinned out or separated off.

See overleaf for more details

***Note – definition of ‘very thick’ fluid**
Any fluid, gravy, sauce or custard in or on food must be very thick.
It holds its shape on a plate or when scooped, can not be poured and does not ‘spread out’ if spilled.

Thinner single texture foods maybe suitable if a person is on thinner fluids –SLT to advise on an individual basis.

SLT = Speech and Language Therapists

1. *Texture D products must be mashed by the manufacturer /originator prior to heating for service i.e. it must be in a pre-mashed state when it reaches the client.*

Dysphagia Diet Food Texture Descriptors

D Pre-Mashed Dysphagia Diet D

In addition to the general description overleaf:

- **Meat**
  Must be finely minced – pieces approximately 2mms. No hard bits of mince.
  Serve in a *very thick*, smooth (non-pouring) sauce or gravy.
  If it cannot be finely minced it should be puréed (to texture C)

- **Fish**
  Serve finely mashed and in a *very thick*, smooth (non-pouring) sauce or gravy.

- **Fruit**
  Serve mashed. Drain away any juice that has separated.

- **Casserole/stew/curry**
  Must be *very thick.*
  Can contain meat, fish or vegetable if prepared as above and overleaf and are fully mixed in.

- **Bread**
  No bread unless assessed as suitable by SLT on an individual basis.

- **Cereal**
  The texture of *very thick* smooth porridge with no lumps.
  Or the texture of fully softened wheat-biscuit breakfast cereal with milk fully absorbed.
  Any milk/fluid must not separate off *(i.e. no loose fluid/no mixed (thick – thin) textures.*
  Overall texture must be *very thick* (Because this is a single texture food it could be served thinner if a person is on thinner fluids – SLT to advise).

- **Desserts**
  The texture of *very thick*, smooth yogurt (no bits) or stewed apple in *very thick* custard.
  Or the texture of soft sponge cake with smooth filling, fully softened by mashing and mixing in with *very thick,* smooth (non-pouring) custard.
  Overall texture must be *very thick.* (If the texture of the dessert is single it could be served thinner if a person is on thinner fluids – SLT to advise).
  No ice-cream or jelly if a person requires thickened fluids (because these can change to normal fluid thickness in the mouth).

Dysphagia Diet Food Texture Descriptors

E Fork Mashable Dysphagia Diet E

General description:

- ☑ Food is soft, tender and moist but needs some chewing.
- ☑ It can be mashed with a fork.
- ☑ It usually requires a thick, smooth sauce, gravy or custard (see next point).
- ☑ Any fluid, gravy, sauce or custard in or on the food is thick (*please see note below).

- ☒ No mixed (thick-thin) textures. No thin loose fluid.
- ☒ No hard, tough, chewy, fibrous, stringy, dry, crispy, crunchy or crumbly bits.
- ☒ No pips, seeds, pith/inside skin. No skins or outer shells e.g. on peas, grapes. No husks.
- ☒ No skin, bone or gristle.
- ☒ No round or long-shaped foods e.g. sausages, grapes, sweets. No hard chunks e.g. pieces of apple.
- ☒ No sticky foods e.g. cheese chunks, marshmallows.
- ☒ No 'floppy' foods e.g. lettuce, cucumber, uncooked baby spinach leaves.
- ☒ No juicy food where juice seperates off in the mouth to a mixed texture e.g. water melon.

Check before serving/eating:

- ☒ No hard pieces, crust or skin have formed during cooking/heating/standing.
- ☒ Fluid/gravy/sauce/custard in or on the food has not thinned out or separated off.

See overleaf for more details

***Note – definition of 'thick' fluid**
Any fluid, gravy, sauce or custard in or on food must be *thick* – a light disposable plastic teaspoon would stand upright if the head were fully but just covered.

Those on Texture E must therefore be able to cope with thinner fluids – stage 2.

Thinner *single* texture foods maybe suitable if a person is on thinner fluids –SLT to advise on an individual basis.

SLT = Speech and Language Therapist

2. Texture E products must be in a consistency that allows them to be mashed easily using a fork at point of service/consumption

Dysphagia Diet Food Texture Descriptors

E Fork Mashable Dysphagia Diet E

In addition to the general description overleaf:

- **Meat**
  Pieces of soft tender meat must be served no bigger than 15mms.
  Or serve meat finely minced. No hard bits of mince. Serve in a *thick* smooth sauce or gravy.

  For children
  Specific guidance on the size of the food particles, especially meat based on the child's swallowing skills, their age and their development level will be provided by a speech and language therapist following individual assessment.

- **Fish**
  Soft enough to break up into small pieces with a fork.
  Serve in *thick* smooth sauce or gravy.

- **Fruit**
  Juicy fruit should be mashed – drain away any juice that has separated.

- **Casserole/stew/curry**
  Must be *thick*.
  Can contain meat, fish or vegetables if prepared as above and overleaf and fully mixed in.

- **Bread**
  No bread unless assessed as suitable by SLT on an individual basis.

- **Cereal**
  The texture of thick smooth porridge with no hard lumps (soft tender lumps no bigger than 15mms are acceptable).
  Or the texture of fully softened wheat-biscuit breakfast cereal with milk fully absorbed.
  Any milk/fluid must not separate off (i.e. no thin loose fluid/no mixed (thick-thin) textures.
  Overall texture must be *thick* (Because this is a single texture food it could be served thinner if a person is on thinner fluids – SLT to advise).

- **Desserts**
  The texture of *thick* smooth yogurt (fork mashable or soft tender pieces of fruit no bigger than 15mms are acceptable). or stewed apple in thick custard.
  Or texture of soft sponge cake with smooth filling, fully softened with thick smooth custard.
  Overall texture must be *thick*. (If the texture of the dessert is single it could be served thinner if the person is on thinner fluids – SLT to advise).
  No ice-cream or jelly if a person requires thickened fluids (because these can change to normal fluid thickness in the mouth).

Thin Purée Dysphagia Diet

B

Food has been puréed or has purée texture	Pass	Fail	Borderline
It does not require chewing	Pass	Fail	Borderline
It is smooth throughout with no 'bits' (no lumps, fibres, bits of shell/skin, bits of husk, particles of gristle/bone etc)	Pass	Fail	Borderline
It may have a fine 'textured' quality as long as the bolus remains cohesive in the mouth	Pass	Fail	Borderline
It is moist	Pass	Fail	Borderline
Any fluid in or on the food is as thick as the purée itself	Pass	Fail	Borderline
There is no loose fluid that has separated off	Pass	Fail	Borderline
The texture is not sticky in the mouth	Pass	Fail	Borderline
No garnish	Pass	Fail	
No hard pieces or crusts have formed during cooking/heating	Pass	Fail	
It has not thinned out and any liquid within the food has not separated off	Pass	Fail	
TEXTURE CHECK			
Does not hold its shape on a plate or when scooped	Pass	Fail	Borderline
Can not be eaten with a fork because it slowly drops through the prongs	Pass	Fail	Borderline
The prongs of a fork do not make a clear pattern on the surface	Pass	Fail	Borderline
It cannot be piped, layered or moulded	Pass	Fail	Borderline
'Spreads out' if spilled	Pass	Fail	Borderline
A light, disposable plastic teaspoon is able to stand upright when the head is fully covered	Pass	Fail	Borderline

Thick Purée Dysphagia Diet

C

Food has been puréed or has purée texture	Pass	Fail	Borderline
It does not require chewing	Pass	Fail	Borderline
It is smooth throughout with no 'bits' (no lumps, fibres, bits of shell/skin, bits of husk, particles of gristle/bone etc)	Pass	Fail	Borderline
It has a fine 'textured' quality and the bolus remains cohesive in the mouth	Pass	Fail	Borderline
It is moist	Pass	Fail	Borderline
Any fluid in or on the food is as think as the purée itself	Pass	Fail	Borderline
It is not rubbery	Pass	Fail	Borderline
There is no loose fluid that has seperated off	Pass	Fail	Borderline
The texture is not sticky in the mouth	Pass	Fail	Borderline
No garnish	Pass	Fail	
No hard pieces or crusts have formed during cooking/heating	Pass	Fail	
It has not thinned out and any liquid within the food has not separated off	Pass	Fail	
TEXTURE CHECK			
Holds its shape on a plate or when scooped	Pass	Fail	Borderline
Can be eaten with a fork because it does not drop through the prongs	Pass	Fail	Borderline
The prongs of a fork make a clear pattern on the surface	Pass	Fail	Borderline
It can be piped, layered or moulded	Pass	Fail	Borderline
Cannot be poured	Pass	Fail	Borderline
Does not 'spread out' if spilled	Pass	Fail	Borderline

Thick Purée Dysphagia Diet

Breakfasts and Desserts

The texture of thick smooth porridge made from powder (purée porridge) with no loose fluids	Pass	Fail	Borderline
The texture of wheat-biscuit breakfast cereal fully softened with milk fully absorbed	Pass	Fail	Borderline
The texture of thick blancmange or mousse with no 'bits'	Pass	Fail	Borderline
The texture of purée rice pudding	Pass	Fail	Borderline
There are no loose fluids	Pass	Fail	Borderline
There are no lumps	Pass	Fail	Borderline

Dysphagia Diet Audit Checklist

Pre-Mashed Dysphagia Diet

Food is soft, tender and moist	Pass	Fail	Borderline
Needs very little chewing	Pass	Fail	Borderline
It has been mashed up with a fork before serving	Pass	Fail	Borderline
It has a very thinck smooth (non-pouring) sauce, gravy or custard	Pass	Fail	Borderline
Any fluid, gravy or custard in or on the food is very thick	Pass	Fail	Borderline
No mixed (thick-thin) textures	Pass	Fail	Borderline
No loose fluid	Pass	Fail	Borderline
No hard, tough, chewy, fibrous, stringy, dry, crispy crunchy or crumbly bits	Pass	Fail	Borderline
No pips, seeds, pith/inside skin	Pass	Fail	Borderline
No skins or outer shells eg. on peas, grapes	Pass	Fail	Borderline
No husks	Pass	Fail	Borderline
No skin, bone or gristle	Pass	Fail	Borderline
No round or long shaped foods eg. sausages, grapes, sweets	Pass	Fail	Borderline
No hard chunks eg. pieces of apple	Pass	Fail	Borderline
No sticky foods eg. cheese chunks, marshmallows	Pass	Fail	Borderline
No 'floppy' foods eg. lettuce, cucumber, uncooked baby spinach leaves	Pass	Fail	Borderline
No juicy food where juice seperates off in the mouth to a mixed texture eg. water melon	Pass	Fail	Borderline
No hard pieces or crusts have formed during cooking/heating	Pass	Fail	
Liquid/gravy/sauce/custard in or on the food, has not thinned out or separated off	Pass	Fail	

Pre-Mashed Dysphagia Diet

D

TEXTURE CHECK			
It must be in a pre-mashed state when it reaches the client	Pass	Fail	Borderline
Any fluid, gravy, sauce or custard in or on food must be very thick - it holds its shape on a plate or when scooped, cannot be poured and does not 'spread out' if spilled.	Pass	Fail	Borderline
FOOD SPECIFIC			
Meat			
Is finely minced - pieces approximately 2mms	Pass	Fail	Borderline
No hard bits of mince	Pass	Fail	Borderline
Serve in a very thick, smooth (non pouring) sauce or gravy	Pass	Fail	Borderline
If it cannot be finely minced it should be puréed (to texture C)	Pass	Fail	Borderline
Fish			
Is finely mashed and in a very thick, smooth (non-pouring) sauce or gravy	Pass	Fail	Borderline
Fruit			
Is served mashed	Pass	Fail	Borderline
Juice that has separated has been drained away	Pass	Fail	Borderline
Casserole/Stew/ Curry			
Is very thick	Pass	Fail	Borderline
Contains meat, fish or vegetables prepared as required for the texture	Pass	Fail	Borderline

Pre-Mashed Dysphagia Diet

CEREAL			
Is the texture of *very thick* smooth porridge with no lumps	Pass	Fail	Borderline
Or the texture of fully softened wheat-biscuit breakfast cereal with milk fully absorbed	Pass	Fail	Borderline
Any milk/fluid must not separate off (ie. no thin loose fluid/no mixed (thick-thin) textures	Pass	Fail	Borderline
Overall texture is *very thick*	Pass	Fail	
DESSERTS			
The texture of thick smooth yogurt (no bits) or stewed apple in *very thick* custard	Pass	Fail	Borderline
Or texture of soft sponge cake with smooth filling, fully softened with *very thick* smooth custard	Pass	Fail	Borderline
Overall the texture must be *very thick*	Pass	Fail	

Fork Mashable Dysphagia Diet

E

Food is soft, tender and moist	Pass	Fail	Borderline
Needs some chewing	Pass	Fail	Borderline
It can be mashed with a fork	Pass	Fail	Borderline
Any fluid, gravy, sauce or custard in or on the food is *thick*	Pass	Fail	Borderline
No mixed (thick-thin) textures	Pass	Fail	Borderline
No thin loose fluid	Pass	Fail	Borderline
No hard, tough, chewy, fibrous, stringy, dry, crispy crunchy or crumbly bits	Pass	Fail	Borderline
No pips, seeds, pith/inside skin	Pass	Fail	Borderline
No skins or outer shells eg. on peas, grapes	Pass	Fail	Borderline
No husks	Pass	Fail	Borderline
No skin, bone or gristle	Pass	Fail	Borderline
No round or long shaped foods eg. sausages, grapes, sweets	Pass	Fail	Borderline
No hard chunks eg. pieces of apple	Pass	Fail	Borderline
No sticky foods eg. cheese chunks, marshmallows	Pass	Fail	Borderline
No ‘floppy’ foods eg. lettuce, cucumber, uncooked baby spinach leaves	Pass	Fail	Borderline
No juicy food where juice separates off in the mouth to a mixed texture eg. water melon	Pass	Fail	Borderline
No hard pieces or crusts have formed during cooking/heating	Pass	Fail	
Liquid/gravy/sauce/custard in or on the food, has not thinned out or separated	Pass	Fail	

Fork Mashable Dysphagia Diet

TEXTURE CHECK			
Mashed easily using a fork at point of service/consumption	Pass	Fail	Borderline
Any fluid, gravy, sauce or custard in or on food must be thick - a light disposable plastic teaspoon stands upright when the head is fully but just covered.	Pass	Fail	Borderline
FOOD SPECIFIC			
Meat			
Pieces of soft tender meat must be served no bigger than 15mms *or* serve meat finely minced	Pass	Fail	Borderline
No hard bits of mince	Pass	Fail	Borderline
Serve in a *thick*, smooth sauce or gravy	Pass	Fail	Borderline
FOR CHILDREN Specific guidance on the size of the food particles, especially meat, based on the child's swallowing skills, their age and their development level will be provided by a speech and language therapist following individual assessment			
Fish			
Is soft enough to break up into small pieces with a fork	Pass	Fail	Borderline
Fruit			
Juicy fruit is mashed	Pass	Fail	Borderline
Juice that has seperated has been drained off	Pass	Fail	Borderline
Casserole/Stew/ Curry			
Is *thick*	Pass	Fail	Borderline
Contains meat, fish or vegetables prepared as required for the texture	Pass	Fail	Borderline
Meat, fish or vegetables are fully mixed in	Pass	Fail	Borderline

Fork Mashable Dysphagia Diet

CEREAL			
Is the texture of thick smooth porridge with no hard lumps (soft tender lumps no bigger than 15mms are acceptable).	Pass	Fail	Borderline
Or the texture of fully softened wheat-biscuit breakfast cereal with milk fully absorbed	Pass	Fail	Borderline
Any milk/fluid must not separate off (ie. no thin loose fluid/no mixed (thick-thin) textures	Pass	Fail	Borderline
Overall texture is thick	Pass	Fail	
DESSERTS			
The texture of thick smooth yogurt (fork mashable of soft tender pieces of fruit no bigger than 15mms are acceptable) or stewed apple in *thick* custard	Pass	Fail	Borderline
Or texture of soft sponge cake with smooth filling, fully softened with thick smooth custard	Pass	Fail	Borderline
Overall the texture must be *thick*	Pass	Fail	

APPENDIX 3

Therapy Outcome Measure for dysarthria (Activity)

Therapy Outcome Measure for dysarthria (Activity)

0	Unable to communicate in any way. No effective communication. No interaction.
1	Occasionally able to make basic needs known with familiar persons or trained listeners in familiar contexts. Minimal communication with maximal assistance.
2	Limited functional communication. Consistently able to make basic needs/conversation understood but is heavily dependent on cues and context. Communicates better with trained listener or family members or in familiar settings. Frequent repetition required. Maintained meaningful interaction related to here and now.
3	Consistently able to make needs known but can sometimes convey more information than this. Some inconsistency in unfamiliar settings. Is less dependent for intelligibility on cues and context. Occasional repetition required. Communicates beyond here/now with familiar persons, needs some cues and prompting.
4	Can be understood most of the time by any listener despite communication irregularities. Holds conversation; requires special consideration, for example, patience, time, attention, especially with a wider range of people.
5	Communicates effectively in all situations.

Source: Enderby, P., John, A., and Petheram, B. (2006). *Therapy outcome measures for rehabilitation professionals: Speech and language therapy, physiotherapy, occupational therapy, rehabilitation nursing, hearing therapists* (2nd ed.). Chichester: John Wiley and Sons.

APPENDIX 4

Information sheet for the participants with dysphagia

University of Strathclyde Glasgow

The impact of acquired neurological oropharyngeal dysphagia on the health-related quality of life of care home residents

The impact of swallowing difficulties on quality of life

Participant information sheet

You are being invited to take part in a **research study**.

Before you decide it is important for you to understand **why the research is being done** and **what it would involve for you**.

Please **take time** to go through the following **information** carefully and feel free to **discuss it with others** if you wish.

Take time to decide **whether or not you wish to take part**.

If you are **interested** in taking part, the **researcher will visit you** and **answer any questions** you have. This should take about **20 minutes**.

Thank you for taking the time to read this.

WHAT is the research about?

After acquiring a neurological disorder, some people find they have **swallowing difficulties.**

Swallowing difficulties can also be called **dysphagia.**

We'd like to find out about how your **swallowing difficulty** affects your **life in the care home.**

We'd like to find out if your swallowing difficulty:

Doesn't bother you;

Makes you feel **sad** or **frustrated**

WHAT is the PURPOSE of this research?

This information has not been collected for any other research **before**.

It is **important to start** collecting information so that **Care Homes and Speech and Language Therapists** can **work together** to **improve services** to people with swallowing difficulties caused by neurological disorders.

This research is also being carried out as part of the researcher's **PhD** study.

WHY have I been invited?

You have been invited to take part in this study because you have a **condition which can affect swallowing.**

Because of this condition you now experience **swallowing difficulties.**

We want to find out more about how **your swallowing difficulty** affects your **life in the care home**.

Do I have to take part?

It's **up to you** to decide whether or not to **take part**.

If you **do decide to take part**, you will be given this **information sheet to keep** and you will be asked to **sign a consent form.**

Even if you sign the consent form it's **ok** to **pull out** at **any time.**

If you decide to pull out we will retain the information that we have collected to that point.

Pulling out of the research will **not** affect the **standard of care** you receive.

WHAT will HAPPEN if I decide to take part?

If you are interested in taking part, **Rebecca Hutchison**, the researcher, will come **and visit you at the care home** and tell you more about the research and give you a chance to **ask questions.**

If you would like to take part, she will ask you to **sign a consent form.**

Remember, you can **pull out** of the research at **any time**, even after you have signed the consent form.

Then, on the same day, Rebecca will **talk to you** about your **swallowing difficulties**.

She will make sure this is a time that is good for you and will last no more than **45 minutes**.

Rebecca will also come to **observe you during a mealtime on two occasions.**

After this Rebecca will come **once more to talk to you** about what she **observed during the mealtimes.**

Again, this will last for no more than **45 minutes**.

Every time Rebecca visits, she will check that you are **still happy to be involved** in the research.

On the two occasions when Rebecca comes **to talk to you, she will record the conversation on a video and tape recorder,** if you agree**.**

This makes it easier for her to **listen** to you **instead of writing** lots of notes.

If there are any questions that you **don't want to answer**, that's **ok** and we'll just move on.

All of these visits will take place within **two weeks**.

Confidentiality

If you agree to take part your **speech and language therapist** will supply us with some **information** about your **swallowing difficulty.** This information will be stored for no more than **6 years.**

The information that you provide will be **stored carefully** for no more than **6 years.**

We will **not hold records of your name** or **other identifying details** and you will be assigned a number instead of your name.

Only the researchers will be able to view any of the information that you provide.

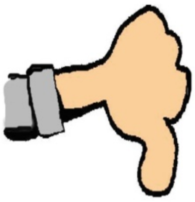
At the end of the research, the **findings** will be **written up in a report.**

These findings may be **published.**

We may **use extracts from the recordings** that have been made, but you will **not be identified.**

Your **name** will **not** be **included** in this report.

When the study is completed, you will be provided with a summary of the findings.



Are there disadvantages to taking part?

Taking part will **take up** some of your **time** during the day.

You may **not want to talk** about living with a **swallowing difficulty.**

What are the benefits of taking part?

We **do not know** whether **you will be helped** by taking part in this research.

However, getting information from you will help us to decide whether **changes need to be made** to the way in which the swallowing difficulties of care home residents are managed.

Where can I get more information about the study?

If you would like to talk to someone **not** closely linked to the study you can contact Dr Anja Lowit at the University of Strathclyde (0141 548 3102).

What to do next

Keep this information sheet. If you do decide you would like to take part, please speak to X (the Speech and Language Therapist who gave you this sheet). She will be coming to visit you again soon to ask if you would like to take part. If you are interested in taking part, X will let us know and the researcher will come and visit you to tell you more about the research.

Thank you for taking the time to read this information sheet and for considering taking part in this study.

This research is being sponsored by the University of Strathclyde.

Contact Details:

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All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by West of Scotland Research Ethics Committee 2.

1 copy of this information sheet is to be kept by the participant

APPENDIX 5

Consent form for the participants with dysphagia

University of
Strathclyde
Glasgow

The impact of acquired neurological oropharyngeal dysphagia on the health-related quality of life of care home residents

The impact of swallowing difficulties on quality of life

Participant consent form

Please initial the box after each statement then sign at the end:

	Yes	No
I have read and understand the **information sheet** about this research study.		
I have **talked** with Rebecca Hutchison (the researcher) about why I am being asked to take part and what is involved and **my questions have been answered**.		
I understand that it is **my free choice** to take part in the research and that I am		

free to withdraw at any time, without giving a reason and without my care being affected.		
If I choose to withdraw from the study I agree that any information collected from me up to that point may be **retained**. I know that all information obtained will be stored securely and destroyed within **six years.**		
I agree that **information about my swallowing difficulty** can be given to the researcher. I know that this and any other information I provide will remain **confidential** and no information that identifies me will be made publically available.		
I agree that **audio and video recordings** will be made during the interview and discussion to assist the collection of relevant information. I agree that extracts may be used in reports. I know that I will **not be identified** and that these recordings will be stored securely and destroyed within **six years.**		

I **agree** to take part in this study.		

Name (participant) :_______________

Date: ________________ Signature: _______________

Name (witness): _________________

Date: ______________ Signature: _______________

1 copy for the participant

APPENDIX 6

Items contained within the Functional Oral Intake Scale (FOIS)

Functional Oral Intake Scale (FOIS)

Crary, Carnaby Mann and Groher, 2005)

FOIS ITEMS:

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 7

Interview schedule for the participants with dysphagia

Interview schedule for the participant

Participant Number _____________

- Good morning/afternoon [*introductions will already have occurred during the explanation of the information sheet and the verbal and written consent process*]. Thank you very much for agreeing to talk to me. It's very much appreciated.

- This interview is the first part of the research and after this is over, I will come and visit you three more times at the care home.

- Today, this interview is going to be in two parts.

- The first part of our discussion is going to involve me reading some statements to you.

- They are all related to your swallowing difficulty.

- I'd like you to listen to the statements and give me a response using the options that I will provide you with. I also have some scales that you can use to show me what you think [*present visual Likert Scales*].
- If there's anything you don't want to answer, that's ok. Just let me know and we'll move on.
- After this part we can just have a chat about anything you want to tell me about your swallowing problem.
- Remember, there's no right or wrong answer here. I am just interested in hearing how you feel about your swallowing problem and how it affects you.
- Does that sound ok? Have you any questions? [*respond to any questions and make clarifications as appropriate*].

Part one- modified SWAL-QOL (McHorney et al, 2002) and ranking item

[*Circle resident's response for each item. Make a note beside any items they declined to answer*]

All statements presented as part of the modified SWAL-QOL are part of the original SWAL-QOL. Some statements have been omitted due to their perceived irrelevance for the target population.

Burden

I'm going to read you some general statements that people with swallowing problems might mention. In the last month, how true have the following statements been for you?

Dealing with my swallowing problem is very difficult

Very much true *Quite a bit true* *A little true* *Not at all true*

My swallowing problem is a major distraction in my life

Very much true *Quite a bit true* *A little true* *Not at all true*

Eating Duration

I'm going to read you some statements about day-to-day eating that people with swallowing problems sometimes talk about. In the last month, how true have the following statements been for you?

It takes me longer to eat than other people

Very much true *Quite a bit true* *A little true* *Not at all true*

It takes me forever to eat a meal

Very much true *Quite a bit true* *A little true* *Not at all true*

Eating desire

I'm going to read you some statements about day-to-day eating that people with swallowing problems sometimes talk about. In the last month, how true have the following statements been for you?

Most days, I don't care if I eat or not

Very much true *Quite a bit true* *A little true* *Not at all true*

I don't enjoy eating anymore

Very much true *Quite a bit true* *A little true* *Not at all true*

I'm rarely hungry anymore

Very much true *Quite a bit true* *A little true* *Not at all true*

Symptom Frequency

I'm going to read you some physical problems that people with swallowing problems sometimes experience. In the last month, how often have you experienced each problem as a result of your swallowing problem?

Coughing

Almost always *Often* *Hardly ever* *Never*

Choking when you eat food

Almost always *Often* *Hardly ever* *Never*

Choking when you take liquids

Almost always *Often* *Hardly ever* *Never*

Having thick saliva or phlegm

Almost always *Often* *Hardly ever* *Never*

Gagging

Almost always Often Hardly ever Never

Drooling

Almost always Often Hardly ever Never

Problems chewing

Almost always Often Hardly ever Never

Having excess saliva or phlegm

Almost always Often Hardly ever Never

Having to clear your throat

Almost always Often Hardly ever Never

Food sticking in your throat

Almost always Often Hardly ever Never

Food sticking in your mouth

Almost always Often Hardly ever Never

Food or liquid dribbling out of your mouth

Almost always Often Hardly ever Never

Food or liquid coming out your nose

Almost always Often Hardly ever Never

Coughing food or liquid out of your mouth when it gets stuck

Almost always Often Hardly ever Never

Fear

I'm going to read you some concerns that people with swallowing difficulties sometimes mention. In the last month, how often have you experienced each feeling?

I fear I may start choking when I eat food

Almost always   Often   Hardly ever   Never

I am afraid of choking when I drink liquids

Almost always   Often   Hardly ever   Never

I never know when I am going to choke

Almost always   Often   Hardly ever   Never

Mental Health

In the last month, how often have the following statements been true for you because of your swallowing problem?

My swallowing problem depresses me

Always true   Often true   Hardly ever true   Never true

Having to be so careful when I eat or drink annoys me

Always true   Often true   Hardly ever true   Never true

I've been discouraged by my swallowing problem

Always true   Often true   Hardly ever true   Never true

My swallowing problem frustrates me

Always true   Often true   Hardly ever true   Never true

I get impatient dealing with my swallowing problem

Always true   Often true   Hardly ever true   Never true

Social

Think about your social life in the last month. How strongly would you agree or disagree with the following statements?

I do not go out to eat because of my swallowing problem

Strongly Agree   Agree   Disagree   Strongly Disagree

My swallowing problem makes it hard to have a social life

Strongly Agree   Agree   Disagree   Strongly Disagree

My usual activities have changed because of my swallowing problem

Strongly Agree   Agree   Disagree   Strongly Disagree

Social gatherings are not enjoyable because of my swallowing problem

Strongly Agree   Agree   Disagree   Strongly Disagree

My role with family and friends has changed because of my swallowing problem

Strongly Agree   Agree   Disagree   Strongly Disagree

Fatigue

In the last month, how often have you experienced each of the following physical symptoms?

Feel weak

All of the time   Most of the time   A little of the time   None of the time

Feel tired

All of the time *Most of the time* *A little of the time* *None of the time*

Feel exhausted

All of the time *Most of the time* *A little of the time* *None of the time*

References for the SWAL-QOL

McHorney, C.A., Bricker, E., Kramer, A.E., Rosenbek, J.C., Robbins, J., Chignell, K.A., Logemann, J.A and Clarke, C (2000a). The SWAL-QOL outcomes tool for oropharyngeal dysphagia in adults: I. Conceptual foundation and item development. Dysphagia 15 (3) pp.115-121.

McHorney, C.A., Bricker, E., Robbins, J., Kramer, A.E., Rosenbek, J.C and Chignell, K.A (2000b). The SWAL-QOL outcomes tool for oropharyngeal dysphagia in adults: II. Item reduction and preliminary scaling. Dysphagia 15 (3) pp. 122-133.

McHorney, C.A., Robbins, J., Lomax, K., Rosenbek, J.C., Chignell, K., Kramer, A.E and Bricker, E (2002). The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. Dysphagia 17 (2) pp. 97-114.

Ranking item

I'm going to read to you and show you a list of different problems. I know you might not have all of these problems. I'd like you to tell me which one of these problems you think affects your life the most and which one would be second *[mark a 1st and a 2nd beside the appropriate items].*

1. My joint/back pain;
2. There are not enough opportunities to talk to people;
3. My swallowing difficulty;
4. Having less independence;
5. My mobility problems – I'm not as able to get around by myself as easily or at all;
6. Other?

Thank you for taking the time to go through this with me.

Part two- discussion of dysphagia-related concerns or issues

Have any of the statements that I have just read to you made you think of any concerns or issues that you have relating to your swallowing problem?

Although it is intended that this discussion is participant led to permit expression of participant experiences, some prompts have been included in the event that a participant is unsure what to contribute to the discussion. These questions have been taken from issues which may be raised in the modified SWAL-QOL.

I noticed that you don't feel like eating anymore. Would you like to tell me a bit more about that? Why do you think that is?

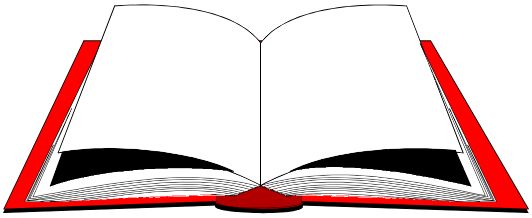
I noticed that you feel that your swallowing problem is a major distraction in your life. Can you tell me a bit more about why you think this is?

Basic notes to be taken here during the discussion in the case of video or audio equipment not functioning correctly.

APPENDIX 8

The original SWAL-QOL

The SWAL-QOL SURVEY



Understanding
Quality of Life
in Swallowing Disorders

Instructions for Completing the SWAL-QOL Survey

This questionnaire is designed to find out how your swallowing problem has been affecting your day-to-day quality of life.

Please take the time to carefully read and answer each question. Some questions may look like others, but each one is different.

Here's an <u>example</u> of how the questions in the survey will look.

1. In the last month how often have you experiences each of the symptoms below.

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Feel weak	1	2	[✓ 3]	4	5

Thank you for your help in taking part in this survey!

IMPORTANT NOTE: We understand that you may have a number of physical problems. Sometimes it is hard to separate these from swallowing difficulties, but we hope that you can do your best to concentrate ***only*** on your ***swallowing problem.*** Thank you for your efforts in completing this questionnaire.

1. Below are some general statements that people with ***swallowing problems*** might mention. In the last month, **how true** have the following statements been for you.

(circle one number on each line)

	Very much true	**Quite a bit true**	**Somewhat true**	**A little true**	**Not at all true**
Dealing with my swallowing problem is very difficult.	1	2	3	4	5
My swallowing problem is a major distraction in my life.	1	2	3	4	5

2. Below are aspects of day-to-day eating that people with ***swallowing problems*** sometimes talk about. In the last month, **how true** have the following statements been for you?

(circle one number on each line)

	Very much true	**Quite a bit true**	**Somewhat true**	**A little true**	**Not at all true**
Most days, I don't care if I eat or not.	1	2	3	4	5
It takes me longer to eat than other people.	1	2	3	4	5
I'm rarely hungry anymore.	1	2	3	4	5
It takes me forever to eat a meal.	1	2	3	4	5
I don't enjoy eating anymore.	1	2	3	4	5

3. Below are some physical problems that people with ***swallowing problems*** sometimes experience. In the last month, **how often** you have experienced each problem as a result of your swallowing problem?

(circle one number on each line)

	Almost always	**Often**	**Sometimes**	**Hardly ever**	**Never**
Coughing	1	2	3	4	5
Choking when you eat food	1	2	3	4	5
Choking when you take liquids	1	2	3	4	5
Having thick saliva or phlegm	1	2	3	4	5
Gagging	1	2	3	4	5
Drooling	1	2	3	4	5
Problems chewing	1	2	3	4	5
Having excess saliva or phlegm	1	2	3	4	5
Having to clear your throat	1	2	3	4	5
Food sticking in your throat	1	2	3	4	5
Food sticking in your mouth	1	2	3	4	5
Food or liquid dribbling out of your mouth	1	2	3	4	5
Food or liquid coming out your nose	1	2	3	4	5
Coughing food or liquid out of your mouth when it gets stuck	1	2	3	4	5

4. Next, please answer a few questions about how your ***swallowing problem*** has affected your diet and eating in the last month.

(circle one number on each line)

	Strongly agree	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
Figuring out what I can and can't eat is a problem for me.	1	2	3	4	5
It is difficult to find foods that I both like and can eat.	1	2	3	4	5

5. In the last month, **how often** have the following statements about communication applied to you because of your ***swallowing problem***?

(circle one number on each line)

	All of the time	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
People have a hard time understanding me.	1	2	3	4	5
It's been difficult for me to speak clearly.	1	2	3	4	5

6. Below are some concerns that people with ***swallowing problems*** sometimes mention. In the last month, **how often** have you experienced each feeling?

(circle one number on each line)

	Almost always	**Often**	**Sometimes**	**Hardly ever**	**Never**
I fear I may start choking when I eat food.	1	2	3	4	5
I worry about getting pneumonia.	1	2	3	4	5
I am afraid of choking when I drink liquids.	1	2	3	4	5
I never know when I am going to choke.	1	2	3	4	5

7. In the last month, how often have the following statements **been true** for you because of your ***swallowing problem***?

(circle one number on each line)

	Always true	**Often true**	**Sometimes true**	**Hardly ever true**	**Never true**
My swallowing problem depresses me.	1	2	3	4	5
Having to be so careful when I eat or drink annoys me.	1	2	3	4	5
I've been discouraged by my swallowing problem.	1	2	3	4	5
My swallowing problem frustrates me.	1	2	3	4	5
I get impatient dealing with my swallowing problem.	1	2	3	4	5

8. Think about your social life in the last month. How strongly would you agree or disagree with the following statements?

(circle one number on each line)

	Strongly agree	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
I do not go out to eat because of my swallowing problem.	1	2	3	4	5
My swallowing problem makes it hard to have a social life.	1	2	3	4	5
My usual work or leisure activities have changed because of my swallowing problem.	1	2	3	4	5
Social gatherings (like holidays or get-togethers) are not enjoyable because of my swallowing problem.	1	2	3	4	5
My role with family and friends has changed because of my swallowing problem.	1	2	3	4	5

9. In the last month, **how often** have you experienced each of the following physical symptoms?

(circle one number on each line)

	All of the time	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
Feel weak?	1	2	3	4	5
Have trouble falling asleep?	1	2	3	4	5
Feel tired?	1	2	3	4	5
Have trouble staying asleep?	1	2	3	4	5
Feel exhausted?	1	2	3	4	5

10. Do you now take any food or liquid through a feeding tube?

(circle one)

No	1
Yes	2

11. Please circle the letter of the one description below that best describes the consistency or texture of the food you have been eating most often in the last week.

Circle one:

A. Circle this one if you are eating a full normal diet, which would include a wide variety of foods, including hard to chew items like steak, carrots, bread, salad, and popcorn.

B. Circle this one if you are eating soft, easy to chew foods like casseroles, canned fruits, soft cooked vegetables, ground meat, or cream soups.

C. Circle this one if you are eating food that is put through a blender or food processor or anything that is like pudding or pureed foods.

D. Circle this one if you take most of your nutrition by tube, but sometimes eat ice cream, pudding, apple sauce, or other pleasure foods.

E. Circle this one if you take all of your nourishment through a tube.

12. **Please circle the letter** of the one description below that best describes the consistency of liquids you have been drinking most often in the last week.

Circle one:

A. Circle this if you drink liquids such as water, milk, tea, fruit juice, and coffee.

B. Circle this if the majority of liquids you drink are thick, like tomato juice or apricot nectar. Such thick liquids drip off your spoon in a slow steady stream when you turn it upside down.

C. Circle this if your liquids are moderately thick, like a thick milkshake or smoothie. Such moderately thick liquids are difficult to suck through a straw, like a very thick milkshake, or drip off your spoon slowly drop by drop when you turn it upside down, such as honey.

D. Circle this if your liquids are very thick, like pudding. Such very thick liquids will stick to a spoon when you turn it upside down, such as pudding.

E. Circle this if you did not take any liquids by mouth or if you have been limited to ice chips.

13. In general, would you say your health is:

	(circle one)
Poor	1
Fair	2
Good	3
Very Good	4
Excellent	5

General Questions About You

What is the date of your birth?

Please write in your date of birth here: ________ / ________ / ________
month day year

What is your age today? _______

Are you –

(circle one)

Male 1

Female 2

What is your main racial or ethnic group?

(circle one)

White or Caucasian, but not Hispanic or Latino 1

Black or African-American, but not Hispanic or Latino 2

Hispanic or Latino 3

Asian 4

Other 5

What is the highest year of school or college you have ever completed?

(circle one number)

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**16+**
Grade School								High School				College				Post Graduate

What is your current marital status?

(circle one)

Never married	1
Married	2
Divorced	3
Separated	4
Widowed	5

Did anybody help you complete this questionnaire?

(circle one)

No, I did it myself	1
Yes, someone helped me fill it out	2

IF SOMEONE HELPED YOU FILL OUT THIS QUESTIONNAIRE, how did that person help you?

(circle one)

Read you the questions and/or wrote down the answers you gave	1
Answered the questions for you	2
Helped in some other way	3

Please write today's date here: ______ / ______ / ______
month day year

Last Page

COMMENTS:

Do you have any comments about this questionnaire? We welcome your comments about the questionnaire in general or about specific questions, especially any that were unclear or confusing to you.

Thank you for completing this questionnaire!

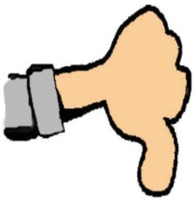
APPENDIX 9

Example of a visual Likert Scale used during modified-SWAL-QOL administration

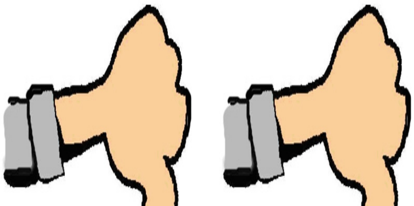
STRONGLY AGREE

AGREE

DISAGREE



STRONGLY DISAGREE



APPENDIX 10

Visual aids used within the ranking item component of the interview

1. My joint/back pain

2. There are not enough opportunities to talk to people

3. My swallowing difficulty

4. Having less independence

5. My mobility problems- I’m not able to get around by myself as easily or at all

6. Other?

APPENDIX 11

Two examples of completed mealtime observation schedules

Mealtime observation schedule

[*verbal consent will be obtained from the participant again prior to commencing the observations*]

Information to be obtained prior to participant receiving their food (Observation to commence 30 minutes before mealtime commences):

Participant number:	CP5
Date:	26/08/11
1st or 2nd observation:	2nd
Meal observed:	Lunch
Menu:	Soup (starter) Cheese toastie or crackers + pate (main course)
Choice provided in relation to the menu?	It appears that the choice of main course is offered prior to the mealtime - will need to ascertain this. CP5 is offered her choice of main course at the mealtime as her order was not taken prior to the mealtime.

Dining environment (location, number of other residents present; seating arrangements; appearance; noise level)	CP5 eats her meals in one of the dining rooms – 16 residents eating in the dining room at this mealtime. 5 rectangular tables positioned around the room. Between 2 + 4 residents sitting at the tables. Cloth tablecloths, cutlery; paper napkins on the tables. Bright room with lots of windows – has just been newly decorated. No background music. Glass of milk served prior to meal provision. Residents are gradually brought into the dining room.

Participant's social status while waiting for meal	CP5 is sitting at a table with 2 other female residents. CP5 engages briefly in conversation with one of the residents who has dementia. Seated at same table as occupied during 1st observation.

Participant's dental status (dentures worn/not worn)	CP5 wears dentures but doesn't have them in for eating her meal.

Seating (regular chair, wheelchair, bed)	Wheelchair.

Assistance with positioning prior to	None required.

meal provision?	

Note any specific problems with positioning (leaning to one side, falling forward, sliding down in chair, poor head support, head too far back, other.	No specific positioning problems noted.

Participant's physical status (vision, hearing, use of two hands)	CP5 doesn't wear glasses. It is necessary to speak loudly + clearly in order to hold a conversation with CP5. CP5 has use of two hands + is able to feed independently but her mobility is restricted + this impacts on her ability to manipulate the cutlery.

Length of time participant is seated before meal is served	10 minutes.

The interval coding observation will occur from the point that the participant receives their food and each category will be recorded at 1 minute intervals.

Codes for the interval coding observation:

Assistance with positioning during the mealtime: AP

Problems with positioning during the mealtime: PP (*Leaning to one side: L1; Falling forward: FF; Sliding down in chair: SD; Poor head support: PHS; Head too far back: HB*)

Provision of mealtime assistance: MAs

Type of assistance provided: AsTy (*Help with preparation of food before eating: Prep; Monitoring: M; Prompting: P; Some feeding: SF; Total feeding: TF)*

Participant's attitude towards eating and drinking: RA (*Positive: Pve; Disinterested: Dis; Rejects food/liquid: Rej*)

Challenging behaviours: CB *(Unresponsive: U; Drowsy: Dr; Distractible: Dtract)*

Participant's social status: SS *(Eating alone: Al; With Staff: WSt; Family/friends: FF; Other residents: OR)*

The presence of social interaction: SInt *(With staff: WSt; Family/friends: FF; Other residents: OR)*

Disruptions of the meal for non-food related issues by staff: StDis *(Drugs: D; Toilet: T; Staff conversation: StConv; Staff feeding more than one resident at one time: Res +1)*

Disruptions of the meal caused by other residents: ResDis *(Noise: N; Taking food: Tfd; Other Challenging behaviours: OCB; Other residents taken to toilet: OT)*

Version 1 29.06.11 Mealtime observation schedule for the participants: The impact of swallowing difficulties on quality of life

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
AP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
PP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
MAs	X	X	X	X	X	X	X	X	X	X	X	N/A	N/A	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
AsTy	X	X	X	X	X	X	X	X	X	X	X	N/A	N/A	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
RA	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	N/A	N/A	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre	Pre
CB	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
SS	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR	OR
SInt	Wst	OR	OR	OR	Wst	X	OR	Wst	X	X	Wst	X	X	X	X	X	X	X	X	X	Wst	X	X	OR	X	X	X	X	X	X
StDis	X	X	X	X	D	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	D	X	X	X	X	X	D	D
ResDis	X	X	X	X	X	N	X	X	X	X	X	X	X	X	X	X	X	X	N	X	X	X	X	X	X	X	X	X	X	X

CPS finishes soup at this point

CPS receives main course at this point

Also at this point

Requesting a drink of milk.

Resident with dementia at the table speaking jargon which is ignored by CPS.

Version 1 29.06.11 Mealtime observation schedule for the participants: The impact of swallowing difficulties on quality of life

Not needed.

	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60
AP																														
PP																														
MAs																														
AsTy																														
RA																														
CB																														
SS																														
SInt																														
StDis																														
ResDis																														

Information to be obtained following the participant's completion of their meal:

Amount of food consumed (all, more than ¾, ½, less than ¼, none)	More than 3/4 of soup consumed. More than 3/4 of cheese toastie consumed – except the crusts.

Amount of liquid consumed (all, more than ¾, ½, less than ¼, none	1 ½ cups of milk consumed.

Time taken for the participant to complete their meal	30 minutes to complete starter + main course (inc. 2 mins between courses).

Sitting in a chair to the front + side of CP5 for this mealtime observation.

Mealtime observation schedule

[verbal consent will be obtained from the participant again prior to commencing the observations] ✓

Information to be obtained prior to participant receiving their food (Observation to commence 30 minutes before mealtime commences)✓

Participant number:	P3
Date:	18/04/12
1st or 2nd observation:	2nd
Meal observed:	Dinner
Menu:	Starter – Lentil soup Main course – Haddock + potatoes (potatoes fork-mashed in front of P3).
Choice provided in relation to the menu?	No choice of main course for P3 – one option brought in. No choice of starter provided.

Seated to the Ⓡ hand side of P3.
Deliberately positioned a small distance away so as not to be too much of a distraction.
P3 spoke to the researcher once briefly during the mealtime.

Dining environment (location, number of other residents present; seating arrangements; appearance; noise level)	Dinner eaten in participant's own bedroom. Private location + no other residents present. Participant is seated in his armchair with a table in front of him, on which there is a cup of juice, a straw + some tissues. Participant is seated near the window. The room is furnished with the participant's own possessions – family pictures, TV etc. The radio is playing very quietly in the background, quietly playing classical music. Several books are located around the room. There are plants positioned on the window sill.
Participant's social status while waiting for meal	Participant eating in own room. Wife is present for this dinnertime meal + spends time with P3 prior to the mealtime. They engage one another in conversation. His wife also reads the paper. (Although the researcher is also present for this ocassion).
Participant's dental status (dentures worn/not worn)	Own teeth.
Seating (regular chair, wheelchair, bed)	Regular chair – soft armchair. P3 is seated on a soft support cushion + has a neck cushion for support. P3 later asks for the neck cushion to be removed.
Assistance with positioning prior to	No assistance provided – P3 provided with an apron prior to meal provision.

meal provision?	

Note any specific problems with positioning (leaning to one side, falling forward, sliding down in chair, poor head support, head too far back, other.	No positioning problems noted.

Participant's physical status (vision, hearing, use of two hands)	No major problems with hearing – just need to speak loudly + clearly. Participant wears glasses + has severe visual difficulties. P3 requires total feeding assistance due to tremor.

Length of time participant is seated before meal is served	Timed with stop watch – Not applicable as the participant is in his own room + is not waiting at a dining table to receive a meal.

The interval coding observation will occur from the point that the participant receives their food and each category will be recorded at 1 minute intervals.

Codes for the interval coding observation:

Assistance with positioning during the mealtime: AP

Problems with positioning during the mealtime: PP (*Leaning to one side: L1; Falling forward: FF; Sliding down in chair: SD; Poor head support: PHS; Head too far back: HB*)

Provision of mealtime assistance: MAs

Type of assistance provided: AsTy (*Help with preparation of food before eating: Prep; Monitoring: M; Prompting: P; Some feeding: SF; Total feeding: TF)*

Participant's attitude towards eating and drinking: RA (*Positive: Pve; Disinterested: Dis; Rejects food/liquid: Rej*)

Challenging behaviours: CB *(Unresponsive: U; Drowsy: Dr; Distractible: Dtract)*

Participant's social status: SS *(Eating alone: Al; With Staff: WSt; Family/friends: FF; Other residents: OR)*

The presence of social interaction: SInt *(With staff: WSt; Family/friends: FF; Other residents: OR)*

Disruptions of the meal for non-food related issues by staff: StDis *(Drugs: D; Toilet: T; Staff conversation: StConv; Staff feeding more than one resident at one time: Res +1)*

Disruptions of the meal caused by other residents: ResDis *(Noise: N; Taking food: Tfd; Other Challenging behaviours: OCB; Other residents taken to toilet: OT)*

Version 1 29.06.11 Mealtime observation schedule for the participants: The impact of swallowing difficulties on quality of life

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
AP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		
PP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		
MAs	✓	✓	✓	✓	✓	✓	✓	✓	X	X	✓	X	X	X	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		
AsTy	TF	TF	TF	TF	TF	TF	TF	TF	X	X	TF	X	X	X	TF	TF	TF	TF	TF	TF	TF	TF	TF	TF	TF	TF	TF	TF		
RA	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	X	X	Pve	X	X	X	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve	Pve		
CB	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		
SS	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF	FF		
SInt	Wst	X	FF	X	Wst	Wst	Wst	FF	X	FF	FF	X	X	X	X	X	X	Wst	Wst	X	Wst	X	Wst	Wst	X	X	X	X		
StDis	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		
ResDis	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		

Also a member of staff present to provide feeding assistance

minor coughing

Care assistant leaves briefly to refill cup of juice

minor coughing

Throat clearing

Soup starter finished + care assistant leaves to fetch main course

Wife provides P3 with a drink of juice

Main course served to P3 after potatoes have been mashed by care assistant

P3 complains that the fish is lumpy – fish is further fork-mashed by care assistant.

P3 pulls a bit of potato skin out of his mouth.

Main course finished. care assistant wipes P3's mouth + provides him with a drink of juice.

Juice served to P3 + P3's face then wiped.

The interactions with the member of staff providing feeding assistance all related to meal consumption + all exchanges were brief. The care assistant + P3's wife also had conversations during the mealtime.

5

NB The care assistant / P3's wife may have spoken to/addressed P3 beyond what has been recorded here but these have not been noted as P3 did not acknowledge/respond to the comments.

Not needed.

	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60
AP																														
PP																														
MAs																														
AsTy																														
RA																														
CB																														
SS																														
SInt																														
StDis																														
ResDis																														

Information to be obtained following the participant's completion of their meal:

Amount of food consumed (all, more than ¾, ½, less than ¼, none)	All of starter consumed: All of main course consumed.

Amount of liquid consumed (all, more than ¾, ½, less than ¼, none	½ of juice consumed. Juice beside the resident before + after the meal.

Time taken for the participant to complete their meal	Total duration of mealtime – 28 minutes. Time to consume starter – 8 minutes. Time to consume main course – 13 minutes.

APPENDIX 12

Reflexive discussion schedule for the participants with dysphagia

Reflexive Discussion schedule

[*verbal consent will be obtained from the participant again prior to commencing this final discussion*]

Participant number: ___________________

Date: ______________________________

Hello __________. It's nice to see you again.

So over the last two weeks I've been coming to visit you as part of the research that I'm carrying out.

The first time I came we had a chat about your swallowing difficulty and the different ways that it affects you.

The last two times I have come when you have been having a meal and I have been observing you during that meal.

I wanted to do this just so I could get an idea about your experience at mealtimes.

I made a record of the things that I observed during the mealtimes.

I wanted to talk to you one last time because I want to ask you about how you feel about mealtimes and a bit about the things that I observed.

So I just want you to tell me honestly how you find mealtimes and how your swallowing difficulty affects mealtimes.

If there's anything I ask that you don't want to answer, just let me know and we'll move on.

There's no right or wrong answer, the important thing is that I find out about how you feel.

Reflexive discussion schedule

[*This discussion schedule provides examples of points that might be raised within the discussion. All points for discussion will be devised according to the data collected from the mealtime observations*, *although they will follow a similar format as those presented below*].

I observed you once while you were eating lunch and once while you were eating dinner. I didn't get a chance to see you eating breakfast. Is there generally a particular mealtime that you prefer or a particular mealtime that you don't like? If so, can you tell me a bit more about why you think this is?

Do you feel as though you are in a comfortable position for eating your meals?

I noticed that one of the care assistants gives you some help during your meals. How do you feel about this help?

I noticed that during one of the mealtimes you only ate about ½ of your meal and drank less than ¼ of your drink. Why was this?

I noticed that you kept pushing your food away from you during the mealtimes. Can you tell me what made you do that?

I noticed that both of the times I observed you, you were eating your meal on your own. Is this a personal choice and if so, can you tell me a bit more about why you've decided to do that?

Can you tell me how you feel about the environment that you eat you meals in? [prompts provided if necessary- What about the noise level? How do you feel about other residents being taken to the toilet when you are eating your meal?]

Can you tell me a bit about how you feel about your pureed diet?

Is there anything you think that could be done to improve your mealtime experience? [prompts provided if necessary- What about the appearance of the dining room? Would you prefer to eat with other people?]

Basic notes to be taken here during the discussion in the case of video or audio equipment not functioning correctly.

APPENDIX 13

Transcript of an interview conducted with a participant with dysphagia

Participant number: P4

Date of interview: 11/05/12

Location of interview: Participant's bedroom

Time of interview: Approx. 10.45 am

001: Researcher: OK (name of participant)? So thank you very much for agreeing to have a wee…

002: P4: (Nods head and has been nodding head during part of the researcher's previous utterance) Ah.

003: Researcher: …chat with me. I really appreciate it.

004: P4: (Nods head and has been nodding head during the researcher's previous utterance) Ah.

005: Researcher: So as I've explained to you, this wee chat today is the first part of the research that I'll do with you and I'll see you at lunchtime today (P4 may be nodding his head in acknowledgement during this utterance)…

006: P4: Ah.

007: Researcher: …and then I'll also come back and see you on Monday.

008: P4: (Nods head and had started to do so during the last part of the researcher's previous utterance).

009: Researcher: And this interview today is going to be in two parts. The first part is going to involve me reading some statements to you.

010: P4: Ah (Nods head).

011: Researcher: And these statements are all about swallowing difficulties.

012: P4: (Nods head and has been nodding head during the researcher's previous utterance).

013: Researcher: And I'd just like you to listen to the statements and give me a response using the options that I'll provide you with (P4 may be nodding his head in acknowledgement during this utterance). So I've some wee scales here (Shows participant an example of a visual Likert Scale). And so I'll just read out a statement and you can just let me know (which) which… (Points to the various response options on the visual Likert Scale)…

014: P4: (Nods head) Ah.

015: Researcher: …response em you agree with.

016: P4: (Nods head).

017: Researcher: Does that sound OK?

018: P4: Ah.

019: Researcher: And if there's anything I ask that you don't want to answer, that's absolutely no problem…

020: P4: (Nods head).

021: Researcher: …you just let me know and we'll move on.

022: P4: (Nods head).

023: Researcher: And after this then we'll just have a chat (gestures) about your swallowing problem.

024: P4: Ah (Nods head and has been nodding head during part of the researcher's previous utterance).

025: Researcher: And there's no right or wrong answer or anything, I'm just interested in finding out how you feel about your swallowing problem and how it affects you…Does that all sound OK?

026: P4: Ah (Nods head).

027: Researcher: Do you have any questions at all?

028: P4: …You might find it difficult understanding what I'm saying (Gestures and points to himself with his pen).

029: Researcher: (Nods head) Say that again for me (name of participant).

030: P4: You might find it (Gestures)…

031: Researcher: Mmm (Nods head).

032: P4: (Starts to write)…

033: Researcher: I might find that I don't understand what you're saying. Was that what you were going to say?

034: P4: Aye (Raises eyebrows).

035: Researcher: Yea. Well that's why (I've) I've given you this (Points to pad of paper on P4's knee)…

036: P4: (Nods head).

037: Researcher: …cus that's really helpful, cus you're very good (at) at communicating…

038: P4: (Nods head and has been nodding head during part of the researcher's previous utterance).

039: Researcher: …through writing.

040: P4: (Nods head) - (It is not entirely clear if P4 is nodding his head here). Ah.

041: Researcher: So that's absolutely fine. OK?

042: P4: (Minor cough)…

043: Researcher: So (we'll) we'll make a wee start then alright?

044: P4: Ah.

045: Researcher: So, I'm going to read you some general statements…

046: P4: (Nods head).

047: Researcher: …that people with swallowing problems might mention.

048: P4: (Nods head and had started to do so before the researcher's previous utterance had been completed).

049: Researcher: In the last month, how true have the following statements been for you? So the first statement: Dealing with my swallowing problem…

050: P4: (Nods head).

051: Researcher: …is very difficult. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say (name of participant) that that statement is Very much true; Quite a bit true; A little true or Not at all true? Which one would you pick?

052: P4: (Points to A little true).

053: Researcher: A little true.

054: P4: (Nods head).

055: Researcher: OK…

Interruption from a member of care staff to deliver P4's medication. While the medication is being prepared, the researcher checks with P4 that he can see the visual aids and that they make sense. He confirms that they are fine. This initial medication interruption lasts for approximately 52 seconds and the care assistant goes to prepare further medication.

055: …Will we do another one just while we're…

056: P4: Aye.

057: Researcher: …while we're waiting. So the next statement (name of participant): My swallowing problem is a major distraction in my life.

058: P4: No (Shakes head).

059: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say it's Very much true; Quite a bit true; A little true or Not at all true?

060: P4: (Points to A little true).

061: Researcher: A little true…

062: P4: XXX

063: Researcher: …again. Yea. That's lovely…

The member of care staff returns to deliver P4's medication and he is assisted in taking this medication. During this time, P4 comments to the care assistant that he can feel a tablet sticking in his throat even though they are small. He is advised to consume further liquid in order to wash it down. When the care assistant leaves, the researcher gives P4 some additional time to finish taking his medication. Although his intelligibility is poor, P4 appears to be explaining to the researcher that his pills seem to stick in his throat. This interruption lasts for approximately 4 minutes and 17 seconds.

063: Researcher: …OK. So (we'll) we'll go on with some of these statements then, alright?

064: P4: XXX (Nods head).

065: Researcher: OK. So I'm going to read you some statements now about day-to-day eating that people with swallowing problems sometimes talk about. In the last month, how true have the following statements been for you? So the first statement of this section: It takes me longer to eat than other people.

066: P4: (Nods head).

067: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say that's Very much true; Quite a bit true; A little true or Not at all true?

068: P4: (Points to Quite a bit true).

069: Researcher: Quite a bit true.

070: P4: Aye.

071: Researcher: OK…And the next one: It takes me forever …

072: P4: (Nods head).

073: Researcher: …to eat a meal or a long time to eat a meal.

074: P4: (Shakes head).

075: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say that's Very much true; Quite a bit true; A little true…

076: P4: XXX (Nods head).

077: Researcher: …or Not at all true?

078: P4: (Points to Quite a bit true).

079: Researcher: Quite a bit true again, yea…OK, that's great…OK…Most days, I don't care if I eat or not. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say that that statement for you is Very much true; Quite a bit true; A little true or Not at all true?

080: P4: Not at all.

081: Researcher: Which one (would you, would you) would you say (name of participant)?

082: P4: (Points to Not at all true).

083: Researcher: Not at all true. That's fine…I don't enjoy eating anymore. Which one of those (would you) would you pick? (At this point, P4 appears to laugh and raise his right hand slightly) (Presents appropriate visual Likert Scale and points at the options when they are read out) Very much true; Quite a bit true; A little true or Not at all true?

084: P4: (Points to Not at all true).

085: Researcher: Not at all true. You still enjoy eating.

086: P4: (Nods head).

087: Researcher: That's good…

088: P4: Ah (Nods head).

089: Researcher: Yea. I'm rarely hungry anymore. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say that's Very much true; Quite a bit true; A little true or Not at all true.

090: P4: (Points to Not at all true).

091: Researcher: Not at all true…OK. I'm now going to read you some physical problems that people with swallowing problems sometimes experience. In the last month, how often have you experienced each problem as a result of your swallowing problem? So coughing. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you say you experience coughing Almost always; Often; Hardly ever or Never?

092: P4: (Studies the visual Likert Scale).

093: Researcher: Coughing.

094: P4: (Points to Often).

095: Researcher: Often…What about choking when you eat food?

096: P4: Aha (Gestures and nods head).

097: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Almost always; Often; Hardly ever or Never?

098: P4: (Points to Hardly ever) XXX

099: Researcher: Hardly ever is that?

100: P4: (Nods head) - (It is not entirely clear if P4 is nodding his head here).

101: Researcher: Yea…What about choking when you take liquids? (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you experience that Almost always; Often; Hardly ever or Never? (It is not entirely clear if P4 is shaking his head during this utterance)

102: P4: XXX (Points to Hardly ever).

103: Researcher: Hardly ever.

104: P4: XXX.

105: Researcher: OK…Oops sorry (knocks participant with interview schedule)…What about having thick saliva or phlegm?

106: P4: Ah (Points to the left hand corner of his mouth).

107: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Almost always; Often; Hardly ever or Never?

108: P4: XXX (Points to the left hand corner of his mouth and traces a downward motion, likely indicating that saliva escapes from this corner of his mouth. He then gestures as if trying to think of what to say)…Saliva comes out of my mouth??? (Points to the left hand corner of his mouth and traces a downward motion, likely indicating that saliva escapes from this corner of his mouth).

109: Researcher: It (/k/) comes out of your mouth?

110: P4: Ah.

111: Researcher: Yea. What about thick saliva or phlegm? Is that a problem for you at all?

112: P4: (Shakes head) XXX.

113: Researcher: Would you have that… (Starts to point at the response options on the visual Likert Scale)…

114: P4: XXXXXX (Gestures).

115: Researcher: I'm not getting you (name of participant), I'm sorry.

116: P4: XXX (Looks for a pen).

117: Researcher: You were saying that somethings, it comes out of your mouth sometimes. Down your, down your mouth…

118: P4: (Points to the left hand corner of his mouth and traces a downward motion, likely indicating that saliva escapes from this corner of his mouth). Aha (Overlap with the latter part of the researcher's previous utterance).

119: Researcher: …down the side of your mouth. Yea. Yea. So…

120: P4: A dribble???

121: Researcher: (Strains to understand participant).

122: P4: A dribble???

123: Researcher: I'm sorry I'm not following you.

124: P4: XXX (Gestures).

125: Researcher: Do you want to write it down for me? (Offers participant pen and he takes it).

126: P4: **Participant writes (While he is writing, the researcher interjects with 'mmm' at one point to indicate her interest and understanding):** A dribble on left hand side of mouth.

127: Researcher: Yea. (Paraphrases what P4 has written) On the left hand side of your mouth.

128: P4: (Completes his sentence as documented above).

129: Researcher: Yea. Yea. So that happens to you sometimes.

130: P4: Aye.

131: Researcher: Yea. What about thick saliva or phlegm? (Would that)…

132: P4: No (Shakes head).

133: Researcher: …(Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Almost always; Often; Hardly ever or Never?

134: P4: Never (Shakes head and had started to do so during the latter part of the researcher's previous utterance).

135: Researcher: Is that, show me which one (name of participant).

136: P4: (Points to Never).

137: Researcher: Never. OK…What about gagging. You know, sort of retching. Would that ever happen? (Presents appropriate visual Likert Scale and points at the options when they are read out) (Would that be) Would that happen Almost always; Often; Hardly ever or Never?

138: P4: (Points to Hardly ever).

139: Researcher: Hardly ever…What about then drooling?

140: P4: Ah XXX (Points to what he has written on the page about dribbling).

141: Researcher: Aha. (You) You've said that sometimes it comes out of (the) the…

142: P4: Ah (Points to the left hand corner of his mouth on his left hand side and traces a downward motion, likely indicating that saliva escapes from this corner of his mouth).

143: Researcher: …left hand side of your mouth.

144: P4: (Nods head).

145: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) So would that be Almost always; Often; Hardly ever or Never?

146: P4: (Studies the visual Likert Scale and then points to Often).

147: Researcher: Often. OK…What about problems with chewing your food?

148: P4: XXX (Gestures and moves head but hard to tell if he is nodding or shaking his head).

149: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Almost always; Often; Hardly ever or Never?

150: P4: Never (Points to Never).

151: Researcher: Never (P4 may be nodding in agreement here)…What about having too much saliva or phlegm? (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be something that you would experience: Almost always; Often…

152: P4: Often.

153: Researcher: …Hardly ever…

154: P4: (Points to Often).

155: Researcher: …Often?

156: P4: (Nods head).

157: Researcher: OK…Having to clear your throat?

158: P4: (Nods head).

159: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you experience that Almost always; Often; Hardly ever or Never?

160: P4: (Points to Often) Often.

161: Researcher: Often…What about food sticking in your throat? (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you experience that Almost always; Often; Hardly ever or Never?

162: P4: (Points to Hardly ever).

163: Researcher: Hardly ever…Food sticking in your mouth. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you experience that Almost always; Often; Hardly ever or Never?

164: P4: (Studies the visual Likert Scale, gestures) Ah (Shakes head).

165: Researcher: Food sticking in your mouth.

166: P4: (Studies the visual Likert Scale) XXX (Moves his head around) XXX

167: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Almost always; Often; Hardly ever or Never?

168: P4: (Points to Hardly ever).

169: Researcher: Hardly ever.

170: P4: (Nods head).

171: Researcher: What about food or liquid dribbling out of your mouth?

172: P4: (Nods head).

173: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that happen Almost Always; Often…

174: P4: (Points to Often).

175: Researcher: Often, OK…Now…What about food or liquid coming out of your nose?

176: P4: (Shakes head).

177: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Almost always; Often; Hardly ever or Never.

178: P4: Never.

179: Researcher: Pardon?

180: P4: (Participant goes to write on the pad of paper)…

181: Researcher: There's the pen, there's your pen there (Hands pen to participant and he takes it).

182: P4: **Participant writes:** Never.

183: Researcher: (Repeats verbatim what P4 has written) Never.

184: P4: XXX.

185: Researcher: That doesn't happen. That's good…(What about having) What about coughing food or liquid out of your mouth when it gets stuck?

186: P4: (Shakes head).

187: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that happen Almost always; Often; Hardly ever or Never?

188: P4: Ah (Points to Hardly ever) Hardly ever.

189: Researcher: Hardly ever.

190: P4: (Nods head).

191: Researcher: Great. So I'm now going to read you some concerns…

192: P4: (Nods head).

193: Researcher: …that people with swallowing difficulties sometimes mention.

194: P4: (Nods head).

195: Researcher: In the last month, how often have you experienced each feeling?...So I fear I may start choking when I eat food.

196: P4: (Shakes head).

197: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be a feeling you would experience Almost always; Often; Hardly ever or Never?

198: P4: (Points to Never) Never.

199: Researcher: Never.

200: P4: (Nods head).

201: Researcher: I am afraid of choking when I drink liquids. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be a feeling you experience Almost always; Often; Hardly ever or Never?

202: P4: (Laughs) XXXXXX (Laughs and gestures).

203: Researcher: (Smiles) I'm not getting you, sorry. Write that down for me.

204: P4: **Participant writes and smiles as he does so:** A big glass of whiskey.

205: Researcher: (Laughs) (Repeats verbatim what P4 has written) A big glass of whiskey. Do you (like) enjoy your whiskey?

206: P4: (Smiles).

207: Researcher: (Laughs) Yea (Laughs). Do you get that now and again?

208: P4: XXX (Laughs).

209: Researcher: (Laughs). So what about (being) feeling afraid of choking when you drink liquids? (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you experience that feeling…

210: P4: (Shakes head).

211: Researcher: …Almost always…

212: P4: Never (Shakes head).

213: Researcher: …Often…

214: P4: (Shakes head).

215: Researcher: …Hardly ever or Never?

216: P4: Never.

217: Researcher: Never is that?

218: P4: (Nods head).

219: Researcher: Mmm (Laughs). I never know when I am going to choke. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you have that Almost always; Often; Hardly ever or Never? Which one of those would it be?

220: P4: Never (Points to Never).

221: Researcher: Never?

222: P4: (Nods head).

223: Researcher: OK…OK. In the last month, how often have the following statements been true for you because of your swallowing problem? So the first one of these: My swallowing problem depresses me. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Always true; Often true; Hardly ever true or Never true.

224: P4: (Looks like he points to Hardly ever true but it is not entirely clear if he is indicating Hardly ever or Never).

225: Researcher: Which one?

226: P4: XXX (Points to Never true).

227: Researcher: Never?

228: P4: XXX (Points to Hardly ever true).

229: Researcher: Hardly ever?

230: P4: (Nods head).

231: Researcher: OK…Alright…Having to be so careful when I eat or drink annoys me. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Always true; Often true; Hardly ever true or Never true?

232: P4: (Points to Often true).

233: Researcher: Often true.

234: P4: (Nods head) (It is not entirely clear if P4 is nodding his head here).

235: Researcher: I've been discouraged by my swallowing problem (It is not entirely clear if P4 nods his head after 'discouraged') (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Always true; Often true; Hardly ever true or Never true?

236: P4: (Points to Hardly ever true).

237: Researcher: Hardly ever true.

238: P4: (Tilts head back).

239: Researcher: My swallowing problem frustrates me. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Always true; Often true; Hardly ever true or Never true?

240: P4: Hardly ever (Points to Hardly ever).

241: Researcher: Hardly ever.

242: P4: (Nods head).

243: Researcher: I get impatient dealing with my swallowing problem.

244: P4: (Shakes head).

245: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would that be Always true; Often true; Hardly ever true or Never true?

246: P4: (Points to Never true).

247: Researcher: Never true.

248: P4: Never.

249: Researcher: OK. So just a few more of these to go.

250: P4: (Nods head).

251: Researcher: Are you alright?

252: P4: (Nods head).

253: Researcher: Are you happy enough to continue?

254: P4: Ah (Nods head).

255: Researcher: OK…(So think about) I'd like you to think about your social life in the last month.

256: P4: (Coughing).

257: Researcher: And how strongly would you agree or disagree with the following statements?

258: P4: (Nods head) (It is not entirely clear if P4 is nodding his head here).

259: Researcher: So the first one of these: I do not go out to eat because of my swallowing problem. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you Strongly agree; Agree; Disagree or Strongly disagree?

260: P4: Pardon???

261: Researcher: It's: I do not go out to eat because of my swallowing problem.

262: P4: Ah XXX (Points to Strongly disagree).

263: Researcher: Strongly disagree (P4 may be nodding his head here but it is not entirely clear)…My swallowing problem makes it hard to have a social life.

264: P4: (Shakes head).

265: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you Strongly agree; Agree; Disagree or Strongly Disagree?

266: P4: XXX (Points to Strongly disagree).

267: Researcher: Strongly disagree…My usual activities have changed because of my swallowing problem. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you Strongly agree; Agree; Disagree or Strongly disagree?

268: P4: Ah (Points to Strongly disagree).

269: Researcher: Strongly disagree.

270: P4: (Nods head).

271: Researcher: OK…And the last page of these ones…Social gatherings are not enjoyable because of my swallowing problem. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you Strongly agree; Agree; Disagree or Strongly disagree?

272: P4: (Points to Strongly disagree).

273: Researcher: Strongly disagree…My role with family and friends has changed…

274: P4: (Nods head).

275: Researcher: …because of my swallowing problem. (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you Strongly agree; Agree; Disagree or Strongly disagree?

276: P4: Ah…(Points to disagree).

277: Researcher: Disagree.

278: P4: (Nods head).

279: Researcher: And the final three of these. In the last month, how often have you experienced each of the following physical symptoms.

280: P4: (Nods head).

281: Researcher: So what about feeling weak?

282: P4: (Nods head).

283: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you experience that All of the time; Most of the time; A little of the time or None of the time?

284: P4: (Points to A little of the time).

285: Researcher: A little of the time.

286: P4: (Nods head).

287: Researcher: What about feeling tired?

288: P4: (Nods head).

289: Researcher: (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you feel tired All of the time; Most of the time; A little of the time or None of the time?

290: P4: (Points to A little of the time).

291: Researcher: A little of the time.

292: P4: (Nods head).

293: Researcher: And finally, feeling exhausted (It is not entirely clear whether P4 is nodding his head here or just looking down). (Presents appropriate visual Likert Scale and points at the options when they are read out) Would you feel exhausted All of the time; Most of the time; A little of the time or None of the time?

294: P4: (Points to A little of the time).

295: Researcher: A little of the time.

296: P4: (Nods head).

297: Researcher: That's great (name of participant).

298: P4: (Nods head).

299: Researcher: Thank you very much for…

300: P4: (Nods head).

301: Researcher: …for bearing with me…

302: P4: (Nods head).

303: Researcher: …and going through those.

304: P4: (Nods head).

305: Researcher: OK…Now for the next bit (name of participant), I'm going to read to you and show you some different problems.

306: P4: (Nods head and had started to do so during the latter part of the researcher's previous utterance).

307: Researcher: Now I know you might not have all or any of these problems, but I'd just like you to tell me whether you have any of these problems…

308: P4: (Nods head).

309: Researcher: …and whether you would say that any of these…

310: P4: (Nods head).

311: Researcher: …affect the quality…

312: P4: (Nods head).

313: Researcher: …of your life.

314: P4: (Nods head).

315: Researcher: So I'll go through these different problems one at a time and you can let me know whether it affects your life or not.

316: P4: (Nods head).

317: Researcher: So the first one is joint or back pain (Presents appropriate visual aid to participant).

318: P4: Ah (Nods head).

319: Researcher: Is that a problem for you (name of participant)?

320: P4: Ah (Nods head).

321: Researcher: Yea. OK. That's great…The second one: There are not enough opportunities to talk to people (Presents appropriate visual aid to participant). Is that something that's a problem or not a problem?

322: P4: (Shakes head) Not a problem.

323: Researcher: Not a problem.

324: P4: (Shakes head).

325: Researcher: OK. That's good…Your swallowing difficulty (Presents appropriate visual aid to participant). Is that a problem or not a problem?

326: P4: Not a problem (Shakes head).

327: Researcher: Not a problem was that (name of participant)?

328: P4: XXX pill (Points to throat).

329: Researcher: I'm sorry (name of participant) could you write that down for me so I can get it?

330: P4: **Participant writes:** I mentioned the small pill.

331: Researcher: (Paraphrases what she thinks P4 has written) You mentioned the small hill?

332: P4: Pill (Points to throat) **and then writes:** PILL.

333: Researcher: (Paraphrases what P4 has written) O the small pill sorry. Yes. And it got stuck, felt a wee bit stuck.

334: P4: Ah (Points to throat).

335: Researcher: Aha. So would you say that (you) your swallowing difficulty is a problem or not a problem for you?

336: P4: (Shrugs shoulders and points to visual aid) That's not a problem???

337: Researcher: Your swallowing difficulty is…

338: P4: Not a problem (Gestures).

339: Researcher: Not a problem?

340: P4: (Nods head).

341: Researcher: OK…What about having less independence? (Presents appropriate visual aid to participant). Is that something that's a problem for you or not a problem?

342: P4: Not a problem (Shakes head).

343: Researcher: Not a problem…Mobility problems, not being able to get around as easily by yourself or at all (Presents appropriate visual aid to participant). Would you say that that's a problem for you…

344: P4: (Shakes head).

345: Researcher: …or not a problem?

346: P4: Not a problem.

347: Researcher: OK…And is there anything else (name of participant) that I haven't mentioned there (that) that is a problem for you…

348: P4: Ah.

349: Researcher: …something that affects your life?

350: P4: XXX

351: Researcher: If there's anything there you…

352: P4: XXX

353: Researcher: You write it down for me.

354: P4: **Participant writes:** Bladder problems.

355: Researcher: OK. (Repeats verbatim what P4 has written) Bladder problems. OK. That would be something else that's a problem for you then.

356: P4: (Nods head).

357: Researcher: OK…

Brief interruption from a care assistant delivering some towels (Approximately 9 seconds).

357: Researcher: OK then (name of participant). So you've mentioned joint or back pain...

358: P4: (Nods head).

359: Researcher: …being a problem for you…

360: P4: (Nods head).

361: Researcher: …is that correct?

362: P4: Ah (Nods head).

363: Researcher: And when I asked you about not enough opportunities to talk to people you said that's not a problem.

364: P4: (Nods head).

365: Researcher: Is that correct?

366: P4: Aha (Nods head).

367: Researcher: Your swallowing difficulty you said that's not a problem.

368: P4: (Shakes head).

369: Researcher: Am I right in (say) in that?

370: P4: Ah (Nods head).

371: Researcher: Is that correct? Having less independence, you said that wasn't a problem. Is that correct?

372: P4: (Nods head).

373: Researcher: Your mobility problems (not) not being able to get around as easily, you said that wasn't a problem?

374: P4: (Shakes head).

375: Researcher: And then you've mentioned bladder problems as well.

376: P4: Aha (Nods head).

377: Researcher: So the two problems really that you've mentioned have been joint and back pain and bladder problems.

378: P4: Ah (Nods head).

379: Researcher: Would there be one of those you would say that (would, would) you would place first, (that, that) as in that affects my (life) life the most?

380: P4: XXX (Gestures)

381: Researcher: Which one would be the (bigger) biggest problem for you? (Presents P4 with the interview schedule listing his ranking item responses). Joint or back pain or bladder problems?

382: P4: XXX (Points to bladder problems on the schedule- can't see this on the video- relying on the researcher's repetition of P4's selection).

383: Researcher: Bladder problems. OK…That would be first then…

384: P4: (Nods head).

385: Researcher: …you'd place that. That would be your biggest problem. OK…And so the other problem then you'd mentioned (is) is joint or back pain. (Would that) Would you place that second then (as) as the second biggest problem…

386: P4: Aye (Nods head).

387: Researcher: …or would there be anything else?

388: P4: Second??? (Nods his head towards the interview schedule).

389: Researcher: That would be second.

390: P4: (Nods head).

391: Researcher: OK…That's great, thank you very much for that (name of participant)…OK. And finally then, for the last part, I'm really just interested in finding out (name of participant) if there's anything you'd like to share with me about your swallowing problem?

392: P4: …

393: Researcher: I'm just interested in finding out how you feel about your swallowing problem…What it's like to have a swallowing problem…Is there anything you'd like to share with me about that?

394: P4: XXXXXX (Points to throat).

395: Researcher: (Could you, would you be able to write) Would you mind writing it down for me, so that I can be 100% sure that I've got you?

396: P4: **Participant writes (as he writes the researcher interjects once with 'OK' to indicate understanding and to assure the participant that she is attending to what he is communicating):** The small pill is inclined to stick in m I* (sp error: participant most likely means 'my') throat whilst trying to wash it down with a drink of liquid…

397: Researcher: OK. (Repeats verbatim what P4 has written so far) The small pill is inclined to stick in my throat whilst trying to wash it down with a drink of liquid…

398: P4: **Participant continues to write:** …results in the liquid by passing the pill- ie. the drink goes down but the pill is still there.

399: Researcher: OK. (Paraphrases what P4 has written overall) So the small pill is inclined to stick in my throat whilst trying to wash it down with a drink of liquid results in the liquid by passing the pill, so the drink goes down but the pill is still there.

400: P4: (Nods head).

401: Researcher: OK. OK.

402: P4: (Nods head).

403: Researcher: (Does that) Is that a regular occurrence then?

404: P4: Ah (Nods head and has been nodding head during part of researcher's previous utterance).

405: Researcher: OK. And how do you feel about that happening (name of participant)?

406: P4: XXX (Gestures) It dissolves??? (Gestures). **Participant then writes:** The pill eventually dissolves.

407: Researcher: OK. (Repeats verbatim what P4 has written) The pill eventually dissolves. It eventually goes away.

408: P4: (Nods head).

409: Researcher: OK (P4 nods head). (How do you feel) How do you feel about (get) having that pill stuck there?

410: P4: (Shrugs his shoulders and shakes his head).

411: Researcher: What do you think of that…

412: P4: (Shakes head).

413: Researcher: …happening?

414: P4: …**Participant writes (as he writes the researcher interjects once with 'mmm' to indicate understanding and to assure the participant that she is attending to what he is communicating):** It makes coughing more likely to happen.

415: Researcher: Yes (Repeats verbatim what P4 has written) It makes coughing more likely to happen. Yes.

416: P4: (Nods head).

417: Researcher: Yes I understand. Yea. Yea. OK so that difficulty with your pill then…

418: P4: (Nods head).

419: Researcher: …(that's) that's a problem.

420: P4: Aha (Nods head).

421: Researcher: That's something related to your swallowing problem.

422: P4: (Nods head and has been nodding head throughout researcher's previous utterance).

423: Researcher: Is there anything else you'd like to share with me about your swallowing problem?

424: P4: …

425: Researcher: What it's like to have a swallowing problem.

426: P4: **Participant writes (as he writes the researcher interjects once with 'OK' to indicate understanding and to assure the participant that she is attending to what he is communicating):** A bigger pill would probably get washed down.

427: Researcher: (Repeats verbatim what P4 has written) A bigger pill would probably get washed down. OK. OK…That's great (name of participant). Thank you for sharing that…Is there anything else about your swallowing difficulty, about what it's like to have a swallowing difficulty that you'd like to share with me?...How it makes you feel, having a swallowing difficulty.

428: P4: **Participant writes:** I know that the danger is although it might be easy enoughh* (sp error: participant means 'enough') to swallow some things there is a danger of the food or whatever going into the lungs.

429: Researcher: Mmm. Mmm. (Parphrases what P4 has written) I know that the danger is that although it might be easy enough to swallow some things there is a danger of the food or whatever going into the lungs. Yes.

430: P4: (Nods head).

431: Researcher: Yes. How do you feel about that, that danger?

432: P4: (Shrugs shoulders) … (Laughs) ……(Does he get a bit emotional here and does he shed a tear a little bit after this utterance or is his eye watering??) XXX (Points to throat) Phlegm XXX

433: Researcher: Sorry (name of participant).

434: P4: XXX phlegm (Points to throat).

435: Researcher: Phlegm?

436: P4: XXX (Gestures).

437: Researcher: I didn't get that sorry (name of participant).

438: P4: …

439: Researcher: I didn't catch that.

440: P4: **Participant writes:** I cannot cough any flem* (sp. error- should be phlegm) up.

441: Researcher: (Repeats verbatim what P4 has written) I cannot cough any phlegm.

442: P4: XXX (Gesture).

443: Researcher: Up. (Is that) Is that right (name of participant)?

444: P4: XXXXXX (Points to his throat).

445: Researcher: Mmm. I cannot cough any phlegm up. OK. OK…

446: P4: Muscle in my throat??? (Points to his throat) the muscle???

447: Researcher: (Strains to understand participant).

448: P4: The muscle (Gestures).

449: Researcher: The muscle?

450: P4: **Participant writes:** The muscle in my throat is weak.

451: Researcher: (Paraphrases what P4 has written) The muscle in your throat is weak, yes.

452: P4: (Nods head).

453: Researcher: Yes. Aha.

454: P4: (Nods head).

455: Researcher: OK. Is there anything else that you'd like to share with me about your swallowing difficulty? … How you feel about it.

456: P4: …

457: Researcher: Anything else you can think of.

458: P4: (Shakes head).

459: Researcher: No?

460: P4: (Shakes head).

461: Researcher: OK. If you don't mind, if we just go back to some of the statements that we were reading out earlier.

462: P4: (Nods head).

463: Researcher: About swallowing problems…And if I just pick on this one here. You said dealing with my swallowing problem is very difficult, you said that was a little true.

464: P4: (Nods head).

465: Researcher: Can you tell me a bit (about) about that, a wee bit more about why that is?

466: P4: XXX (Gestures and starts to write)

467: Researcher: Do you want to turn over the page, give you a new page (turns over the page in the notepad). There we go, a new page.

468: P4: **Participant writes:** I dare say that I occasionally feel a longing for food that I am warned to risk eating.

469: Researcher: OK (Paraphrases what P4 has written) I dare say I occasionally feel a longing for food that I am warned to risk eating. (Is that) Is that correct?

470: P4: XXX (Nods head).

471: Researcher: Mmm.

472: P4: (Nods head).

473: Researcher: Mmm. And what kind of food would that be?

474: P4: Ah…

475: Researcher: What sort of food would that be?

476: P4: **Participant writes:** Lettuce (and also says XXX)

477: Researcher: Mmm (Repeats verbatim what P4 has written) Lettuce, yea.

478: P4: **Participant writes:** Tomatoes.

479: Researcher: (Repeats verbatim what P4 has written) Tomatoes, yea.

480: P4: **Participant writes:** Link sausges* (sp error: participant means ‘sausages’)…

481: Researcher: Mmm (Repeats verbatim what P4 has written) Link sausages, yea.

482: P4: **Participant writes:** …due to having a skin on them.

483: Researcher: Yea (Paraphrases what P4 has written) Due to them having a skin, yea. Yea, so those are foods sometimes you’d quite like to have.

484: P4: Ah (Nods head).

485: Researcher: But they’re risk, they’re quite risky foods aren’t they?

486: P4: (Nods head and has been nodding his head throughout the researcher’s previous utterance).

487: Researcher: Yes.

488: P4: (Nods head).

489: Researcher: OK. And this statement here (name of participant), you’d said my swallowing problem is a major distraction in my life. You’d said that was a little true.

490: P4: Aye (Nods head).

491: Researcher: Can you tell me why that is?

492: P4: Well, XXX…XXX **Participant writes:** I just have to do with other alternatives.

493: Researcher: (Paraphrases what P4 has written) You just have to do with other alternatives.

494: P4: (Nods head).

495: Researcher: Yes. You mean other alternatives to these foods here?

496: P4: Aye (Nods head).

497: Researcher: Yea. Yea. OK…Now let me have a wee look and see (Flicks through interview schedule)…And then we talked about these two, you said (the) the statement here, it takes me longer to eat than other people and it takes me forever or a long time to eat a meal, you said those were both quite a bit true.

498: P4: Ah (Nods head).

499: Researcher: Why is that? Why do you think that is (name of participant)?

500: P4: Well I have to chew them more??? (Gestures)

501: Researcher: Would you mind writing it down for me? I'm sorry, I'm tiring you out (Laughs).

502: P4: **Participant writes:** If I, for instance eat steak, I have to chew it more thorouly* (sp error: participant means 'thoroughly').

503: Researcher: Mmm (Paraphrases what P4 has written) If you eat steak you have to chew it more thoroughly.

504: P4: (Nods head).

505: Researcher: Yes.

506: P4: (Nods head).

507: Researcher: And that takes a bit of time then doesn't it.

508: P4: Ah (Nods head).

509: Researcher: OK.

510: P4: (Nods head).

511: Researcher: OK. And then these ones here, (you) you said that all of these were not at all true. Most days I don't care if I eat or not, you said that was not at all true.

512: P4: (Nods head).

513: Researcher: And I don't enjoy eating anymore, again you said that was not at all true.

514: P4: (Nods head and had started to do so during the latter part of the researcher's previous utterance).

515: Researcher: And I'm rarely hungry anymore, you said that's not at all true.

516: P4: (Nods head and had started to do so during the latter part of the researcher's previous utterance).

517: Researcher: So you still have an appetite.

518: P4: O aye (Nods head).

519: Researcher: And you enjoy eating still.

520: P4: Ah (Nods head).

521: Researcher: Good.

522: P4: (Nods head).

523: Researcher: That's really good. And then we talked about some physical problems to do with swallowing. And you'd mentioned that coughing, that often happens.

524: P4: Ah.

525: Researcher: Drooling often happens.

526: P4: (Nods head).

527: Researcher: Having too much saliva or phlegm often happens; having to clear your throat often happens and food or liquid dribbling out of your mouth often happens.

528: P4: Ah.

529: Researcher: So there's a few different physical problems there that you'd mentioned.

530: P4: XXX (Points to the left hand corner of his mouth on his left hand side and traces a downward motion, likely indicating that saliva escapes from this corner of his mouth).

531: Researcher: (Nods head).

532: P4: XXX (Raises his left arm and points to it).

533: Researcher: Could you write that down for me (name of participant)? Sorry.

534: P4: **Participant writes (as he writes the researcher interjects once with 'Mmm' to indicate understanding and to assure the participant that she is attending to what he is communicating):** The left hand side of my body is most affected by the result of the stroke.

While he is writing this there is a brief interruption from a care assistant who is delivering P4's newspapers (Approximately 14 seconds).

535: Researcher: Yes (Paraphrases what P4 has written) The left hand side of your body is most affected by the result of the stroke, yes.

536: P4: (Nods head).

537: Researcher: And so you find that (Points to the corner of her mouth)…

538: P4: Ah (Points to the left hand corner of his mouth).

539: Researcher: …saliva and things come out there.

540: P4: And my hand??? (Lifts his left hand and grasps it).

541: Researcher: Your hand.

542: P4: XXX

543: Researcher: Your arm.

544: P4: XXX (Gestures and demonstrates the difficulty he experiences when picking up and trying to hold a pen in his left hand).

545: Researcher: Yes, it's difficult to use.

546: P4: XXX (Gestures).

547: Researcher: Yes, so it's the left hand side of your body's…

548: P4: XXX (Nods head).

549: Researcher: …affected then.

550: P4: (Nods head).

551: Researcher: OK.

552: P4: (Nods head).

553: Researcher: So can you tell me how you feel about experiencing these different difficulties, the coughing and the drooling and the, you know, having too much saliva and phlegm and having to clear your throat and food and liquid dribbling out of your mouth? How do you feel about experiencing these different things?

554: P4: **Participant writes (had started to write during the researcher's previous utterance):** Frustrating.

555: Researcher: (Repeats verbatim what P4 has written) Frustrating.

556: P4: (Nods head).

557: Researcher: OK, yes.

558: P4: (Nods head).

559: Researcher: Yea, that's how you feel about that, yea. We're nearly finished (Laughs).

560: P4: (Nods head).

561: Researcher: And I'd read out some statements about sort of fear of choking and things and you said that those…

562: P4: Ah.

563: Researcher: …were, that never happened.

564: P4: (Nods head).

565: Researcher: Is that correct, you don't really feel afraid of choking?

566: P4: No (Shakes head).

567: Researcher: OK…Now, there was one statement here I wanted to ask you about. You said having to be so careful, the statement having to be so careful when I eat or drink annoys me.

568: P4: (Nods head).

569: Researcher: You said that was often true.

570: P4: Ah.

571: Researcher: Can you tell me a wee bit more about that (name of participant)?

572: P4: XXX (Gestures). **Participant writes (as he starts to write, researcher interjects with 'That's great'):** Going out for a Chinese or Indian curry…

573: Researcher: (Reads verbatim what P4 has written so far) Going out for a Chinese or Indian curry…

574: P4: (Nods head).

575: Researcher: What about that?

576: P4: **Participant continues to write (as he writes the researcher interjects once with 'Mmm' to indicate understanding and to assure the participant that she is attending to what he is communicating):** …which I find is no problem I am still advised not to risk it.

577: Researcher: OK (Paraphrases what P4 has written overall) Going out for a Chinese or Indian curry you find's no problem…

578: P4: (Nods head).

579: Researcher: …but you're advised not to risk it.

580: P4: (Nods head).

581: Researcher: OK and how do you feel about being advised not to risk it?

582: P4: (Gestures and Laughs).

583: Researcher: (Laughs) How do you feel about that?

584: P4: **Participant writes:** I couldn't do that for the rest of my life.

585: Researcher: (Paraphrases what P4 has written) You couldn't do that for the rest of your life. You couldn't do what for the rest of your life?

586: P4: XXX (Gestures).

Video recording ran out of battery power at this point and so the remainder of the transcription is based upon the audio recording. Therefore no non verbal communication can be transcribed beyond this point.

587: Researcher: You couldn't not risk, you couldn't not eat those things…

588: P4: Aha.

589: Researcher: …for the rest of your life. Is that what you're…

590: P4: Aha.

591: Researcher: …saying to me? Yea. Yea. OK. And we'd also talked about, I'd read you out different statements about social aspects of swallowing difficulties. And you'd really indicated that (it) your swallowing problem doesn't seem to affect you socially. Is that correct?

592: P4: Aha.

593: Researcher: Is that fair enough?

594: P4: ???

595: Researcher: Yea. OK. And finally then, we'd talked about some em things, statements like feeling weak, feeling tired, feeling exhausted. You say you experience these feelings a little of the time.

596: P4: XXX

597: Researcher: (Why) Why do you think you experience these feelings a little of the time?

598: P4: I've got a bad back???

599: Researcher: Pardon (name of participant)?

600: P4: **Participant writes:** I've got a bad back.

601: Researcher: (Paraphrases what P4 has written) You've got a bad back. OK. OK…OK, well I think that's us finished (name of participant), unless there's anything else you'd like to share with me about your swallowing difficulty and how you feel about that?

602: P4: ???

603: Researcher: Nothing else?

604: P4: ???

605: Researcher: Have we covered everything?

606: P4: Ah.

607: Researcher: OK, well that’s wonderful. I’ll turn off these recording things now, OK?

608: P4: Aha.

Total length: 52 minutes and 46 seconds (this time includes the medication-related interruption which lasted for approximately 5 minutes and the other two smaller interruptions). Note the extra time involved in P4 writing the majority of his responses.

APPENDIX 14

Transcript of a reflexive discussion conducted with a participant with dysphagia

Participant number: P3

Date of reflexive discussion: 19/04/12

Location of reflexive discussion: Participant's bedroom

Time of reflexive discussion: 10.45am

001: Researcher: Alright?

002: P3: Fine.

003: Researcher: OK. Let's get going…

004: P3: In the Metro, you know that freebie?

005: Researcher: Yes.

006: P3: There was a screen about Parkinson's.

007: Researcher: Was there an article about it?

008: P3: By eh, what do you call him, (name of consultant)…

009: Researcher: OK.

010: P3: …who's a consultant…

011: Researcher: OK.

012: P3: …over at the (name of hospital where consultant is based).

013: Researcher: I see, I see. And he was writing an article about it.

014: P3: So my daughter's got it away, reading it XXX.

015: Researcher: Very good.

016: P3: Basically, can I just talk? (Gestures)

017: Researcher: Of course.

018: P3: Right. Basically, there's about 6 things can go wrong, but it's all a downward dive (Gestures).

019: Researcher: Mmm.

020: P3: XXX some things like disseminated XXX you get your euphoric /t/, cheerful times… (Gestures)

021: Researcher: Mmm.

022: P3: …but not with Parkinson's (Gestures).

023: Researcher: Mmm.

024: P3: Parkinson's is generally degenerative (Gestures).

025: Researcher: Yes.

026: P3: Permanent (Gestures).

027: Researcher: Yes.

028: P3: First thing I noticed was…a fast, rapid pulse.

029: Researcher: You noticed what?

030: P3: XXX A rapid pulse.

031: Researcher: Mmm.

032: P3: And then we learned to control that…

033: Researcher: Mmm.

034: P3: …with (name of drug)...

035: Researcher: Mmm.

036: P3: …which XXX dampens down the rate (Gestures).

037: Researcher: Aha.

038: P3: And then the next one was (Demonstrates the existence of tremor)…this…

039: Researcher: Yea, the tremor.

040: P3: …the tremor (Demonstrates the existence of tremor).

041: Researcher: Yea.

042: P3: (Now that's) That's with you four hours everyday (Gestures).

043: Researcher: Mmm.

044: P3: Somedays less, somedays (P3 mouths something after this but is unclear what it is- possibly 'more')… (Gestures)

045: Researcher: Mmm.

046: P3: Just interrupt me if you want (Gestures).

047: Researcher: No, no, carry on.

048: P3: The em, the next dip that I went down was reactive (dep) depression…

049: Researcher: Mmm.

050: P3: …reacting to (the) this rapid pulse which was quite difficult to control (Gestures).

051: Researcher: Yea.

052: P3: And eh, that as I say, gave me reactive depression. Fortunately, I'm not a depressive and I managed to throw that feeling off…Then you've got…you've got the muscles of facial expression (Gestures).

053: Researcher: That's right.

054: P3: XXX My family said to me, 'Why are you so angry with us?'

055: Researcher: (Laughs).

056: P3: I'm not angry (Laughs).

057: Researcher: Yea.

058: P3: And eh, so I'd to give them a lecture….

059: Researcher: Mmm (Laughs).

060: P3: …on how to react.

061: Researcher: You'd to tell them why that happens.

062: P3: XXX

063: Researcher: Yea.

064: P3: And now they live with that.

065: Researcher: Yes, yea.

066: P3: And eh…now what's the next one?...are we recording?

067: Researcher: Mmm, carry on (P3 says something at this point but it is unclear what it is)…we're fine…

068: P3: For some reason, eh, the next one is (Laughs), memory.

069: Researcher: Mmm.

070: P3: XXX remember my list…

071: Researcher: Mmm.

072: P3: …is very difficult.

073: Researcher: Mmm.

074: P3: XXX.

075: Researcher: Yea.

076: P3: Obviously it's the, the eh recent memory (Gestures).

077: Researcher: Yea.

078: P3: You've read all that in the books, have you?

079: Researcher: I have, yea.

080: P3: And eh…then my family come in and say, 'Dad, how do you remember that?'

081: Researcher: (Laughs).

082: P3: I say because I have (a) a visual em…picture… (Gestures)

083: Researcher: Yes.

084: P3: …XXX taking in ten years ago (Gestures).

085: Researcher: Yea.

086: P3: I don't take it in anymore (Gestures).

087: Researcher: Aha.

088: P3: And that's a bit eh of a downer.

089: Researcher: Aha.

090: P3: XXX my attitude (im) improves when I start to think… (Gestures)

091: Researcher: Mmm.

092: P3: …about how difficult it is for some people who are worse off than I am… (Gestures)

093: Researcher: Mmm.

094: P3: …who have no memory…

095: Researcher: Mmm.

096: P3: …before.

097: Researcher: Mmm.

098: P3: I have a memory of before.

099: Researcher: Mmm.

100: P3: And eh XXX did you meet my dentist pal who was in XXX?

101: Researcher: I didn't, no.

102: P3: Aw he…he's got no memory at all.

103: Researcher: Mmm.

104: P3: And eh, so there's some consolation… (Laughs)

105: Researcher: Yea.

106: P3: …in all these illnesses.

107: Researcher: Mmm.

108: P3: …Names of diseases I find difficult.

109: Researcher: Names you find difficult.

110: P3: XXX The recent memory (is) /d/ doesn't register… (Gestures)

111: Researcher: Yea.

112: P3: …whereas the far away memory… (Gestures)

113: Researcher: Yea.

114: P3: …I can quote what day…

115: Researcher: Yea.

116: P3: …of the week it was that you had your birthday. All that kinda.

117: Researcher: Mmm. Mmm.

118: P3: XXX you see XXX good and bad and indifferent.

119: Researcher: Mmm.

120: P3: But unfortunately, (trying to) trying to eh take a broad look of your problem, that's very difficult (Gestures).

121: Researcher: Yea.

122: P3: Especially when you've been in medicine.

123: Researcher: Yea, absolutely.

124: P3: It doesn't help.

125: Researcher: No. You know more about what's happening, don't you?

126: P3: That’s right.

127: Researcher: Yea, yea, I can understand that.

128: P3: So eh…(my) my dentist pal, I introduced him to his wife and I took all the credit (Smiles).

129: Researcher: (Laughs).

130: P3: But he, his memory’s awful.

131: Researcher: Yea.

132: P3: XXX say, ‘How’s John so and so?’ ‘John so, who was that?’

133: Researcher: Mmm.

134: P3: His memory’s XXX, it’s no use at all.

135: Researcher: Yea.

136: P3: So you’ve gotta count your, count your blessings (Laughs).

137: Researcher: Mmm. Mmm… Well (It’s a) It’s a difficult disease, isn’t it?

138: P3: Very.

139: Researcher: Yea.

140: P3: But as I say, when you step back it is XXX (Gestures).

141: Researcher: Yea.

142: P3: And this article by (name of consultant)…

143: Researcher: Yea.

144: P3: …tells you, quite plainly, XXX expected his treatment to be effective (Gestures).

145: Researcher: Mmm.

146: P3: 6 years, which didn’t (cheer) cheer me up, really (Smiles).

147: Researcher: Yes. Mmm.

148: P3: Interestingly XXX I saw him as a patient.

149: Researcher: Did you?

150: P3: And eh his wife and he run a double clinic.

151: Researcher: Right.

152: P3: And guess what?

153: Researcher: What?

154: P3: I reckon that his wife was a better doctor.

155: Researcher: (Laughs).

156: P3: (Don’t, don’t) Don’t quote me! (Laughs).

157: Researcher: (Laughs).

158: P3: XXX a very nice guy.

159: Researcher: Aha.

160: P3: But she has this, sort of gift…

161: Researcher: Mmm.

162: P3: …in being able to pick up on something, ‘And what do you think of so and so?’ (Gestures)

163: Researcher: Yes.

164: P3: And that was a great help to me.

165: Researcher: Yes.

166: P3: So then one day, I went to his clinic XXX and eh I said to my wife ‘Look, I’m going to speak to him and tell him I’m not coming back’. Cus I’m not making any progress so I may as well pack it in now.

167: Researcher: Mmm.

168: P3: ‘O that’s terrible’, she said, ‘I don’t think you should do…’ And I phoned him up and I said, ‘Look you were a good friend to me but I was terribly upset at your clinic. I saw a 17 year-old girl, with a brother (on) on either arm helping her into the clinic’. And (she was) she would only be about 19 or 20 (Gestures).

169: Researcher: Mmm.

170: P3: And this was obviously a deteriorating situation.

171: Researcher: Mmm.

172: P3: XXX and I came home, awk almost in (/t/) tears…

173: Researcher: Yea.

174: P3: …XXX I’m lucky I’ve had 80 odd years.

175: Researcher: Aha.

176: P3: And this poor wee lassie, and the two brothers obviously adored the girl (Gestures).

177: Researcher: Yea.

178: P3: It was very touching (Gestures).

179: Researcher: Yes.

180: P3: So that was my history of eh…

181: Researcher: Yes…That’s difficult, isn’t it…Mmm…Do you mind if I em, if I ask you some questions this morning?

182: P3: Sure, sure.

183: Researcher: You OK with that?

184: P3: (Mouths something here- possibly ‘sure’).

185: Researcher: So as you’re aware I’ve been coming to visit you as part of the research that I’ve been doing.

186: P3: Yea, yea.

187: Researcher: And when I came on Tuesday for the first time we'd a wee chat about your swallowing difficulty.

188: P3: Yea.

189: Researcher: And I've also come twice when you've been having a meal, and you've very kindly just let me sit in and watch and I've just been observing you during that meal and I've just been making some notes. And why I wanted to do that, was just to get an idea about your experience at mealtimes. And I wanted to talk to you just one last time today because I just want to ask you how you feel about mealtimes and just a wee bit about the things that I observed. So I just want you to tell me how you find mealtimes and how your swallowing difficulty affects mealtimes. And if I ask you any question that you don't want to answer, just let me know and we'll move on. And there's no right or wrong answer or anything, I'm just interested in finding out about how you feel. Does that sound OK?

190: P3: Sounds OK.

191: Researcher: OK…So first of all, I'm just interested (name of participant), just check that (checks audio recorder is functioning correctly), yea that's fine, how do you feel about mealtimes?

Before P3 can respond to this question, the staff nurse enters with P3's medication and assists him in taking this medication. This interruption is not transcribed as no more of the reflexive discussion was conducted until the nurse had finished administering the medication. When the staff nurse left to get more juice for P3 the following interaction between the researcher and P3 took place. In this interaction, P3 is alluding to the difficulty which he has in swallowing medication:

Researcher: Is that alright? Is it away?

P3: XXX (Gestures)

Researcher: Pardon?

P3: 3 swallows (Gestures)

Researcher: 3 swallows

P3: Two were unsuccessful (Gestures)

Researcher: Yes

P3: XXX (Gestures)

Researcher: A couple of attempts at getting it down

P3: Yea

Researcher: Yea, yea.

During this interruption, the researcher also requested that the air mattress be switched off to reduce background noise. This interruption lasted for 4 minutes and 20 seconds.

Continuation of 191: Researcher: OK. Is that you? All swallowed?

192: P3: (Appears to be struggling to swallow tablet and points to throat. P3 also mouths something- possibly 'it's a bit stuck').

193: Researcher: Is it a bit stuck?

194: P3: Yea (Nods head).

195: Researcher: Do you want another wee drink (name of participant)?

196: P3: (Nods head and seems to mouth ‘Yea’).

197: Researcher: Just to wash it down.

198: P3: Yea.

199: Researcher: (Provides assistance to P3 in drinking through the straw in his cup), O sorry……

200: P3: That’s it.

201: Researcher: That it?

202: P3: (Nods head).

203: Researcher: OK. That’s good.

204: P3: This is new.

205: Researcher: Pardon?

206: P3: This is new in the last 3 or 4 weeks.

207: Researcher: What’s new?

208: P3: This swallowing difficulty (Gestures).

209: Researcher: With…With juice or with everything?

210: P3: With everything (Mouths this utterance).

211: Researcher: With everything.

212: P3: (Nods head).

213: Researcher: Mmm…OK (name of participant), so can you tell me how you, how do you feel about mealtimes here?

214: P3: Well I’m quite happy with them because the XXX a small place.

215: Researcher: Pardon (name of participant)?

216: P3: There’s 20…

217: Researcher: Aha.

218: P3: …20 patients on the same floor…

219: Researcher: Mmm.

220: P3: …served by the same, what do you call it…chef (Gestures).

221: Researcher: Yes.

222: P3: And eh he does his best to make things interesting (Gestures).

223: Researcher: Yes…

224: P3: He’s a bit of an expert.

225: Researcher: Aha.

226: P3: And eh, what’s the word…what do they do to…(Coughing episode)…that’s terrible…won’t come (Gestures).

227: Researcher: It won’t come.

228: P3: …The eh, the chef’s a very nice guy.

229: Researcher: Aha.

230: P3: And he’ll come into the dining XXX and he’ll say, ‘Look, I XXX this through the mixer’. Or I’ve done this to it or I’ve done that to it.

231: Researcher: Yes.

232: P3: And he’ll say you should find it should slide down better.

233: Researcher: Yea.

234: P3: He’s interested…

235: Researcher: Yes.

236: P3: …so that stimulates me to try and be helpful (to) to his work.

237: Researcher: Mmm. Mmm…

238: P3: XXX The food’s, you know, it’s not 5-star…

239: Researcher: Mmm.

240: P3: …but (it’s) it’s nourishing…(you) you get a good mixture.

241: Researcher: Aha.

242: P3: And eh XXX otherwise I wouldn’t see so many people (Gestures).

243: Researcher: Say that again (name of participant).

244: P3: Well (having, having) having my meals in my room… (Gestures)

245: Researcher: Yes.

246: P3: …if I didn’t look forward to that, it would be pretty grim (Gestures).

247: Researcher: Yes.

248: P3: But XXX sometimes my wife eats with me (Gestures).

249: Researcher: Yes.

250: P3: At least once, XXX 24 hours, and that makes a difference too (Gestures).

251: Researcher: Yes.

252: P3: So…question 2 (Smiles).

253: Researcher: OK. Well that’s great. And you’ve answered two questions there already cus I was going to ask you how about the food. How you feel about the food, but (you’ve) you’ve answered that for me as well, so…Em so I came once when you were eating your lunch and once when you were eating your dinner. And I didn’t get a chance to come at breakfast time, that would have been a bit early (Laughs). And I’m just wondering, do you have a favourite mealtime?

254: P3: (I enjoy) I enjoy breakfast.

255: Researcher: You enjoy breakfast. Can you tell me why that is?

256: P3: It slides down easily (Smiles).

257: Researcher: OK (P3 laughs)…And is there a particular mealtime that you don't like?

258: P3: …Well (when) when XXX they're so short-staffed and I've got to submit and go out and join (the) the gang.

259: Researcher: OK.

260: P3: And there's two ladies who shall be nameless and they make such a song and dance, cursing and swearing.

261: Researcher: OK.

262: P3: And eh, (I was never) I've never been a (swear) (Laughs) swearing man.

263: Researcher: Mmm.

264: P3: But I can't stand these two ladies, once they start. Awk, it's part of their disease, I mean they've got very confused ideas. And they'll curse and swear about the food…

265: Researcher: Mmm.

266: P3: …that's being brought to them.

267: Researcher: Mmm.

268: P3: And they sit there and eat it all (Smiles).

269: Researcher: Mmm.

270: P3: And XXX that's the (most) most difficult thing…

271: Researcher: OK.

272: P3: …about living here.

273: Researcher: OK…So you don't really enjoy mealtimes when you have to leave your room (and) and go out to the…

274: P3: That's right.

275: Researcher: …the main bit. OK. OK. Now (I no) I noticed as well that the food that you're served is a wee bit softer than normal.

276: P3: Yea.

277: Researcher: How do you feel about eating this softer diet?

278: P3: Em…before it was a matter of cutting it up for yourself (Gestures).

279: Researcher: Yes.

280: P3: Now (one of those) one of the wee lassies XXX cuts it up… (Gestures)

281: Researcher: Mmm.

282: P3: …and if she doesn't get it right then she'll go back to the kitchen (Gestures).

283: Researcher: Mmm.

284: P3: Whether she gets the machinery, I don't know.

285: Researcher: Yea.

286: P3: But it’s not, it’s not eh…what’s the word, (it’s not) it’s not floppy (Gestures).

287: Researcher: Yea.

288: P3: You know what I mean? (Gestures)

289: Researcher: Yea.

290: P3: It’s eh…XXX and it’s not liquidised (Gestures).

291: Researcher: Yes.

292: P3: It’s sort of half between XXX (Gestures).

293: Researcher: Yes.

294: P3: And it seems to please my digestion because I don’t have any real indigestive problems apart from the (dys) dysphagia (Points to throat).

295: Researcher: Yes. Yes…

296: P3: Question number two and a half (Smiles).

297: Researcher: (Laughs)…And I noticed as well at (the) the mealtimes that I’ve been in, you weren’t offered a choice. You know the staff didn’t say, ‘(name of participant) would you like this or would you like this?’ You weren’t given an option.

298: P3: XXX That’s not /n/ normal XXX…

299: Researcher: Pardon.

300: P3: That’s not the normal practice.

301: Researcher: That’s not normal?

302: P3: No it’s not normal.

303: Researcher: OK. OK.

304: P3: I always get two choices (Shows two fingers).

305: Researcher: You always are offered two choices?

306: P3: At (/b/, /b/, /b/) breakfast, I have porridge at breakfast and a little floppy toast… (Gestures)

307: Researcher: Mmm.

308: P3: …which I dip because of (the) the dysphagia (Gestures)

309: Researcher: Yea.

310: P3: Em then at lunchtime…what happens at lunchtime…choice of two main… (Gestures and shows two fingers)

311: Researcher: Mmm.

312: P3: …(/f/) First offer might be some XXX cracker biscuits with eh…you know, pate…

313: Researcher: Mmm.

314: P3: …or fish of somekind.

315: Researcher: Mmm.

316: P3: Fish is great here.

317: Researcher: You like that.

318: P3: It’s very well, well served…and a great social programme…which I quite enjoy.

319: Researcher: Mmm.

320: P3: XXX (I’ve seen) I’ve seen many (a) an old folks home I wouldn’t put my cat in. And the smell is something awful. But this place has got the right attitude and the wee lady, who XXX a carer, and she sings and she XXX the social programme which she (or) organises…

321: Researcher: Aha.

322: P3: …is great.

323: Researcher: Good.

324: P3: First class.

325: Researcher: Good. So you are usually offered a choice (of) of meal?

326: P3: O yes.

327: Researcher: OK. OK.

328: P3: Could tell you on a Friday XXX (Smiles).

329: Researcher: Pardon?

330: P3: I can tell you on a Friday what one will be.

331: Researcher: Mmm.

332: P3: But not everybody that likes (/f/) fish and chips.

333: Researcher: (And that) Fish and chips on a Friday? (Laughs).

334: P3: …(Laughs) (Coughing episode).

335: Researcher: Now both of the times that I came to see you, (you were, you were eating) as you’ve already said you were eating here in your room. Is that the usual arrangement for your mealtimes?

336: P3: Yea.

337: Researcher: OK. And how do you feel about this arrangement, eating in your room?

338: P3: I’m quite happy. (I’m a) I’m a bit of a loner.

339: Researcher: Mmm……

340: P3: No there’s no eh XXX (prob) problem. I’m quite happy to. I mean obviously you’ve gotta come and go, you can’t just say no all the time.

341: Researcher: Mmm.

342: P3: And if they’re short of staff then XXX I’ll trot through to the back shop...

343: Researcher: Yes.

344: P3: …and join the gang (Smiles).

345: Researcher: Yes (Laughs)…OK. So on Tuesday when I was here, I came at lunchtime on Tuesday and eh you’d no company, just except for the member of staff (who was) who was helping you.

346: P3: Yea.

347: Researcher: And yesterday evening at dinner your wife was with you then.

348: P3: That's right.

349: Researcher: And is that the usual arrangement?

350: P3: That's the usual XXX

351: Researcher: OK. And how do you feel about, first of all, eating with the member of staff at lunchtime?

352: P3: …I'm quite happy XXX, some of them are better servers than others.

353: Researcher: Yes.

354: P3: But they're not all, we can't all be perfect.

355: Researcher: (Laughs).

356: P3: And eh I find it very satisfying…and there's no bagged up feelings or problems XXX that can't be (explained) explained on the basis of dysphagia…XXX

357: Researcher: (W) What do you mean by that (name of participant)?

358: P3: Well any symptoms that I have… (Gestures)

359: Researcher: Yes.

360: P3: …XXX feeling blown up, puffed up or burpy… (Gestures)

361: Researcher: Yea.

362: P3: …you can easily tie that down to a…mmm…specific meal. And I'll say that eh obviously didn't agree with me' (Gestures).

363: Researcher: Yes.

364: P3: But it's how I relate that now XXX stomach problems (Gestures).

365: Researcher: Mmm.

366: P3: I relate that (to) to my…illness.

367: Researcher: Mmm. Mmm.

368: P3: Trouble is everybody wants to jump on the bandwagon and blame Parkinson.

369: Researcher: (Laughs).

370: P3: XXX I always argue that when a man puts his (/n/) name initial on a diagnosis unless he gives me a clear…em…it's away, unless I get a clear indication, for example, Parkinsonism, Parkinson was a German (Gestures).

371: Researcher: Mmm.

372: P3: You've probably read the history.

373: Researcher: (Not) Not in a lot of detail, I know a bit, bits and pieces…

374: P3: XXX As far as I'm concerned, they're right, most of my problems are related to Parkinson's.

375: Researcher: Yes. Yes…And how do you feel about then (your) your having your wife's company at teatime then?

376: P3: Do you want me to start singing? (Smiles)

377: Researcher: (Laughs).

378: P3: We're very lucky. My wife was a refugee and came to this country from Nazi Germany.

379: Researcher: Right.

380: P3: Eh…and eh I met her at a youth rally…out at (names a castle) (Gestures).

381: Researcher: Aha.

382: P3: Lovely spot.

383: Researcher: Aha.

384: P3: …And just before the war started, everybody had to join a youth programme (Gestures).

385: Researcher: Mmm.

386: P3: So I joined a youth programme from Lanarkshire and (name of wife) happened to be there…

387: Researcher: Aha.

388: P3: …at the age of 13. And eh I was 15, just about to sit my highers.

389: Researcher: Mmm.

390: P3: XXX…XXX people laugh at me but there was (no) XXX nobody else XXX ever turned me on (Laughs).

391: Researcher: (Laughs).

392: P3: And eh she's Jewish and I was Christian but she's a XXX, she and I discussed progress from the first five chapters of the Bible right through and it's quite a fascinating… (Gestures)

393: Researcher: Yes.

394: P3: …to hear what she has to say (Gestures).

395: Researcher: Yes.

396: P3: And she's prepared to listen to me…XXX Have you met her?

397: Researcher: I have, I met her last night.

398: P3: (Raises head in acknowledgement and mouths something but it is unclear what it is).

399: Researcher: It was lovely to meet her.

400: P3: She's an angel.

401: Researcher: (Smiles).

402: P3: To (be) have patience to put up with me (Laughs).

403: Researcher: (Laughs). So how do you feel about having her company then at mealtimes, at teatime then?

404: P3: I'm very happy XXX.

405: Researcher: Yea.

406: P3: Be pretty miserable (if) if it didn't happen (Laughs).

407: Researcher: Mmm. Mmm. Good. Good. And both times that I came to see you, you were sitting here (in this) in this armchair.

408: P3: Yea.

409: Researcher: Em is that usually where you sit then when you're eating your meals in here?

410: P3: (Not) Not always.

411: Researcher: Not always.

412: P3: Sometimes I put one of these tables … we try not to get too sloppy (Smiles and gestures).

413: Researcher: Yes. Sometimes you put your table by your bed, do you mean?

414: P3: Yea. Yea.

415: Researcher: And sit in your bed?

416: P3: …No, XXX out from the dining room (Gestures).

417: Researcher: Pardon (name of participant)?

418: P3: I'm not making it clear, I'm sorry.

419: Researcher: No, it's OK.

420: P3: …We sometimes put a table like this… (Gestures to table in front of him)

421: Researcher: Aha.

422: P3: …eh…put two together (Gestures).

423: Researcher: Mmm.

424: P3: And then we, we don't just XXX a spoon (Gestures).

425: Researcher: Yes.

426: P3: We try to keep some of the social graces (Smiles and gestures).

427: Researcher: Yes. Yes. Yes. So do you usually sit in this chair?

428: P3: XXX

429: Researcher: When you're eating.

430: P3: I bought this before I came in here.

431: Researcher: Did you?

432: P3: And my family (they) they, we have a flat…

433: Researcher: Aha.

434: P3: …down in eh /p/ (struggles to remember name)…(names area where flat is located)… (Gestures)

435: Researcher: Yes.

436: P3: …looking over to Ibrox.

437: Researcher: Mmm.

438: P3: To Rangers…

439: Researcher: Mmm.

440: P3: …football club.

441: Researcher: Mmm.

442: P3: And eh so they decided they would bring the chair over XXX…the kitchen… (Gestures)

443: Researcher: Mmm.

444: P3: It's very adequate.

445: Researcher: Yes.

446: P3: So that's it then.

447: Researcher: Good. And do you feel as though, when (you're sit) you're seated comfortably when you're eating your meals?

448: P3: O yes.

449: Researcher: Yea. Good. Good. At lunchtime, when I came on Tuesday, I noticed you were leaning a wee bit to the left…a wee bit down to the left. Were you aware of that?

450: P3: (Nods head) XXX…

451: Researcher: Pardon (name of participant)?

452: P3: …XXX 3 months and … flop XXX (leans to the right).

453: Researcher: Mmm.

454: P3: And eh so I try to go out twice a day…and then when I come back, exhausted, I go and have a lie down.

455: Researcher: Mmm.

456: P3: But eh…XXX floppiness is really quite XXX…We've been round looking at a whole lot of different places…Can you hear me alright? (Gestures)

457: Researcher: Mmm.

458: P3: And eh……see (I interrupt) I interrupted (my) myself (Laughs)…

459: Researcher: (Laughs). You were saying (you were) you been round looking at a lot of different places.

460: P3: That's right. And some of the places I went into, the smell would have blown you XXX.

461: Researcher: Mmm.

462: P3: So this was a builder firm, who were building an estate… (Gestures)

463: Researcher: Mmm.

464: P3: …of eh two blocks…six in each block…and eh…we're back to blaming Parkinson (Gestures).

465: Researcher: (Laughs).

466: P3: If he'd done his research better, then maybe we'd be able to cope.

467: Researcher: (Laughs)…So…

468: P3: One of the places I went to see…Did you come in the (main) main door? (Gestures)

469: Researcher: Mmm.

470: P3: And have you seen (the) the big, round table? (Gestures)

471: Researcher: Yes.

472: P3: XXX The first day I came in here, to look round really…not yet as a patient…

473: Researcher: Yea.

474: P3: …and there was a lady, XXX the side of her head was there and she was right over (Gestures and leans head to left).

475: Researcher: Mmm.

476: P3: And I thought to myself (sure) surely that's not gonna happen to me.

477: Researcher: Mmm.

478: P3: But you know it does.

479: Researcher: Mmm.

480: P3: XXX I find myself doing that (tilts head forward).

481: Researcher: Yea.

482: P3: And it's very…distressing…

483: Researcher: Mmm.

484: P3: …for the family.

485: Researcher: Mmm.

486: P3: But it's also (distress) (Laughs) distressing for the patient.

487: Researcher: Absolutely, mmm…mmm. And I'm aware (name of participant) as well that (you've) you've difficulty with your eyesight, you've difficulty seeing, is that right?

488: P3: It's getting worse too.

489: Researcher: Mmm…And does this have any affect on you at mealtimes at all…(your) your difficulty with seeing?

490: P3: Breakfast…at breakfast I get a…XXX (Gestures).

491: Researcher: Mmm.

492: P3: And eh…these…if you /k/ come to breakfast I can show you, a green bowl… (Gestures)

493: Researcher: Mmm.

494: P3: …and a blue bowl (Gestures).

495: Researcher: Mmm.

496: P3: And eh that helps me to know whether I'm near the end… (Gestures)

497: Researcher: Yes.

498: P3: …of the bottom (Gestures).

499: Researcher: Yes.

500: P3: …That's why I get a choice, cranberry, nice red colour (Gestures).

501: Researcher: Yea.

502: P3: Helps a wee bit…But the nurses are all very good.

503: Researcher: Mmm.

504: P3: There's XXX nobody quite like the Glasgow XXX.

505: Researcher: (Laughs).

506: P3: And the nurse XXX I'm sitting listening and then when she's bringing me up from the table, I say to her, 'Can I say something to you?'…'Don't ever change your accent'.

507: Researcher: (Laughs)…You like that.

508: P3: I do.

509: Researcher: (Laughs).

510: P3: And the sense of humour.

511: Researcher: Yes, absolutely. (Laughs).

512: P3: I'd one wee Glasgow woman who took my table in theatre. And of course it's mostly microsurgery of the ear or the throat I'd be doing…And eh one guy who was senior to me, he eh used to say '(name of individual) XXX'. And eh she was obviously, she thought he was going to let the patient slide off the operating table (Gestures and Laughs).

513: Researcher: O dear (Laughs).

514: P3: XXX

515: Researcher: (Laughs).

516: P3: 'Is that enough, is that enough, is that enough?' He says, 'Why do you keep asking XXX? I'll tell you when I'm ready to stop.'

517: Researcher: Aha.

518: P3: XXX 'Why do you hesitate?' She says, 'Well, (you /t/) you tell me to trust naebody'.

519: Researcher: (Laughs).

520: P3: (Laughs). So lovely. Even he had to laugh.

521: Researcher: Yes.

522: P3:XXX dear old (name of colleague). Her hair might be pink or it might be blue or it might be… (Smiles)

523: Researcher: (Laughs).

524: P3: …red…And eh XXX…(I miss, I miss) I miss the XXX joking all the time. And he says, ‘Why do you keep asking?’ She said, ‘Well, you tell me to trust naebody’.

525: Researcher: (Laughs).

526: P3: It was a standing joke.

527: Researcher: (Laughs). That’s good. And I noticed as well (name of participant) that em a member of staff gives you some help with eating at mealtimes.

528: P3: …

529: Researcher: How do you feel about getting this help?

530: P3: Eh…some of them who eh XXX one of the nurses XXX… (Gestures)

531: Researcher: Sorry (name of participant), I didn’t make that out.

532: P3: …

533: Researcher: One of the nurses was…

534: P3: One of the nurses would take the whip and say, ‘Come on, you’ve done that well, now take the next one’ (Gestures).

535: Researcher: Mmm.

536: P3: You know XXX encouraging XXX, without bullying.

537: Researcher: Yes.

538: P3: That’s what I’m trying to say.

539: Researcher: Mmm.

540: P3: But eh…XXX the thing I miss the most, I miss operating and I miss XXX repartee.

541: Researcher: Mmm.

542: P3: XXX…So…have I given you enough?

543: Researcher: Mmm. Do you mind if I ask you a few more questions?

544: P3: Sure.

545: Researcher: So I noticed that you were coughing, just a wee bit, during the meals that I was in watching. How do you feel when (you) you cough at mealtimes?

546: P3: …XXX I don’t panic.

547: Researcher: Aha.

548: P3: XXX all my staff XXX three pots in one, you know like flower pots… (Gestures)

549: Researcher: Mmm.

550: P3: …and eh I’ve taught them XXX…seems crazy to be emotional talking about your days XXX staff under your charge.

551: Researcher: Mmm.

552: P3: But I miss XXX terribly.

553: Researcher: Yea. Yea.

554: P3: And eh you say how do you feel about it. Can't turn the clock back. XXX (Laughs) 84, I'll be 85 in November.

555: Researcher: Mmm.

556: P3: And my wife's 82.

557: Researcher: Mmm.

558: P3: So we've had a good innings. But as I say XXX, 'Would you like a start tomorrow?', I would be the first in the car.

559: Researcher: Yea. Yea…And I noticed as well (name of participant) that you ate up all of your food at the mealtimes that I was in observing. Is this usually the case that you tend to eat up all your food?

560: P3: I don't leave much.

561: Researcher: Pardon?

562: P3: I don't leave much.

563: Researcher: Yes. Yea. Yea.

564: P3: It's well prepared and it's well flavoured.

565: Researcher: Yes.

566: P3: And the gravy tastes very good.

567: Researcher: Yes…Good…Is there anything at all that you would change about mealtimes?

568: P3: …Well XXX I feel terribly eh dependent.

569: Researcher: Mmm.

570: P3: And it would be nice if, these hands XXX just get all jerky or… (Gestures)

571: Researcher: Mmm.

572: P3: …twitchy. If they would behave themselves.

573: Researcher: Mmm.

574: P3: Then (I would) I would be happy to do it myself.

575: Researcher: Yes.

576: P3: But eh…

577: Researcher: Yea…Mmm. And finally is there anything eh you'd like to tell me about your swallowing difficulty and how it affects mealtimes?

578: P3: …Fortunately, I've never got to total blockage on any occasion, but (when) when I feel it (stick) sticking, I say right, sit back, take it easily… (Gestures and points to throat)

579: Researcher: Mmm.

580: P3: …drink plenty of fluid…

581: Researcher: Mmm.

582: P3: …and eh the thing will pass.

583: Researcher: Mmm.

584: P3: And eh, it does.

585: Researcher: Yes. Yes…OK. I think (that's, that) that's really us (name of participant). And just to finish, is there anything at all, just anything else that you'd just like to share with me about your swallowing difficulty?

586: P3: Sure. I said to myself, you're lucky. You were digging deep in…the pharynx……whereas I would feel XXX the two ladies that drive me nuts…

587: Researcher: Mmm.

588: P3: …I respect them because one was a very successful business woman.

589: Researcher: Right.

590: P3: Selling highpowered XXX…

591: Researcher: Mmm.

592: P3: …in a posh atmosphere (Gestures).

593: Researcher: Aha.

594: P3: And then the other old dear, muttering away to herself, blaspheming and then the next thing is she's started (Gestures spooning food into mouth), clears her plate…

595: Researcher: Yea.

596: P3: …XXX. But I wonder whether their eh input should be talked about as well.

597: Researcher: (Their, wh, wh) Their input to…

598: P3: Input to swallowing.

599: Researcher: OK. OK. You think they should be asked as well,

600: P3: ….

601: Researcher: Is that what you mean (name of participant)?

602: P3: That's what I mean, yes.

603: Researcher: Yea, yea. **(Brief interruption from cleaning staff)…** Well I think that's everything (name of participant). Unless there's anything else that (you) you want to share with me about swallowing difficulties?

604: P3: …I'm sorry to be so emotional.

605: Researcher: That's OK. (It's) It's very understandable…(You) You keen to just finish up now then?

606: P3: …(/w/, /w/) When are you going to bring back the…photocopy? (Gestures)

607: Researcher: Pardon (name of participant)?

608: P3: Are you going to bring me a copy?

609: Researcher: (Of the) Of the results?

610: P3: Yea.

611: Researcher: I will indeed. It'll be a wee while though (Laughs). By the time I get things sorted out and I've spoken to more people. And then I'll collate everything together and (I will) I will give you a copy…So I'll just turn this off now (name of participant). I think we're finished with…

612: P3: Yes.

613: Researcher: …with our chat. So…

Total length: 47 minutes and 59 seconds

APPENDIX 15

Example of an emergent theme from the data obtained from the control participants

EMERGENT THEME ----- BARRIERS TO MEALTIME ENJOYMENT

↓

THEME CLUSTERS

(The number assigned to each formulated meaning corresponds with the associated significant statement)

Physical barriers

(1) Eating duration has increased as a result of the participant’s visual impairment. The participant’s visual impairment is the source of her mealtime-related difficulties (CP1, Interview, 028).

(2) There were no mealtime-related issues prior to the onset of the visual impairment (CP1, Interview, 032).

(3) Although the participant does not take longer to eat than the other residents, her eating duration has increased as a result of her visual impairment (CP1, Interview, 036).

(4) Although she has reported an increased eating duration due to her visual impairment, the participant does state that it does not take her a long time to eat a meal. She has no problem eating a meal if she is feeling alright (CP1, Interview, 046).

(7) The participant’s enjoyment of eating has been taken away by the visual impairment, as it is not possible to see the food that has been provided. Assistance is provided to try and compensate for this difficulty (CP1, Interview, 056; 058).

(14) The participant’s visual impairment is detracting from her enjoyment of mealtimes (CP1, Interview, 082; 084).

(15) The care home staff are implementing strategies in an attempt to compensate for the participant’s visual impairment. One strategy involves the participant sitting at an angle to the table, while another involves serving food on a blue plate (CP1, Interview, 086; 088).

(19) Not being able to see food properly at mealtimes is difficult, but assistance is provided. The care staff have implemented various strategies

in an attempt to compensate for the visual impairment and gratitude is expressed for this assistance (CP1, Interview, 208; 210; 212; 214).

(20) The participant does not like going down for mealtimes as a result of her visual impairment. The care staff try to compensate by explaining the location of the foods on her plate. However, sometimes larger than anticipated pieces of food are ingested. She does feel that the care staff are doing their best to help her (CP1, Interview, 216; 218; 220).

(25) The participant's visual impairment affects her ability to see how much food she has consumed (CP1, Interview, 246; 248).

(27) It is possible to chat with the other residents. However, the participant's visual impairment impacts upon her ability to see which residents are sitting at her table, meaning that she has to ask whom she is sitting with (CP1, Interview, 254).

(28) Although her visual impairment means that she is not able to see who is sitting next to her, this does not impact upon the participant's ability to have a conversation, as she knows the residents (CP1, Interview, 256; 258; 260).

(30) The participant's visual impairment has negatively affected her enjoyment of mealtimes. The onset of her visual impairment has upset her and she feels nervous going for her meals because she can't see the food that she has been served. The care staff describe the location of the foods on her plate and are doing their best to help her. Before the onset of the visual impairment, the participant had no trouble at mealtimes (CP1, Reflexive discussion, 017; 019; 021; 023).

(32) The participant's visual impairment is the thing that is causing her bother (CP1, Reflexive discussion, 033).

(33) Not being able to see the food that has been served impacts upon the enjoyment of mealtimes. Care staff have to tell the participant what food she has been served and where it is on the plate. They are doing their best (CP1, Reflexive discussion, 039).

(35) The participant's visual impairment makes it difficult to see what food has been provided, leading to a reduced enjoyment of mealtimes. The participant enjoys breakfast because she is aware of what she is eating (CP1, Reflexive discussion, 083; 085).

(36) The care home staff have implemented various strategies in an attempt to compensate for the participant's visual impairment. The blue plate sometimes helps and sometimes doesn't. The care staff also sit the participant at an angle to the table and try various positions to see which is best. This can confuse the participant (CP1, Reflexive discussion, 091; 093; 095).

(37) The food that is provided is viewed in a positive light, especially the puddings. However, the participant is unable to enjoy the meals as much anymore because of her visual impairment (CP1, Reflexive discussion, 097; 099).

(38) Although she doesn't enjoy the meals as much anymore because of her visual impairment, the participant tries to eat as much as she can of her meals to avoid creating concern for the care home staff (CP1, Reflexive discussion, 101; 103; 105).

(39) The participant feels that her visual impairment places her in a worse position than if she had cancer, as being unable to see the food that has been provided removes the pleasure from mealtimes and causes the participant to feel worried. The care staff are doing their best to help her (CP1, Reflexive discussion, 111; 113).

(40) The participant finds the strategies employed by the care staff to help compensate for her visual impairment 'a bit' helpful. The care staff describe the location of foods on her plate, but sometimes larger portions of food than anticipated are eaten. She gets confused about which is the best position to sit at the table, as what she finds helpful differs from what the staff think would be helpful. The main thing is that some food is eaten as the care home staff don't believe in residents going to bed with an empty stomach (CP1, Reflexive discussion, 125; 127; 129; 131).

(43) The participant can experience feelings of fear at mealtimes because her visual impairment impacts upon her ability to see the food that has been provided. Sometimes she is eating something that she doesn't really like, but feels she is best to eat something (CP1, Reflexive discussion, 155; 157).

(68) Being unable to see the food that has been provided really affects the participant at mealtimes (CP1, Reflexive discussion, 376; 378).

(69) The participant has always enjoyed mealtimes at the care home, although they are now less enjoyable as a result of her visual impairment (CP1, Reflexive discussion, 392).

(74) The participant really misses not being able to see her food. Sometimes the position suggested by the care staff in an attempt to compensate for her visual impairment is effective, while at other times, the participant thinks that another position is better. Breakfast does not cause the participant any trouble because she knows what she has been served (CP1, Reflexive discussion, 414; 416; 418; 420; 422).

(76) The participant's visual impairment has detracted from her enjoyment of mealtimes. The care home staff are providing assistance as a means of compensating for the visual impairment and this assistance is appreciated. She describes a positive encounter with a member of staff providing assistance (CP1, Reflexive discussion, 452; 454; 456).

(77) Swallowing can be difficult at times because the participant suffers from a condition which can cause swelling in the throat. This impacts upon the speed at which he is able to eat (CP2, Interview, 024; 026; 028; 030; 032).

(78) Food can sometimes stick in the participant's throat as a result of a condition which he suffers from (CP2, Interview, 056; 058).

(122) A hearing impairment impacts upon the participant’s ability to hear what other residents are saying at mealtimes. She hopes that a hearing aid will alleviate this issue (CP3, Interview, 449; 451; 453; 455).

(123) Other residents have been here much longer than the participant and converse with one another. The participant’s hearing impairment affects her ability to engage in conversation with other residents at mealtimes (CP3, Interview, 483; 485).

(124) Being unable to hear what other residents are saying is a shame. The participant hopes that receiving a hearing aid will help her to hear other residents. Other residents converse at mealtimes (CP3, Interview, 487; 489; 491; 493).

(126) Experiencing leg pain impacted upon the participant’s ability to enjoy mealtimes, although this issue has now been resolved and mealtimes are once again enjoyable events (CP3, Interview, 517; 519; 521; 523; 525; 527; 529; 531; 533; 535).

(129) The participant would love to be able to hear the conversations of the other residents at the table (CP3, Interview, 549; 551; 553; 555; 557).

(143) The participant enjoys socialising at mealtimes, but feels that receiving a hearing aid will enhance her ability to do so (CP3, Reflexive discussion, 248; 250).

(144) Being unable to hear what others are saying at mealtimes is an unpleasant experience (CP3, Reflexive discussion, 254; 256).

(154) The participant does not look forward to mealtimes as much as she used to due to a reduced appetite (CP4, Interview, 204; 206).

(176) The participant’s visual impairment does not prevent her from eating, but she does have difficulty seeing the food with which she has been provided and therefore has to ask what she is getting (CP4, Reflexive discussion, 106; 108).

(177) The participant cannot really see her food at mealtimes, with the exception of the food which is served to her at breakfast. She feels she is managing, however (CP4, Reflexive discussion, 110; 112; 114; 116; 118).

(178) The participant does not feel that her visual impairment has much of an impact upon her mealtime enjoyment- she is still eating. However, she makes a comment at a later stage which would suggest that her visual impairment is a concern for her at mealtimes (CP4, Reflexive discussion, 120; 122; 124; 126).

(185) The participant’s visual impairment is an issue for her at mealtimes (CP4, Reflexive discussion, 196).

(188) A difficulty with chewing food is experienced because dentures are not worn when eating as they detract from the enjoyment of food (CP5, Interview, 084; 086; 088; 090; 092; 094).

(189) Choking when eating food is not a common occurrence, however a fear of choking when eating exists (CP5, Interview, 114; 116; 118).

(201) There have been occasions when the participant has been chewing meat and has had to spit it out. This may be due to the fact that she does not wear dentures at mealtimes (CP5, Interview, 384; 386; 388; 390; 392; 394).

(226) Although she previously commented on the difficulties with chewing she experiences as a result of not wearing dentures, the participant states here that not wearing dentures at mealtimes does not affect her in any way. Thus, the extent to which not wearing dentures at mealtimes affects the participant is unclear (CP5, Reflexive discussion, 450; 452).

Institutional barriers

(57) The residents like to get on with eating and don't like to converse during the meal, although they may engage in conversation once they have eaten something. On one occasion, another female resident started to converse with the participant during the meal and this made it difficult to concentrate on eating. The participant feels that you should wait until your meal is finished and then chat (CP1, Reflexive discussion, 304; 306).

(58) The participant has already indicated her desire to wait until the meal is finished before conversing. Although staff want to clear the dining room after the meal, there are plenty of opportunities to talk in the lounge (CP1, Reflexive discussion, 308).

(59) Like her, the participant feels that a lot of the residents prefer to eat in silence and chat afterwards (CP1, Reflexive discussion, 316).

(60) The participant does not welcome conversation during the meal as she wants to focus on eating. This problem only occurs with the women as the men just get on with eating (CP1, Reflexive discussion, 318; 320; 322).

(75) The participant does not wish to converse at mealtimes. She feels that this viewpoint applies to many of the other residents as well. There are plenty of opportunities to converse in the lounge (CP1, Reflexive discussion, 426).

(79) A concern exists relating to the length of mealtimes, which are long events due to the fact that much time is required by the staff to assist more dependent residents to the dining room and position them at tables in preparation for meal provision (CP2, Interview, 111; 113; 115; 117).

(86) The participant finds that mealtimes are a chance to chat with other residents. However, he later voices his opinion that socialising at mealtimes is inappropriate (CP2, Interview, 161).

(98) The waiting time at mealtimes is a concern for the participant. It takes the staff some time to position more dependent residents at the dining tables, and so he feels that he needs to arrive forty-five minutes prior to the beginning of the mealtime (CP2, Reflexive discussion, 104; 106; 108; 110; 112; 114; 116).

(101) Conversation is not a frequent occurrence at mealtimes. The only times when there is likely to be more conversation is when a new resident has entered the care home or if a good topic for conversation arises, such as the football results. The participant later voices his opinion that socialising at mealtimes is inappropriate (CP2, Reflexive discussion, 137; 139; 141; 143; 145).

(102) Whilst conversation is not a frequent occurrence at mealtimes, arguments are a common occurrence as people with physical and communication difficulties are all sitting at a table together (CP2, Reflexive discussion, 147; 149; 151; 153).

(103) The participant's upbringing has taught him that talking at mealtimes is bad manners and so does not wish for more opportunities to socialise at mealtimes (CP2, Reflexive discussion, 159; 161; 163; 165; 167).

(104) The participant doesn't feel that it is appropriate to engage in conversation at the table, as the task in hand relates to eating rather than conversation (CP2, Reflexive discussion, 169; 171; 173).

(105) The participant does not personally think that it is appropriate to engage in conversation at the table (CP2, Reflexive discussion, 177; 179).

(146) Many of the residents fall asleep in the dining room meaning that conversation at mealtimes can be minimal. The participant would love to chat to other residents at mealtimes (CP3, Reflexive discussion, 336; 338; 340; 342; 344; 346).

(241) The participant does not get particularly involved in socialising at mealtimes. The mood of other residents can vary from day to day (CP6, Interview, 384; 386; 388; 390).

(244) The participant comments on experiencing feelings of sadness at times when observing other residents who have dementia. Residents are seen eating from the tablecloths and the floor in the dining room is covered with cereal at breakfast time due to various spillages (CP6, Interview, 478; 482; 484; 486; 488; 490; 492; 494; 496; 498).

(248) The participant comments on the unsettled behaviour of some of the residents which can be evident at mealtimes. This is something which she has got used to. The participant indicates that she can choose where she sits at mealtimes. She doesn't have one seat in which she always has to sit (CP6, Reflexive discussion, 076; 078; 080; 082; 084; 086; 088; 090; 092).

(250) The participant recounts an experience of observing a resident with dementia who had forgotten that they had eaten their breakfast. She

acknowledges that these encounters require some getting used to, although she has been used to communal living (CP6, Reflexive discussion, 104; 106; 108; 110; 112; 114; 116; 118; 120).

(256) The participant generally eats her meals in the dining room (CP6, Reflexive discussion, 242; 244; 246).

(257) The participant describes an experience she had earlier that morning with a resident with dementia at her table, who was eating sugar from the sugar bowl and drinking milk from the milk jug on the table (CP6, Reflexive discussion, 268; 270; 272; 274; 276; 278; 280; 282).

(258) The challenging behaviour of residents with dementia at mealtimes is not too off-putting, but sometimes it can be off-putting (CP6, Reflexive discussion, 284).

(259) It is not uncommon for residents with dementia to cause disruptions (CP6, Reflexive discussion, 318; 320).

(260) The disruptive behaviour of other residents at mealtimes does not bother the participant excessively (CP6, Reflexive discussion, 322; 324).

(261) The participant seems to accept the existence of noise at mealtimes created by residents with dementia. However, this noise is contrasted with the kind of noise that exists in a café or a restaurant (CP6, Reflexive discussion, 344; 346; 348).

(262) The participant explains that other residents speak to her. The participant indicates that she can choose where she sits at mealtimes- she does not consistently occupy the same seat in the dining room. The participant doesn’t seem too interested in socialising with other residents at mealtimes. The area of the dining room near the door is left free for residents in wheelchairs and it is acknowledged that the area closer to the door and the servery tends to be noisier than the back of the dining room (CP6, Reflexive discussion, 374; 376; 378; 380; 382; 384; 386; 388; 390; 392; 394).

(265) The participant tends not to initiate much conversation with fellow residents at mealtimes and avoids getting involved in any topics which she perceives to be controversial (CP6, Reflexive discussion, 410; 412; 414; 416; 418).

APPENDIX 16

Example of an emergent theme from the data obtained from the participants with dysphagia

EMERGENT THEME ----- SOCIAL IMPACT OF DYSPHAGIA

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THEME CLUSTERS

(The number assigned to each formulated meaning corresponds with the associated significant statement)

Embarrassment and Self-consciousness

(24) The participant feels embarrassed when he chokes on his food at mealtimes (P1, Reflexive discussion, 172).

(51) ‘Tension’ is a more appropriate word than ‘fear’ to describe how the participant feels at mealtimes. He experiences feelings of tension at mealtimes because he doesn’t want to embarrass himself or his wife when eating (P3, Interview, 404; 406; 408).

(53) Drooling is perceived to be a social issue and the participant appears to feel demeaned by his drooling in the presence of competent family members (P3, Interview, 422; 424; 426; 428; 430; 432).

(54) The participant is concerned with how his drooling is perceived by his wife (P3, Interview, 442).

(155) The participant is always last to finish his meals and feels embarrassed about this (P5, Interview, 446; 448).

(164) The participant feels embarrassed about his swallowing difficulty. He experiences feelings of embarrassment when eating with others at mealtimes as a result of the occurrence of various dyshagia-related physical issues, namely coughing; nasal regurgitation; choking and throat clearing. Sometimes the participant does not finish his meal because the other residents have already finished theirs. He justifies his decision to leave some food on the basis that he doesn’t need the remaining food, although acknowledges that this may not be the case. Other than these negative social experiences at mealtimes, the participant is very socially at ease and has good relationships with the other residents (P5, Interview, 840; 842; 844; 846; 848; 850; 852; 854; 856; 858; 860; 862).

(165) The presence of dysphagia causes the participant to experience embarrassment at mealtimes/when eating with others (P5, Interview, 866).

(168) The participant feels embarrassed about his dysphagia. He is unable to do the things he used to do like sitting for a meal with others. He is conscious of the fact that he is always the last person left eating. He is unable to finish his meals. Whilst embarrassment is not such an issue when eating with his family, embarrassment is experienced when eating with anyone else (P5, Interview, 890; 892; 894; 896; 898).

(171) The participant appears self-conscious about his eating duration. A short time after the other residents have finished their meal, the participant will stop eating (P5, Interview, 946; 948).

(173) The participant feels that he is provided with too much food. He stops eating a short time after the other residents have finished their meal (possibly due to feeling self-conscious about his eating duration), although he does feel that he has consumed a sufficient amount of food to fill him up (P5, Interview, 958; 960; 962; 964; 966; 968).

(180) It can be embarrassing when eating with others and coughing occurs (P5, Interview, 1106; 1108).

(182) Embarrassment is the main issue experienced by the participant as a result of his dysphagia (P5, Interview, 1122).

(217) The participant had chosen not to eat in the dining room for both of the observed mealtimes because he wanted privacy. He had also chosen to eat meals by himself when at a day hospital because he was embarrassed by the fact that everyone had to wait on him to finish his meal. In his current situation in the care home, this is no longer such an issue/ he doesn’t feel the need to eat alone because although he is still last to finish, the other residents are also a bit slower at eating. However, on occasions like this, the participant prefers the privacy. Although in this instance, embarrassment does not seem to be an issue for the participant, he has indicated experiencing embarrassment at mealtimes in the care home elsewhere (P5, Reflexive discussion, 326; 328; 330; 332; 334; 336; 338; 340; 342; 344; 346; 348).

(225) Other residents also experience some coughing episodes so embarrassment is not such an issue for the participant at mealtimes in the care home. Some residents are also a bit slower at eating as well. Infrequently, the participant has experienced a coughing episode where he has had to leave what he has been eating and drink water. The participant would be more embarrassed in front of a younger person and feelings of embarrassment were more of an issue for him when at a day hospital. Although in this instance, embarrassment does not seem to be an issue for the participant, he has indicated experiencing embarrassment at mealtimes in the care home elsewhere (P5, Reflexive discussion, 440; 442; 444; 446; 448; 450; 452; 454; 456; 458; 460; 462; 464; 466; 468; 470).

(313) Feelings of awkwardness were experienced by the participant when food became stuck in his throat, indicating that others were likely to have been present for this incident (P7, Interview, 520).

(321) Dysphagia detrimentally impacts the participant's enjoyment of social gatherings because choking may occur (P7, Interview, 632).

(322) The participant would feel terrible if choking occurred (P7, Interview, 636).

Adjustments to social life

(96) The participant is advised not to risk going out for specific types of food, even though these foods are not perceived to be problematic in relation to swallowing. Such restrictions could not be tolerated forever (P4, Interview, 572; 576; 584).

(157) The participant is frustrated by his swallowing problem. The participant used to drink Guinness in the pub, but is no longer able to drink Guinness because the froth of the Guinness sticks in his throat (P5, Interview, 454; 456; 458; 460; 462; 464; 466; 468).

(158) The participant drinks sherry in place of the Guinness, which he enjoys. He drinks a glass of sherry in the evenings with his wife (P5, Interview, 470; 472; 474; 476; 478; 480; 482; 484; 486; 488; 490; 492).

(159) Although the participant used to enjoy going out, he can no longer do so. However, he had recently been out for a meal with his family when his daughter had been to visit. Because he knew the restaurant, he was confident that they would liquidise his soup for him, which they did, and he selected a pudding which was suitable for him. This was the first time he had been out for quite some time. The weather impacts upon the participant's ability to get out and about (P5, Interview, 502; 504; 506; 508; 510; 512; 514; 516; 518; 520; 522; 524; 526; 528; 530; 532; 534; 536).

(160) Dysphagia is partly responsible for the decline in the participant's social life, due to the fact that he is no longer able to drink Guinness. He used to have a pint in the pub with friends, but that no longer happens. However, other factors also contribute, namely the participant's age and health and the weather (P5, Interview, 606; 608; 610; 612; 614; 616; 618).

(169) The participant is no longer as socially active as he used to be. He used to go out to the pub with his friends, but that no longer happens. Factors other than dysphagia also contribute to his reduced social activity, such as the participant's age (P5, Interview, 916; 918; 920).

(320) Dysphagia makes it hard for the participant to have a social life because he is afraid of choking (P7, Interview, 620).

(323) The participant’s role with family and friends may have changed slightly because of his swallowing problem, but he is unsure why this has happened (P7, Interview, 644; 646).