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“I live with it...I have no Plan B, only a Plan A”:

Psychosocial Impact and Quality of Life in the Stroke

Population with Dysphagia

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A thesis submitted to the University of Dublin in partial fulfilment of the
requirements for the degree of

Doctor of Philosophy

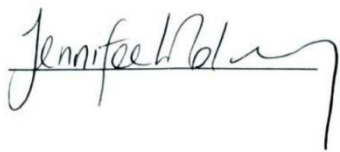
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Declaration

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A handwritten signature in black ink, appearing to read 'Jennifer Moloney', written over a horizontal line. The signature is cursive and includes a long, sweeping tail that extends to the right and then curves downwards.

Jennifer Moloney

Summary

Modern healthcare recognises the importance of assessing, and where possible, supporting psychosocial wellbeing and quality of life. This has become particularly relevant in recent decades where simple measures of mortality are no longer enough to demonstrate the efficacy of the myriad of treatment approaches and interventions that are often at the disposal of healthcare workers and clinicians. With the number of people living with stroke disability continuing to grow, there is increasing acknowledgment of the importance of exploring and considering psychosocial wellbeing and quality of life in this clinical population.

Dysphagia is the medical term used to describe any difficulty with swallowing. While varying prevalence rates are reported in the literature, it is widely accepted that dysphagia is one of the most common physical consequences associated with stroke. Although the vast majority of people will see a relatively good recovery in their swallow function within a number of months following their stroke, a small group of people will continue to live with long-term dysphagia. For persons living with dysphagia following stroke, they are likely to experience frequent coughing and choking episodes, difficulties with saliva management, and pain and discomfort when eating and drinking.

Previous research has demonstrated the significant impact that general stroke disability can and does have on psychosocial wellbeing and quality of life. Research has also demonstrated a significant link between wider eating difficulties and quality of life in the stroke population. By comparison, our understanding of the specific impact of dysphagia is under-developed. With a paucity of research to inform clinical practice, speech and language therapists are likely to find this clinical area challenging. As a result, the care that is provided to persons living with dysphagia following stroke may not

always be person-centred, holistic and complete. In an attempt to improve the quality of care that is currently provided to this vulnerable clinical group, this thesis takes an exploratory, and predominantly qualitative approach, to the examination of psychosocial wellbeing and quality of life in the stroke population with dysphagia. This is achieved by focusing on three key areas.

Firstly, this thesis develops our understanding of the experiences of adults who are living with dysphagia following stroke and the subsequent impact this condition has on psychosocial wellbeing and quality of life. In order to explore the impact of dysphagia during the acute and rehabilitation stages of the stroke journey, ten autobiographical texts written by persons following stroke were examined and analysed using an interpretative approach. The significant and wide-ranging influence of dysphagia is demonstrated in the findings of this study, and a new appreciation for the complexities inherent in the dysphagia rehabilitation journey following stroke is developed. The experiences of persons with long-term dysphagia following stroke are then explored. One-to-one interviews with three persons with persistent swallowing difficulties were used to gather the relevant data. Again, taking an interpretative approach to the analysis of the gathered information, the findings of this study demonstrate the persistent impact of dysphagia on psychosocial wellbeing and also highlight the need that this clinical group has for ongoing and regular speech and language therapy intervention.

Secondly, this thesis explores the current clinical practice patterns of speech and language therapists when addressing psychosocial wellbeing and quality of life in the stroke population with dysphagia. An international survey study was used to gather information regarding speech and language therapist attitudes, beliefs, and approaches to the assessment and management of quality of life. Significant variations and

inconsistencies in practice are demonstrated with a number of challenges to clinical practice referenced throughout. In order to explore these challenges in more detail, an international focus group of speech and language therapists was then completed. A lack of stroke-specific quality of life clinical assessment tools, uncertainty regarding the stroke rehabilitation journey, a lack of clarity as to if and when active rehabilitation should be withdrawn, and limitations in healthcare service structures, are all cited as significant barriers to effective and holistic practice in this area. The findings of both of these studies develop a new appreciation for the complexity faced by speech and language therapists when attempting to address and support quality of life in the stroke population with dysphagia.

Finally, following the significant difficulties in the clinical assessment process reported by the speech and language therapist participants, and the gaps in service delivery reported by persons with dysphagia following stroke, this thesis examines the clinical tools that are currently available to assess and consider psychosocial wellbeing and quality of life in this population. In both research and clinical practice, a measure of a person's quality of life is often made using a patient-reported outcome measure (PROM). A scoping review identified only two PROMs in common use in clinical trials on dysphagia in stroke – the Swallowing Quality of Life Questionnaire (SWAL-QOL) and the Eating Assessment Tool (EAT-10). A subsequent qualitative analysis of both of these tools demonstrated significant limitations in their use in the stroke population. The findings of this study highlight the lack of appropriate clinical tools for use in the assessment of quality of life in the stroke population with dysphagia.

Although the research in this thesis is not without its limitations, the overall findings have a number of implications for both speech and language therapists working

clinically and researchers with an interest in dysphagia following stroke. The significant impact of dysphagia on quality of life following stroke needs further recognition and consideration in both the literature and in clinical practice. It is recommended that the assessment of quality of life should become routine practice for speech and language therapists, particularly when working with persons during the stroke rehabilitation stage and for persons with long-term swallowing difficulties following stroke. With a detailed and appropriate assessment of psychosocial wellbeing and quality of life, person-centred and holistic intervention plans can be developed which fully address the needs of the person with dysphagia. Further research which explores the experiences of persons with dysphagia following stroke is required and quality of life should be included as part of a core outcome set for all dysphagia clinical trials in the stroke population. The development of a stroke-specific quality of life assessment tool will be an essential requirement in reaching these goals.

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List of Abbreviations

COMET	Core Outcome Measures in Effectiveness Trials
COREQ	Consolidated Criteria for Reporting Qualitative Research Checklist
COS	Core outcome set
CROSS	A Consensus Based Checklist for Reporting of Survey Studies
DHI	Dysphagia Handicap Index
DS	Descriptive Statistics
EAT-10	Eating Assessment Tool
EQ-5D	EurOQOL-5 Dimension
ESSD	European Society of Swallowing Disorders
FOIS	Functional Oral Intake Scale
GQOL-74	Generic Quality of Life Inventory
JM	Jennifer Moloney – PhD Candidate
IASLT	Irish Association of Speech and Language Therapists
ICF	International Classification of Functioning, Disability and Health
IPA	Interpretative Phenomenological Analysis
MDT	Multidisciplinary team
MASA	Mann Assessment of Swallowing Ability
MMASA	Modified Mann Assessment of Swallowing Ability
NIHSS	National Institute of Health Stroke Scale
NPO	Nil per oral
PAS	Penetration Aspiration Scale
PHAD	Parramatta Hospitals’ Assessment of Dysphagia
PPI	Patient and public involvement
PRISMA-ScR	Preferred Reporting Items for Systematic Review and Meta-Analyses Extension for Scoping Reviews
PROM	Patient reported outcome measure
QOL	Quality of Life
RCT	Randomised controlled trial
RBHOMS	Royal Brisbane Hospital Outcome Measure for Swallowing
RIG	Radiographically Inserted Gastrostomy
SLT	Speech and language therapist/therapy

SSA	Standardised Swallowing Assessment
SWAL-QOL	Swallowing Quality of Life Questionnaire
TA	Thematic Analysis
TIA	Transient ischemic attack
VDS	Videofluoroscopic Dysphagia Scale
WHO	World Health Organisation
WSO	World Stroke Organisation

Publications and Research Output to Date

Published Peer-Reviewed Papers:

1. Moloney J. & Walshe M. (2018). “I had no idea what a complicated business eating is...”: A qualitative study of the impact of dysphagia during stroke recovery. *Disability and Rehabilitation*, 40(13), 1524-1531. DOI: 10.1080/09638288.2017.1300948.
2. Moloney J. & Walshe M. (2019). Managing and supporting quality of life issues in dysphagia: A survey of clinical practice patterns and perspectives in the UK, Ireland and South Africa. *International Journal of Language and Communication Disorders*, 54(1), 41-49. DOI: 10.1111/1460-6984.12429.
3. Moloney J., Regan J. & Walshe M. (2021). Patient reported outcome measures in dysphagia research following stroke: A scoping review and qualitative analysis of content. *Dysphagia*, DOI: 10.1007/S00455-022-10448-y.

Published Peer-Reviewed Abstracts:

1. Moloney J. & Walshe M. (2020). Challenges faced by the SLT profession when addressing quality of life in dysphagia post stroke. *Dysphagia*, 9th European Society for Swallowing Disorders Congress, 35, 133-205.
2. Moloney J. & Walshe M. (2018). Dysphagia rehabilitation following stroke: More than just functional recovery. *European Stroke Journal*, European Stroke Organisation Conference, 3(15), 205.
3. Moloney J. & Walshe M. (2018). The beliefs and practices of speech and language therapists regarding quality of life issues in dysphagia management: An

international survey. *Dysphagia*, 7th European Society for Swallowing Disorders Congress, 33, 484-588.

4. Moloney J. & Walshe M. (2016). The lived experience of dysphagia rehabilitation following stroke: What can we learn from published autobiographies? *Dysphagia*, 6th European Society for Swallowing Disorders Congress, 32, 126-207.

Oral Conference Presentations:

1. *Irish Association of Speech and Language Therapists Biennial Conference (Dublin, September 2021)* – “Quality of life in the stroke population with dysphagia: Patterns and challenges in speech and language therapy clinical practice.”
2. *Irish Association of Speech and Language Therapists Biennial Conference (Dublin, May 2017)* – “The value of qualitative research in the stroke population with dysphagia: reflecting, learning and advancing.”
3. *30th World Congress of the International Association of Logopedics and Phoniatrics (Dublin, August 2016)* – “The experience of dysphagia post stroke: What can we learn from published autobiographies?”
4. *SPHeRe Network 4th Annual Conference (Dublin, January 2018)* – Supporting quality of life in dysphagia management following stroke: Comparing clinical practice with patient priorities.”

SECTION 1: INTRODUCTION

Chapter 1: Introduction and literature review

1.1 Introduction

This is the introductory chapter of this thesis. To enhance readability, the chapter opens by outlining the overall aim and associated objectives of the research that was undertaken. This is followed by a description of the overall structure of this thesis, including an overview of the layout and content of each of the thesis sections and the associated chapters.

The chapter then proceeds by outlining the background and rationale for this thesis. In doing so, consideration is firstly given to the stroke population and in particular, the stroke population with dysphagia. Dysphagia as a common consequence of stroke is introduced and the current lack of research specific to the psychosocial impact of stroke-related dysphagia is highlighted. The need to expand our understanding of the experiences of this vulnerable clinical group towards providing holistic and person-centred care is rationalised.

Next, the influence that our limited understanding of the impact of stroke-related dysphagia has on speech and language therapy (SLT) clinical practice is proposed. By considering relevant research in similar clinical areas, the complexity inherent in addressing and supporting the psychosocial impact of dysphagia in the stroke population is demonstrated. The need to further explore this area towards optimising future clinical care and SLT practice is justified. The chapter concludes by outlining the theoretical framework, aims, and objectives of this thesis.

1.2 Research Aim and Objectives

The overall **aim** of this thesis is to investigate psychosocial wellbeing and QOL in the adult stroke population with dysphagia, with consideration for the first-hand accounts of persons living with dysphagia, current SLT clinical practice patterns and the content and appropriateness of the assessment tools commonly being used in this area.

The four key **objectives** that guided this thesis were:

1. To develop a greater understanding of the impact that dysphagia has on psychosocial wellbeing and QOL in adults living with swallowing difficulties following stroke
2. To determine current approaches to the assessment and management of psychosocial wellbeing and QOL by SLTs, particularly when working with adults with dysphagia following stroke
3. To explore how SLTs can be best supported to assess and manage psychosocial wellbeing and QOL in adults with dysphagia following stroke
4. To identify and evaluate commonly used assessment tools when considering psychosocial impact and QOL in adults with dysphagia following stroke

1.3 Thesis structure

As outlined in Table 1.1, this thesis is presented in five sections and nine chapters. Section 1 contains the first two chapters. **Chapter 1** opens by outlining the structure of

this thesis. The background and rationale for the research that was undertaken is presented. The importance of recognising and addressing psychosocial wellbeing and quality of life (QOL) in stroke care is highlighted, alongside the current paucity of research specific to the stroke population with dysphagia. The likely impact of this research gap on clinical practice is discussed. This chapter concludes by presenting the theoretical framework and by revisiting the aims, and objectives of this thesis.

Chapter 2 is a methodology chapter. The overall research paradigm, methodological approach and research design are described. Justification is then provided for the chosen data collection and analysis methods that were adopted in each of the research studies completed as part of this thesis. The positionality and influence of JM as the lead researcher for this thesis is also discussed

Section 2 presents two research studies that were completed towards addressing the first objective of this thesis. **Chapter 3** presents a qualitative exploration of the experiences of persons living with dysphagia during the stroke rehabilitation journey. Data was collected through the use of autobiographical texts and was analysed using Interpretative Phenomenological Analysis (IPA). **Chapter 4** presents a qualitative exploration of the experiences of persons living with long-term dysphagia following stroke. One-to-one interviews were used to collect the relevant data. This data was then analysed using IPA.

Section 3 of this thesis presents two research studies that were completed towards addressing the second and third objectives of this thesis. **Chapter 5** presents an international survey study which explored current practice patterns, attitudes, and beliefs

of SLTs when assessing and supporting psychosocial wellbeing and QOL in the stroke population with dysphagia. The findings of this survey are then built upon in **Chapter 6**, which reports on an international focus group that explored how SLTs can be best supported to practice effectively in this clinical area.

Section 4 addresses the fourth and final objective of this thesis. In this section, **Chapter 7** presents a scoping review and qualitative analysis which examined the appropriateness of commonly used patient-reported outcome measures (PROMs) in randomised controlled trials (RCTs) that have been reported in the stroke population with dysphagia.

The final two chapters of this thesis are presented in Section 5. **Chapter 8** integrates the main findings from each of the five studies completed as part of this thesis. **Chapter 9** presents a critical reflection on the strengths and limitations of the overall research methodology and outlines the recommendations for both clinical practice and future research that arise from this piece of work.

Table 1.1: Thesis structure

SECTION 1 – INTRODUCTION

Chapter 1	Introduction and literature review
Chapter 2	Methodology

SECTION 2 – THE IMPACT OF DYSPHAGIA ON PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE FOLLOWING STROKE

Chapter 3	<i>Study 1</i> – The impact of dysphagia on psychosocial wellbeing and quality of life during the stroke rehabilitation journey ¹
Chapter 4	<i>Study 2</i> – The impact of long-term dysphagia on psychosocial wellbeing and quality of life following stroke

SECTION 3 – CLINICAL PRACTICE WHEN ADDRESSING PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE IN DYSPHAGIA FOLLOWING STROKE

Chapter 5	<i>Study 1</i> – Current clinical practice patterns of speech and language therapists when addressing psychosocial wellbeing and quality of life in dysphagia following stroke ²
Chapter 6	<i>Study 2</i> – Challenges to assessing and supporting psychosocial wellbeing and quality of life in dysphagia following stroke

SECTION 4 – CLINICAL ASSESSMENT TOOLS FOR EXPLORING PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE IN DYSPHAGIA FOLLOWING STROKE

Chapter 7	<i>Study 1</i> – Patient reported outcome measures in dysphagia research following stroke: A scoping review and qualitative analysis of content ³
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SECTION 5 – DISCUSSION

Chapter 8	Integration of findings
Chapter 9	Strengths, limitations and recommendations

1.4 Stroke and stroke-related disability

The World Health Organisation (WHO) defines stroke as “rapidly developing clinical signs of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent cause other than of vascular origin” (WHO 1988, p.106). Using a simpler definition, the Intercollegiate Stroke Working Party describe a stroke as occurring when blood supply to any part of the brain is interrupted, resulting in the damage or destruction of brain cells, subsequently affecting body functions (Intercollegiate Stroke Working Party 2016). The pathological background for stroke may be due to either ischaemic or haemorrhagic changes to cerebral blood flow (Sacco et al. 2013).

Stroke is a leading cause of both death and disability across the world today (Nguyen et al. 2015, Katan & Luft 2018, Kyu et al. 2018). The World Stroke Organisation (WSO) estimates that there are over 13.7 million new strokes each year, with one in four people over the age of 25 likely to have at least one stroke in their lifetime (Feigin et al. 2016, WSO 2019). In 2017, across the European Union, there were 1.12 million new incidents of stroke and approximately 9.5 million stroke survivors, making stroke the leading cause of adult disability in this region (Wafa et al. 2020).

Within the Irish context, there are upwards of 30,000 people living with the consequences of stroke-related disability at any one time (Irish Heart Foundation 2017). The most recent report on the cost of stroke care across the country was made back in 2007 and was estimated at €805 million. This accounted for 5% of the total healthcare expenditure of that year. It was estimated that the ongoing cost of stroke care in Ireland

would increase by between 52% and 57% between the years 2007 and 2021 (Smith et al. 2013). The Burden of Stroke in Europe report predicts that the number of strokes in Ireland will increase by 59% by the year 2035. Across the European Union, this figure will increase by 34% in the same time (Stroke Alliance for Europe 2017).

The risk of stroke increases with age, with the highest risk in persons aged over 65 years. Women and persons of African-American descent are more likely to have a stroke. The risk of stroke is also higher in persons with a family history of stroke, and in persons who have had a previous stroke or a transient ischaemic attack (TIA) (Benjamin et al. 2017). High blood pressure, high cholesterol, smoking, Type 1 or Type 2 Diabetes, physical inactivity, obesity, atrial fibrillation and other heart conditions have all been shown to place people at a higher risk of stroke (Kelly-Hayes 2010, O'Donnell et al. 2010). Stroke is more common amongst persons with a history of alcohol abuse and/or drug abuse and in persons from lower socioeconomic backgrounds (Boden-Albala & Sacco 2000, Avan et al. 2019).

1.4.1 Physical, cognitive and behavioural changes following stroke

Persons who have had a stroke may present with a range of physical, cognitive and behavioural changes that can have a significant impact on their autonomy, their ability to participate in day-to-day activities and their overall QOL (Min & Min 2015, De Wit et al. 2017). The potential physical, cognitive and behavioural consequences that can occur following stroke are wide-ranging and complex. The particular changes experienced by any individual person will be dependent on the specific location and severity of their stroke within the brain (Cheng et al. 2014). Approximately 65% of

persons who have had a stroke will experience hemiparesis, or weakness on one side of the body (Bindawas et al. 2017). Foot drop is common and results from weakness in the muscles of the foot and ankle (Johnson et al. 2004). Persons may experience increased muscle tone, known as spasticity, with an associated risk of developing contractures and chronic pain (Francisco & McGuire 2012). Over one third of people following stroke will experience long-term difficulties with bowel and bladder control (Harari et al. 2003). Fatigue is a common experience, with persons with post-stroke fatigue experiencing low energy and persistent tiredness, regardless of level of physical activity, sleep or rest (Hinkle et al. 2017).

Slurred speech, known as dysarthria, and difficulty with swallowing, known as dysphagia, are expected in over 65% and 40% of persons who experience a stroke respectively (Flowers et al. 2013, Ali et al. 2015). Up to one third of people will have some level of difficulty with speaking, understanding, reading or writing, known as aphasia (Flowers et al. 2013, Khedr et al. 2020a). Difficulties with both memory and thinking are common (Mellon et al. 2015), while some persons who survive stroke may also have difficulty controlling their mood and emotions, meaning that they laugh more, or cry more, and often for no reason at all (Kim 2016). Post-stroke depression and anxiety are frequently reported (Khedr et al. 2020b).

More people than ever before are surviving and living with stroke-related disability (McKevitt et al. 2011). With increasing public awareness, and advances in medical treatments such as the wide spread roll out of thrombolysis and thrombectomy, it is expected that this number will continue to increase. The concurrent increase in the

number of stroke incidents and the reduction in the associated mortality rates means that the number of people living with stroke-related disability will subsequently grow. Present projections show that the number of people living with chronic stroke-related disability in Europe will increase by 25% in the next 20 years (Stroke Alliance for Europe 2017). As a result, stroke is being increasingly recognised as a long term and chronic condition, resulting in calls for healthcare services to be developed to meet the long-term needs of this population (Sumathipala 2012).

1.4.2 The impact of stroke-related disability

With a sudden onset and a diverse range of chronic disabling conditions, persons who have experienced a stroke and their caregivers may be ill prepared to deal with the long-term consequences of living with stroke disability. Consequently, beyond the range of physical and cognitive disabilities persons may live with following stroke, there has been increasing recognition in recent years of the substantial social and psychological challenges also faced by this clinical population. With continuing research demonstrating the significant impact of stroke and stroke-related disability, international clinical care guidelines are beginning to acknowledge the need for healthcare clinicians to actively address psychosocial wellbeing and QOL in this group (e.g. National Institute for Health and Care Excellence 2013, Intercollegiate Stroke Working Party 2016). Furthermore, the recent Burden of Stroke in Europe Report has recommended that ongoing research needs to specifically focus on patient reported experiences, QOL and the development of appropriate outcome measures (Stroke Alliance for Europe 2017).

The psychosocial impact of stroke is both far-reaching and complex. Changes in social relationships and participation, mental health, personal identity, mood and behaviour are all reported in the literature (Knapp et al. 2000, Hackett et al. 2008, Ferro et al. 2009). Over 70% of persons report a significant lack of confidence following stroke, with nearly half reporting that they find it difficult to confide in others regarding the impact that their stroke disabilities have on their lives (Stroke Association 2017). It is estimated that one third of stroke survivors will present with post-stroke depression symptoms and up to 20% will experience significant anxiety in the first 12 months following their stroke (Kirkevold et al. 2012). Depression following stroke has been associated with poor QOL and a worse physical recovery (Northcott et al. 2016a). Furthermore, a consistent link between post-stroke depression and social isolation is continuing to be reported (Astrom et al. 1993, Pallesen 2014, Northcott et al. 2016b).

It has been suggested that changes in a person's social functioning and wellbeing may have a greater impact on their subsequent QOL following stroke than changes in their physical abilities (Lynch et al. 2008). The impact that stroke disability can have on a person's social network has been well documented, with a systematic review reporting on the significant strain felt within family units following stroke, the vulnerability of relationships with non-kin contacts in particular and the limited participation of the person with stroke disability in social activities (Northcott et al. 2016b). Changes in familial roles and social identities, the excess demands and pressure placed on family members and close friends, and the reduced social capacity of the person living with stroke disability, all contribute to the inevitable changes in social relationships and connections that emerge (Martinsen 2012, Pallesen 2014, Nars 2016).

In a study of the long-term needs of stroke survivors, participants highlighted the importance of social support and social connections as a key contributor to successfully living with stroke disability (Sumathipala 2012). The support of family and friends facilitated functioning across a number of domains including independence in activities of daily living (e.g. shopping, housework, personal care), accessing financial support and benefits, accessing health-related information, and participation in community events and activities (Sumathipala 2012).

Beyond the importance of strong and supportive social relationships, a number of other factors have been identified which contribute to successful coping and the process of learning to live with stroke disability. Personal characteristics such as a motivation to regain independence, awareness and knowledge of the recovery process, adopting positive attitudes and approaches to problem solving, and placing faith in religious and spiritual beliefs have all been described in the literature (Popovich et al. 2007, Kuluski et al. 2014, Visser et al. 2015). Furthermore, a process of adjusting personal expectations and standards to align them with a new reality or sense of self has also been reported (Rochette et al. 2006). Later described as 'meaning perspective transformation' (Kessler 2009, p.1058), it has been suggested that the process of adapting to life with disability following stroke involves multiple transformations. These include changed perspectives on what constitutes normal life, a renewed focus on opportunities and abilities despite disability, and increasing autonomy and independence in managing one's own health (Pilkington 1999, Kirkevold 2002, Kessler 2009, Wood 2010).

1.5 Dysphagia following stroke

Dysphagia is the medical term most often used to describe any disruption to the normal swallow process (Murry & Carrau 2012). A person with dysphagia may not have the ability to eat, drink and swallow safely, meaning that they are at risk of food and/or drink entering their respiratory tract (or airway). This is known as aspiration. A person who experiences aspiration on a regular basis will be at risk of developing malnutrition, dehydration and aspiration pneumonia (Logemann 1998).

The presence of dysphagia following stroke can often go undetected (Martino et al. 2012). Accordingly, the prevalence of dysphagia in persons following stroke varies significantly in the literature, with studies reporting incidence rates of between 37% and 78% in the acute stage (Martino et al. 2005, Guyomard et al. 2009). This discrepancy is often attributed to variations in the methods used to assess dysphagia, to differences in the timing at which the assessment was completed post-stroke and to underlying differences in the groups of patients that were studied (Rofes et al. 2018). It is widely accepted however, that some level of dysphagia is likely in approximately 50% of persons in the first 7 days post-stroke (Ickenstein et al. 2012). This makes dysphagia one of the most common physical disabilities a person may experience following a stroke (González-Fernández et al. 2013).

Numerous studies have been completed towards developing our understanding of the factors that may predict the presence and severity of dysphagia following stroke. Persons may be more likely to experience dysphagia following stroke if they are male, if they have had a previous stroke and/or if they have an initial stroke National Institutes of

Health Stroke Scale (NIHSS) score greater than 6, while the risk of experiencing dysphagia after stroke also increases with age (Broadley et al. 2003, Lapa et al. 2017, Fernández-Pombo et al. 2019).

Thanks to advances in radiological imaging (fMRI), there is increasing understanding of the cerebral regions associated with swallowing difficulties following stroke, with the pattern and severity of dysphagia predominantly determined by the location of the lesion within the brain (Chen et al. 2000, Zhu et al. 2010). Despite ongoing research however, the concept of hemispheric dominance for dysphagia following stroke remains unclear (Roje-Bedekovic et al. 2020). It has been shown that unilateral strokes in both hemispheres can cause dysphagia, but findings vary as to whether dysphagia is more likely to result following a right or a left hemisphere lesion (Suntrup et al. 2015, Marian et al. 2017). What the research does show is that persons who experience brainstem strokes (i.e. pons and medullary) have a statistically higher chance of developing dysphagia (Flowers et al. 2017, Rofes et al. 2018, Khedr 2021).

Early identification of dysphagia following stroke has been shown to have a positive impact on overall outcomes in this population (Martino et al. 2009, Eltringham et al. 2018). As a result, rapid swallow screening for patients with suspected stroke is becoming common practice, with screening tools used to quickly identify the presence or absence of dysphagia in this group (Hinchey et al. 2005, Daniels et al. 2013). For those persons where dysphagia is suspected, a suitably trained clinician, most often the SLT, completes an in-depth bedside swallowing assessment.

When managing dysphagia following stroke, SLTs generally take a compensatory approach, a rehabilitative approach, or a combination of both (Rogus-Pulia & Robbins 2013). A compensatory approach to dysphagia management is concerned with immediately improving the safety and effectiveness of the person's swallow, ideally allowing them to have some form of oral intake. This approach does not alter underlying swallow function (Vose et al. 2014). In contrast, rehabilitative approaches aim to restore swallow function by permanently altering the underlying swallow physiology (Rogus-Pulia & Robbins 2013). Dysphagia rehabilitation following stroke targets the specific motor and sensory functions which have been affected, with the goal of returning the person to as close to their pre-stroke baseline for eating and drinking as is possible (Carnaby & Madhavan 2013, Langmore & Pisegna 2015).

The evidence base for the various rehabilitative approaches in dysphagia management following stroke remains unclear, with a particular need for well-designed RCTs noted in the literature (Bath et al. 2018). As of yet particular recommendations regarding dosage, intensity and the use of specific treatment approaches in the various dysphagia presentations are unavailable (Langmore & Pisegna 2015). In a Cochrane review completed by Bath and colleagues in 2018, the authors concluded that although dysphagia therapy may have an impact on length of hospital stay, swallowing ability and respiratory infections, the quality of the current evidence base is questionable and further high quality trials are needed to determine the effectiveness of specific treatments (Bath et al. 2018).

Dysphagia as a predictor of overall outcomes and prognosis in stroke, has been linked with a greater risk of dehydration, malnutrition, infection, longer hospital stays and increased likelihood to require nursing home care on discharge (Smithard et al. 2007, Altman et al. 2010). Dysphagia in stroke has also been shown to be an independent predictor of mortality (Singh & Hamdy 2006), with patients with dysphagia at an 8.5 fold higher risk of death at 3 months (Arnold et al. 2016). In fact, mortality at 3 months post-stroke is more strongly associated with severe dysphagia than with the overall level of stroke severity at baseline (Arnold et al. 2016).

The vast majority of persons who experience swallowing difficulties following stroke can expect to make a relatively good recovery within the first 7 days (Broadley et al. 2003). However, a number of persons will continue to require modification of their food and fluids at 6 months, with up to 80% of persons demonstrating persistent swallowing abnormalities on radiographic examination at this time (Mann 1999, Smithard et al. 2007). Approximately 20% of stroke patients may require some form of enteral tube feeding during the acute phase of their journey, with 8% requiring some form of long-term alternative feeding at 6 months (Calvo et al. 2019).

Persistent dysphagia at hospital discharge has been associated with a number of predictive factors. The presence of dysarthria, a baseline NIHSS score of ≥ 12 , bi-hemispheric infarcts, advanced age and the need for intubation during admission have all been highlighted as potential risk factors for long-term dysphagia in this clinical population (Broadley et al. 2003, Kojima 2014, Kumar 2014).

Despite dysphagia being one of the most common physical consequences a person is likely to experience following stroke (González-Fernández et al. 2013), international stroke care clinical guidelines have only recently begun to recognise the potential impact that this condition may have on the psychosocial wellbeing and QOL of this clinical group. Although these guidelines acknowledge the link between dysphagia and psychosocial wellbeing, they do not offer any specific recommendations regarding if this area should be specifically addressed in clinical practice, and if so, what should be offered by clinicians towards addressing this need. (See Appendix 1 for further details). The lack of clarity evident in these documents may be linked to the current paucity of research that currently exists in this area, with a number of international guidelines suggesting future studies should focus specifically on psychosocial impact and QOL in the stroke population with dysphagia (Intercollegiate Stroke Working Party 2016, Scottish Intercollegiate Guidelines Network 2010).

1.5.1 The impact of eating difficulties following stroke

A number of qualitative explorations have been reported which have focused on the impact of eating difficulties in the stroke population. In the context of these studies, eating focuses on all aspects of mealtime related activities including food sourcing, mealtime preparation and cooking, food ingestion, and enjoyment and satisfaction in eating-related activities (Klinke et al. 2013). As shown in Figure 1.1, eating difficulties are therefore seen as any issue that occurs across the ‘spectrum of eating tasks’ (Jones & Nasr 2018, p.112).

Qualitative explorations into the impact of eating difficulties subsequent to stroke have predominantly focussed on the first 6 months following the onset of disability. In this time frame, difficulties with motor function impacting on a person's ability to not only swallow safely, but also on their ability to independently buy and prepare food and to physically attend social occasions in restaurants and cafes can be seen (Klinke et al. 2013, Jones & Nasr 2018). Furthermore, alterations in sensory function such as the ability to judge the temperature of food, and new cognitive deficits which may impact the person's ability to follow a recipe or plan the preparation of a meal, place restrictions on the independence of the person following stroke (Perry & McLaren 2003, Klinke et al. 2013, Jones & Nasr 2018).

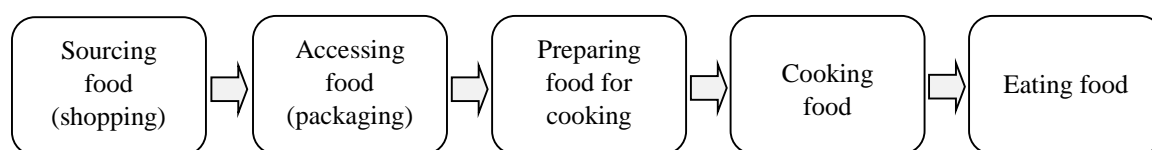


Figure 1.1: 'Spectrum of eating tasks', adapted from Jones & Nasr 2018

Strong emotions in relation to eating and drinking are reported in these early stages following stroke. Fear of choking, embarrassment when eating and drinking in public, and a sense of guilt for having to rely on others for support have been commonly reported (Jacobsson 2000, Perry & McLaren 2003). The person with eating difficulties and their close family and friends also have to deal with significant changes in their daily

lives. Adjusting to new mealtime regimes, potential disruptions to long established familial roles and a new dependence and significant reliance on others may all contribute to the difficult process of adaptation faced by this clinical group.

The process of learning to adapt and cope with eating difficulties following stroke has been described in a number of articles. In a study exploring the experiences of thirteen persons who were six months following stroke, Medin and colleagues describe the participants' ongoing 'desire to master eating situations', which was impacted by both the person's individual values and previous beliefs, and the availability of support they had from family and close friends (Medin et al. 2010a, p.1348). In a separate study, the same group of authors describe participants continually 'striving for control' in an exploration of the experiences of eleven persons who were three months following stroke (Medin et al. 2010b, p.776). This continuing desire to achieve control when eating and drinking was described as requiring an ongoing balance between both eating safely and eating properly. Similarly, Jones and colleagues describe this drive to master new skills in a group of persons six months following stroke, reporting that the person with stroke will learn coping and adjusting strategies from others but will also generate their own solutions (Jones & Nasr 2018).

In a concept analysis of the literature, 33 studies, which examined difficulties with eating following stroke, were explored and appraised (Klinke et al. 2013). These studies, which covered a timeframe of acute stroke through to 6 months post-onset, included structured interviews, documentation reviews, patient questionnaires and ratings on relevant assessment scales. The complexity of living with difficulties with feeding, eating,

drinking and swallowing because of stroke was highlighted and a three part conceptual framework was subsequently proposed to capture the experiences of persons with eating difficulties following stroke. The first component of this framework describes how persons may continually compare their new post-stroke reality with their old post-stroke eating habits. Throughout this process of continual comparison, eating and drinking is influenced by functional, meaning-related and contextual factors such as physical disabilities, social consequences and practical limitations. The framework suggests that the interaction of these factors will impact the outcome of eating difficulties in the person following stroke.

Only two studies have qualitatively explored the experiences of those with eating difficulties beyond six months following stroke. Carlsson and colleagues completed repeat interviews with three persons who were between 1.5 and two years following stroke (Carlsson et al. 2004). A constant comparative analysis of the data revealed a core theme described as ‘striving to live a normal life’ (Carlsson et al. 2004, p.830). Participants describe the process of wanting to return to their old life, but also learning to live with a new normalised life as a result of their stroke. In 2014, Klinke et al. reported on the findings of in-depth interviews completed with seven young stroke survivors (under 65 years of age) (Klinke et al. 2014). A number of themes are described, including the participants’ reluctance to eat and drink outside of their home, their ongoing attempts to preserve their dignity in social settings by trying to mask their eating difficulties and a desire to move on with life following stroke, without missing out.

1.5.2 The impact of dysphagia following stroke

Although a link between both dysphagia and QOL has been demonstrated in a number of quantitative studies, (Hong & Yoo 2017, Kim et al. 2020), qualitative research which has specifically addressed the impact of dysphagia in the stroke population, remains comparatively sparse. In 2019, Eltringham and colleagues reported on the experiences of three caregivers and five persons with dysphagia, using semi-structured interviews and a thematic approach to data analysis. There was a specific focus on the first 72 hours following stroke and the participants' experiences of having their swallow screened and assessed (Eltringham et al. 2019).

The findings of this study suggest that persons with dysphagia experience a confusing and anxious time in the early days following their stroke. Participants with dysphagia do not fully understand what has happened to them, and as a growing realisation of the extent of their difficulties emerges, they describe mixed emotional responses, often linked to past experiences and life history. Although the participants with dysphagia described positive attitudes towards the healthcare workers involved in their care, references are made to inconsistencies in the standard of care provided. Participants report mixed experiences regarding communication with their healthcare workers, with some persons with dysphagia and their caregivers feeling a need to search for their own answers and information regarding the management of their medical condition.

Difficulties in relationships with healthcare workers was also reported in a study by Helldén and colleagues, where the experiences of persons with longer-term dysphagia following stroke were described (Helldén et al. 2018). Qualitative content analysis was

used to analyse the interview transcripts of five persons who were between 3 and 10 years following their stroke. One of the findings of this study, was that participants reported significant gaps in the availability of follow up services and access to healthcare professionals and described feeling left on their own to learn how to cope and adapt to their long-term swallowing difficulties (Helldén et al. 2018).

In the process of learning to live with their dysphagia, the participants in Helldén's study described experimenting with different consistencies of food and drink, risk taking with 'special' food and drink because it tasted good, and the impact of weight loss, taste changes and additional time required to complete meals. Participants described an ongoing reluctance to eat and drink in public, with a subsequent impact on social activities and participation in family events. Despite the significant amount of time that had passed since their stroke, participants described holding onto hope for ongoing recovery and improvement in their swallowing ability (Helldén et al. 2018).

1.5.3 Current gaps in our understanding

Although there is learning from the relatively larger number of studies that have explored the experiences of eating difficulties following stroke, studies which have focussed on difficulties across the eating spectrum may include persons with little or no swallowing difficulties. Furthermore, if persons with swallowing difficulties are included, it is impossible to fully discern the findings and learnings relevant to those with dysphagia. Research specific to the impact of dysphagia on psychosocial wellbeing and QOL following stroke is limited, whilst also having its limitations.

Of the two studies that have been completed, one has focussed predominantly on the first 72 hours following stroke onset, and the other has focussed on persons with long-term dysphagia, a number of years later. As a result we have no understanding of the impact of dysphagia during the stroke rehabilitation journey. The acute and sub-acute phase of stroke rehabilitation can be a time of significant change for the person and their family and caregivers. The onset of symptoms and associated disability is often sudden and unexpected. Expectations regarding recovery may not be clear. For some an intensive rehabilitation journey over a number of months may be needed, and the person's experiences of dysphagia may also evolve and change over this time. Exploring individual experiences of dysphagia through the different stages of the stroke rehabilitation journey is therefore necessary to allow us to develop a greater understanding of the ongoing impact of dysphagia on QOL in this clinical group.

It has been shown that persons with acute dysphagia perceive and prioritise their psychosocial needs very differently to those with chronic dysphagia (Martino et al. 2010). We know that a proportion of persons with dysphagia following stroke may not make a full recovery and may live with long-term swallowing difficulties (Smithard et al. 1997, Calvo et al. 2019). Valuable insights into the long-term experiences of persons with post-stroke dysphagia have been reported by Helldén and colleagues (Helldén et al. 2018). However, this study represents what is essentially an initial exploration of the experiences of this population. Furthermore, in using qualitative content analysis, this study adopted an arguably reductive approach to the examination of the data collected, thereby limiting the richness and complexity of the findings that were presented (Elo et al. 2014). Further research using a more detailed and interpretative approach to data analysis is required in

order to build on and triangulate these research findings, and to develop a deeper understanding of the experiences of this clinical group.

1.6 Gaps in our understanding – impact on clinical practice

Arguably, the overall goal of stroke rehabilitation should be to enhance psychosocial wellbeing and QOL, with holistic and person-centred stroke care grounded in an understanding of the experiences, feelings and wishes of the person living with stroke (National Institute for Healthcare and Excellence 2013). It has been proposed that for a clinician to be truly person-centred in their approach to assessment and management, they need to clearly understand the perspectives and experiences of their patients and to actively incorporate this understanding into their practice (Kristensen et al. 2016, Vennedey et al. 2020).

By specifically addressing, considering and exploring psychosocial wellbeing and QOL, clinicians can ensure that person-centred priorities are continually incorporated into management plans, thus making healthcare experiences and interactions more meaningful (Michie et al. 2003). Furthermore, by evaluating the impact of healthcare interventions, not just on physical recovery, but also on psychosocial wellbeing and QOL, ongoing decision making in respect of treatment options and intervention goals is enriched (Makai et al. 2014, Karimi & Brazier 2016). Until we develop our understanding of the experiences of persons living with dysphagia following stroke, it is likely that clinical practice in this area is not fully meeting the needs of the stroke population with dysphagia.

1.6.1 Variations in approaches to dysphagia management following stroke

It has been shown that inconsistencies and discrepancies in the assessment and management of dysphagia exist between and amongst SLTs. Surveys which have examined SLT approaches to the management of dysphagia in people with head and neck cancer (Krisciunas et al. 2012) and in individuals with Parkinson's disease (Miller et al. 2011) have shown significant variations in clinical practice. Furthermore, several survey studies have looked at dysphagia practice in mixed patient populations and have all described variability and inconsistency in the approaches reported by the SLT participants (Mathers-Schmidt & Kurlinski 2003, Martino et al. 2004, Bateman et al. 2007, Pettigrew & O'Toole 2007, Cocks & Ferreira 2013).

Similar inconsistencies have been reported in studies which have looked specifically at dysphagia management following stroke. In 2013, Archer and colleagues reported on a UK and Ireland based survey, which explored SLT approaches to dysphagia therapy in the stroke population. Although the findings suggested that the participants attempted to adopt a holistic and person-centred approach to care, there was significant variability in the therapy being offered. It was suggested that SLT practice lacks objectivity due to the limited use of specific outcome measures, and that resource limitation was likely a contributory factor to the inconsistencies that were seen (Archer et al. 2013).

A similar study was completed in the US in the same year. Using a web-based survey, the authors explored the current practice patterns of licensed SLTs in the treatment of adults with dysphagia. As part of the survey, respondents were presented

with a clinical case example of a young man with a brainstem injury. Clinical and instrumental data were provided and respondents were invited to provide specific information with regards the treatment decisions and approaches they would take. The responses to this question showed that more than 47 different treatment techniques and 96 different combinations of therapy techniques were recommended for the treatment of this single hypothetical patient (Carnaby & Harenberg 2013).

Finally, in 2018, a survey of Australian practices in dysphagia therapy following stroke showed similar variations and inconsistencies in practice (Jones et al. 2018). A number of contributing factors were suggested to explain the low level of agreement seen amongst clinicians, including the impact of cognitive deficits in persons following stroke and their level of motivation when participating in rehabilitation. However, the sheer complexity in treatment decision-making that is faced by SLTs when working with persons with dysphagia following stroke was also acknowledged.

1.6.2 Patients and clinicians – a difference of opinions

Previous research has suggested that the priorities of care for both clinicians and patients may not always be consistent or comparable. Within the stroke population, it has been shown that health care clinicians will often view rehabilitation within a purely biomedical framework, with a primary emphasis on physical recovery. In contrast, the person who has had a stroke is often concerned not just with the biomedical consequences of the stroke, but also with the social and psychological implications (Bendz 2003, Harrison et al. 2017). In a qualitative study on the long term needs of stroke survivors,

participants emphasised throughout, the importance of ongoing psychosocial resources and support to help them adjust to their new life (Sumathipala 2012).

Discrepancies in the expectations of clinicians and patients have also been reported in the literature exploring goal setting and prognostic hopes within the stroke population. It has been reported that patient's expectations for recovery following stroke are often very high – sometimes unrealistically so (Wottrich 2012). In a study of how clinicians negotiated patient-reported goals that were deemed unrealistic or unachievable, it was reported that ambitious goals were often discouraged by clinicians or in some cases completely ignored (Levack 2011). As a result, documented goals by clinicians were often more representative of what was achievable within the scope of the rehabilitation service and not of the issues or concerns that were personally relevant to the patient (Rosewilliam et al. 2016, Rose et al. 2017). Interestingly, in one study, of the 45 different types of goals identified in the rehabilitation of 9 stroke patients, none were related to psychological or social functioning (Levack 2011).

Beyond the process of setting goals to guide management, disagreements between clinicians and patients in the value and importance of recommended treatment approaches have also been reported. Although no studies have been completed which have specifically focused on patients with dysphagia following stroke, in the general dysphagia population it has been estimated that up to 21% of patients never fully adhere to management recommendations made by their SLT (Davis 2007). Furthermore, it has been reported that SLTs can over estimate their patient's adherence to these recommendations by more than 30% (Leiter & Windsor 1996, Krekeler et al. 2018). A number of

contributory factors to these high rates of non-adherence have been suggested including complicated recommendations, the need for long-term use of strategies and socially stigmatising intervention approaches (e.g. modified diet and fluids) (Sharp & Bryant 2003, Colodny 2005, Davis 2007).

In dysphagia management, it has been suggested that SLTs may place an emphasis on functional and physical recovery, whereas persons with dysphagia may be more concerned regarding the psychosocial consequences of their difficulties with eating and drinking (Davis 2007, O’Keeffe 2018). In order for intervention approaches to become more meaningful and appealing to patients, SLTs need to be more aware of the individual psychological and social impact that dysphagia has on their patient’s lives and to achieve this, a robust assessment process is needed (Colodny 2005). Formal validated assessment tools such as the Swallowing Quality of Life Questionnaire (SWAL-QOL) (McHorney et al. 2002) and the Dysphagia Handicap Index (DHI) (Silbergleit et al. 2012) are in common use and referenced frequently in both research and clinical practice. However, beyond establishing an impact of dysphagia on QOL and psychosocial wellbeing, these assessment tools do little to guide the clinician in supporting and managing these important issues. Furthermore, these tools were developed with a general dysphagia population in mind, and so may not adequately capture the impact of dysphagia in persons following stroke.

1.6.3 Potential professional development needs

Research to date in other clinical populations, such as those with aphasia (Northcott et al. 2017), dysarthria (Collis & Bloch 2012) and palliative care needs

(O'Reilly & Walshe 2015), has found that SLTs believe they have a significant role to play in supporting QOL and the psychosocial needs of the persons that they work with, but often feel unsupported to do so. The participants in these studies cited a lack of confidence, a lack of specific clinical training, a lack of clinical resources and a lack of clinical guidelines as contributing factors.

With similar limitations in the evidence base, and with a lack of clinical resources and clinical guidelines available to support clinical practice, it is likely that comparable difficulties exist for SLTs when working with those with dysphagia following stroke. However, the practice patterns of SLTs when addressing and supporting psychosocial wellbeing and QOL in the stroke population with dysphagia has not been explored to date. To inform clinical practice, future research priorities, and the development of appropriate and beneficial psychosocial and QOL resources and guidelines, an exploration of SLT clinical practice in this area is warranted.

Consideration should be given to the beliefs and current practice patterns of SLTs, alongside the content and suitability of the clinical assessment tools that are currently available to support clinical practice in this area. When considered in the context of the experiences of persons living with dysphagia following stroke, this information can be used to move towards a high quality and consistent delivery of care for persons with dysphagia following stroke. Furthermore, information regarding potential educational, clinical and professional needs will allow the development of the profession in this important clinical area.

1.7 Theoretical framework, research aims and objectives

The theoretical framework of this thesis is that our understanding of the impact of dysphagia on psychosocial wellbeing and QOL following stroke is fundamentally interlinked with clinical practice, clinical care guidelines and research priorities in this area. Subsequently, a lack of research which has specifically focused on the experiences of persons with dysphagia following stroke, is likely to impact on the quality of care that is being offered to this clinical group. The concepts and associated relationships which underpin this theoretical framework are presented in Figure 1.2.

As outlined in this figure, an understanding of the impact of dysphagia on psychosocial wellbeing and QOL following stroke can be developed from two primary sources – the first being the available research and evidence base and the second being an individual and holistic clinical assessment with the person living with dysphagia. In terms of research and policy, once a clear understanding of the impact of dysphagia on psychosocial wellbeing and QOL has been developed, this information can inform clinical care guidelines, future research priorities and professional development needs. At a clinical level, this understanding of the experiences of persons living with dysphagia following stroke can subsequently inform clinical practice in this area.

The overall purpose of this thesis is to inform both clinical practice and future research. Therefore, with consideration for this theoretical framework, it was important to address and explore three key areas.

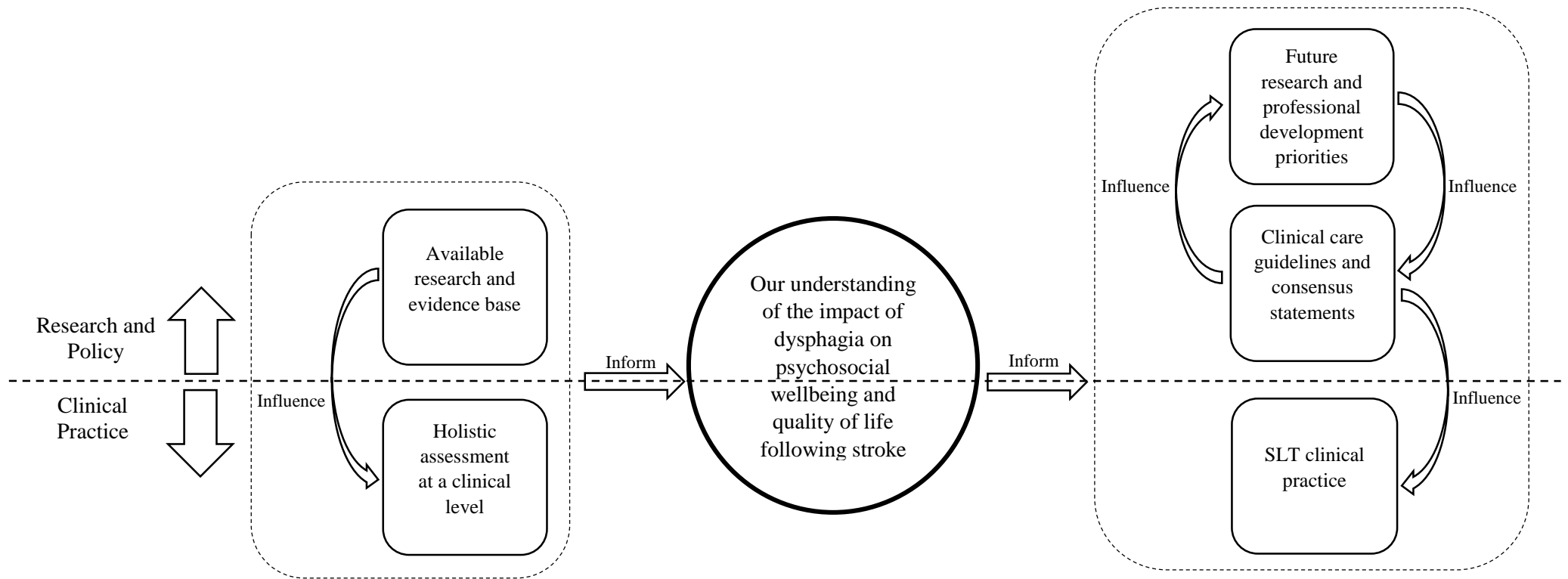


Figure 1.2: Theoretical framework of this thesis

Firstly, it was imperative to develop our understanding of the impact of dysphagia in the stroke population, as this information forms the foundation for guiding both clinical practice and future research priorities. To this end and with consideration for the limited research that has been completed in this area to date, this thesis examined the experiences of both persons living with dysphagia during the stroke rehabilitation journey and persons living with long-term dysphagia following stroke.

Secondly, with a greater understanding of the experiences of this clinical group, it was important to then look at current SLT clinical practice patterns and behaviours. This was necessary so that potential gaps and inconsistencies in clinical care could be highlighted and professional development needs identified. For this reason, this thesis explored current SLT practice patterns in the assessment and management of psychosocial wellbeing and QOL in the stroke population with dysphagia, with a particular focus on how SLTs can be best supported to work effectively in this clinical area.

Finally, with a clearer understanding of the current clinical practice patterns of SLTs working in this area, it was then necessary to focus specifically on the clinical assessment process reported by these SLTs. This was an important area to explore, as alongside the available research and evidence base, the information gathered by SLTs in a clinical setting is key to SLTs understanding the impact of dysphagia on psychosocial wellbeing and QOL following stroke. If the clinical assessment process is limited, then the clinician's understanding of the experiences of the person living with dysphagia will also be incomplete. This thesis therefore identified and evaluated the clinical assessment

tools which are presently being used to evaluate psychosocial wellbeing and QOL in the stroke population with dysphagia. When considered in the context of the findings from both the experiences of persons living with dysphagia following stroke and the challenges reported by SLTs working clinically in this area, an evaluation could be made regarding the appropriateness and comprehensiveness of these tools when used in a clinical context.

Therefore, the overall **aim** of this thesis is to investigate psychosocial wellbeing and QOL in the adult stroke population with dysphagia, with consideration for the first-hand accounts of persons living with dysphagia, current SLT clinical practice patterns and the content and appropriateness of the assessment tools commonly being used in this area. The findings of this thesis will have relevance for ongoing clinical practice and the direction of future research in this area.

The focus and direction of this thesis has undoubtedly been influenced by my professional background and experience working clinically as a SLT in stroke care. Throughout my clinical career I have always had an interest in psychosocial wellbeing and QOL in the stroke population with dysphagia. In particular, I have always struggled with what I perceived to be a lack of emphasis on this important aspect of care in both clinical practice and the research literature. This frustration was one of the primary motivators which led me to pursue a PhD in this topic area. A further reflection on the positionality of JM as the lead researcher in this thesis is presented in Chapter 2.

The four key **objectives** that guided this thesis were:

- To develop a greater understanding of the impact that dysphagia has on psychosocial wellbeing and QOL in adults living with swallowing difficulties following stroke
- To determine current approaches to the assessment and management of psychosocial wellbeing and QOL by SLTs, particularly when working with adults with dysphagia following stroke
- To explore how SLTs can be best supported to assess and manage psychosocial wellbeing and QOL in adults with dysphagia following stroke
- To identify and evaluate commonly used assessment tools when considering psychosocial impact and QOL in adults with dysphagia following stroke

1.8 Conclusions

Dysphagia is a common physical consequence of stroke. Our understanding of the impact of dysphagia on psychosocial wellbeing and QOL in the stroke population is limited due to a paucity of research in this area. This paucity of research is likely to have an impact on the current clinical practice of SLTs.

This thesis aims to explore the experiences of adults with dysphagia following stroke, current clinical practice patterns of SLTs working in this area and the suitability of current clinical tools available to support the assessment of psychosocial wellbeing and QOL in this population. The focus of this thesis has been influenced by my clinical

experience as a SLT working in stroke care. The findings of this thesis will have implications for clinical practice and future research priorities.

Chapter 2: Methodology

2.1 Introduction

This chapter outlines and discusses the relevant methodological aspects of this thesis. Firstly, an overview of the research paradigm which framed the studies that comprised this thesis is provided. This is followed by a description of the methodological approach and the associated research design. The data collection and analysis methods used in each of the studies are then introduced and justified. The chapter concludes with a reflection on the positionality of JM as the lead researcher in this thesis.

2.2 The research paradigm

A research paradigm can be defined as a belief system that guides the way in which we take action (Mertens 2019). It represents the researcher's perspective or worldview (Mackenzie & Knipe 2006), the lens through which the researcher considers the methodological aspects of their research project and the particular methods that will be used to gather and analyse the data (Kivunja & Kuyini 2017). There are three widely recognised research paradigms – the Positivist paradigm, the Critical paradigm and the Constructivist (also known as Interpretivist) paradigm (Kivunja & Kuyini 2017).

2.2.1 Positivism

Research that adopts a positivist approach is based on experimentation and observation, and is concerned with searching for cause and effect relationships in nature.

The ontological view of positivist researchers is that there is one universal reality that can be objectively measured. For this reason, the positivist paradigm is often referred to as the scientific method of investigation and is most often associated with quantitative research methods (Park et al. 2020). Carefully designed scientific studies using large data samples, clear measurement systems and statistical analysis are commonplace (Park et al. 2020).

2.2.2 Critical paradigm

Research which is completed under the critical paradigm is most often concerned with exploring social, political or economic issues associated with oppression, conflict or inequality. For this reason, researchers in the critical paradigm are most often concerned with investigations aimed at fostering social change in the research participants and societies that are being studied (Asghar 2013). The epistemological assumptions associated with the critical paradigm, are that knowledge is socially constructed through institutional structures, society and media (Detel 2015). The research methods adopted under the critical paradigm are flexible and can include qualitative, quantitative or mixed method approaches (Kivunja & Kuyini 2017). The particular approach that is chosen is adopted as necessary to the aims and objectives of the research.

2.2.3 Constructivism

Within a constructivist paradigm, the researcher seeks to understand and describe human experience (Denicolo et al. 2016). Research that is guided by a constructivist paradigm relies whenever possible on the direct views, perspectives and experiences of

the participants of the study. The ontological view of constructivist researchers is that there is no one universal reality, and that there are as many realities as there are people constructing them. Reality is therefore dependent on context, time and space in any given situation and cannot be generalised into one common understanding. In this way, the constructivist researcher searches for complexity and detail in the research participants experiences and does not attempt to reduce the meaning of the study data in to a few narrow themes or categories (Creswell 2014). This thesis adopts a constructivist paradigm.

With regards epistemology, constructivists hold the view that all knowledge is subjective and is constructed. Therefore, it is acknowledged that reality needs to be interpreted by the researcher in order to discover meaning. Constructivist researchers recognise the active role that they play in the collection and analysis of data. They acknowledge their own historical experiences and biases and consider how these may impact and shape their interpretation of meaning and the subsequent generation of the research findings (Denicolo et al. 2016).

Constructivist research aims to generate a theory or new understanding of a particular phenomenon. Data is frequently collected using open-ended questions and/or observations, and the findings of a constructivist research study often “create an agenda for change or reform” (Creswell 2014, p.37). Research designs within a constructivist paradigm are generally qualitative in nature, although it has been acknowledged that quantitative approaches can also be combined with qualitative methodology if and when necessary (Given 2008).

2.3 Methodological approach and research design

A largely qualitative approach was adopted in this thesis. This decision was guided by both the research paradigm and the overall aim and objectives of the research. The research objectives were primarily inductive in nature i.e. they sought to develop a new understanding of both the experiences of persons living with stroke-related dysphagia and clinical practice in this area. The inductive nature of these objectives most readily fits with qualitative research (Polgar & Thomas 2008). Furthermore, this study sought to examine an area about which little research has already been completed. Qualitative methodology was therefore most appropriate, as it is often the chosen approach when little is known about the topic under investigation (Merriman & Tisdell 2015).

This thesis is comprised of five different studies. These five studies included two qualitative explorations of the experiences of persons living with dysphagia following stroke, an international survey of SLT clinical practice patterns, an international focus group with SLTs, and a scoping review. On completion, the findings of all five studies were integrated towards developing recommendations for both clinical practice and future research.

Although largely qualitative in nature, this thesis did incorporate quantitative data where necessary to support and contextualise the qualitative findings. Therefore, the research design that best describes the approach adopted in this thesis is a mixed methods triangulation design using a convergence model.

CONSTRUCTIVIST PARADIGM – MIXED METHODS

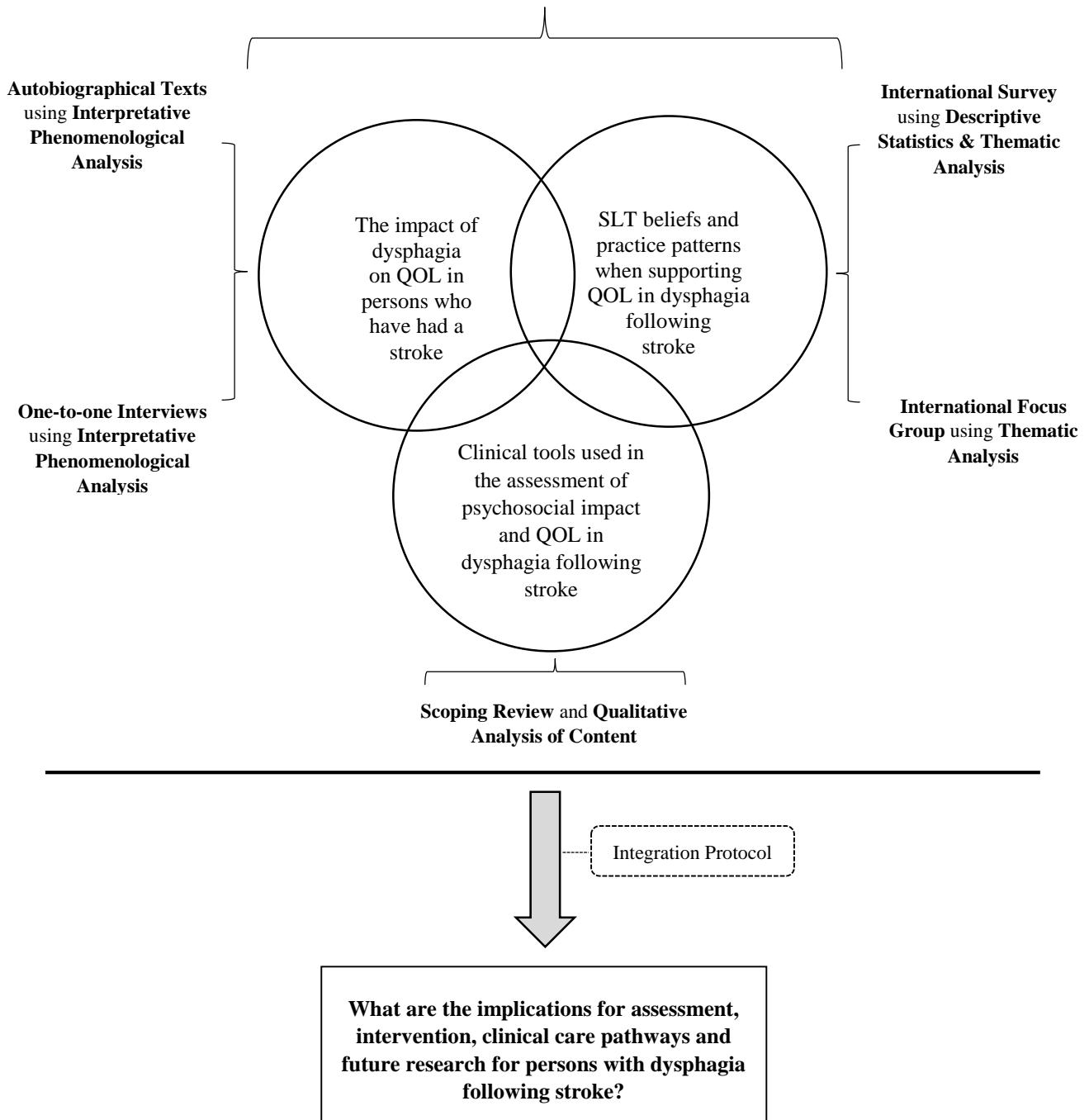


Figure 2.1: Overview of the research design

2.4 Data collection and analysis methods

This thesis incorporated a number of data collection and analysis methods. These methods were chosen with consideration for the research paradigm, the research design and the overall research aim and objectives. Specific details regarding how these data collection and analysis methods were used are described throughout this thesis in the relevant study chapters. An introduction to these methods and justification for their selection in these studies is outlined here.

2.4.1 The experiences of persons with dysphagia following stroke

Autobiographical accounts are used as the data collection method for exploring the psychosocial impact of dysphagia during the stroke rehabilitation journey. Autobiographical accounts often provide a valuable source of information on the personal experience of living with a particular health condition (Norcross et al. 2011). As a result, published autobiographies have been used for many years to help students in healthcare professional courses understand the experience of specific illnesses (Mathibe et al. 2008).

In recent years there has been increasing recognition that the experiences recounted in these published autobiographies may also hold valuable information when viewed through the eyes of a qualitative researcher (Van Manen 1997). According to Mathias and Smith, autobiographies hold the power of the ‘story of one’s experiences’ and so offer a level of insight that is both detailed and unique (Mathias & Smith 2016, p. 205).

The use of autobiographical accounts as a data collection method in qualitative research has a number of advantages. Firstly, autobiographies are readily available and easily accessible, limiting the amount of time needed to both recruit and engage with participants and to subsequently collect the data (Norcross et al. 2011). Secondly, autobiographical accounts provide first-hand accounts of the person's experience. These accounts are often also provided in some detail. This combination contributes to the overall quality of the data collected, ensuring that it is both reflective of the participants' real experiences, and that it provides enough depth for new understandings to be developed (Power et al. 2012). Finally, the information that is generated by authors in writing their autobiographical accounts has not been influenced by the presence of a researcher. It is therefore relatively unsolicited, meaning the topics discussed and highlighted within the texts, and subsequently analysed, are those which the author feels are most important and pertinent to the topic under study (Mathias & Smith 2016).

Importantly, autobiographies detail a person's experience throughout a specific period of time (Backman et al. 2006, Power et al. 2012). Alongside the advantages outlined above, this was a key motivation for using autobiographies as the data source for this study. In doing so, an exploration of how the person's experience of dysphagia may have changed throughout the stroke rehabilitation journey could be considered.

One-to-one interviews were used as the data collection methods for exploring the psychosocial impact of long-term dysphagia following stroke. The use of one-to-one interviews with study participants is a common data collection method used within

qualitative research. This method allows first-hand accounts of individual experiences to be gathered in detail (Polgar & Thomas 2008).

The main strength of one-to-one interviews lies in the depth of information which can be gathered. This information has the potential to be more detailed and insightful than the data collected using any other qualitative method (Ryan et al. 2013, McGrath et al. 2018). The information comes directly from the participant and so the first-hand accounts provided represent a description which is truly representative of the participant's experiences and perceptions (Gill et al. 2008). Furthermore, one-to-one interviews also provide a relatively high level of flexibility for researchers and can be adapted to meet the requirements of most qualitative research studies (DeJonckheere & Vaughn 2019). The use of various structures (e.g. structured or unstructured) and different strategies (e.g. intensive and informational) mean that the method can often be tailored to the specific needs of the particular study (Jamshed 2014, Flick 2018).

Similar to the use of autobiographical texts when considering dysphagia during the stroke rehabilitation journey, the use of one-to-one interviews in exploring the impact of long-term dysphagia allowed detailed information to be gathered from study participants, in a way that ensured the participant's first-hand accounts were accurately captured and reflected. The flexibility inherent in one-to-one interviews also meant that the method could be easily adapted to suit the needs of this study.

Interpretative Phenomenological Analysis (IPA) was used to analyse the transcripts produced from both the autobiographical accounts and the one-to-one interviews with persons with dysphagia following stroke. IPA, as a distinct qualitative

data analysis method, was first documented in the UK in the mid-1990s (Smith 1996). In the short time since it was first proposed, IPA has been employed across a range of domains including health, psychology, education, and the humanities.

IPA is concerned with seeking to understand the research participant's lived experiences through both description and interpretation (Tuohy et al. 2013). It has two primary aims. The first, is to examine in detail, the way in which a person makes sense of a particular experience. The second, is to then provide a detailed interpretation of the person's first-hand account, in order to broaden our understanding of their experience (Thomas 2016, Tuffour 2017). In short, IPA is used when the research aim is to try and understand what a particular experience is like from the research participant's perspective.

IPA challenges the traditional belief that a greater number of participants will lead to more valuable research findings, and is generally associated with a small sample size, and a relatively homogenous participant profile (Reid et al. 2005). With an emphasis on a comprehensive and in-depth analysis of each case, IPA strives to provide detailed insights and understandings of this smaller group, as opposed to a wider or more general claim about a larger population. As a result, it has been suggested that IPA should be considered as contributing to theoretical and not empirical generalisability. In this way, the findings from an IPA study should be considered alongside both the extant literature and the reader's specific experience, in order to provide new understandings and insights and to shed light on a wider context (Smith et al. 2009).

One of the basic premises of IPA, is the value it places on the experiences, perceptions and opinions of the individual participant – as opposed to only considering the experiences of the group of participants as a whole (Barbour 2007). This principle is reflected in the steps involved in the analysis of data in IPA, where each individual transcript is reviewed and analysed in full, before the entire data set is then considered. This idiographic approach to data analysis, which is core to the use of IPA, strengthens the subsequent findings in a number of ways (Peat et al. 2019).

A detailed review of each transcript prior to considering the data set as a whole, allows a deeper and richer analysis to be completed, when compared to other qualitative approaches (Smith et al. 2009). This in-depth and individual examination also ensures that the final themes and findings which are developed, are rooted directly in the information provided by the participants. In this way, the first-hand accounts of the study participants are truly captured. Furthermore, consideration of the accounts of each individual participant allows both the similarities and the differences in their experiences to be revealed and included (Reid et al. 2005).

It is suggested that the focus that IPA places on not only the commonalities between participants accounts, but also the variations which exist, adds validity and depth to the contribution that the findings of the study can make in the development of a wider ‘Theory’ within the literature (Reid et al. 2005, Pringle et al. 2011). Beyond the idiographic nature of IPA, the suitability of its use in the analysis of a wide range of written data sources including individual interviews, postal and email questionnaires, social media and blog entries, diaries and autobiographical accounts and other extant

literature, means it offers a level of flexibility in its use when exploring a particular area or research topic (Smith et al. 2009, Mackey 2005).

As outlined in Chapter 1, the first objective of this thesis was to examine the impact of dysphagia on psychosocial wellbeing and QOL in the stroke population. This objective indicates the interpretative aim at the heart of this study. The study seeks to not only describe the psychosocial impact of dysphagia in this population, but also to develop a greater understanding of the consequences this impact has on the participant's QOL. As a result, a data analysis method that aligns with a high level of interpretation, such as IPA, was required.

Another consideration when selecting IPA as an appropriate data analysis method, was the overall research paradigm. As outlined earlier in this chapter, this study adopts a constructivist paradigm. The ontology and epistemology embedded in IPA readily aligns with this constructivist paradigm i.e. IPA does not seek to uncover one universal truth or common understanding and it acknowledges the active role of the researcher in interpreting the data in order to uncover meaning.

Finally, IPA was deemed an appropriate approach to data analysis as it aligned with the data collection methods used to gather the first-hand accounts of the participants. IPA is most readily used to analyse written information and is particularly suitable for analysing transcripts generated by individual participant interviews (Smith et al. 2009). Therefore, the use of autobiographical accounts and one-to-one interviews in the data collection phase supported the use of IPA in data analysis.

2.4.2 Current clinical practice patterns of SLTs

An international *survey questionnaire* was used to explore the clinical practice patterns and beliefs of SLTs working internationally with persons with dysphagia following stroke. Survey questionnaires are one of the two primary types of survey research – the other being survey interviews (Joye et al. 2016). Survey questionnaires involve asking a predetermined set of questions of a large group of participants in order to develop a greater understanding of their behaviours, attitudes and opinions (Schofield & Forrester-Knauss 2013). Survey questionnaires are an efficient data collection method that offer a good level of flexibility, with their design and style of questions led by the overall research aims and goals (Joye et al. 2016). Survey questionnaires can be used to examine trends or patterns within groups and can be a useful starting point from which a more focused and in-depth study can be planned (Joye et al. 2016).

In order to develop an understanding of the current clinical practice patterns and beliefs of SLTs working with persons with dysphagia following stroke, it was necessary to collect a large amount of information from a large group of people. A survey questionnaire was chosen as the most appropriate data collection tool as it would allow information regarding current SLTs clinical practice patterns to be collected in a systematic way. Furthermore, the use of internet based survey questionnaires meant that this information could be collected from participants who were spread out over a large geographical area. As no previous research has been completed in this area to date, the use of a survey questionnaire also meant that preliminary and tentative findings could be

generated, and if necessary, these findings could then be explored in more detail using an alternative methodology.

A *focus group* was used to further explore the findings from the SLT survey questionnaire. Focus group interviews have been used throughout healthcare research for many years to explore the perspectives of those working in the healthcare system (Tausch & Menold 2016). A focus group interview is typically facilitated in an interactive setting, where a group of usually 8-12 participants discuss the particular research topic under study, with facilitation and guidance as required by the researcher (Krueger & Casey 2014, Stewart & Shamdasani 2014). Focus group interviews allow a deep insight and understanding into the research phenomenon and are a useful data collection method when little is already known about the area under study (Hsieh & Shannon 2005, Nagle & Williams 2013). Focus group interviews are often used to add context to the findings of survey questionnaires and to allow deeper understandings of the data to be developed (Creswell & Hirose 2019).

The use of a focus group interview allowed the interesting points that arose from the survey questionnaire analysis to be explored in detail and for points that were unclear or vague to be further clarified (Tariq & Woodman 2013, Morgan & Hoffman 2018). The focus group interview provided a relatively efficient and effective method for achieving this, with the group dynamic contributing to the possibility that further and more revealing insights would be developed (Tausch & Menold 2016). Combining both methods allowed both triangulation of the overall research findings and clarification and further discussion

of the interesting and complex findings that arose from the survey study (Creswell & Hirose 2019).

Thematic analysis (TA) was used to analyse the qualitative data gathered using the survey questionnaire and the transcripts produced following the focus group interview. TA as a method for the analysis of qualitative data, was first formally outlined by Braun and Clarke in 2006 (Braun & Clarke 2006). It has been described as a foundational method in qualitative research as it is often the first approach early researchers will use, in order to develop core qualitative analysis skills (Nowell et al. 2017).

The aim of TA is to identify, analyse, organise and describe common themes within collected data. Each theme that is identified is representative of a repeated pattern that was present across the data set. In this way, each theme reflects an important aspect of the data, in relation to the specific aim of the study (Braun & Clarke 2006). TA is an inherently flexible approach and can be used in the analysis of a wide variety of qualitative data including interview transcripts, surveys, diaries, printed materials and social media entries. Furthermore, the sample size and characteristics of participants can vary and will be dictated by the specific research aims of the study (Braun & Clarke 2006).

Although the steps involved in the analysis of a data set using TA will vary slightly depending on the particular approach adopted, as a general rule, analysis involves repeated reading of the data, reducing the data into smaller chunks of meaning (known as codes) and then making connections between these codes to form overarching themes. These themes are often presented in the form of a thematic map, with this map

representing a clear summary of the main findings of the research (Maguire & Delahunt 2017).

There are a number of advantages to the use of TA as a data analysis method. Firstly, TA is widely acknowledged to be a relatively straight forward and accessible method, making it appropriate for use by researchers with limited experience. Although TA is easy to conduct, it is still effective and useful for summarising key features within a large body of data, making it a popular choice across a wide range of disciplines (Nowell et al. 2017). Secondly, TA offers a generous level of flexibility in its use and application (Creswell 2014). There are no specific guidelines or recommendations regarding sample size, participant characteristics or data sources, meaning it can be adopted and used across a variety of research studies. Furthermore, TA is not tied to any specific research ontology or epistemology and so will align with a wide range of research paradigms (Braun & Clarke 2006).

The use of TA as the data analysis method in examining the open ended questions from the SLT survey questionnaire and the interview transcript from the focus group interview with SLTs, was firstly guided by the underlying research objective i.e. to explore how SLTs respond to and consider dysphagia-related QOL in the stroke population. This research objective is largely descriptive in nature, with the desired outcome being a description of current SLT clinical practice patterns when working with this clinical group. Further and more in-depth analysis through the use of interpretation and higher level abstraction of findings is not needed. Therefore, TA adequately fulfils the research aim. Secondly, it was anticipated that the use of both the SLT survey

questionnaire and the SLT focus group interview would produce a large amount of qualitative data. Given the ability of TA to manage and summarise the important features of a large data set in a relatively straight forward way, it was an attractive option for use in this study. Finally, as previously outlined, the flexibility of the use of TA means that it can easily align with a number of research paradigms. It was therefore appropriate to use in the current study, which adopts a constructivist paradigm.

Alongside TA, *Descriptive Statistics (DS)* were used to summarise and present the quantitative data collected using the survey questionnaire. DS is a basic approach to the analysis of quantitative data. The goal of DS is to simply describe and summarise what it is that a data set shows or represents. This description, which is presented in a simple summary format, allows the reader to quickly understand and make sense of a large volume of quantitative data (Sue & Ritter 2012). The main advantage of DS is its ability to quickly and efficiently summarise large amounts of quantitative data, allowing important patterns and understandings to be developed (Scott & Mazhindu 2005). This makes DS an attractive data analysis method in the use of survey studies and questionnaires.

DS was selected as the most appropriate method for analysing the quantitative data generated through the SLT survey as it was necessary to both describe and summarise the large volume of information that was gathered. As the quantitative data in the SLT survey was primarily gathered to provide a context within which to consider the qualitative findings, a basic level of description was suitable. Further analysis, involving higher level interpretation and attempts at generalisability was not appropriate or

necessary. Furthermore, DS allowed the data that was gathered to be examined, described, and presented in a concise and accessible manner. DS also provided a relatively quick and straight forward method for achieving this.

2.4.3 Psychosocial wellbeing and quality of life clinical assessment tools

A *scoping review* was used to identify commonly used PROMs in dysphagia clinical trials following stroke. Scoping reviews aim to map existing literature in a given area towards synthesising the research evidence (Pham et al. 2014). In comparison to systematic reviews, which often ask a specific question about the effectiveness of a given intervention, scoping reviews are exploratory and tend to address a relatively broad question (Munn et al. 2018).

Scoping reviews are most commonly used when the topic under investigation has not yet been extensively examined. The results of a scoping review can indicate the types of evidence that are available in a given area and can outline the way in which research in this area has been conducted (Tricco et al. 2016). For this reason, a scoping review was appropriate for use in this study. This methodology provided a standardised and structured process to identify which PROMs are commonly used in dysphagia research following stroke.

Once these commonly used PROMs had been identified, it was necessary to evaluate the content and appropriateness of these measures for use in the stroke population with dysphagia. A *qualitative analysis of content* was used to achieve this. The content of the identified PROMs was mapped to both the International Classification

of Functioning and Disability Framework (ICF) (WHO, 2002) and the Core Outcome Measures in Effectiveness Trials (COMET) Taxonomy (Dodd et al. 2018). This content mapping process was guided by previously established coding rules which are outlined in detail in Chapter 7. Analysing the content of these tools in this way, allowed an evaluation of their suitability for use in the stroke population with dysphagia to be made.

2.5 Integration of study findings

In order to develop clear recommendations for clinical practice and future research priorities, it was necessary to integrate the findings of the individual studies that were completed as part of this thesis.

To achieve this, the triangulation protocol outlined by Farmer and colleagues in 2006 was adopted (Farmer et al. 2006). This protocol was initially designed to integrate findings from largely qualitative research studies, but has since been adapted for use in studies which adopt mixed methods (Farmer et al. 2006, O’Cathain et al. 2010). The purpose of the protocol is to generate new understandings regarding the wider area of study, beyond the individual research study findings. The use of a structured protocol to integrate the findings from the individual studies in this thesis added transparency and objectivity to the integration process.

The triangulation protocol outlined by Farmer and colleagues is comprised of six steps (Farmer et al. 2006). When completed these steps lead to the development of a convergence coding matrix. This matrix considers the main themes that have arisen from

each component of the wider research project and then searches for agreement, partial agreement, silence or dissonance across these components. An overview of this triangulation protocol is provided in Appendix 2. Further details regarding the use of the triangulation protocol in this thesis are outlined in Chapter 8.

2.6 Conceptualising ‘Quality of Life’ and ‘Wellbeing’

This thesis adopted the definition and model of QOL proposed by the WHO. In this definition, QOL is described as ‘an individual’s 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’ (WHO 1997, p.1). Although there is ongoing debate in the literature regarding the exact definition of QOL (Post 2014), the definition proposed by the WHO has been endorsed by all 191 WHO member states as the international standard to describe and measure health and health-related experiences. It is also one of the most commonly recognised and cited QOL models in healthcare research today (Bakas et al. 2012).

For the purpose of this thesis, the term QOL is freely interchanged with commonly associated terms including *well-being*, *psychosocial well-being* and *psychosocial impact*. The concept of QOL also includes any reference to the four key domains that are often included in QOL measures as outlined in Table 2.1 (Aaronson 1988). This may include reference to concepts such as participation, identity, functioning and mental health.

Finally, this thesis recognises the individual and personal nature of QOL that is described in the literature pertaining to QOL measures. This thesis therefore accepts that any inference or judgement regarding QOL that is made by a clinician or healthcare worker should be based on the subjective experiences and perspectives of the person experiencing the health condition (Slevin et al. 1988, Addington-Hall & Kalra 2001).

Table 2.1: Common QOL measurement domains, adapted from Aaronson 1988

DOMAIN	DEFINITION
Physical Health	Disease symptoms, treatment side effects, somatic sensations
Mental Health	Positive sense of well-being, psychological distress, diagnosable psychiatric disorder where relevant
Social Health	Quantitative and qualitative aspects of social interactions and contacts
Functional Health	Physical function such as self-care and mobility, physical activity level, social role functioning in relation to family and work

2.7 Use of the ICF framework

Throughout the course of completing this thesis, it became necessary to use a standardised framework when describing the impact of dysphagia on psychosocial wellbeing and QOL in the stroke population. This allowed a consistent language to be used when discussing the complex experiences of the persons living with dysphagia who participated in this research. It also contributed to the ease with which the study findings could subsequently be integrated.

The ICF was chosen to fulfil this need. The ICF was first published back in 1980 and has undergone many revisions and modifications since (WHO 2002). The ICF is a hierarchical model which is organised into two parts, with each part containing two components. Part 1 is known as ‘Functioning and Disability’ and comprises the two components ‘Body Functions and Structures’ and ‘Activities and Participation’. Part 2 is known as ‘Contextual Factors’ and incorporates the two components ‘Environmental Factors’ and ‘Personal Factors’. Each component – except for ‘Personal Factors’, which has not yet been classified – is subdivided into chapters. Each chapter is further divided into a number of sub-categories.

Although the ICF was not explicitly designed as a tool for considering psychosocial impact and QOL, the framework is based on a biopsychosocial model of disability, meaning that it recognises the interaction between biological factors (e.g. disease), psychological factors (e.g. emotional wellbeing) and social factors (e.g. access to healthcare services) in an individual’s experience of health (Engel 1977). Therefore, it is possible to map the impact of a person’s health condition on psychosocial wellbeing and QOL by considering how and where their experiences sit within the varying components and levels within the framework (WHO 2002, McDougall et al. 2011). By way of an example, Figure 2.2 demonstrates the basic structure of the ICF and how it can be used to map the experiences of a person who is living with a vocal fold palsy

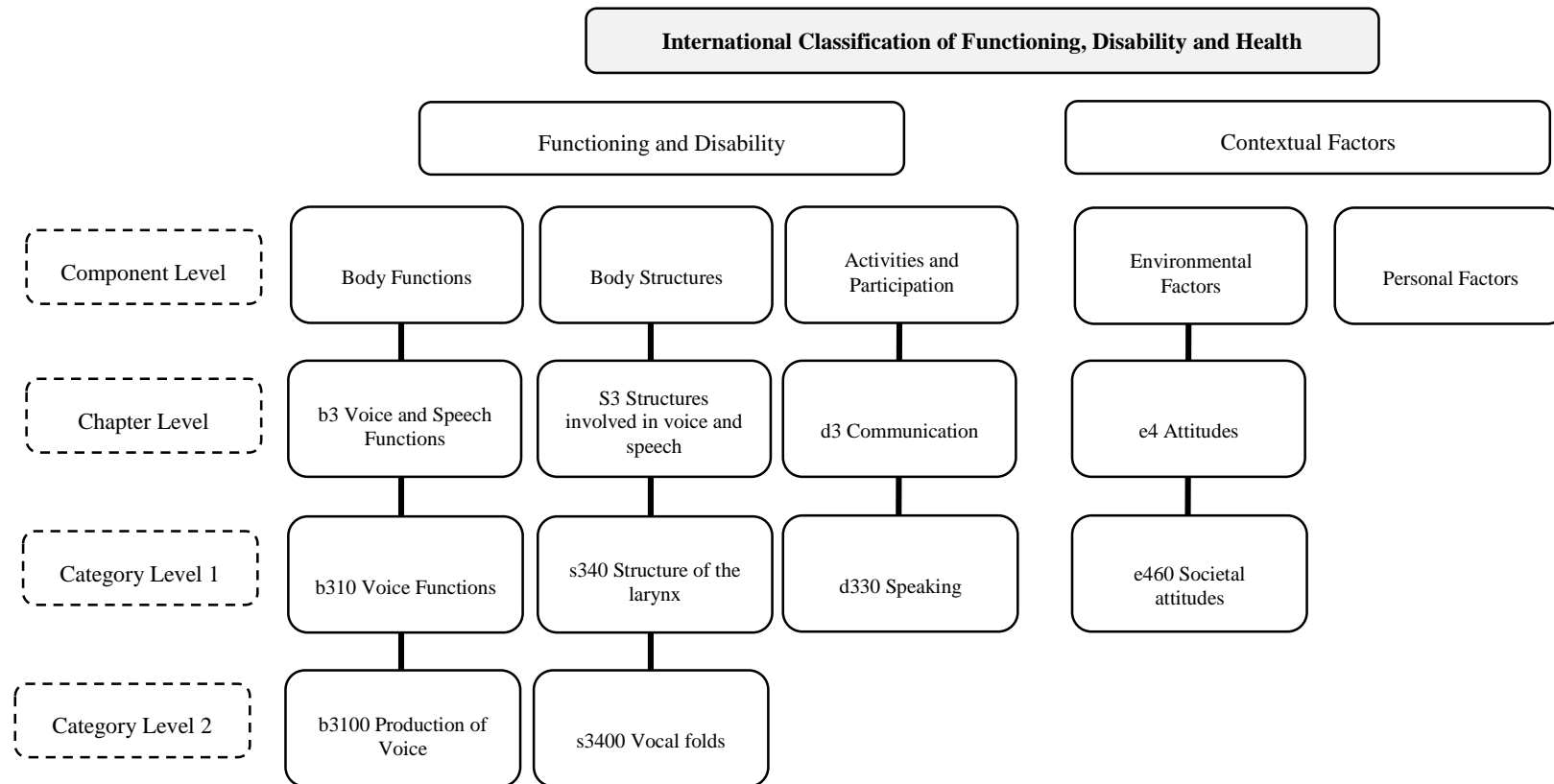


Figure 2.2: Structure of the WHO-ICF using a mapped example, adapted from ‘The International Classification of Functioning, Disability and Health (ICF)’, WHO 2013

2.8 My background, experiences and beliefs

Modern qualitative research widely accepts that the qualitative researcher should be viewed as an additional research instrument (Galdas 2017). Although steps can be taken towards minimising researcher bias, achieving a completely objective approach in the collection and analysis of the study data is often not attainable. For this reason, it is important for all qualitative researchers to clearly recognise and name any potential biases that may exist prior to the study's completion (Pannucci & Wilkins 2010). Furthermore, it is important for the researcher to be cognisant of these biases throughout the research process and to consider their potential impact at all stages (Noble & Smith 2015). In recognition of this, it is important that I describe and discuss my background, previous experiences and perceptions that are relevant to this thesis.

Before moving into management in late 2020, I worked clinically as a SLT for 11 years. Throughout my clinical career, I worked almost exclusively with persons with dysphagia following stroke, most recently as a Clinical Specialist in a large acute teaching hospital. In my career to date, I have had the opportunity to work with persons with a wide variety of dysphagia presentations. I have worked with persons with mild oral stage difficulties which have resolved relatively quickly, and persons with significant pharyngeal stage difficulties which have persisted long term, despite prolonged and intensive rehabilitation. I have always been interested in the different responses I have observed in persons with an acute onset dysphagia following stroke. I have experienced persons who have been devastated by the smallest change in their swallowing function.

Conversely, I have worked with persons facing a long-term dependence on artificial nutrition and hydration who have continued to lead a self-reported full and happy life.

As a clinician, I have always placed value on the importance of taking a truly holistic and person-centred approach with all the patients that I work with. Beyond the facilitation of effective, timely and appropriate functional rehabilitation, the absolute necessity to also support my patients in living with the significant psychosocial challenges associated with stroke disability has been a key element of my clinical practice. I feel strongly that all health professionals working in stroke have a responsibility to be cognisant of, and responsive to, the psychosocial and emotional well-being of our patients. For me, one of the crucial measures of the success of all healthcare interventions should be QOL – which is subjective and personal to each and every individual.

I believe this has been one of the pivotal influences which led me towards the exploration of this topic in my PhD research. In my clinical practice, I consistently felt that I wasn't 'doing enough' to address the psychosocial needs of the persons I was working with, who had dysphagia following stroke. When I went to the available literature in search for guidance and support, I was continually frustrated by the lack of evidence and in some cases complete lack of acknowledgement of this important aspect of the care I was providing. In conversation with colleagues and peers I found that there appeared to be little consensus regarding if, when, and how QOL in dysphagia following stroke should be addressed. I always found this puzzling when I considered the relatively clear approach to assessing and supporting QOL in those with dysphagia secondary to head and neck cancer or progressive neurological diseases. Although I recognised the

differences in the healthcare journeys and prognosis faced by these other clinical populations, I always felt there were unique challenges faced by those with dysphagia following stroke. A rapid and acute onset, a level of uncertainty regarding prognosis and potential for recovery, and the concurrent onset of a range of other disabilities, to name but a few.

Considering this, it is clear that the subject of this PhD study is one that is intrinsically woven into both my personal beliefs and clinical background. As a result of my experiences, I feel I have come to this study with a hope that I can be an advocate and a voice for the patients with whom I have worked with every day. I also hope to highlight the need for further research in, and acknowledgement and inclusion of, the significant impact of dysphagia on the psychosocial wellbeing and QOL of all the persons we work with following stroke.

Having acknowledged this bias early in the development of this research study, I hope to have been able to consider its potential impact throughout the process of data collection and analysis. With a reflexive diary, an audit trail and regular de-briefing sessions with my PhD supervisor I have continuously engaged in a process of self-reflection and self-awareness. Although it is unlikely that my role as an additional research instrument in this study has been undertaken completely free of bias, by providing this background information and detail, the full context in which the data for this study has been collected and analysed can be realised.

Dr Margaret Walshe was the primary research supervisor for this thesis. Dr Walshe is a Speech and Language Therapist and an Associate Professor in Clinical

Speech and Language Studies in Trinity College Dublin. She has a particular interest in acquired motor speech disorders, evidence based practice and neurological dysphagia, and has an extensive list of publications in these areas of interest.

Dr Julie Regan joined the research team in 2020. Dr Regan is a Speech and Language Therapist and Assistant Professor in Clinical Speech and Language Studies in Trinity College Dublin. Her research interests lie in the area of adult dysphagia, including instrumental evaluation, and rehabilitation of people with neurological and oesophageal dysphagia. She has published widely in these areas.

2.9 Conclusions

This thesis adopts a constructivist paradigm. Using a predominantly qualitative approach and a mixed methods triangulation research design, five studies were completed towards achieving the research aim and objectives. These studies incorporated a number of different data collection and analysis methods, which were chosen with consideration for the associated research objective. The findings of all five studies were integrated towards developing recommendations for both clinical practice and future research. Where appropriate, the ICF framework was used throughout this thesis to contextualise the impact of dysphagia following stroke on psychosocial wellbeing and QOL.

The methodological aspects of this thesis will have been influenced by the background, experiences and beliefs of JM as the lead researcher, having worked as a SLT in stroke care for many years. Where appropriate, steps were taken throughout the completion of this thesis to continually challenge and address the influence of these beliefs.

SECTION 2: THE IMPACT OF DYSPHAGIA ON PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE FOLLOWING STROKE

Chapter 3: The impact of dysphagia on psychosocial wellbeing and quality of life during the stroke rehabilitation journey¹

3.1 Abstract

Aim: Persons with dysphagia following stroke may experience uncomfortable symptoms such as persistent coughing, choking and poor salivary management. They may also spend long periods of time unable to eat or drink or with restrictions on oral intake. Experiences of dysphagia post-stroke are richly described in unsolicited narratives such as autobiographies on the stroke event, which often include details of the author's journey through their stroke recovery. The aim of this study is to use autobiographical accounts to explore the experiences of those living with dysphagia during the stroke rehabilitation journey.

Methods: Published autobiographies narrating the author's experiences of living with dysphagia following stroke were sourced. Ten autobiographies were retrieved and the texts were manually inspected. All references to eating, drinking and swallowing were extracted and pooled to form the data set. A qualitative approach using a six-step Interpretative Phenomenological Analysis (IPA) process was taken to analyse the data set.

¹ Adapted in Moloney J. & Walshe M. (2018). "I had no idea what a complicated business eating is...": A qualitative study of the impact of dysphagia during stroke recovery. *Disability and Rehabilitation*, 40 (13), 1524-1531. DOI: 10.1080/09638288.2017.1300948.

Findings: A wide range of interconnected themes were developed from the data, allowing further synthesis into six overarching super-ordinate themes. These super-ordinate themes were: ‘Physical consequences of dysphagia’, ‘Process of recovery’, ‘Coping and adjusting’, ‘Changed relationships’, ‘Society’, and ‘Control’.

Conclusions: This study highlights the unique contribution of autobiographical accounts in developing our understanding of living with dysphagia following stroke. The findings emphasise the significant emotional and social impact of dysphagia during the stroke recovery process and add further depth to our understanding of the experience of this clinical group.

3.2 Introduction

Difficulty with swallowing (dysphagia) is one of the most common physical consequences of having a stroke (McMicken & Muzzy 2009). It is estimated that up to 78% of stroke patients will experience some level of dysphagia in the early stages of their hospital admission (Martino et al. 2005). Some will continue to present with a chronic dysphagia that persists for a period of 6 months or longer, while others may never return to eating or drinking by mouth (Singh & Hamdy 2006).

People with acute stage dysphagia typically have longer lengths of hospital stay and are more likely to require long-term care on discharge (Smithard et al. 1996, Smithard et al. 2007, Arnold et al. 2016). People with long-term dysphagia post-stroke often live with an ongoing risk of aspiration pneumonia and malnutrition. They can experience

uncomfortable and undesirable symptoms associated with their dysphagia such as persistent coughing, choking and poor salivary management (Forster et al. 2011, Shaker & Geenen 2011) and they may be required to spend long periods of time where they are unable to eat or drink by mouth or with restrictions on their oral intake. Long-term artificial feeding through the use of nasogastric or percutaneous endoscopic gastrostomy tubes may be necessary to maintain nutrition and hydration (Alshekhlee et al. 2010, Ojo & Brooke 2016).

The potential impact of these impairments on the psychological well-being, social participation and QOL of individuals with dysphagia has gained increasing recognition from healthcare providers and policymakers, a trend which is now being reflected in the published literature (Jones et al. 2018). The ongoing research on living with dysphagia in long-term progressive neurological conditions (Ayres et al. 2016, Da Costa Franeschini & Mourão 2015) continues to highlight the intrinsic link between QOL and dysphagia. Furthermore, recent investigations into the experiences of dysphagia in the head and neck cancer population have captured the wide-ranging effects of dysphagia on social and emotional well-being (Ganzer et al. 2015), and the associated impact on families, friends and carers (Nund et al. 2014).

Although certain commonalities will likely exist across these different clinical populations, it can be argued that the experiences of those with dysphagia following stroke cannot be entirely inferred from the personal accounts of those with dysphagia as a result of other acquired conditions. Unlike progressive neurological conditions such as Parkinson's or Motor Neurone Disease, and cancers of the head and neck, dysphagia as a

result of stroke has an immediate and sudden onset, often with no warning signs or expectations. Furthermore, following the onset of their stroke, the person with dysphagia must face a long rehabilitation journey, often with an uncertain potential for recovery and must do so while also adjusting to life with the range of associated physical, cognitive and communication deficits which are common in stroke. All of these factors may contribute to experiences and findings that are specific and unique to the stroke population.

Patient experiences are recognised as central to evidence based practice as they provide vital insights which can inform both health service delivery and care (Sullivan 2003, Doyle et al. 2013). It has been recommended that ongoing research in the area of stroke rehabilitation needs to include an emphasis on exploring the experiences of stroke survivors (Luker et al. 2015). Furthermore, best practice guidelines in stroke management emphasise the importance of understanding the personal experiences of living with an impairment, not only in order to deliver high-quality services, but also to understand the coping mechanisms used and to gain insight into what self-management strategies may be important (National Institute for Health and Care Excellence 2008).

To date, research on the efficacy of interventions for dysphagia in stroke has included QOL and participant feedback as outcome measures. This information is typically sought using quantitative measures and tools such as the SWAL-QOL (McHorney et al. 2002) or the Eating Assessment Tool (EAT-10) (Belafsky et al. 2008). However, the reliability and validity of these tools has been previously questioned in the literature (Keague et al. 2015). Furthermore, quantitative measures by their very nature

are limited to capturing information on the impact of symptoms only (Keague et al. 2015) and frequently do not account for the complex psychological and social dynamic which many persons living with dysphagia may experience (Ware et al. 2016).

Valuable information on the experiences of living with dysphagia in the stroke population has been provided by researchers such as Klinke and colleagues, who explored and appraised 33 studies examining difficulties with eating following stroke (Klinke et al. 2013). These studies, which covered a timeframe of acute stroke through to 6 months post-onset, highlighted the complexity of living with difficulties with feeding, eating, drinking and swallowing as a result of stroke, particularly in the context of eating as a core activity in everyday life. Klinke and colleagues analysed structured observations and interviews, documentation reviews, patient questionnaires and ratings on relevant assessment scales. These methods, while valuable, fail to capture the personal account of living with dysphagia within the context of other impairments associated with stroke and also the experiences across the disease trajectory.

One valuable source of information on the personal experience of living with a condition can be found in published autobiographies (Norcross et al. 2011). The material within these texts is easily accessible, is not influenced by the presence of a researcher and often provides rich accounts of lived experiences (Power et al. 2012). According to Mathias and Smith, autobiographies hold the power of the “story of one’s experiences” and so offer the reader a level of insight that is both detailed and unique (Mathias & Smith 2016, p.205).

The purpose of this study is to gain insight into the personal experience of having dysphagia as a result of a stroke. These perspectives should provide valuable information on the experiences that may be unique to these individuals who have a sudden but non-progressive illness trajectory. Personal autobiographical accounts of stroke frequently reference dysphagia. The aim of this study is to examine the personal autobiographical accounts of persons who have experienced dysphagia as a result of stroke.

3.3 Methods

3.3.1 Data collection

In a novel approach to data collection, published autobiographies written by persons who have experienced dysphagia as a result of stroke were sought as the data sources for the purpose of this study. Unlike traditional methods of data collection in qualitative studies, such as the use of interviews or focus groups, autobiographical texts will allow the collection of data that has been largely unsolicited and will not have been biased by the presence of a researcher. The criteria used to search for these autobiographies were:

1. The text must describe the author's experience of having a stroke and engaging in stroke rehabilitation.
2. The author must have experienced oropharyngeal dysphagia which required a "nil per oral" status (NPO) and/or modification of either diet or fluid consistencies.

3. The text must be available in English.

The autobiographies were sourced through Internet and library database searches and communication with considered experts in the area. The autobiographies were read in full and all sections of text that made reference to feeding, eating, drinking or swallowing were extracted and inputted into a data file. These extracts were treated as interview transcripts for each individual author. The extracted sections from each autobiography were then pooled to form individual transcripts, ready for analysis.

3.3.2 Data analysis

An interpretative phenomenological approach (IPA) (Tuohy et al. 2013) was the methodology employed for data analysis. IPA is a qualitative research methodology that is concerned with seeking to understand the participants' lived experiences through description and interpretation (Mackey 2005). It involves a dynamic approach to data analysis during which researchers immerse themselves in the data through reading and re-reading the transcripts and making notes of any thoughts, reflections and understandings that are developed as a result of this interaction (Mackey 2005).

The step by step guide to IPA outlined by Smith, Flower and Larkin was adopted (Smith et al. 2009a), and the following steps were taken in the analysis of the extracted transcripts:

1. Each transcript was read and re-read. On the second reading, important words, phrases and references were highlighted and the researcher's preliminary thoughts, reflections and interpretations were noted.

2. The transcripts were read once again, and emerging codes based on the researcher's preliminary interpretations, were recorded.
3. These codes were then listed chronologically for each transcript and potential connections between them were highlighted and identified. Connected codes were grouped together, resulting in a number of preliminary themes for each transcript.
4. The preliminary themes for each transcript were then compared for similarities and differences. This comparison resulted in the development of a smaller number of refined themes. All data were accounted for. No data were deemed inappropriate or discarded from analysis.
5. These refined themes were then further clustered, leading to the development of over-arching superordinate themes, which were representative of all transcripts. Each of these superordinate themes had a number of associated subordinate themes.
6. Finally, all the extracts from each of the transcripts was recorded under the relevant themes in a large table. The themes and extracts were then reviewed and refined independently by both the lead researcher and the research supervisor. Any disagreements in coding or analysis were resolved through discussion.

An example of the data analysis process is available in Appendix 3.

3.4 Findings

Ten autobiographical texts as shown in Table 3.1, were sourced using the criteria outlined. These texts represented the stories of 7 men and 3 women, all of whom had experienced oropharyngeal dysphagia as a result of stroke.

Table 3.1: Overview of autobiographical texts

AUTHOR	YEAR	BOOK TITLE	STROKE	SEVERITY OF DYSPHAGIA
Andrew Davis	2015	Pressed but not Crushed	Brainstem	Prolonged period NPO, then modified diet and fluids
Richard Marsh	2014	Locked In	Brainstem	Prolonged period NPO, then modified diet and fluids
Allison O'Reilly	2014	Out of the Darkness	Brainstem	Prolonged period NPO, then modified diet and fluids
Peter Coghlan	2013	In the Blink of an Eye	Brainstem	Prolonged period NPO, then modified diet and fluids
Charles Firus	2013	Stroke This	Right hemisphere	Relatively quick return to normal diet and fluids
Kate Allatt	2011	Running Free	Brainstem	Prolonged period NPO, then modified diet and fluids
Margaret Cromarty	2008	Stroke: It Couldn't Happen to Me	Brainstem	Prolonged period NPO, then modified diet and fluids
Robert McCrum	1998	My Year Off	Right hemisphere	Relatively quick return to normal diet and fluids
Jean-Dominique Bauby	1997	The Diving Bell and the Butterfly	Brainstem	Remained NPO long-term
Gilbert Vaux	1994	When Lightning Strikes	Unknown	Relatively quick return to normal diet and fluids

The majority of authors (n=7) had experienced a brainstem stroke, a number of whom also experienced locked-in syndrome. All authors described their experience of

inpatient rehabilitation, during which they spent a period of time NPO and/or with recommendations of modified diet/fluids in place. All but one author (Bauby), recovered to a point where they were well enough to resume oral intake and eventually return home.

Initial analysis of these autobiographical texts using IPA, resulted in the development of 23 themes. Further clustering of these 23 themes resulted in the development of six over-arching superordinate themes. Each of these six superordinate themes had a number of associated subordinate themes (Table 3.2).

Table 3.2: Themes associated with the impact of dysphagia during the stroke rehabilitation journey

SUPERORDINATE THEMES	SUBORDINATE THEMES
Physical consequences of dysphagia	Becoming familiar with the physical consequences of dysphagia Living with the impact of the physical consequences of dysphagia
Process of recovery	What will the future hold Setting and achieving goals Dealing with setbacks
Coping and adjusting	Coping strategies Self-management techniques
Changed relationships	Relationship with food and drink Relationship with family Relationship with healthcare professionals
Society	Feeling excluded from society Concerns regarding the perceptions of others Re-integrating into society
Control	Loss of control Helplessness and reliance on others Attempting to regain control

3.4.1 Physical consequences of dysphagia

The ‘Physical consequences of dysphagia’ was as a consistent theme across all the autobiographical accounts. Two associated subordinate themes were ‘Becoming familiar with the physical consequences of dysphagia’ and ‘Living with the impact of the physical consequences of dysphagia’.

Early in their experiences, individuals describe learning about the seriousness of their dysphagia.

*“I was warned that failure to clear my throat could lead to phlegm in my lungs and possibly pneumonia. And that, for a man in my frail condition, could prove fatal”
(Marsh 2014, p. 198)*

Individual authors made reference throughout to how they explored the new limits of their physical movements.

“I was unable to find my mouth in to which to put my own food. My lips and cheeks could not function normally” (Vaux 1994, p.13)

A sense of fear was often evident with individuals describing many moments of panic and terror.

“Spittle was collecting in my throat. There wasn’t too much of it yet, but that was still more than enough to send me into a panic. I was convinced I’d soon be drowning in my own saliva again” (Marsh 2014, p. 66)

As individuals tell the stories of their stroke experience, the impact that the physical consequences of dysphagia have on day to day living is evident. The effort and concentration required to eat and drink even minimal amounts is portrayed, along with an ongoing fear of the risk of developing aspiration pneumonia.

“I have to be very focussed when eating or drinking or I can aspirate; it is exhausting and annoying” (O’Reilly 2014, Chap. 3, Sec. 6, Para. 4)

The persistence and relentlessness of the physical consequences of the swallowing disorder is apparent along with the discomfort associated with them.

“Wake up with a wet pillow. It’s always wet” (Coghlan 2013, Chap. 2, Para. 32)

“Leafy lettuce, corn, peas, etc., still make me cough. In fact, I tend to cough and sneeze every time I eat!” (O’Reilly 2014, Chap.3, Sec. 3, Para. 2)

Furthermore, many of the authors describe the psychological consequences of these physical difficulties, sensing shame and indignity during this period of stroke recovery.

“But inside I was squirming with embarrassment. I found the mess I made and the coughing and spitting that I did, very hard to take” (Cromarty 2008, p. 72)

3.4.2 Process of recovery

The theme ‘Process of recovery’ encompassed a number of subordinate themes including ‘What will the future hold’, the process of ‘Setting and achieving goals’ and inevitably ‘Dealing with setbacks’.

In the early stages of their rehabilitation, a sense of anxiety regarding what the future might hold is expressed and is often accompanied by a fear that dysphagia may get worse.

*“How could I be sure that my capacity to swallow a mouthful of spit would hang around much longer?”
(Marsh 2014, p. 38)*

There is also however, suggestions of hope and expectation about the possibility of improvement and recovery of swallowing.

“It gave me hope that one day I would be able to drink without the hoover (oral suction equipment)” (Allatt 2011, Chap. 12, Para. 5)

Alongside this hope and expectation, many individuals discuss the importance of setting goals, even those which may seem trivial or minor to others. These goals were set at different stages of the rehabilitation process.

“For me those early goals sounded small but were in fact huge: sitting up, moving my hand in order to relieve an itch, call for help and hold a pen, standing upright, breathing without a tube and drinking liquids again” (Allatt 2011, Chap. 14, Para. 5)

Individuals are often relentless in their dedication to achieving these goals and there can be a sense of impatience and a desire to expedite progress in swallowing recovery.

“If I don’t break the rules slightly, I won’t progress fast enough. Eating fish three times a week is just not enough, it just doesn’t provide sufficient practice” (Coghlan 2013, Chap. 17, Para. 18)

However, an overriding sense of joy emerges from the stories when authors relate their experiences of eventually achieving these goals.

“No words could describe that moment as I drank my first cup of tea” (Allatt 2011, Chap. 33, Para. 25)

“The entire second floor staff were so excited and happy for me when I passed the test on January 6, 2011. I had not been allowed to eat or have liquids up to then”. (O’Reilly 2014, Chap. 3, Sec. 3, Para. 3)

Unavoidably, some authors experience setbacks in their rehabilitation.

“As soon as I’d arrived disaster had struck and my Earl Grey tea was withdrawn because it was trickling into my lungs and slowly killing me” (Allatt 2011, Chap. 14, Para. 3)

These setbacks can be associated with disappointment and guilt.

“I had failed the swallow test in November, still aspirating. Everyone agrees that it was too early, but we had to try. I felt like I had let Kevin (husband) down” (O’Reilly 2014, Chap. 3, Sec. 3, Para. 3)

There are also descriptions of anger and annoyance.

“Having fought so hard to get out of hospital, imagine how pissed off I was when I ended up back in A&E just a few weeks later, thanks to a turkey curry” (Allatt 2011, Chap. 42, Para. 1)

3.4.3 Coping and adjusting

The theme of ‘Coping and adjusting’ was developed with a number of associated subordinate themes. These included the different ‘Coping strategies’ used, the development of ‘Self-management techniques’ and attempts at ‘Learning to live with dysphagia’.

For those authors who spent a period of time not eating or drinking orally, some coped through the use of imagery and imagination.

“I can watch cookery programmes like ‘Ready Steady Cook’ for hours, and take much pleasure in imagining the taste of the food, a taste that is now denied” (McCrum 1998, p. 108)

“The spoon was completely dry to avoid any unwanted moisture trickling into my lungs but sometimes I imagined it contained a mouthful of my favourite roast chicken dinner and clamped my mouth shut”. (Allatt 2011, Chap. 28, Para. 4)

Individuals also use memories of happier times and previous experiences as a way of managing difficult stages of rehabilitation when they are having little or nothing to eat or drink by mouth.

“For pleasure, I have to turn to the vivid memory of tastes and smells, an inexhaustible reservoir of sensations. Once, I was a master of recycling leftovers. Now I cultivate the art of simmering memories” (Bauby 1997, p.36)

However, this use of visual imagery is not always effective, as it occasionally serves to also remind people what they have lost.

“Rarely do I feel my condition so cruelly as when I am recalling such pleasures” (Bauby 1997, p. 17)

In the autobiographical stories there is evidence of the development and use of self-management techniques to deal with dysphagia and associated symptoms and risks. Some of these techniques are learned from healthcare staff and professionals.

“Occasionally, I feel the food going down the wrong way and I have a toothbrush on hand and tickle the back of my throat, as I was shown by the ward manger on Osborn 4 (name of ward)” (Allatt 2011, Chap. 42, Para. 2)

Other techniques come about as a result of the individual’s experimentation, as well as trial and error.

“On that holiday, I discovered I could drink wine without any thickener, provided I used a cocktail straw with a really narrow bore to give me as much control as possible” (Davis 2015, Chap. 12, Para. 8)

Through the use of these coping strategies and self-management techniques, the authors slowly learn to adjust and live with their dysphagia.

“Christmas dinner was the best of all. But after the turkey choking incident I was extra careful to tilt my head forward and eat slowly without speaking, which was quite a challenge” (Allatt 2011, Chap. 44, Para. 9)

In this way, people begin to re-establish previous roles and routines in their lives.

“When lunch was ready we all sat around the table and the rest of the family helped themselves. My dinner had been blitzed in the food processor so it looked like baby food, but boy did it taste good. It felt so good to be back at the heart of the family” (Allatt 2011. Chap. 34, Para. 8)

Some individuals even take on new roles.

*“I have even started hosting a charity coffee evening”
(Cromarty 2008, p. 115)*

3.4.4 Changed relationships

A number of different relationships are alluded to throughout the autobiographical accounts. These include ‘Relationship with food and drink’, ‘Relationship with family’ and ‘Relationship with healthcare professionals’.

Throughout the stories, a clear appreciation for the value of eating and drinking can be seen. Individuals report having previously taken food and drink for granted and now have an altered perspective on eating, drinking and swallowing.

*“I had no idea what a complicated business eating is. It is one of the many functions of daily life that we all take for granted. I was affronted that it was no longer an automatic process”
(Cromarty 2008, p. 71)*

This realisation often leads to reflection on the important role that food and drink once played in their lives.

“With horror I thought that this was the end of my leisurely breakfasts” (Cromarty 2008, p. 22)

“Gone too, the happy afternoons and evenings preparing a meal for friends and loved ones and sharing it with them” (Cromarty 2008, p. 22)

Food and drink is no longer a source of comfort or pleasure.

“Taste, and the pleasure in food, has gone” (McCrum 1998, p. 86)

Relationships with family and friends also change as a result of dysphagia. There are reports of a role reversal, with family and friends taking on a significant support role, assisting in everyday tasks and contributing to the rehabilitation process.

“The girls took their turn feeding me, and with remarkable forbearance they and Iain (husband) would give me ‘eating practice’ every day” (Cromarty 2008, p. 72)

In this example, Cromarty has become suddenly dependent, even relying on her young children to tend to basic needs. Bauby (1997) describes a similar scenario;

“Théophile (young son) dabs with a Kleenex at the thread of saliva escaping my closed lips” (Bauby 1997, p. 69)

This change in relationship leads to negative emotions and there is a sense of guilt and remorse that family and friends have to take on this role of carer and person who is assisting at meals

*“I was ashamed. This was disgusting”
(Cromarty 2008, p.72)*

“They endured chocolate spray in their faces, down their clothes, and all over their hands and arms as I spat, coughed, choked and dribbled my way through the pot” (Cromarty 2008, p. 72)

Alongside changes in relationships and roles within families and amongst friends, individuals describe their relationships with the healthcare professionals involved in their care and the impact that this has on their experience of living with dysphagia post stroke. There are accounts of disagreements between authors and health care professionals. Often these disagreements relate to expectations of rehabilitation. Marsh (2014) provides an example of his perception of a healthcare professional who he considered too optimistic.

“The woman was deluded” (Marsh 2014, p. 173)

At other times, these disagreements arise when healthcare professionals are perceived as not being optimistic enough or overly blunt.

“What he (Consultant Neurologist) said was the law and as he was always saying things that were contrary to what I wanted to hear, he could be very frustrating. He was the one who said I would never walk again, or even swallow” (Allatt 2011, Chap. 14, Para. 16)

Despite these criticisms, there is also evidence that the authors felt well supported by their healthcare professionals. They discuss the dedication of staff in ensuring that their rehabilitation goals were met.

“Thankfully, the head of the speech and language therapy service heard about these plans and insisted that we persist with soft food orally. She worked hard with me and I was weaned off all food through my nasal-gastric tube” (Davis 2015, Chap. 4, Para. 11)

As they journey through rehabilitation, some authors begin to take a more assertive role in their relationship with their healthcare professional, often through negotiating rehabilitation goals and management recommendations.

“For my last few weeks here in Shenton, I ask David (Speech and Language Therapist) if I can eat a normal diet. At first he looks dubious but finally relents” (Coghlan 2013, Chap. 20, Para. 6)

3.4.5 Society

There were societal influences and changes related to dysphagia evident in these autobiographical accounts. The theme of ‘Society’ was developed with three subordinate themes. These were experiences of ‘Feeling excluded from society’, ‘Concerns regarding the perceptions of others’ and eventual attempts at ‘Re-integrating into society’.

There are multiple examples throughout the authors’ stories, which convey an underlying sense of exclusion. It is very clearly described during social occasions or holidays, which are traditionally planned around food and drink.

*“To me, once he (husband) left in the afternoon, it was just another day. Yet again, I could not eat Christmas dinner”
(O’Reilly 2014, Chap. 3, Sec. 4, Para. 15)*

The importance of food and drink in everyday life and the exclusion from these routines was a recurrent theme in the autobiographies.

“And all over the country, activities are underway for the great domestic event of the day. I know mothers everywhere are tired of preparing it, but for me it is a legendary forgotten ritual: lunch” (Bauby 1997, p. 102)

Simple everyday salutations and greetings could serve to highlight this sense of exclusion further, as described by Bauby.

*“And every day, since by now it is noon, the same stretcher bearer wishes me a resolutely cheerful ‘Bon appétit!’ – His way of saying ‘See you tomorrow.’ And of course, to wish me a hearty appetite is about the same as saying ‘Merry Christmas’ on August 15 or ‘Good night’ in broad daylight”
(Bauby 1997, p. 35)*

Throughout their stories, individuals reference their worries about the perceptions of other people, particularly during mealtimes, and the impact that this has on them psychologically.

“One of my mealtimes, when I was undoubtedly tucking into mashed potato yet again, a patient who had had a head injury affecting his personality said that watching me eat was putting him off his food” (Davis 2015, Chap. 5, Para. 15)

This comment resulted in Davis changing his mealtime routine.

“It worried me that people thought the same but were far too polite to say so. Consequently, I ate in bed from then on, rather than in the dining room” (Davis 2015, Chap. 5, Para. 15)

Embarrassment and exclusion from social situations in order to preserve dignity was described further by Davis (2015);

“Not only would Emma (wife) have to feed me, which was undignified enough, but I would be eating with my mouth open and also, no doubt, be coughing on my food. I stuck myself in the corner and tried to concentrate on my chewing and not who was watching” (Davis 2015, Chap. 10, Para. 11)

However, as the authors’ stories progress, attempts at re-integrating into society emerge. Efforts to participate again in social occasions that involve eating and drinking are described, even if this participation is limited.

“I laughed. Not so long ago, I’d thought I’d seen my last Thanksgiving. Even if I managed only a sliver of turkey this year, I would enjoy myself like never before” (Marsh 2014, p. 218)

This feeling of re-integration is further supported by the accommodation of family and friends to the individual’s dysphagia. O’Reilly describes two occasions where this happened and her appreciation of the gesture.

“We also celebrated Kevin’s (husband) birthday with a moist chocolate cake that I shared in, savouring every delicious bite!” (O’Reilly 2014, Chap. 3, Sec. 2, Para. 69)

*“I was exhausted. My aunt made a wonderful brunch on Sunday though, which consisted of things that were soft”
(O’Reilly 2014, Chap. 5, Para. 4)*

3.4.6 Control

‘Control’ was developed as a theme throughout the authors’ stories. The relevant subordinate themes were ‘Loss of control’, ‘Helplessness and reliance on others’, and ‘Attempting to regain control.’

A feeling of loss of control is initially apparent from accounts of the early stages of recovery in descriptions of loss of control of movements associated with swallowing.

“I could feel myself gulping, funnelling the spittle that had built up in my mouth to safety. But, I was chastened to realise, it was happening on autopilot. I was not even in control of that” (Marsh 2014, p. 38)

Loss of control is experienced further when individuals have no control over meal choices.

“He (Dietician) told me there’d be no choosing my own food, as I was on a moist, minced diet” (Coghlan 2013, Chap. 9, Para. 25)

This loss of control gives rise to feelings of frustration and despair as described by Davis in this extract

“If I coughed, my food would get taken away because I wasn’t coping. One morning I was having my breakfast in my usual

slumped position when I coughed and, knowing what was coming, I burst into tears” (Davis 2015, Chap. 4, Para. 8)

Many authors describe feelings of helplessness throughout the rehabilitation journey, having no choice but to rely on others, whether family and friends or healthcare professionals, for support.

“Not only was I unable to sit up or move a finger, I could not even breathe or swallow for myself. I was completely helpless” (Allatt 2011, Chap. 1, Para. 3)

“They watched over me while I ate to see if I didn’t choke and to track what I ate” (Firus 2013, p. 19)

Helplessness and reliance on others can result in feelings of anger and frustration. This is described by Cromarty in the following extract along with her coping mechanism for this situation:

“I had to be fed, and while I was having pureed food, fed with a spoon. I had a bib around my neck. I felt like a baby. How I hated that! Yet, I played along, I laughed” (Cromarty 2008, p. 77)

As well as anger and frustration, loss of control can give rise to feelings of guilt and regret, particularly when authors reflect on the impact their reliance on others has on their family and loved ones.

“They endured it stoically, even cheerfully” (Cromarty 2008, p. 72)

At the time of discharge home from hospital, this reliance on others and loss of control, increases the anxiety that is felt.

“I’d had people to help me breathe, help me swallow. Teams of experienced professionals had monitored me, exercised me and encouraged me. Now I only had one – and that was only because I was married to her” (Marsh 2014, p. 216)

However, as they progress throughout their rehabilitation journey, the authors often make attempts to regain and take back some of the control they may have lost. As the authors make progress in their dysphagia rehabilitation, they take a more assertive role in goal setting and plans.

“Once I had succeeded with the spoon and water trials I decided that I was ready to drink tea” (Allatt 2011, Chap. 33, Para. 25)

Risk taking behaviours and non-adherence to recommendations are examples of reasserting control as described by Cromarty (2008).

“This was highly unorthodox, even dangerous, so we kept it a secret from the staff to begin with. I did not want to be stopped. Particularly when my sister started bringing me little bottles of ready mixed gin and tonic to put in my syringe” (Cromarty 2008, p. 70)

All authors, except Bauby (1997), eventually return to oral intake. In doing so, this regaining of control often results in feelings of elation and relief. This can be seen in Allatt (2011) where she describes her experience of drinking tea again.

“No words could describe that moment as I drank my first cup of tea. I was in control” (Allatt 2011, Chap. 33, Para. 26)

“I was drinking on my own and it felt good” (Allatt 2011, Chap. 33, Para. 26)

3.5 Discussion

3.5.1 Overview of findings

This study takes a fresh approach to the examination of the impact of dysphagia in the stroke population. The use of published autobiographical texts as a data source offers a unique and insightful perspective which has been generated and reported by the respective authors, without input or contribution from a researcher. The findings of this study add to the limited knowledge that currently exists on the lived experience of dysphagia following stroke. The themes that were developed from these autobiographical texts suggest that there are common experiences that can inform our understanding of what it is like to live with dysphagia, particularly in the early stages post-stroke.

These early stages of the authors’ stories are often dominated by feelings of anxiety and panic. Individuals suddenly find themselves in a situation where their basic bodily functions are no longer automatic and struggle to comprehend the enormity of what has happened. Quickly, they come to realise the seriousness of their situation and as is seen in other studies (Jacobsson et al. 2000, Carlsson et al. 2004), an overriding sense of fear and alarm is apparent. This realisation is often accompanied with further anxiety and uncertainty when they begin to contemplate the future and start to question their

potential for recovery. Similarly, Jacobsson and colleagues describe how the people with stroke whom they interviewed felt they were in an “uncontrollable situation” (Jacobsson et al. 2000, p.255), imprisoned as a result of the consequences of their stroke and unsure of their prospects for recovery. An unavoidable dependence on others seems to further reinforce this feeling of helplessness. The authors of these autobiographies have no choice but to rely on the care and support of family members and friends, even young children at times. A theme that is common to individuals following stroke in general, this reliance on others is often associated with feelings of fear, frustration and unease (Luker et al. 2015).

Eating and drinking is intrinsically linked with social engagement (Farri et al. 2007). Similar to the experiences of dysphagia across other populations (Ekberg et al. 2002), in these autobiographical accounts the authors often make reference to the social isolation they feel as a result of their dysphagia. Many of the authors describe feeling isolated and unable to fully participate in occasions involving food and drink. They are reminiscent of the important structural and societal role that food and drink used to play in their life and are distressed by its loss. However, although they wish to be included in these occasions, they are also often reluctant to eat and drink in public for fear of being judged negatively by others. They are embarrassed by the change in their mealtime rituals and the support they require from other people – a hesitancy echoed in the experiences of dysphagia in other clinical populations (Timmerman et al. 2014). This embarrassment at times leads them to withdraw from previously enjoyed social engagements and activities and their social circle can be seen to diminish. Common amongst the stroke population

in general, strains on social relationships and outlets can often contribute to poorer QOL and post-stroke depression (Northcott et al. 2016a).

As physical recovery and evidence of functional improvements in the authors' swallowing begins to appear, the process of learning to live and cope with their dysphagia can be seen. An important step in re-integrating into community and learning to live with stroke disability (Wood 2010), the authors rely on a combination of self-learned strategies and support from healthcare professionals to develop what has been previously referred to as "new normalised" way of being (Perry & McLaren 2003, p.188). The well-established importance of person-centred goal setting and collaborative planning with healthcare professionals (Rosewilliam et al. 2016) is further reinforced in the authors' descriptions of this process.

With this improvement in function, some authors begin to engage in what may be described as risky behaviours, pushing the boundaries of their physical limitations and not always fully abiding by the recommendations of the healthcare professionals involved in their care. These actions are most likely the authors' attempts at regaining some level of autonomy and independence. Many persons who have had a stroke associate increasing autonomy with functional recovery (Proot et al. 2000).

At the conclusion of their stories, the authors often describe how they have attempted to re-establish themselves, as much as possible, in their previous lives. Similar to the findings of Medin and colleagues, this may involve regaining roles in former routines, or establishing and mastering new rituals and practices (Medin et al. 2010b).

This point in the authors' stories often coincides with their discharge from inpatient rehabilitation, and their return to living within their local community.

3.5.2 Using the ICF framework as a reference

By considering the findings of this study in the context of the ICF framework, the significant and wide-ranging impact that dysphagia has on all aspects of a person's life following stroke can be seen. The themes that were developed suggest that dysphagia has an impact across three of the four major components that are considered within the ICF – namely 'Body Functions', 'Activities and Participation' and 'Environmental Factors'.

Throughout their stories, the authors discuss both the physical and emotional impact that their dysphagia has on their day-to-day lives. The symptoms associated with their dysphagia, such as coughing, drooling and poor saliva control are persistent and relentless. These symptoms, alongside an uncertain future and expectation regarding potential for recovery have a significant impact on their emotional wellbeing, with feelings of anxiety, worry and frustration cited throughout. These physical and emotional experiences, reported by the authors, are captured within the 'Body Functions' component of the ICF.

The authors also discuss how their role within their families and communities has changed due to their dysphagia. This is particularly evident in the themes of 'Society' and 'Changed relationships'. The authors describe the many steps they take in an attempt to regain some sense of control over their new found way of life and their desire to re-

establish themselves in former roles within their community. These experiences are captured within the ‘Activities and Participation’ component of the ICF.

Finally, the authors reference the impact of ‘Environmental Factors’ throughout their stories. Throughout the stroke rehabilitation journey they discuss the importance of their relationships with both family and friends and in particular the additional caring roles that these people must now take on. The importance of good family and carer support is clearly seen, with the authors reflecting on the positive impact that this support has on their overall psychosocial wellbeing. Furthermore, the authors describe their experiences of eating and drinking in public. In particular, they reference the perceived attitudes within society regarding acceptable behaviour when eating and drinking and the negative impact this has on their social identity and subsequent QOL.

3.5.3 Methodological considerations

Although the above findings expand our current knowledge of the experiences of persons with dysphagia following stroke, and particularly the complex rehabilitation journey that they face, it is recognised that there are some limitations in the use of published autobiographies as a source of data in this study. A certain level of bias exists with regard the authors themselves as they represent a subgroup of stroke patients who felt compelled and motivated enough to write an autobiographical text. Two of the authors were journalists (Bauby and McCrum) and one a nurse (Cromarty). The majority of authors were men, a high number experienced a brainstem stroke and a high number experienced locked-in syndrome. All of the scripts will have been subject to editorial review prior to publication and prepared for a general audience. Furthermore, it was not

possible to gather specific details regarding the context of the author's dysphagia i.e. level of diet modification, length of rehabilitation, which somewhat limits the transferability of the findings.

Nonetheless, the data sourced in these autobiographical texts provide a rich and in-depth account, with details of the lived experiences which were particularly important to the author. Unlike traditional data collection methods, the descriptions are largely unsolicited and will not have been influenced by the presence or direction of a researcher and there is evidence of continuity and consistency across the accounts with recurrent themes of loss of control, negative reactions of society, altered relationships and the need for continuing adjustment and coping with new experiences.

3.6 Conclusions

Little is known about the lived experience of dysphagia following stroke. In an approach to data collection that has not been used to date, this study makes use of readily accessible published autobiographies to further the current understanding of this experience. The findings of this study show that the dysphagia rehabilitation process is a complex journey, involving the interaction of many physical, emotional and social considerations. The importance of early education and reassurance, collaborative and individualised goal-setting and planning, involvement of the person's family and caregivers, and open and regular communication when working with people with dysphagia following stroke is highlighted. Increasing healthcare professionals' awareness

of these many complexities will contribute to high-quality and evidence-based care that ensures service delivery is truly person-centred.

As the literature in the area of patient experiences of dysphagia following stroke continues to grow, further research may wish to explore the experiences of individuals who are further along in their stroke journey, namely those who have been living long term in their community with dysphagia. More generally, the value of autobiographical texts as a rich, unbiased and easily accessible source of data for qualitative studies, should be recognised.

Chapter 4: The impact of long-term dysphagia on psychosocial wellbeing and quality of life following stroke

4.1 Abstract

Aim: Although many persons who experience dysphagia following stroke can expect to make a relatively good recovery, a small number will continue to live with dysphagia and dysphagia-related consequences for many years. The impact that dysphagia has on psychosocial wellbeing and QOL in this clinical group is currently under-researched. The aim of this study is to explore the lived experiences of adults with long-term dysphagia following stroke.

Methods: One-to-one interviews with three persons living with long-term dysphagia following stroke were used to collect the study data. The interviews were audio-recorded and subsequently transcribed. The resulting interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Findings: Analysis of the interview transcripts resulted in the development of four superordinate themes – ‘Coping’, ‘Identity’, ‘Hope’ and ‘Interactions with healthcare providers’. Each of these themes had a number of associated subordinate themes.

Conclusions: The findings of this study demonstrate the ongoing and significant impact of dysphagia on psychosocial wellbeing and QOL in the stroke population with dysphagia. Furthermore, the potential influence that interactions with healthcare providers, in particular SLTs, has on this experience is demonstrated.

4.2 Introduction

The findings from Chapter 3 contribute to our understanding of the impact of dysphagia during the immediate stroke rehabilitation journey. However, this study does not include persons who are living with long-term dysphagia following stroke.

As discussed in Chapter 1, one previous study has been published which has explored the experiences of this clinical group. Helldén and colleagues (2018) qualitatively analysed one-to-one interviews completed with five persons living with dysphagia for between 3 and 10 years following stroke. The findings of this study suggested that the services available to persons with long-term dysphagia following stroke might not be meeting their ongoing and individualised healthcare needs. However, with a small sample size and a relatively high number of participants who were male, additional research is required in order to build on and triangulate these research findings.

The study completed by Helldén and colleagues made use of descriptive or thematic approaches to data analysis. The resulting findings provide an explanation of what it is like to live with the phenomenon on a day-to-day basis, but do little towards developing an understanding of the impact of this phenomenon on the quality of the person's life and psychosocial wellbeing. Further research in the area should take an interpretative approach to data analysis, allowing not just a description of the participants' experiences, but also the development of an understanding of the meanings participants assign to these experiences (Spiers & Riley 2019).

The aim of this study is to explore the impact of long-term dysphagia on psychosocial wellbeing and QOL in persons living with long-term dysphagia following stroke.

4.3 Methods

Ethical approval for this study was obtained from both the Research Ethics Committee at the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and the Primary Care Research Committee of the Health Service Executive in Ireland (Appendix 4). This study was reported with consideration for the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al. 2007) (Appendix 5).

4.3.1 Data Collection

One-to-one interviews with persons living with long-term dysphagia following stroke were used to collect the data for this study. The use of one-to-one interviews with study participants is a common data collection method used within qualitative research. This method allows first-hand accounts of individual experiences to be gathered in detail (Polgar & Thomas 2008).

Participants were recruited using purposeful sampling. The following criteria were used to guide participant recruitment:

- The participant must be over 18 years of age.

- The participant must be living in the community either independently or with support from family or informal carers and/or with support from formal services.
- The participant must present with oropharyngeal dysphagia following stroke.
- In order to target those most likely to experience an impact on QOL, the participant's dysphagia must require a recommendation of ongoing use of modified diet and fluids or a full nil per oral status.
- The participant must be at least 12 months post stroke.
- The participant must be capable of participating in a one-to-one interview either independently or with formal/informal communication supports.
- The participant must be capable of providing written consent.

Recruitment advertisements were circulated through the Irish Association of Speech and Language Therapists (IASLT), through national SLT professional interest groups (e.g. the national Dysphagia group), and on social media outlets including Twitter and Facebook (Appendix 6). Community based SLTs were contacted and asked to display recruitment posters in their clinic waiting areas or to share the study information with any persons they felt may be suitable and interested in participating (Appendix 7). Recruitment advertisements were also circulated to the Irish Heart Foundation and local stroke support groups for dissemination amongst members.

Persons living with dysphagia following stroke who were interested in participating in the study, were invited to contact the lead researcher. They were advised to make contact directly, through a family member/carer, or alternatively through their

SLT or other healthcare worker. On making contact, potential participants were provided with additional study information (Appendix 8) and were given at least 7 days to consider this information before consenting to participate further.

The lead researcher facilitated the interviews. Once each participant had given verbal consent to participate in the study, they were given an aide memoire to support interview preparation and a time, date and venue to conduct the interview was suggested and agreed (Appendix 9). Written consent was obtained from all participants at the beginning of each interview (Appendix 10). An overview of the purpose of the study and format of the interview was provided and participants were informed of their right to withdraw their participation at any point without explanation or consequence. Relevant communication supports for each participant were discussed and participants were invited to have a family member or carer present to support communication if they wished to do so.

A semi-structured format was used to conduct each interview. This involved the use of a simple interview guide (Appendix 11) which prompted the interviewer throughout the data collection process. However, no pre-set questions were used. An open-ended approach to questioning was adopted with participants encouraged to share their experiences of how their swallowing difficulties have changed over time, how their difficulties impact on their QOL and what has been particularly helpful or particularly difficult throughout their journey. The use of a semi-structured format therefore offered a flexible approach. Particular topic areas could then be incorporated based on previous interview findings or the literature, but the participant was allowed to lead the

conversation throughout. This ensured that opportunities for new information, which may not have previously been thought pertinent, could still be generated (DiCicco-Bloom & Crabtree 2006).

Each interview was audio recorded using an Olympus VN-765 Digital Voice Recorder. The resulting audio-recordings were transcribed verbatim by the lead researcher immediately following the interview. All participant information was coded at the point of transcription, and each participant was assigned a pseudonym. Any identifying information provided by the participants during the interview was removed at the point of transcription. Once the interview had been fully transcribed, the audio recording was deleted. Therefore, the interview transcript was the main product of data collection.

4.3.2 Participants

Five persons living with dysphagia contacted the researcher. All five persons met the study criteria. Three participants were subsequently recruited and participated in this study (Table 4.1). All participants were male and were living with dysphagia for between 2 and 6 years following their stroke. All participants described their experience of living with long-term dysphagia following stroke.

Participant 1 (pseudonym Ben) invited his wife in and out of the interview to support communication as needed and he was described by the link SLT as having a mild cognitive impairment. Participant 2 (pseudonym Tom) participated in the interview independently. Participant 3 (pseudonym Pat) chose to have his wife present throughout

the entire interview to support his communication. The three interviews lasted a total of 183 minutes.

Table 4.1: Overview of participant interviews

	BEN	TOM	PAT
GENDER	Male	Male	Male
AGE	58	87	76
YEARS SINCE STROKE	2	2	6
STROKE LOCATION	Unknown	Brainstem	Brainstem
ORAL INTAKE AS PER FOIS*	3: Tube dependent with consistent oral intake of food or liquid	3: Tube dependent with consistent oral intake of food or liquid	1: Nothing by mouth
INTERVIEW LENGTH (MINS)	64	82	37
DYSARTHRIA SEVERITY RATING**	3: Reduction in speech intelligibility	1: No detectable speech disorder	4: Natural speech supplemented by augmentative techniques
LOCATION OF INTERVIEW	Own home	Own home	Zoom call

*Functional Oral Intake Scale, Crary et al. 2005 **Yorkston et al. 1999

4.3.3 Data Analysis

The final transcripts were analysed using IPA. The same step-by-step guide to IPA that was outlined in Chapter 4 (Smith et al. 2009a, Smith et al. 2009b) was adopted in this study. By way of a reminder, the principal steps involved in this approach are presented in Appendix 12. An example of the data analysis process completed using these steps is available in Appendix 13.

4.4 Findings

Analysis of the transcripts produced from the interview recordings resulted in the development of four superordinate themes, each with a number of associated subordinate themes (Table 4.2). Three of these themes – ‘Coping’, ‘Identity’ and ‘Hope’ – describe the impact of long-term dysphagia on the participants’ QOL. The fourth theme – ‘Interactions with healthcare providers’ – was developed as a stand-alone theme that was also noted to have an influence on the participant’s experiences of the other three themes.

Table 4.2: Themes associated with the impact of long-term dysphagia following stroke

SUPERORDINATE THEMES	SUBORDINATE THEMES
Coping	Trial and error Importance of routine Symptom management
Identity	Self-identity Social-identity
Hope	Daring to hope Hope for the future
Interactions with healthcare providers	Limitations and variations Knowing the system

4.4.1 Coping

The theme ‘Coping’ was consistently evident across all three interviews. There were three associated subcategory themes – ‘Trial and error’, ‘Importance of routine’ and ‘Symptom management’.

All three participants describe some level of ‘figuring things out as you go along’, and detail how they are still learning to live with their dysphagia and dysphagia-related symptoms. For the two participants who eat and/or drink orally, they reference a number of compensatory strategies that they have developed over time in order to achieve this.

“I can only drink, the, am, cappuccino because it’s thicker and frothier and I can put in a sugar” (Tom)

“I have to concentrate 100%. If I’m even looking at telly or talking, I can’t talk to anyone because I’d forget and next thing it goes the wrong way and I’m trying to clear it” (Tom)

“I need to chew everything into a ball and then let it go down in a small ball” (Ben)

“They’re there to help me concentrate on it going down...I take my time” (Ben)

All three participants describe experimenting with food and drink in an attempt to figure out what they may or may not be able to manage orally.

“I sometimes put a tiny drop on the back of my tongue and taste it” (Pat)

“She (wife) would bring different things from the restaurant for me to try. I remember one day she brought a piece of chocolate and I tried that and I loved chocolate. Oh god the taste, but I can’t take too much chocolate, it floats around if it’s too much chocolate. I can take it, I work it out” (Tom)

“I was able to munch the crackers...they break up you see, they become kind of liquid on your tongue” (Tom).

“We’ve tried everything, like ice-cream, but I squash it...we got KFC and blended it, and we’ll try everything” (Ben)

The participants take these certain food and drinks for pleasure even though it may not be deemed safe by their SLT. They acknowledge the risk involved in this experimentation but describe balancing this with the opportunity to eat something they previously enjoyed.

*“Yeah I like to try everything, but I don’t think that’s good”
(Ben)*

*“But I wouldn’t try anything else because I’d be afraid I couldn’t move it. Just a small drop of something for taste”
(Pat)*

Participants describe a constant balancing act, particularly with regards secretion management. Difficulty with drooling and coughing secondary to secretions are reported by all participants as being one of the most difficult symptoms to cope with.

“When I am talking I have to put on enough patches (saliva medication) to keep me reasonably dry enough. If I have too many patches I dry up and I’m too dry and if I’m too dry and then it’s uncomfortable...sometimes I get it wrong and more times I don’t and more times we do” (Pat)

“I’m still not naturally getting rid of the saliva in my mouth. I thought by all this food and teaching my throat to swallow that it would start dealing with the saliva but it doesn’t. At night time I’m coughing all the time” (Tom)

Difficulties with saliva management are described as being constant in nature, and impact significantly on day to day life.

“The saliva, that’s all, it’s always there” (Ben)

“All the time, 24 hours a day, 7 days a week” (Ben)

“I still go through a pile of tissues” (Tom)

“I have a lot of secretions in my mouth too and I’m not able to move the secretions because the tongue doesn’t move them in my mouth, so they stay there and it’s always full” (Pat)

“The secretions in the mouth are a major problem” (Pat)

In order to cope with these dysphagia symptoms on a day-to-day basis, participants make reference to the importance of a clear routine.

“I get up at 8 o’clock and then hoisted and then Pam has to go to work...then once Pam comes back I have my breakfast...then, we might go to the shop, and then come back at 1o’clock to have lunch and a cup of soup and then I might go to bed...we’re getting there aren’t we” (Ben)

“I do that every night so it reduces infections” (Pat, in reference to oral hygiene routine)

“I inject Ensure Fibre and Procal (oral nutrition drinks) and water all through the RIG. So the breakfast is all RIG. And then lunch, I now have lunch and tea without going near the RIG except to put the water in to rehydrate because I can’t take water. I have soup and after that I put a Procal into the soup, the natural one” (Tom)

Participants and their caregivers feel their daily routine limits spontaneity in day-to-day life, but also acknowledge its importance in ensuring the safe management of their dysphagia and associated symptoms.

*“Not regimented, but institutionalised, very institutionalised”
(Ben’s wife)*

*“You have to have that, otherwise things won’t go as normal
as you would like. You have to have a routine” (Pat)*

4.4.2 Identity

‘Identity’ is the second theme that was developed from the participants’ transcripts. In this context, identity can be thought of as the characteristics and attributes by which a person is known or recognised. The relevant subcategories for this theme were ‘Self-identity’ and ‘Social-identity’.

All participants reference the impact that their dysphagia has had on who they are as a person. In particular, they reference who they used to be before they had their stroke.

*“I used to eat a fry every second day...oh yeah I’d eat like a
horse...I’m a very different person now” (Ben)*

Participants reminisce throughout, discussing previous routines and rituals relevant to food and drink.

“Every Sunday we used to go out for our dinner” (Ben)

“And I loved my food. I’d eat anything” (Tom)

The participants also acknowledge the impact their dysphagia has had on the social lives of their family and caregivers.

“I couldn’t bring Lily out for a meal because we used to eat out twice a week, down to the (local restaurant) or out with friends, we’d go out a lot” (Tom)

“I miss going out in company and also with Mary, we don’t go anywhere. Mary and I used to go out but not now” (Pat)

Although participants miss being able to go out for a meal or to meet friends for a social drink, they acknowledge the significant difficulties they would now face if they attempted to do this.

“I’d like to maybe go out more...it’s hard, upsetting...it’s not worth the hassle of going out” (Ben).

“You get the impression that we shouldn’t go out...we should just be hidden away like” (Ben)

When participants do socialise with friends or family, they discuss navigating their difficulties with swallowing in this social setting.

“And I was able to eat all the dumplings. So while they were having their main course I was able to have soup and another starter” (Tom)

“We used to always have a hot whiskey. I meet this crowd in the rugby club about once a month. And they’re all nearly drivers so they can only have one drink. They’re a boring lot...so I thought what will I have? I’ll try the hot whiskey, feck it...and I was able to drink it very slowly so that was all I could take. I would leave half of it” (Tom)

“I live with it...I have no Plan B, only a plan A” (Pat)

They also reference an ongoing fear that something will go wrong and describe the impact this has on their psychosocial wellbeing.

“No say I’m sitting there and there was another person there, eating dinner and he had a...and he choked....it’s all up there with me” (pointing to head) (Ben)

4.4.3 Hope

The theme of ‘Hope’ could clearly been seen throughout the participants’ transcripts. There were two relevant subordinate themes – ‘Daring to hope’ and ‘Hope for the future’.

In discussing life with their current swallowing difficulties, participants report feeling they were given unclear information regarding recovery and progress and describe frustration that there were no clear expectations regarding prognosis and relevant timelines.

“I’d say to the professor (medical consultant) – is this going to come back? And he’d say, I don’t know, nobody knows. It could come back after a month, two months, two years, three years. I can’t say which” (Tom)

“It was just...give it time...things improve with time” (Pat)

The participants also reference discussions with healthcare workers where they felt they were given unrealistic hope for improvement.

“We’ll have you out in a week, you’ll be better in a week. You know this is what he said to me, and I knew I wasn’t going to be out in a week” (Tom)

“We were under the impression that (Rehab Centre) was a miracle place, like he’s going to go and come back like his old self again, but it didn’t happen” (Pat’s wife)

As a result, participants had hoped they would be able to return to their old lives, but then felt unprepared for the ongoing difficulties they were experiencing with their swallowing.

“Nobody actually sat down and explained...we weren’t prepared...just to be told...how long is a piece of string” (Ben)

“I don’t think it was explained to us properly” (Ben)

Two of the participants describe how they are continuing with therapy exercises despite not regularly seeing a SLT.

“The speech and language therapist used to do exercises on my neck...and I’ve been doing them for over a year” (Ben)

“Well, what I do, what exercises I have to do, to stick my tongue out and then I (unintelligible) and hopefully someday then if my speech becomes good then I may be able to swallow” (Pat)

Their motivation for continuing therapy independent of their therapist was that it was their only hope to improve their swallowing.

“But if I continue with the speech therapy it might do some good for my swallow, but if I don’t then it won’t” (Pat)

The participants also acknowledge the impact that continuing to hope for improvement has on their mental health.

“Because once you resign that you’re going to stay the same you’ll get depressed” (Tom)

4.4.4 Interactions with Healthcare Providers

Throughout their interview transcripts, participants make reference to ‘Interactions with healthcare providers’ and this was developed as the fourth theme. There were two associated subordinate themes – ‘Limitations and variations’ and ‘Knowing the system’.

Participants describe the inconsistencies in service provision that they have experienced throughout their stroke journeys.

“Everything was different – they’re completely different” (Ben, in reference to the difference between two acute hospitals)

“I’m lucky where I live – just think if a person in (other county) wanted that treatment” (Tom)

The participants feel that the limitations in what was offered with regards SLT services has a direct bearing on their progress and recovery.

“But there I had speech therapy every day (Ben)...They just left him you know...he was able to speak much better...because they didn’t keep it up...they just left him you know” (Ben’s wife, in reference to the difference between two acute hospitals)

“I should probably have been getting that from the beginning. There would have been nobody to give it to me...Imagine if I was on that from the beginning, we just don’t know what it would have done” (Tom in reference to VitalStim® Therapy)

Two participants discuss their experiences of not having access to regular and active SLT input and what they feel they are missing out on as a result.

“Sometimes it’s only a phone call – how are you doing, do you have any problems? And you can understand their situation, but before that (Name of SLT) would come once, maybe it was every 3 months, she’d come and spend an hour out there in the kitchen going through my food and what I could eat...which was great, I felt her back up” (Tom)

“She was very good to listen to even on a one to one basis...Even the social interaction driving over in our car...I was learning from her and looking at her” (Pat)

On a very practical level, one participant raised concerns regarding the lack of ongoing assessment of his swallow function.

“The only thing is that if my swallow was to improve, I have no way of measuring that...that would help to keep that option open...That is important to have, to check if there’s improvement, because I wouldn’t know” (Pat)

In comparison, one participant who was still actively engaging in SLT rehabilitation at the time of the interview, discusses the positive impact this has had.

“So she was putting the belief back into me...I needed patience and convincing....She taught me this method, hold my breath, move it around my tongue and swallow it” (Pat)

“That gave me great confidence and from then on I started trying a meal a day...I’m experimenting and that’s what (Name of SLT removed) taught me to do” (Tom)

All three participants make reference to managing what one participant called ‘The System’. At one point in the interview, Pat’s wife interjected to say:

“We got a letter to say do we still want to continue and so I signed that just so we could keep Pat in the system...just so she’s aware of us and all that” (Pat’s wife)

The participants discuss arguments and disagreements they have had with healthcare workers regarding the level of services offered and what they could potentially access for ongoing rehabilitation.

“So I queried them, I know they can’t be perfect but I queried that as well and got her attention after that...but she eventually got them to agree in the end” (Tom)

Ben’s wife, who was present during the interview added:

“So we’re doing nothing but fighting with (Name removed) to try and get it sorted” (Ben’s wife)

There was a sense that participants felt abandoned, or let down by ‘The System’ and that they needed to be able to advocate for their own needs in order to progress.

“If we discontinue though he won’t be in the system” (Pat’s wife)

“He went back to the hospital then, because we were waiting for somewhere to live, and they just left him you know” (Tom)

“I said look I’ll do it myself and after a lot of arguments they agreed...I suppose I’m lucky, I’m interested in my own case...they probably thought I was a bloody nuisance” (Tom)

4.5 Discussion

4.5.1 Overview of findings

This study makes use of one-to-one semi-structured interviews to explore the impact of long-term dysphagia on QOL following stroke. The findings of this study add to the limited knowledge that currently exists in this clinical area. The themes that were developed from these interviews can inform both our understanding of what it is like to live with long-term dysphagia following stroke, and our understanding of what healthcare workers can do to support people living with this condition.

Comparable to the findings of Helldén and colleagues in 2018, the participants in this study describe the day-to-day struggles they experience when living with long-term dysphagia following stroke (Helldén et al. 2018). With regards physical symptoms, the participants particularly report ongoing difficulties with saliva management. Relentless attempts to find the perfect balance of saliva medications are reported with little or no support from healthcare workers described. Participants acknowledge that a day-to-day routine is useful in supporting this balancing act, but also reference the significant limitation this places on their freedom and autonomy.

Similar to the autobiographical accounts in Chapter 4 (Moloney & Walshe 2018), the participants in this study discuss how they experiment with different foods and drinks, even if these foods and drinks include consistencies or textures that have been deemed unsafe by their SLT. These reports support the findings of previous studies which have showed that modified consistencies have a negative impact on QOL (Swan et al. 2015, McCurtin et al. 2018). The participants acknowledge the risk involved but are happy to accept this in exchange for the perceived benefit this ‘rule-breaking’ will have on their psychosocial well-being.

As has been shown in previous studies in both persons with dysphagia following stroke (Helldén et al. 2018) and in other clinical populations (Ekberg et al. 2002), the findings suggest long-term dysphagia has a significant impact on social participation and relationships. The participants describe difficulties in participating in previous social routines and rituals, and when they do there is an overriding sense of fear and anxiety associated with eating and drinking. Similar to the autobiographical accounts in Chapter 4, the participants with dysphagia describe how they have developed self-learned compensatory strategies in an attempt to normalise their ability to eat and drink. Again, this has been previously identified as an important step in the person with stroke reintegrating into their community and learning to live with their stroke disability (Wood 2010).

Beyond the impact of dysphagia on the participants’ social-identity, the findings of this study also demonstrate the significant impact of their ongoing swallowing difficulties on their self-identity. This is a finding that has not been reported in the limited

research that has been previously completed in this area. The participants in this study describe how the limitations their dysphagia places on their day-to-day lives has affected the routines and rituals that were core to their previous lifestyle, interests and abilities. Furthermore, the participants acknowledge the knock-on effect this has on the lives of their family and friends, who would have been intrinsically involved in these previous lifestyle activities.

Throughout all of the participant interviews, there is reference to the importance of hope for ongoing improvement. All the participants continue to engage in rehabilitation therapy, either independently or with the support of a SLT. The participants are motivated by the potential to improve their swallow function and the ability to eat and drink normally, but also acknowledge the positive impact that engaging in active rehabilitation has on their psychosocial wellbeing. The findings of Helldén (2018) were similar in that the participants in their study also hoped for ongoing improvement in swallow function. However, previous research that has explored the impact of more general eating difficulties following stroke differs (Jacobsson et al. 2000), with participants reporting a sense of hopelessness when considering the future.

Interestingly, the findings of this study suggest that the impact of dysphagia on the QOL of the participants in this study can be influenced by interactions and engagement with healthcare workers, and in particular, SLTs. All the participants describe feeling frustrated and unprepared to live with long-term swallowing difficulties after their stroke. This frustration was seen from very early in their stroke journey when the participants describe inconsistent conversations with healthcare workers regarding

their prognosis and expectations for recovery. Although research has suggested that patient expectations for recovery following stroke can be relatively high (Wottrich 2012, Groeneveld et al. 2019), there was evidence in this study that the participants felt they were given unrealistic hopes for the future. There is a sense that participants then feel betrayed when these hopes do not transpire.

There were significant variations in the long-term dysphagia services available to the participants. The participants described an acute awareness of these inconsistencies and discrepancies, and acknowledge the impact it has on both their dysphagia recovery and their ability to cope with their dysphagia on a day-to-day basis. Ongoing research has shown the potential for recovery of swallow function, not just in the first number of months, but also in the years that follow a stroke (Bogaardt et al. 2009, Layfield & Ballard 2013, Michou et al. 2014). The two participants in this study who do not have ongoing access to SLT input describe independently continuing with dysphagia therapy at home. The accuracy and appropriateness of this therapy would have to be questioned and as pointed out by one participant, even if the therapy did work he would have no way of knowing this as he needed access to an SLT service to have his swallow function assessed.

Beyond active rehabilitation, the participants reference the impact that ongoing SLT input could have on their ability to manage their dysphagia on a day-to-day basis. The importance of regular education and advice from a SLT is acknowledged and for the one participant who has access to ongoing services, he references the impact this has had on his confidence, motivation and overall psychosocial wellbeing. All three participants describe having to fight 'The System' in an attempt to access services and ongoing input

from healthcare workers. This suggests that dysphagia follow-up care for this group is inadequate and insufficient.

4.5.2 Using the ICF framework as a reference

When the findings of this study are considered in the context of the ICF, it again demonstrates the wide-ranging impact that dysphagia has on all aspects of the life of the person with long-term dysphagia following stroke. Similar to the autobiographical study exploring the experiences of persons during the stroke rehabilitation, the themes that were developed in this study suggest that dysphagia has an impact across three components within the ICF – ‘Body Functions’, ‘Activities and Participation’ and ‘Environmental Factors’.

All three participants in this study describe the ongoing day-to-day impact that the physical symptoms associated with their dysphagia has on their QOL and psychosocial wellbeing. They describe both the severity and relentless of these symptoms and the need to continually monitor and manage their difficulties. In particular, the participants describe the impact of saliva management and the difficulty they have in controlling excess drooling and dribbling. This experience of symptom management is captured within the ‘Body Functions’ component of the ICF.

Throughout their interviews, all three participants discuss the many steps they have taken towards attempting to self-manage and live with their dysphagia. They describe a process of trial and error and learning as they go along, and reference the importance of a daily routine. Although a number of these references are made in relation

to the management of their physical symptoms, the context in which these references are made is linked to the participants need to manage these symptoms so that they continue to engage in day-to-day life in so far as is possible. Therefore, this aspect of their experience is captured within the ‘Activities and Participation’ component of the ICF.

Finally, the participants in this study describe the significant impact that their dysphagia has had on their relationships with family and friends, their role within society and their perception of themselves within this society. The participants discuss their reluctance to socialise with family and friends due to perceived societal attitudes regarding their dysphagia. The participants also describe the impact that their relationships with healthcare professionals can have on their experience of dysphagia and there is reference throughout to the limitations in the services that are available to them for long-term follow up and support. Both of these influences on the experience of the person with long-term dysphagia following stroke are represented in the ‘Environmental Factors’ component of the ICF.

4.5.3 Methodological considerations

Firstly, this study is limited by the sample size and the fact that all three participants are men. At the outset it had been planned to recruit at least five participants (Smith et al. 2009b). The inclusion of female participants would also have been desirable given that their experiences have been under-represented in the research to date (Helldén et al. 2018). However, participant recruitment proved to be extremely challenging. On reflection, the reason for this may be linked to the findings of the study itself. It could be hypothesised that the recruitment of persons with long-term dysphagia following stroke

through SLT based services was always going to be problematic, given that many of these persons may no longer be accessing these services. Furthermore, the latter stages of the data collection stage were impacted by the COVID pandemic, when data collection was restricted to video calls only. This may have potentially limited participation for some persons living with dysphagia, who would have otherwise been interested in taking part in the study.

Despite the difficulties with recruitment, the sample size did represent participants with varied age profiles and varied dysphagia severity. Furthermore the participants were dispersed geographically across Ireland and so had experiences from varied healthcare services. There was a strong level of consistency across the participants' transcripts and with one participant still receiving ongoing active SLT input, it allowed comparisons to be made between his experience and the experiences of those who had been discharged from SLT services.

Persons with both communication and cognitive deficits were included. Although this strengthens the credibility of the findings, it could also be argued that interviewing participants with cognitive and communication difficulties may have limited the depth in which the topic could be explored. Participants answers may have been shorter and in some cases closed questions were necessary to support communication difficulties. Unfortunately, due to restrictions associated with the COVID pandemic, the interview with Participant 3 – Pat, had to be completed virtually. Research has suggested that there are minimal differences in the quality of interviews completed virtually compared to those completed in person (Krouwel et al. 2019). However, Pat's significant communication

difficulties coupled with the unavoidable time lags and connection issues associated with virtual calls, likely impacted the quality and depth of the information that was gathered.

Finally, two of the participants chose to have their partners participate in at least part of their interview, which had its benefits. The participants' partners could provide clarification and explanation when there was a communication breakdown. Furthermore, the partners often offered details of their own experiences in relation to the topic being discussed. However, it has to be acknowledged that the presence of an additional person in the interview process might have inhibited the participants from fully discussing or disclosing their experiences and perspectives.

4.6. Conclusions

This study provides a detailed exploration of the experiences of three persons who are living with long-term dysphagia following stroke. The findings of this study demonstrate the significant impact that dysphagia has on day-to-day life and highlights the potential impact that access to healthcare services, and in particular ongoing SLT, can have. The need for regular and ongoing access to SLT for persons with dysphagia following stroke is highlighted. Input from SLT services at this point may include education and advice for the patient and their family/carers, development and continual review of individualised swallow care plans, support in ongoing management of secretions and guidance regarding options for ongoing active rehabilitation.

THE IMPACT OF DYSPHAGIA ON QUALITY OF LIFE FOLLOWING STROKE: SUMMARY OF FINDINGS FROM SECTION 2

- In the acute stages following stroke, persons with dysphagia report feelings of panic and anxiety associated with their swallowing difficulties.
- There may be a discrepancy in the views of the person with dysphagia following stroke and their healthcare provider regarding their swallowing prognosis and realistic expectations for the future.
- There are many physical symptoms associated with dysphagia following stroke, particularly difficulties pertaining to saliva management and control.
- Many persons with dysphagia experiment with different food textures and fluid consistencies with an awareness of the associated risk – they do this in an attempt to broaden the variety of food and drink available to them, thus enhancing their QOL.
- Persons with long-term dysphagia following stroke and those living with dysphagia during the stroke rehabilitation journey, develop individual compensatory and self-management strategies, either independently or with the support of their SLT – these strategies are aimed at allowing the person with dysphagia to live as ‘normal’ a life as possible.
- Persons with dysphagia following stroke describe an awareness of negative societal attitudes towards people with swallowing difficulties and this impacts negatively on their QOL.
- Persons with long-term dysphagia following stroke may continue to hope for and expect ongoing improvement in their swallowing function.
- Persons with long-term dysphagia following stroke experience significant gaps and inconsistencies in the availability of healthcare services – this negatively impacts on their experience of living with their swallowing difficulty.
- Persons with dysphagia following stroke see many reasons for continuing to access ongoing SLT intervention, including regular re-assessment of their swallow function, education and information sharing and the development of highly individualised swallowing care plans.
- Formal and informal support from family, friends and caregivers is an important aspect to living well with dysphagia following stroke.
- The experience of dysphagia following stroke is linked to three components of the ICF model – ‘Body Functions’, ‘Activities and Participation’ and ‘Environmental Factors’.

**SECTION 3: CLINICAL PRACTICE WHEN ADDRESSING
PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE IN
DYSPHAGIA FOLLOWING STROKE**

Chapter 5: Current clinical practice patterns of speech and language therapists when addressing psychosocial wellbeing and quality of life in dysphagia following stroke²

5.1 Abstract

Aim: There is increasing recognition that dysphagia has significant implications for a person's psychological wellbeing, social participation and QOL. However, a paucity of research currently exists regarding the clinical management of this area, particularly for persons living with dysphagia following stroke. To inform future research and the development of appropriate and beneficial resources and guidelines, a better understanding of the current practice of SLTs in this area would be useful. This information will highlight current challenges to clinical practice and the ongoing development needs of the profession, which are, as of yet, undocumented.

Methods: An anonymous cross-sectional, non-experimental survey study was used. The survey consisted of 30 questions. The first 19 questions explored participants' beliefs and opinions regarding dysphagia and QOL, and current clinical practice in the area, perceived facilitators and barriers, and education, training and development needs. Participants who indicated that they work in the clinical area of stroke were invited to complete the remaining 11 questions which focused on similar areas to the first 19 but

² Adapted in Moloney J. & Walshe M. (2019). Managing and supporting quality of life issues in dysphagia: A survey of clinical practice patterns and perspectives in the UK, Ireland and South Africa. *International Journal of Language and Communication Disorders*, 54(1), 41-49. DOI: 10.1111/1460-6984.12429.

with a specific emphasis on QOL and psychosocial wellbeing in the stroke population. The quantitative data that was gathered was analysed using Descriptive Statistics (DS), while the qualitative data was analysed using Thematic Analysis (TA).

Results: A total of 223 SLTs working across 20 different countries completed the survey. 142 of these respondents also completed the stroke-specific questions. Over 90% of respondents believe that dysphagia has a negative impact on QOL, but less than 30% are currently satisfied with the amount of clinical time they can dedicate to this area. Staffing, resources, a lack of best-practice guidelines and stroke-specific QOL assessment tools were cited as contributing factors. A number of facilitators and barriers to best practice were also highlighted.

Conclusions: SLTs believe they have an important role to play in supporting psychosocial wellbeing and QOL issues in dysphagia. However, it is reported that the area is currently under-developed, under-resourced and under-supported. In tackling the challenges highlighted in this survey, SLTs may become more confident in tackling the complex QOL issues faced by people living with dysphagia following stroke.

5.2 Introduction

The World Health Organisation (WHO) defines QOL as an ‘individual’s 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’ (WHO 1997, p.1). Additionally, this definition describes QOL as 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 relationships to salient features in the environment' (WHO 1997, p.1).

Research continues to report on the significant impact of living with dysphagia on QOL and psychosocial wellbeing. For example, in persons with progressive neurological diseases, it has been shown that those with Parkinson's disease demonstrate lower swallowing-related QOL scores when compared with normal healthy controls, and that these scores worsen in line with disease progression (Pyn-Leow et al. 2010, Carneiro et al. 2013). This association between the severity of the person's dysphagia and poor QOL assessment scores is also evident in people with amyotrophic lateral sclerosis (Paris et al. 2013, Da Costa Franceschini and Mourao 2015). Within the head and neck cancer population, dysphagia is known to impact the person's social, emotional and psychological well-being, potentially resulting in anxiety, depression and low self-esteem (Nguyen et al. 2005, Nund et al. 2014, Ganzer et al. 2015).

By comparison, the impact of dysphagia in the stroke population remains comparatively under-researched (Moloney & Walshe 2018, Helldén et al. 2018). This lack of research is likely to make the assessment and management of psychosocial wellbeing and QOL in the stroke population a particularly challenging area of practice for SLTs. Furthermore, a lack of specific guidelines to inform clinical practice in this area may lead to variations and inconsistencies in the practice patterns of SLTs both nationally and internationally (Bateman et al. 2007, Archer et al. 2013). Although the importance of addressing and supporting the psychosocial needs of persons with dysphagia following

stroke has been cited in various international clinical guideline documents (e.g. Intercollegiate Stroke Working Party 2016, Scottish Intercollegiate Guidelines Network 2010, Irish Heart Foundation 2010), at present specific details regarding recommended assessment and management approaches in QOL in the stroke population remain scarce. Progress to date has been largely limited to the development and publication of a number of clinical QOL assessment tools, such as the SWAL-QOL (McHorney et al. 2002), which are aimed at quantifying the impact of dysphagia on QOL. However, these tools have not been developed specifically for the stroke population, and beyond establishing an impact on QOL and psychosocial wellbeing, they do little to guide the clinician in supporting and managing these important issues.

In order to inform future research and the development of appropriate and beneficial psychosocial and QOL resources to support clinical practice in the stroke population with dysphagia, a better understanding of the beliefs and current practice of SLTs in this area would be useful. As with similar investigations in other clinical areas (Collis & Bloch 2012, O'Reilly & Walshe 2015, Northcott et al. 2017), this information can then be used to highlight current challenges and the ongoing development needs of the profession. These are, to date, undocumented.

This study aims to gain an insight into the beliefs and current practice of SLTs when supporting psychosocial wellbeing and QOL in persons living with dysphagia following stroke.

5.3 Methods

Using a descriptive research methodology, an anonymous cross-sectional, non-experimental survey study was used. This approach matched the aim of the research, allowing the collection and analysis of opinions from a large number of people, based internationally, in a standardised way. Ethical approval for this study was obtained from the Research Ethics Committee at the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin (Appendix 14). This study was reported with consideration for the Consensus-Based Checklist for Reporting of Survey Studies (CROSS) (Sharma et al. 2021) (Appendix 15).

5.3.1 Development of the survey tool

The clinical and research experience of the research team, coupled with a curiosity about current clinical practice in this area, and a review of the limited literature on the impact of dysphagia on QOL in the stroke population (e.g. Moloney & Walshe 2018), informed the development of the questions included in the survey. Survey Monkey (www.surveymonkey.com) was used to create and disseminate the online survey. Following a pilot of the initial draft of the online survey by three SLTs who met the inclusion criteria but who did not participate beyond this pilot stage, minor adjustment and amendments to the wording and layout of the survey were made.

The final survey consisted of 30 questions (Appendix 16). The first 19 questions of the survey aimed to explore the participants' understandings of and beliefs about the definition of QOL, their perceptions of the impact of dysphagia on psychosocial

wellbeing and QOL, and their current clinical practice in this area, including relevant facilitators and barriers. Participants who indicated that they work with persons with dysphagia following stroke were invited to complete the final 11 questions. These questions explored similar areas to the first 19, but were focused particularly on the stroke population.

Both open and closed questions were used as appropriate to the information sought throughout. Closed questions required the respondent to indicate their level of agreement with a statement, to rank statements in order of priority, or to indicate their choice of response from a selection of statements. Participants were invited to add additional comments throughout the survey.

5.3.2 Participants

The target population for the survey was SLTs working globally, including the Republic of Ireland, the UK, South Africa, Australia, New Zealand, Canada, the United States, Singapore and mainland Europe. Countries were chosen based on having well-established and active SLT services and professional bodies. Both purposive and snowball sampling were used to recruit participants. The researchers disseminated the relevant survey information and associated electronic link via e-mail using contacts with professional SLT bodies, SLTs working in academic institutions and clinical SLT networks.

The inclusion criteria for the study were that the participant must be a qualified SLT working with adults with dysphagia, have sufficient proficiency in the English

language to complete the survey, and access to a computer and the internet. Participants self-selected based on the information provided by the researchers, and their completion of the survey implied their consent. The survey sought no identifying information, and any identifying information provided by respondents was removed at the time of data analysis.

5.3.3 Data collection and analysis

Data were collected over a 6-week period between March and April 2017. On closure of the survey link, all data were downloaded to a Microsoft Excel spreadsheet and prepared for analysis. Where relevant, data was anonymised and confidentiality was protected.

Analysis of closed questions was completed by the lead researcher, using DS. This allowed a basic summary of the data to be produced (Sue & Ritter 2012). Analysis of the open questions and qualitative information volunteered by the respondents in the comment boxes was analysed using TA. On closure of the survey link, all the qualitative information was collated according to the survey questions. A six step approach to TA was then adopted to complete the data analysis (Braun & Clarke 2006):

1. Familiarisation with the data: The qualitative information was read multiple times with the researcher taking initial notes regarding potential patterns and codes.
2. Generating initial codes: Codes identify an important feature within the data that is interesting or relevant to the aim of the study. On review of the

qualitative information and notes from the researcher, a list of all potential codes was generated.

3. Searching for themes: Once a list of codes was generated, they were sorted into potential themes by considering potential links and associations.
4. Reviewing themes: The resulting themes were reviewed and refined. The themes were compared to the initial codes to ensure accuracy and were also reviewed in relation to the entire data set to ensure they accurately reflected the overall meaning of the data.
5. Defining and naming themes: Once finalised, a clear definition of each theme and what it encompasses was generated, along with a name that represented its full content.
6. Producing the report: The findings were finally collated and written up.

The lead researcher completed the qualitative data analysis, and the resulting themes were reviewed and considered by the research supervisor. Any disagreements were discussed until a consensus was reached. An example of the data analysis process completed using these steps is available in Appendix 17.

5.4 Results

As shown in Figure 5.1, 223 respondents across 20 different countries responded to the survey. 154 respondents responded to all questions, giving a completion rate of

69%. The largest group of respondents were working in the UK (32.29%) (n=72), Ireland (17.49%) (n=39) and South Africa (17.04%) (n=38) respectively.

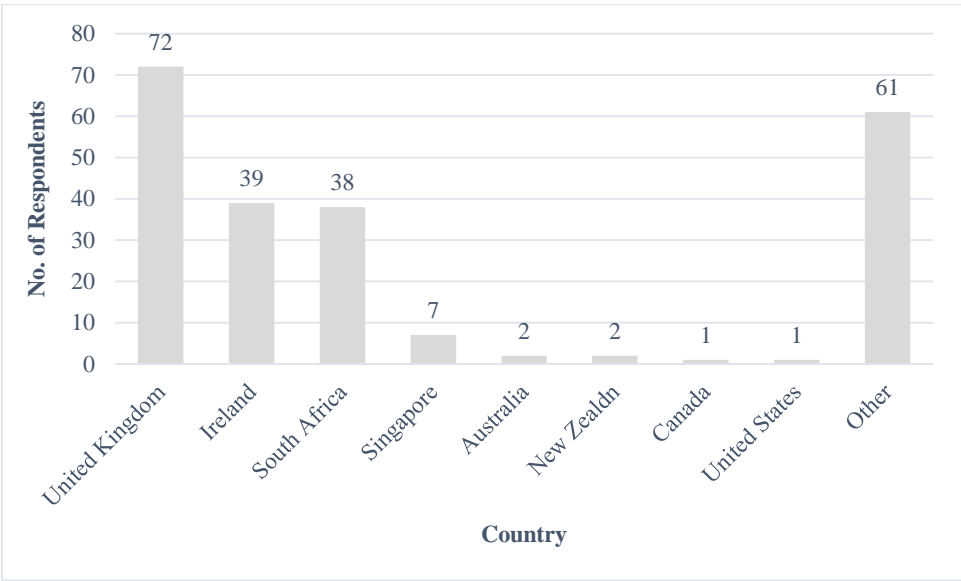


Figure 5.1: Number of respondents from each country

5.4.1 Profile of the respondents

As shown in Figure 5.2, 42.60% (n=95) of respondents worked in an acute hospital setting and 13.90% (n=31) in an inpatient rehabilitation setting. The remaining cohort reported working across a range of community-based services including outpatient clinics, residential settings and private practice. Close to 40% (n=76) of respondents reported that between 80% and 100% of their current caseload includes persons with dysphagia.

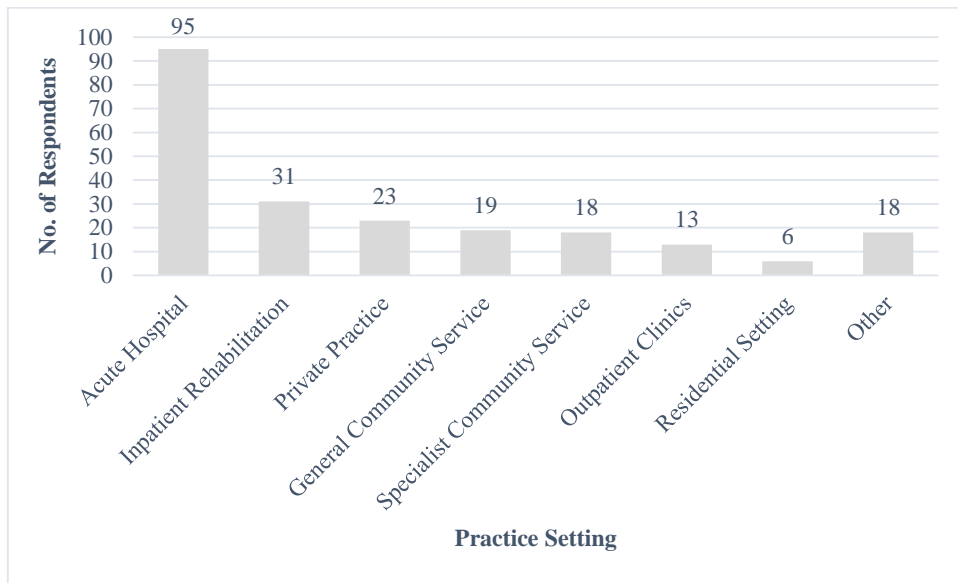


Figure 5.2: Number of respondents in each practice setting

5.4.2 Understanding and beliefs regarding quality of life

Over 80% (n=172) of respondents agreed with the WHO's current definition of QOL. Those who only somewhat agreed (16.67%) (n=35) or disagreed (1.43%) (n=3) commented that the definition overly focused on the individual and should also consider the impact of QOL on both family and society at a wider level. These respondents also believed that the definition was not accessible, with one commenting '*I think it's too wordy and complicated.*' Alternative, more user-friendly definitions were proposed including this suggestion from one respondent: '*QOL could be defined succinctly as what matters most to the person*'.

Over 90% (n=191) of respondents agreed that dysphagia has a negative influence on QOL, with dysphagia outcomes having a strong impact on the person's overall health and wellbeing. However, when asked to elaborate on this, respondents indicated that the severity of the person's dysphagia and personal factors such as their level of insight and their coping mechanisms, may determine the extent of the impact on QOL.

When asked which clinical populations were most likely to experience poor QOL as a result of dysphagia, respondents rated those living with progressive neurological conditions (40.64%) (n=76) and head and neck cancer (32.50%) (n=65) as most at risk. Only 16.93% (n=32) and 3.02% (n=6) of respondents rated persons experiencing dysphagia as a result of stroke/head injuries and dementia respectively, as most likely to experience poor QOL associated with their dysphagia.

5.4.3 Current practice patterns

Although respondents rated QOL as an important aspect of dysphagia management that should be incorporated throughout assessment and intervention, less than 30% (n=54) were satisfied with the amount of clinical time they currently dedicate to this area. One respondent reported '*It can be difficult to accommodate lengthy client and carer information sessions to help the person work through QOL issues.*' Of note, respondents believed that QOL is more suitably addressed by SLTs based in a community setting as '*In the acute healthcare most of the time the focus is still on recovery.*'

As can be seen in Figure 5.3, just under 95% of respondents (n=181) reported that they use case history details to gather information on the impact of a person's dysphagia

on their QOL, with almost 93% (n=177) also using informal observations. 33% (n=63) use rating scales and 22.51% (n=43) use specific assessment tools to support these clinical judgments. When used, the most commonly cited tools were the SWAL-QOL (McHorney et al. 2002), the MD Anderson Dysphagia Inventory (Chen et al. 2001), the EAT-10 (Belafsky et al. 2008) and the Therapy Outcome Measures for Rehabilitation Professionals (Enderby & John 2015) respectively.

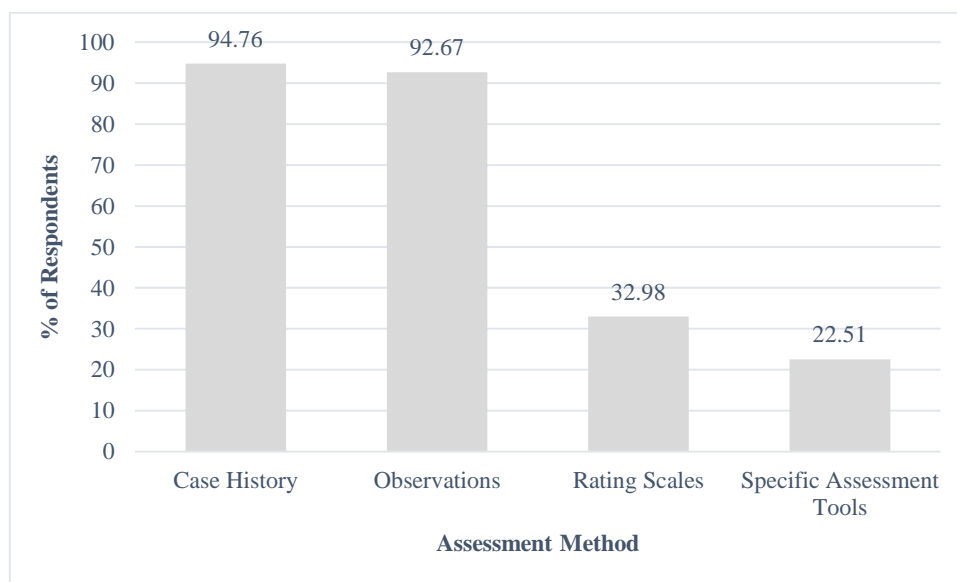


Figure 5.3: Methods currently used by respondents to gather information on quality of life

Just over 55% (n=106) of respondents reported gathering information on QOL on a routine basis. Time constraints and cognitive impairment in the person with dysphagia, were cited as common reasons for not specifically assessing QOL. One respondent commented ‘*It is supposed to be (included) but often isn’t due to time constraints.*’ Again,

respondents suggested it was an area more accurately addressed in the community setting, rather than in the acute hospital environment.

5.4.4 Education, training and development needs

Only 37.24% of respondents rated themselves as ‘extremely’ (n=8) or ‘very’ (n=62) confident in working with QOL issues in dysphagia, with a lack of professional guidelines and diagnosis-specific assessment tools reported as contributing factors to this.

Only 7.49% (n=14) of respondents reported that QOL in dysphagia was sufficiently addressed or given adequate priority in their pre-qualification training as an SLT, with one respondent reporting ‘*quality of life issues are usually left as the last session in the university course in dysphagia*’. Additional training in end of life care and palliative management was highlighted as a professional need. However, it was acknowledged that practical experience is also necessary to enhance competence.

5.4.5 Barriers and facilitators

With regards to the identified barriers and facilitators to the effective management of QOL issues in dysphagia, four key themes were developed from the respondents’ answers.

- The *Availability of Resources* was as a key factor impacting the effectiveness of SLT practice in this area. A lack of clinical time, staffing and availability of appropriate follow up services were all mentioned. Furthermore, respondents suggested that further research in the area, the publication of QOL

diagnosis-specific clinical tools and more readily available education and training courses would support the management of this clinical group. In particular, respondents suggested that *‘having rating scales that are disease specific’* and *‘validated and easy to use’* would be useful, as at present there is a *‘lack of available tools and measures’* and a *‘lack of clarity as to what to do when QOL issues arise.’*

- *The Multidisciplinary Team* was a common theme. A lack of MDT awareness of the impact of dysphagia on QOL and appropriate management approaches was reported as a common barrier. Respondents also believe that MDT colleagues can view SLTs as *‘risk averse’*. SLTs reported not always being adequately involved in decisions around QOL or anticipatory care planning as there is a *‘lack of knowledge amongst the team of the value of SLT.’* Early SLT involvement with wider recognition for the role of SLT, MDT *‘buy-in’*, alongside *‘collaborative MDT working’*, standardised management approaches, and effective communication, were all highlighted as facilitators to effectively supporting this clinical group. As one respondent stated *‘cooperation within the multidisciplinary team, effective communication via any means necessary and a supportive environment’* will support good quality care in this area.
- *The Knowledge, Skills and Training of the SLT* was the third theme developed with regards facilitators and barriers to practice. SLTs acknowledged that therapists working in this clinical area need to have the appropriate experience and ability to take a fully holistic approach and to adequately balance risk with

QOL. Empathy and clear structures for supervision and reflective practice were suggested as facilitators of this. Respondents stated that a '*person-centred approach to intervention*' is necessary, alongside '*an open mind to different people's values, priorities, concerns and choices.*' One respondent suggested that SLTs '*should have an excellent understanding of how to approach a person holistically rather than focusing on just clinical care.*'

- *Patient Factors* was the fourth theme highlighted by respondents. Cognitive impairments, behavioural and emotional changes and non-adherence with SLT recommendations were all reported as barriers to the effective management of QOL. Conversely, respondents commented that individuals with dysphagia who presented with good insight into their difficulties, motivation, '*resilience*' and adherence to SLT recommendations all facilitated the management of QOL issues. The importance of good family and social supports with '*well-trained and informed primary care-givers*' and exploring what QOL really means to the individual with dysphagia were reported as key enablers to good quality care in this area.

5.4.6 Variations in practice

Analysis for trends and variations in practice were made across all respondents and between the three countries with the highest response rates, the UK (32.29%) (n=72), Ireland (17.49%) (n=39) and South Africa (17.04%) (n=38) respectively.

Of note, respondents who trained in South Africa reported higher satisfaction with the level of training they received on their pre-qualification course regarding QOL in

dysphagia management. Almost 20% (n=8) of those who trained in South Africa felt their undergraduate training adequately addressed this area, compared to 2.56% (n=1) in Ireland and 1.47% (n=1) in the UK. However, respondents from South Africa were less likely to use formal assessment tools (11.36%) (n=5) when assessing the impact of dysphagia on QOL when compared to both the UK (25%) (n=17) and Ireland (33.33%) (n=13).

Trends and variations in practice were also seen across clinical settings. Respondents based in community settings reported spending less clinical time managing QOL issues in dysphagia than respondents based in both acute and rehabilitation settings. Less than 30% (n=29.03) of respondents based in rehabilitation settings reported using formal assessment tools or rating scales compared to 57.89% (n=55) working in acute hospitals and 52.00% (n=26) in the community.

5.4.7 Stroke-specific findings

Of the 223 respondents, 142 indicated that they currently work with persons who experience dysphagia following stroke, and so were invited to complete the final 11 questions of the survey, which focused specifically on the management of QOL issues relevant to persons with stroke. 81 respondents responded to all of these additional questions giving a completion rate of 57.04%.

As shown in Figure 5.4, the largest group of respondents for the stroke-specific questions were again working in the UK (30.99%) (n=44), Ireland (17.61%) (n=25) and South Africa (18.31) (n=26). Again, many of the respondents to this section of the survey

were based in the acute hospital setting (Figure 5.5), with just under 40% (n=54) reporting that between 80% and 100% of their current clinical caseload includes persons with dysphagia.

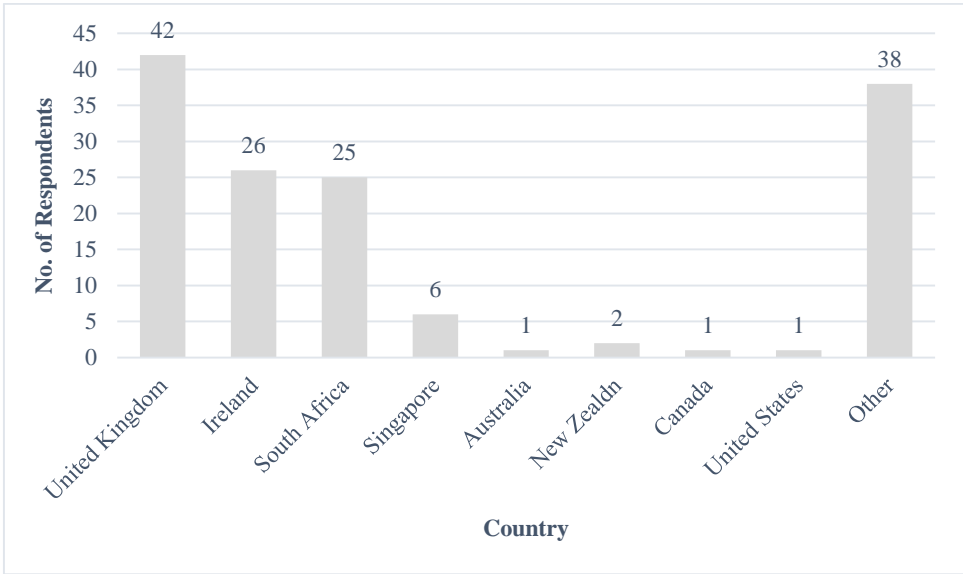


Figure 5.4: Number of respondents from each country (stroke-specific)

With regards their perceived knowledge when working with QOL issues specific to dysphagia following stroke, 42.19% (n=54) of these respondents reported they feel either extremely (n=6) or very knowledgeable (n=48) in this clinical area. 50.78% (n=65) reported they feel somewhat knowledgeable. 6.25% (n=8) reported having limited knowledge and 0.78% (n=1) reported no knowledge at all. Of the respondents who participated in this stroke-specific section of the survey, 52.8% (n=66) reported that QOL issues should be addressed throughout all stages of a person’s journey following stroke.

23.3% (n=29) felt QOL issues were most appropriately addressed during a person’s sub-acute inpatient rehabilitation stay, 10.4% (n=13) indicated the most appropriate time was when swallow function had plateaued, 8% (n=10) indicated community-based rehabilitation was most appropriate, with only 5.6% (n=7) indicating the acute stage of a person’s care.

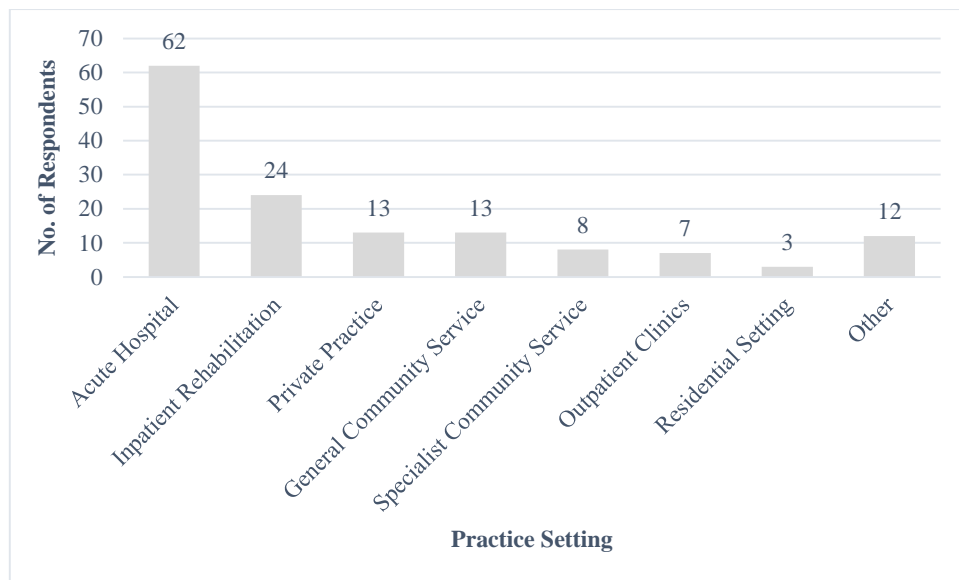


Figure 5.5: Number of respondents in each practice setting (stroke-specific)

Regarding the goals of dysphagia management in the stroke population, 75.81% (n=94) reported that safety (i.e. preventing aspiration) was the most important goal in the acute phase, followed by maintenance of adequate nutrition and hydration (11.57%, n=14), QOL (5.65%, n=7), other (5.05%, n=5) and education and training (3.33%, n=4). In comparison, when asked about the goals of long-term dysphagia management in the

stroke population, 38.02% (n=46) reported that QOL would be the most important goal. This was closely followed by safety (i.e. preventing aspiration) at 27.87% (n=34), maintenance of adequate nutrition and hydration (23.97%, n=29), other (6.25%), and education and training (5.93%).

When asked about the most appropriate time to withdraw active dysphagia rehabilitation if no ongoing progress was evident, 29.51% (n=36) of respondents indicated that 3-6 months following onset would be most appropriate. Both 6-9 months and 9-12 months were reported as the most appropriate time frame by 20.49% (n=25). 9.84% (n=12) of respondents indicated 0-3 months, 9.02% (n=11) indicated 2+years, 6.56% (n=8) indicated 12-18 months and 4.10% (n=5) indicated 18-24 months. A number of contributing factors to this decision making process were suggested by respondents including limitations imposed by specific service guidelines and/or funding authorities, the motivation and distress of the person with dysphagia and the site and severity of the initial stroke.

Once it has been agreed that further improvement in swallow function is unlikely, 41.13% (n=4) of respondents indicated that they were unlikely to keep the person open and active on their clinical caseload and 20.16% (n=25) were very unlikely. In comparison, only 9.68% (n=12) were likely and 1.61% (n=2) were extremely likely to do so. 27.42% of respondents reported that they were somewhat likely to continue offering a service to the person. Again, a number of contributing factors were suggested including specific service policies and guidelines, and the other supports available to the patient such as their general medical practitioner.

If respondents were to keep the person with dysphagia open and active on their caseload at this point, 41.03% (n=48) reported that QOL would then become the highest priority of care. Safety (i.e. preventing aspiration) was still indicated as the main priority of care for 28.32% (n=32), education and training was indicated by 19.30% (n=22), nutrition and hydration was indicated by 12.61% (n=14) and other by 4.71% (n=4).

With regards to the facilitators and barriers to effective clinical practice in this area, a number of themes were developed from the respondents' answers.

- The *Characteristics of the SLT* was as an important facilitator to clinical practice in this area. Respondents reported a need for the managing SLT to be 'experienced' and 'open to counselling (the patient) on the risks and benefits' involved. Furthermore, the SLT should have the 'confidence' to facilitate 'frank and open discussions regarding the impact of dysphagia with the patient and their family/carers' and should understand the important need to 'establish the patient's wishes' and to 'involve the patient in decision making'.
- The impact of *Service Delivery and Configuration* was also evident in the respondents' answers. 'Timely' access to relevant services was reported as an important facilitator. The 'establishment of specific community rehab teams' and access to 'good support from voluntary agencies' were also reported as positive contributions to best quality care in this area. In contrast a lack of 'long term support services' was reported as limiting the effectiveness of clinical input. Furthermore, the configuration of some services mean that the person with dysphagia has 'several different teams input into care throughout

the stroke care pathway’ affecting the consistency and quality of the care provided.

- Similar to the facilitators and barriers reported when working with psychosocial wellbeing and QOL issues more generally, the importance of *The Multidisciplinary Team* was a common theme. Again, respondents felt that awareness of the MDT members on the impact of dysphagia on QOL in persons with stroke and ‘*team recognition of the importance of these issues*’ had an important influence on the quality of care provided. A ‘*supportive environment*’ with effective ‘*joint-working*’ and ‘*good communication*’ were all cited as positive contributing factors.
- Again, similar to the facilitators and barriers reported when working with QOL issues generally, the impact of *Patient Factors* were reported by respondents when working with QOL issues following stroke. ‘*Cognitive, emotional and motivational difficulties*’ alongside ‘*fatigue*’, ‘*limited family participation*’ and not being ready to ‘*accept dysphagia*’ were all cited as barriers to effective practice. Conversely, a ‘*positive attitude*’ and an ‘*acceptance of the diagnosis*’ were reported as positive factors influencing the quality of care provided.
- Finally, the influence of *Stroke Trajectory* was developed as a relevant theme. Respondents reported that the ‘*acute onset*’ of stroke means that the significant change in the person’s life and subsequent impact on QOL is ‘*more apparent to everyone involved*’. Furthermore, respondents reported that the potential for ‘*spontaneous recovery*’ might benefit the person’s outlook on

their dysphagia and in turn their QOL as the person will likely live with '*hope that there may be improvement in their swallow function*'. It was acknowledged by respondents that dysphagia in this clinical group '*often recovers to some degree*' and therefore '*oral diet limitations are often temporary*'.

When asked about the main QOL issues that persons with long-term dysphagia following stroke will likely face, three main areas were evident in the respondents' answers.

- Respondents commented on the *Social Impact* that the person's dysphagia would likely have on their life. Respondents reported that these persons may have restricted '*participation in social events*' and may have '*difficulty eating out*'. It was recognised by respondents that these restrictions may result in a '*loss of social opportunities*', and that the person with dysphagia may '*feel isolated*' with a potential for '*relationships to change*'.
- Respondents also commented on the *Emotional Impact* that a person's dysphagia was likely to have. '*Anxiety*', '*embarrassment*', '*stress*', '*frustration*', '*burden*', '*stigma*', '*fear*' and '*grieving*' were all associated with the person's experiences of dysphagia following stroke.
- Finally, respondents recognised the potential for the person's dysphagia to have a *Physical Impact*. The additional '*care requirements*' involved in preparing food and/or looking after feeding tubes were acknowledged alongside the potential for '*regular infections and/or hospital admissions*'.

Ongoing '*coughing and choking*' were also reported as physical symptoms that may affect psychosocial wellbeing and QOL.

5.5 Discussion

5.5.1 Overview of findings

Surveys such as this one provide SLTs with an opportunity to provide feedback and suggestions on important clinical topics – in this instance, the assessment and management of QOL in dysphagia, particularly in the stroke population. The findings from this survey suggest that the SLTs who participated, believe QOL management in dysphagia merits attention and emphasis in clinical practice, but is an area that is insufficiently developed, resourced and supported. This trend was reported internationally. Furthermore, despite the time lag between surveys, the dissatisfaction with time, training, clinical resources and support tools reported by respondents in this study, is comparable to the findings of other survey studies in related areas (Collis & Bloch 2012, O'Reilly & Walshe 2015, Northcott et al. 2017).

Although the respondents believe that dysphagia has a significant impact on QOL and health-related outcomes, the majority are dissatisfied with the amount of clinical time they can spend supporting the psychological, social and emotional impact of dysphagia, with a lack of time and staffing cited as reasons for this. When respondents do allocate clinical time to addressing and supporting the impact of dysphagia on QOL, they feel a

lack of confidence to do so, with non-specific training and education at the undergraduate level and a scarcity of post-qualification courses further contributing to this.

When the respondents reported that they do address QOL, significant challenges and inconsistencies in clinical practice are reported. Although the respondents acknowledge that psychosocial wellbeing and QOL should ideally be addressed at all stages of a person's care, they feel it is most suitable to address this area in community settings, or particular to the stroke population, during sub-acute inpatient rehabilitation. Addressing QOL in sub-acute rehabilitation or community care correlates with the respondents' prioritisation of QOL as a treatment goal during the stroke journey. However, it is interesting to note that respondents based in the community setting were the group that were least likely to spend clinical time supporting QOL issues. Furthermore, respondents in rehabilitation settings were less likely to use formal QOL assessment tools to guide their approach.

In the acute stages following stroke, respondents feel there should be an emphasis on both safety and maintenance of nutrition and hydration. In the longer-term management of dysphagia, priorities change and QOL becomes more of a focus. However, with over 60% of respondents reporting that they are unlikely to keep the person with dysphagia open and active on their caseload if they have no on-going rehabilitation needs, the availability of long-term dysphagia services is questionable. Of note, education and training was not prioritised as a goal for intervention at any point in the stroke journey.

When respondents do address QOL they report a difficult assessment process due to a scarcity of clinical guidelines and disease-specific clinical tools to support their decision-making and approach to intervention in this area. Furthermore, the resources that SLTs report they are currently using in assessment, such as the Therapy Outcome Measures for Rehabilitation Therapists (Enderby & John 2015), are tools that were not originally designed or intended as specific QOL tools, but rather as general outcome measures. Therefore, they are unlikely to be comprehensive enough to fully explore the extensive and broad-ranging impact of dysphagia. This lack of a full and detailed assessment will likely have an impact on subsequent goal setting and intervention planning, while also limiting the respondents' ability to track change over time.

The respondents believe SLTs are not always involved in team discussions and decisions pertinent to QOL in dysphagia management, with limited awareness amongst MDT members on the role of SLT and the valuable contribution the profession can potentially make. A number of respondents suggested that this may be due, in part, to MDT members viewing SLT as a profession that focuses primarily on risk management. However, the significance of a holistic, person-centred approach to management in this clinical area is clearly stated, with respondents emphasising the importance of ensuring an appropriate balance between both QOL and risk management in dysphagia.

The impact of MDT working was also referenced when the respondents discussed service delivery structures and limitations. The respondents felt that stroke care pathways are not always optimised, particularly for those with longer-term dysphagia. The variations in service structures reported by the respondents may explain the

inconsistencies seen in the respondents' decision-making regarding if and when to withdraw active stroke rehabilitation. The respondents suggest that the decision to withdraw active rehabilitation is influenced by patient factors such as motivation and cognition. Interestingly, patient factors such as cognitive impairment, engagement and outlook were also cited as barriers to supporting QOL in this clinical group.

Finally, the respondents describe inherent challenges in forecasting the post-stroke trajectory and prognostication in this clinical group. There is a suggestion that most patients return to some level of oral intake and so psychosocial wellbeing and QOL may only be temporarily affected. This may go some way towards explaining why QOL is not prioritised by the respondents in the early stages following stroke. It may also go some way towards explaining why the respondents feel persons with stroke are less likely to experience poor QOL when compared to those with progressive neurological diseases or head and neck cancer.

5.5.2 Methodological considerations

This study has a number of limitations. Firstly, although the respondents represented SLTs working in a variety of clinical settings and with varying levels of experience, a larger sample size would have been desirable, particularly for those countries where which were represented by only a small number of respondents. The use of snowball sampling makes it impossible to know how many SLTs the survey reached. Furthermore, an accurate response rate could not be calculated.

A larger number of SLTs may have responded if the survey was shorter or if there were less open-ended questions. Of the SLTs who did respond, there is the possibility that they are a subsection of the profession who feel very strongly about this clinical area. This may have biased the findings of the survey.

Despite the limitations, the findings offer a useful overview and cross-section of the current practices patterns of SLTs when working with the impact of dysphagia on psychosocial wellbeing and QOL, particularly in the stroke population. The findings of this study also suggest there are a number of challenges faced by the profession when working in this clinical area. A better understanding of these challenges will allow specific development areas and priorities for the profession to be highlighted.

5.6 Conclusions

This study shows that the SLTs who responded perceive psychosocial wellbeing and QOL to be an area that should be given priority for assessment and management in clinical practice. However, they feel unsupported to do so with variations in practice and approaches to care reported.

The respondents report that the stroke population pose a unique challenge given the uncertainty regarding prognosis, if and when to withdraw active rehabilitation, and limitations in service delivery structures. Furthermore, the respondents reference a number of significant barriers to effective clinical practice in this area including dissatisfaction with time, training, clinical resources, and clinical support tools. Further

and more detailed exploration of these challenges will allow a more thorough understanding of the key issues raised by the respondents in this study to be developed.

Chapter 6: Challenges in assessing and supporting quality of life in dysphagia following stroke

6.1 Abstract

Aim: The findings of the international survey study reported in Chapter 5 highlighted a number of specific barriers to the effective practice of SLTs when considering psychosocial wellbeing and QOL in the stroke population with dysphagia. The aim of this study was to further explore the specific challenges faced by SLTs when working in this area, towards optimising the quality of care provided to this clinical population.

Methods: A focus group comprised of SLTs working internationally in the area of dysphagia care following stroke was used to collect the relevant data. Data collection was guided by a short focus group protocol which was developed with consideration for the findings from the international survey study reported in Chapter 5. The collected data was analysed using Thematic Analysis (TA).

Findings: Eleven SLTs working across five different countries participated in the focus group. These SLTs report that difficulties in supporting psychosocial wellbeing and QOL in dysphagia following stroke begin at the point of assessment and continue through the process of goal-setting and intervention planning. These difficulties are compounded by a lack of clarity regarding the true meaning of QOL and the priority that this aspect of care should be given, particularly in the early stages following stroke. Furthermore, the SLT respondents report that the complexity in supporting psychosocial wellbeing and

QOL in dysphagia following stroke, becomes more apparent when they compare their practice in this area to their practice in other clinical populations such as those with progressive neurological conditions or head and neck cancer.

Conclusions: SLTs face unique challenges when addressing and supporting psychosocial wellbeing and QOL in the stroke population with dysphagia. These challenges contribute to inconsistencies and variations in clinical practice patterns and impact the quality of care that is offered to this vulnerable clinical group.

6.2 Introduction

With current international guideline documents failing to provide direction on how best to manage and support the psychosocial needs of persons with dysphagia following stroke, variations and inconsistencies in practice patterns of SLTs both nationally and internationally are likely to exist (Bateman et al. 2007, Archer et al. 2013, Moloney & Walshe 2019). The findings of the survey study reported in Chapter 5 support this hypothesis.

It is therefore imperative that we develop both our understanding of the impact of dysphagia on psychosocial wellbeing and QOL in the stroke population, and our understanding of how the SLT profession may be able to support the needs of this vulnerable clinical group. This information can then be used as an impetus for further development of the SLT profession in this clinical area.

This study aims to explore the specific facilitators and barriers to effective assessment and management of psychosocial wellbeing and QOL in dysphagia following stroke. In conjunction with a growing body of literature on the experiences of those persons living with dysphagia following stroke (Moloney & Walshe 2018, Helldén et al. 2018), the findings will contribute to the development of best practice guidelines in the assessment and management of dysphagia in the stroke population.

6.3 Methods

This study made use of an international focus group interview to further explore the findings from the SLT survey questionnaire reported in Chapter 5, with a specific emphasis on the current barriers to SLT practice in this area. Although the findings of the survey provided valuable information towards exploring the current clinical practices and behaviours of SLTs when addressing the impact of dysphagia on psychosocial wellbeing and QOL following stroke, it was necessary to gain more detailed and in-depth information regarding the specific challenges that arise in clinical practice. For this reason, a focus group interview was chosen.

Ethical approval for this study was obtained from the Research Ethics Committee at the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin (Appendix 18). This study was reported with consideration for the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al. 2007) (Appendix 5).

6.3.1 Participant recruitment

Purposeful sampling was used to facilitate the international component of this study. Participants were recruited in conjunction with the 8th Annual Congress of the European Society of Swallowing Disorders (ESSD) which was held in Dublin in September 2018. ESSD is an international association comprised of persons working and doing research in the area of dysphagia.

Recruitment advertisements were shared through the social media outlets associated with ESSD and circulated through international SLT professional bodies and dysphagia specialist interest groups (Appendix 19). SLTs with an interest in participating were instructed to contact the lead researcher using a generic email address associated with the study. The following criteria were used to guide participant recruitment:

- The participant must be a professionally qualified SLT, working with adults with dysphagia following stroke.
- The participant must have adequate proficiency in the English language to participate in the focus group interview.
- The participant must be available to participate in the study in Dublin, between the 25th and the 29th September 2018.

On contacting the email address, the interested SLTs were provided with a detailed participant information leaflet (Appendix 20) and given a closing date to indicate their interest in participating in the study. Once all participants were confirmed, a mutually convenient time, date and location was organised via email.

6.3.2 Data collection

The focus group interview was guided by a short focus group protocol (Appendix 21). The development of this protocol was informed by the findings of the international survey, with a particular focus on what the participants felt were the main challenges to clinical practice in this area, and what would be the most useful clinical resources in supporting their ongoing clinical practice when supporting QOL management in persons with dysphagia following stroke.

The lead researcher facilitated the focus group, guided by the focus group protocol. A brief overview of the purpose of the focus group was given, written consent from each participant was sought and all participants were given time and space to ask any relevant questions. Throughout the focus group, the lead researcher posed relevant questions to the group, invited contributions from all participants, summarised and clarified the information put forward by participants and ensured that all relevant topic areas were discussed.

The research supervisor acted as a note-keeper, making written notes of important information presented by the participants and any other relevant observations. As the focus group came to an end, the research supervisor was given the opportunity to ask any additional relevant questions that may not have already been addressed.

The focus group was facilitated in a private conference room in the Aviva Stadium, Dublin, with all participants and the research team seated around a large conference table. With appropriate consent (Appendix 22), the focus group was audio-

recorded using two Olympus VN-765 Digital Voice Recorders. The resulting audio-recording was manually transcribed immediately following the interview by the lead researcher. Any identifying information provided by the participants was removed at the time of the transcription. Once fully transcribed, the audio recording was deleted. Therefore, the interview transcript was the main product of data collection.

6.3.3 Data analysis

Analysis of the focus group transcript was completed using TA, and was guided by the framework and steps for TA outlined by Braun and Clarke in 2006 (Braun & Clarke 2006). An introduction and overview of TA was presented in Chapter 7 and so to avoid duplication, it will not be repeated here. By way of a reminder, the principal steps involved in TA are presented in Appendix 23. An example of the data analysis process completed using these steps is available in Appendix 24.

6.4 Findings

As shown in Table 6.1, eleven SLTs working across five countries participated in the focus group interview. Of these participants, three reported that they were working in an acute setting, five in stroke rehabilitation, one in a community-based service and two in private practice. Participants reported that they had been working in the area of dysphagia following stroke for between 1 and 21 years, with the mean number of years of experience being 8 and the median being 7.

Table 6.1: Overview of focus group participant characteristics

	COUNTRY OF GRADUATION	COUNTRY OF WORK	PRACTICE SETTING	YEARS OF EXPERIENCE	YEARS OF DYSPHAGIA EXPERIENCE
1	New Zealand	New Zealand	Rehabilitation	11	11
2	Singapore	New Zealand	Rehabilitation	10	10
3	Ireland	New Zealand	Acute	6	6
4	Switzerland	New Zealand	Rehabilitation	7	7
5	England	New Zealand	Rehabilitation	8	7
6	Greece	Greece	Private Practice	1	1
7	Ireland	Singapore	Acute	6	5
8	Ireland	Ireland	Community	4	3
9	New Zealand	New Zealand	Rehabilitation	15	15
10	Germany	Germany	Acute	22	21
11	Ireland	Ireland	Private Practice	2	1

Initial analysis of the interview transcript resulted in the development of 21 themes. Further clustering of these 21 themes resulted in the development of seven overarching superordinate themes. Each of these seven superordinate themes had a number of associated subordinate themes (Table 6.2).

6.4.1 Professional roles in supporting quality of life

‘Professional roles in supporting quality of life’ was developed as a clear theme in the analysis of the interview transcript. Two associated subthemes were ‘The role of the speech and language therapist’ and ‘The speech and language therapist working relationship with psychology’.

It was unanimously accepted by all participants that the assessment and management of QOL in dysphagia following stroke is an important part of the role of the SLT.

Table 6.2: Themes associated with challenges in supporting psychosocial wellbeing and quality of life in dysphagia following stroke

SUPERORDINATE THEMES	SUBORDINATE THEMES
Professional roles in supporting quality of life	The role of the speech and language therapist The speech and language therapist working relationship with psychology
Quality of life as a priority in stroke care	Quality of life in acute versus the community setting Quality of life and competing demands Quality of life in stroke versus other populations
What is quality of life?	The definition of quality of life The changing nature of quality of life
Assessing quality of life	Use of standardised assessments Using informal clinical skills
The process of goal-setting	Patient participation in goal-setting Differing perspectives regarding management goals
Withdrawing active rehabilitation	Stopping active treatment: when and why? Active treatment has stopped, what next?
Importance of education	The impact of education on quality of life Factors impacting education

“I do see it as my responsibility because it involves a lot of understanding about swallowing.” (Participant 10)

However, the participants acknowledged that the role of the SLT will change throughout the stroke journey. In the acute stages following a person’s stroke, the participants felt that although QOL should be an important aspect of the care they provide, they also need to consider their other responsibilities.

In the acute setting, participants reported it was more difficult to focus on psychosocial wellbeing and QOL due to a need to also focus on preventing aspiration and maintaining nutrition and hydration.

“I wouldn’t guide my decisions so strongly by what the patient’s wishes are, because there’s just so many things that have to be considered.” (Participant 10)

“It does change a lot for us in the acute, like you’re saying, when you just want to keep them safe.” (Participant 9)

In comparison, when working in the community setting, the participants felt that they were much more likely to address QOL.

“Coming from community and the primary care side....quality of life is always considered.” (Participant 8)

“We’ve got a different role of problem solving to fit in with them which is what it should be anyway, being patient-centred.” (Participant 5)

Participants made a number of suggestions regarding what the management of QOL in persons with dysphagia following stroke should encompass or include. For some participants it involved referring the person with dysphagia to appropriate support groups.

“You’re not following your duty of care if you don’t at least point them in the right direction of someone who might be important.” (Participant 11)

“Or even local stroke groups they could link in with.” (Participant 11)

Other participants described a more active approach to supporting psychosocial wellbeing and QOL, involving exploration of specific barriers in the person’s life and the development of management plans to overcome these barriers.

“Well if you look at what the barriers are (...) is it that they’re embarrassed (...) or when they do go out what are the things that are preventing them from socialising?” (Participant 9)

“Practical things – where to go, what to do, things like that. It’s great for people when they’re out and about, if they feel isolated.” (Participant 11)

“That way they know life goes on and doesn’t stop and they can still do lots of things and participate and you know that might be restricted in ways but you can still have a full life.” (Participant 11)

However, participants acknowledged that their ability to fully explore and support QOL in this way was dependent on local service delivery models and the availability of resources.

“Have you the capacity to act in that manner?” (Participant 4)

“I think it depends on the resources available to you.” (Participant 11)

“I really need to have time to talk to the patient and understand what his particular needs are.” (Participant 10)

In discussing the role of SLT in supporting QOL in dysphagia following stroke, the participants discussed the benefit of working closely with psychology services and the benefit of a strong working relationship between the two professions.

“I think that combination of really teaming up with a psychologist is a perfect one.” (Participant 10)

“If you’re educating him on dysphagia isn’t enough and it really is about how’s my future going to be and there are real fears and anxieties, I would be very very glad if I could team up with a psychologist.” (Participant 10)

“We had quite a close relationship...they really valued the speech therapist.” (Participant 5)

However, the participants also discussed the significant inconsistencies regarding access to psychology, particularly psychologists who have experience in working with persons following stroke.

“Our community stroke team had a psychologist one day a week, which is pretty rare.” (Participant 5)

“Psychology services are often poorly resourced or it can be difficult to find one that specialises in stroke.” (Participant 9)

The participants recognised that where they could provide expertise in dysphagia, swallowing, and the associated changes, the psychologist could contribute specialist skills in supporting the person with dysphagia to come to terms with their new difficulty. Furthermore, the participants acknowledged the lack of specific training in counselling as part of their professional degree.

“My education is purely about how we can adapt the environment and how can I help education and how can I bring in the family.” (Participant 10)

“She (psychologist) would be helping them cope with their changes, whether that was dysphagia or other changes.” (Participant 1)

“It really lacked a course in counselling in my Master’s degree, I would have loved that.” (Participant 1)

6.4.2 Quality of life as a priority in stroke care

Throughout the focus group interview, participants considered the importance of ‘Quality of life as a priority in stroke care’. Within this theme, three subthemes were developed; ‘Quality of life in the acute versus the community setting’, ‘Quality of life and competing demands’ and ‘Quality of life in stroke versus other populations’.

Early on in the focus group it was clear from participants that they felt QOL should be prioritised differently, depending on the point in which the person with dysphagia was at in their stroke rehabilitation journey. Within the acute setting, participants advocated for the importance of functional rehabilitation above all else, meaning that QOL is not often considered.

“Rehabilitation is so important and swallow rehabilitation is so important, that it’s (quality of life) not a thing that we often address.” (Participant 2)

“Quality of life is not something that you think about when you’re managing patients acutely, there’s just so many things to settle.” (Participant 2)

“It’s underneath all the other topics.” (Participant 10)

Participants felt that psychosocial wellbeing and QOL was also not likely to be a priority for patients during the acute stage of their stroke journey.

“People are usually so shocked with everything that is happening and their whole world has changed, whether they also have a swallowing difficulty or not, is not a major question.” (Participant 10)

Furthermore, participants reported feeling that even if a patient reported that QOL was a priority in the acute stage, that they would not necessarily take these wishes into consideration when planning their approach to management.

“There’s just so many things that have to be considered that if I follow my patient’s wishes, I’m really brining him into a huge risk.” (Participant 9)

“I would try to convince them to be a lot more aggressive as compared to someone who’s two or three years post onset where the future is a bit different than with my patient that’s just a couple of hours post onset.” (Participant 10)

It was generally perceived by the participants that QOL becomes more of a priority for patients when they return home and therefore is more appropriately addressed by community SLT services.

“I think it’s only when they get back into their normal routine, you know their normal social routine, that they really feel the consequences of having dysphagia.” (Participant 11)

“When you get home the priorities kind of shift.” (Participant 11)

“Coming from the community and the primary care side, I’m definitely coming at it from a very different angle and really quality of life is always considered.” (Participant 8)

Furthermore, participants described how they felt QOL in dysphagia is more of a priority in persons with a progressive neurological condition or head and neck cancer when compared to those with dysphagia following stroke.

“I would think that stroke is like a separate group in that respect.” (Participant 5)

“I think if you see quality of life as just adhering to your patient’s goals then I think it just applies across the board. But I think with those progressive neurological disorders like dementia or Parkinson’s (...) or maybe like with patients with MND, where their life expectancy is limited you might, their goals are different.” (Participant 3)

“I think that there really is a huge difference in stroke versus other populations with dysphagia.” (Participant 10)

As a result, participants described a much clearer approach to supporting QOL in these populations.

“I think its a little discipline dependent, like say they were geriatric doctors, or palliative doctors (...) they would already be coming with a lot more knowledge than others and you don’t have to try so hard.” (Participant 2)

“I think with a progressive patient, sometimes quality of life is put to the forefront because of the way, they don’t have much time left, so we put that as a priority.” (Participant 11)

6.4.3 What is quality of life?

Throughout the interview, the participants discussed varying perspectives on the meaning of QOL, which led to the development of the theme ‘What is quality of life?’

This theme had two associated subthemes – ‘The definition of quality of life’ and ‘The changing nature of quality of life’.

Participants continually alluded to the lack of a clear understanding of what QOL means within a clinical setting.

“I think there’s a big spectrum and we’re not always talking about the same thing.” (Participant 4)

“What is meant by quality of life and how we define that?” (Participant 3)

“I’m actually now thinking I actually don’t know how I would define it.” (Participant 5)

Although participants made a number of suggestions regarding what QOL may encompass, no universal definition was agreed upon.

“I think quality of life is really poorly defined and sometimes it’s put into a box of risk feeding.” (Participant 3)

“Is it feeding at risk or is it the provision of therapy or is it you know focusing on patient centred goals.” (Participant 3)

Additionally, it was recognised that QOL may change or vary, further contributing to the lack of clarity regarding its true meaning.

“I think it depends as well on your view of quality of life.” (Participant 1)

“And I also think like, quality of life is not something that you can determine once.” (Participant 3)

“It changes and the situation changes and factors change.”
(Participant 7)

6.4.4 Assessing quality of life

Two subthemes were developed under the theme ‘Assessing quality of life’ – ‘Use of standardised assessments’ and ‘Using informal clinical skills’.

Overall, participants discussed a difficult process in assessing QOL in persons with dysphagia following stroke. Many participants felt there was a lack of suitable formal or standardised assessments available, with the most widely cited tool, the SWAL-QOL (McHorney et al. 2002), posing significant difficulties in a clinical setting.

“I wouldn’t use that tool in acute because it’s just too much.”
(Participant 10)

“It’s very community based.” (Participant 1)

“You need to be eating to complete it.” (Participant 9)

Participants highlighted the need for a stroke-specific QOL tool that could be easily used in the acute setting, and that would also be suitable for persons who are NPO.

“If it were shorter and more realistic to be applied in an acute setting, I think that would be something quite interesting.”
(Participant 10)

“For people who can’t eat as well.” (Participant 9)

In the absence of a formal or standardised stroke-specific tool, participants described relying on other clinical skills and judgements to determine the impact of dysphagia on a person's QOL.

“How much the family bring in and also what is their response as well is often very telling about how important food and drink and everything is.” (Participant 5)

“What I find is that sometimes you have these people that like their eyes turn all gleamy, and they're like ooh I really like that.” (Participant 10)

However, the limitations of relying on informal assessment and observations is also acknowledged.

“I mean it's not standardised at all.” (Participant 10)

6.4.5 The process of goal-setting

Throughout the focus group, the participants discussed ‘The process of goal-setting’ when considering QOL in dysphagia management following stroke. Two subthemes were developed in relation to goal setting; ‘Patient participation in goal-setting’ and ‘Differing perspectives regarding management goals’.

Participants reported differing experiences and approaches when considering the participation of patients in the process of goal setting. For some participants, the importance of including patients in this process was fundamental to the success of their intervention.

*“We try together to decide what is acceptable.”
(Participant 10)*

“They respect better the recommendations.” (Participant 5)

For other participants, they felt that patients found it difficult to partake in the process of goal-setting or in some cases, preferred to have their goals set for them by their managing therapist.

“It’s something very abstract to talk about goals and I don’t think it’s very easy to give them questions and get them to answer it.” (Participant 4)

“That sort of generation as well, will say, why are you asking me how I feel, just tell me what to do.” (Participant 5)

“People just want to be told what to do.” (Participant 5)

The personal nature of goals and different priorities regarding the management of dysphagia was reported as a further challenge in the process of goal-setting. Participants acknowledged that each patient is likely to have unique concerns and objectives.

“Everyone has different goals.” (Participant 6)

“They are working towards a personal goal.” (Participant 1)

“It probably comes back to personal motivation which is obviously linked to their belief system.” (Participant 5)

*“I think it depends really on their personality.”
(Participant 10)*

Participants reported feeling that for patients who have specific personal goals, and particularly patients who place a high value on QOL, they may choose not to follow the recommendations made by the therapist.

“We have huge noncompliance because they’re going to do what’s in their best interest.” (Participant 8)

“It goes in one ear and out the other because they’re just going to do what makes them happy.” (Participant 8)

“It’s either you’re the speech therapist, you know what you’re talking about, I’m going to follow things to the tee, or you’re a speech therapist, what do you know.” (Participant 5)

Furthermore, participants describe how difficulties and ambiguity in making management decisions and recommendations, may further contribute to what they described as noncompliance amongst persons with dysphagia.

“Our recommendations, at least for me, are not always very convincing (...) I think that makes it really hard for patients.” (Participant 4)

“She was immobile, she was frail, she was everything that you would expect to develop an aspiration pneumonia and it’s been two years of proving me wrong.” (Participant 10)

In this scenario, where the person with dysphagia may choose to eat and drink at risk, participants described a difficult process of discussing this decision with the multidisciplinary team in order to gain further advice, information and support.

“It’s difficult to access the team around you for support.” (Participant 8)

“To undergo that decision you need to have discussed it with a whole load of people that are hard to get in touch with.”

(Participant 5)

“Trying to contact GPs is the bane of my life.”

(Participant 5)

6.4.6 Withdrawing active rehabilitation

The focus group participants unanimously described a difficult process when considering ‘Withdrawing active rehabilitation’. The two subthemes that were developed within this theme were ‘Stopping active treatment: when and why?’ and ‘Active treatment has stopped, what next?’

Throughout the focus group interview, participants described varying approaches and guidelines to deciding if and when to withdraw active rehabilitation for dysphagia following stroke. For some participants, ongoing rehabilitation was the expected standard of care.

“Well with the service that we’re coming from, it never stops.” (Participant 3)

“I just can’t envision that happening (rehabilitation being withdrawn).” (Participant 2)

For other participants, experiences of limited rehabilitation and long-term availability of SLT services for patients with ongoing dysphagia following stroke were common.

“They go on thickened fluids and just stay on them forever and ever and ever.” (Participant 3)

“I think there’s maybe a lack of rehabilitation in dysphagia which I think has a huge impact on quality of life.” (Participant 3)

“In my last work place they were discharged on thickener forever.” (Participant 5)

Throughout the discussions, no clear consensus was reached amongst the group regarding if active rehabilitation should continue indefinitely.

“It’s really hard to make a decision on whether to stop or not.” (Participant 6)

“I would probably discharge but first I would definitely have a big conversation about social engagement and participation.” (Participant 8)

In a situation where active rehabilitation has been withdrawn, there was further disagreement as to what the potential role of SLT might be if it has been agreed that further improvement in swallow function is unlikely.

“Well if you can’t provide rehab then what are you doing?” (Participant 9)

“We need to give them hope that they can still work on things and that they can still improve.” (Participant 9)

Some participants described the need to signpost and link the person with dysphagia with relevant support groups.

“Make sure they have access to any stroke groups in the area.” (Participant 5)

“Linking them in with other people with similar experiences...they don’t feel so isolated and alone.” (Participant 3)

For others, the argument remained that providing ongoing active rehabilitation would be in the person with dysphagia’s best interests.

“You might as well be using that time to provide a block of therapy.” (Participant 9)

“Provision of therapy might add to their quality of life.” (Participant 3)

6.4.7 Importance of education

Throughout the focus group interview, the ‘Importance of education’ was highlighted and discussed by the participants when considering their management of QOL in dysphagia following stroke. This theme had two associated subthemes – ‘The impact of education on quality of life’ and ‘Factors impacting education’.

A clear link between education and QOL was reported, with participants acknowledging the importance of empowering persons with dysphagia to become active participants in the management of their dysphagia.

“Education, that’s a huge one.” (Participant 10)

“If I explain it more, then the patient will do the things right as well and I also have the feeling that they respect better the recommendations.” (Participant 10)

“Really doing a lot of teaching and educating the patient and the family I’ve always had the feeling makes a huge change in the way they feel themselves with their dysphagia.” (Participant 4)

“Give them as much information as they need to decide for themselves.” (Participant 5)

However, participants also discussed significant difficulties in ensuring they provide enough education and advice to patients and their families, with both patient factors and resources impacting on their ability to do so.

“If they are capable, cognition and language wise.” (Participant 11)

“I think it’s really time consuming.” (Participant 10)

“In the acute setting most of the times we just don’t have the time.” (Participant 10)

“People are so often out the door so quickly and they don’t know anything.” (Participant 4)

6.5 Discussion

6.5.1 Overview of findings

The findings of this study demonstrate the multifaceted and unique difficulties faced by SLTs when working with persons with dysphagia following stroke. The many complexities inherent in supporting QOL in this population are revealed and the variation in practice patterns and beliefs amongst the profession are shown.

As has been previously demonstrated in the literature (De Wit & Hajos 2013, Post 2014, Pinto et al. 2017), a lack of consensus regarding the definition and meaning of QOL was reported by the participants. Although the participants of this study acknowledged that the assessment and support of QOL in dysphagia following stroke is an important professional role for SLTs, this lack of clarity regarding what QOL actually means and represents, may contribute to the variation in practice that was subsequently reported.

Beyond a lack of consensus regarding the definition of QOL, the difficulties faced by the profession begin at the point of assessment, where participants describe a lack of disease-specific and user-friendly clinical tools and resources to support their practice in this area. Validated tools that are currently available, such as the SWAL-QOL (McHorney et al. 2002) are reported as being cumbersome and unsuitable, particularly in the acute stages following stroke. As a result, participants have to rely on informal observations and other clinical reasoning skills – resulting in an approach that is not standardised, objective or truly measurable.

Following assessment, participants describe varying approaches and attitudes towards the process of goal-setting. For some participants, the importance of including the patient whenever possible and considering the person's priorities is paramount. For others, their experience has been that person's with dysphagia prefer a more authoritarian approach where their management is fully guided and directed by the clinician. This is despite the literature that exists to support the importance of person-centred and collaborative goal-setting in stroke rehabilitation (Levack et al. 2009, Rosewilliam et al. 2011, Leonardi & Fheodoroff 2021). Furthermore, the participants feel that the complexity of goal-setting is compounded by ambiguity in decision-making regarding risk, regarding if and when to withdraw active rehabilitation, and by clear international and national variations in service delivery models and available resources.

Arguably the greatest complexity faced by SLTs when working in this clinical area, is in the process of developing appropriate management plans and intervention strategies. Participants describe how their approach to management continually changes throughout the stroke journey. In the early acute stages, participants feel that they cannot make QOL a priority for care. An emphasis on safety, risk management and early recovery, coupled with limited resources and many other competing demands, means participants feel unable to fully consider the psychosocial and QOL needs of their patients. Indeed, for some participants, they note that even if QOL is a priority for their patients at this time, they feel a duty of care to negotiate a more 'aggressive' approach to management.

Many participants reported that it is often more appropriate to focus on psychosocial wellbeing and QOL once the person has returned home. However, a difficult process is again described. Participants report that the extent of their ability to intervene in this clinical area is often dictated by the availability of resources and local policies and procedures regarding the provision of ongoing SLT input. Furthermore, when participants do have the opportunity to address QOL in this clinical population, varying approaches to management are seen, ranging from simply signposting and referring the person with dysphagia to relevant support groups, to an active collaborative process of identifying and overcoming relevant psychosocial barriers,

Education appeared to be the only approach that was unanimously agreed upon by participants as being necessary to support QOL, but again, limitations in time and resources dictated the participant's ability to provide this level of support when necessary. A lack of multidisciplinary communication to support the management of QOL is also described. Similar to the work of Northcott and colleagues in 2017, participants noted extreme variations in availability of stroke-specific psychology services, with a joint SLT-psychology approach suggested as being the optimum service delivery model (Northcott et al. 2017).

Finally, the complexity of supporting the psychosocial and QOL needs of persons with dysphagia following stroke is clearly demonstrated, when the participants compare their knowledge and practice in this area to other clinical populations, particularly those with progressive neurological diseases and head and neck cancer. Participants describe a much clearer approach to the prioritisation and support of QOL in these populations,

which they attribute to enhanced awareness amongst the MDT, more simplicity in decision-making processes and widely recognised care pathways.

6.5.2 Methodological considerations

As with all studies, this study has some limitations which should be noted. Firstly, all participants attended the same international conference in 2018. This conference was within the area of dysphagia, so it did afford a unique opportunity to involve clinicians working internationally, but as a result a potential for bias within the group exists. All participants volunteered to take part, but no purposeful sampling was employed. Furthermore, there were a high proportion of participants currently living and working in New Zealand.

Beyond the bias which may exist in the group of participants itself, there are also inherent limitations in focus group methodology, which should be considered. These limitations include the risk that some of the participants may have been reluctant to share their true experiences and opinions in a public setting, and/or individual participants may have been swayed or influenced by the common perspectives held within the group. Furthermore, any group discussion relies heavily on the facilitator or moderator of that group. Thorough planning in the development of the focus group protocol, and the presence of both the lead researcher and research supervisor, will have gone some way towards mitigating the risk of moderator bias in the phrasing and posing of questions and exploratory comments. However, the influence of the moderator on the group dynamic can never be completely neutralised.

Despite these limitations, the use of focus group methodology allowed the interesting points that arose from the survey questionnaire analysis to be explored in detail and for points that were unclear or vague to be further clarified. The focus group interview provided a relatively efficient and effective method for achieving this, with the group dynamic contributing to the possibility that further and more revealing insights would be developed.

6.6 Conclusions

This study provides an in-depth exploration of the barriers and facilitators to SLT practice in the assessment and management of QOL in persons with dysphagia following stroke. When considered alongside the findings of the survey study presented in Chapter 5, key actions for the development of the role of SLT in this important clinical area can be developed.

The study highlights the unique complexity in supporting psychosocial wellbeing and QOL in the dysphagia population following stroke, alongside the many challenges faced by practicing clinicians in this area. SLTs feel unsupported by a lack of appropriate assessment tools, a lack of clinical resources and a lack of professional consensus to direct management and intervention. As a result, clear variations in approaches to assessment, goal-setting and intervention are evident. These variations are further compounded by noteworthy differences in reported service delivery models, resources and local clinical care pathways.

SPEECH AND LANGUAGE THERAPY PRACTICE WHEN ADDRESSING QUALITY OF LIFE IN DYSPHAGIA MANAGEMENT FOLLOWING STROKE: SUMMARY OF FINDINGS FROM SECTION 3

- SLTs believe that QOL is an important feature of dysphagia management, but are dissatisfied with the amount of clinical time that they can allocate to this aspect of the care they provide.
- SLTs question the suitability of prioritising and addressing QOL in the acute stages following stroke, as there is an overriding emphasis on maintaining nutrition, hydration and swallow safety.
- SLTs feel that QOL in the stroke population with dysphagia is most suitably addressed in inpatient rehabilitation or community-based services.
- Significant variations and inconsistencies exist in SLT approaches to both the assessment and management of QOL in the dysphagia population in general.
- These variations and inconsistencies are seen in the assessment and management of QOL specific to the stroke population with dysphagia.
- SLTs also report significant challenges in the assessment of QOL in dysphagia following stroke – the lack of a stroke-specific QOL assessment tool is cited a particular barrier to effective clinical practice in this area.
- SLTs describe a difficult process in deciding if and when active dysphagia rehabilitation should be withdrawn following stroke.
- Uncertainty regarding the potential for recovery and the stroke trajectory were also cited as significant barriers in prioritising and addressing QOL.
- SLTs feel that the assessment and management of QOL in other clinical populations, such as in persons with progressive neurological diseases, is relatively straight forward in comparison to the stroke population.
- Varying approaches to the inclusion of the person with dysphagia in the development of relevant intervention and management plans are reported.
- SLTs feel there is a lack of MDT awareness regarding the role of the profession in supporting and managing QOL in dysphagia following stroke.
- Service delivery structures and policies can limit the scope of the SLT in assessing and supporting QOL, particularly in persons with long-term dysphagia following stroke.

**SECTION 4: CLINICAL ASSESSMENT TOOLS FOR EXPLORING
PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE IN
DYSPHAGIA FOLLOWING STROKE**

Chapter 7: Patient reported outcome measures in dysphagia research following stroke: a scoping review and qualitative analysis of content³

7.1 Abstract

Aim: The findings from Section 2 of this thesis demonstrate the complex and multifaceted impact of dysphagia on psychosocial wellbeing and QOL in the stroke population with dysphagia. The SLT participants in Section 3 report significant difficulties and limitations in their ability to holistically and consistently assess and evaluate this impact, with the lack of stroke-specific QOL assessment tools cited as a particular barrier. A limited assessment process is likely to influence the quality of care that is subsequently provided.

In both clinical practice and quantitative research, patient-reported outcome measures (PROMs) are commonly used to evaluate the impact of a health condition on psychosocial wellbeing and QOL. The aim of this study was to identify commonly used PROMs in dysphagia research following stroke and to analyse the content of these PROMs using both the International Classification of Functioning and Disability (ICF) and the COMET Taxonomy for outcome classification.

Methods: A scoping review was conducted to identify commonly used PROMs in randomised controlled trials (RCTs) which have been reported in the dysphagia

³ Adapted in Moloney J., Regan J. & Walshe M. (2021). Patient reported outcome measures in dysphagia research following stroke: A scoping review and qualitative analysis of content. *Dysphagia*, DOI: 10.1007/s00455-022-10448-y.

population with stroke. A search of five databases was conducted. The individual assessment items and meaningful concepts contained within each identified PROM were mapped to both the ICF and the COMET Taxonomy using existing mapping rules.

Findings: A total of 110 papers met the inclusionary criteria. Twelve of these 110 papers included a dysphagia PROM. Following review, two PROMs were identified as being in common use – the SWAL-QOL (McHorney et al. 2002) and the EAT-10 (Belafsky et al. 2008). These two tools consisted of 47 items, which on analysis contained 78 meaningful concepts that were subsequently mapped to the ICF and the COMET Taxonomy. Mapping to the ICF showed that although items in both tools considered ‘Body Functions’ and ‘Activity and Participation’, neither tool directly assessed the impact of ‘Environmental Factors’ on the experience of dysphagia. Mapping to the COMET Taxonomy showed that both PROMs considered the ‘Physiological/Clinical’ and ‘Life Impact’ of dysphagia, but again neither tool considered the impact of ‘Role Functioning’ on the person’s experience of dysphagia.

Conclusions: The findings of this study highlight the lack of priority that current intervention research gives to PROMs in the stroke population with dysphagia. This study also highlights the lack of suitable stroke-specific dysphagia PROMs. The development of a suitable and appropriate patient-reported assessment tool for use in those with dysphagia following stroke is warranted.

7.2 Introduction

The findings from the studies presented in Section 2 demonstrate the complex and extensive impact that dysphagia can have on QOL in the stroke population. These findings suggest that any assessment tool or measure that is used in the stroke population with dysphagia needs to consider and assess a wide-range of relevant areas and concepts.

In Section 3 of this thesis, the SLT participants in both the international survey study and the international focus group described the assessment of psychosocial wellbeing and QOL in persons with dysphagia following stroke as a particularly challenging aspect of clinical practice. More specifically, the clinicians described a lack of suitable stroke-specific tools to support the clinical assessment process. Commonly used tools reported by the participants included the SWAL-QOL (Mc Horney et al. 2002), the MD Anderson Dysphagia Inventory (Chen et al. 2001) and the EAT-10 (Belafsky et al. 2008). However, the participants described significant limitations with the use of these tools at a clinical level including feasibility and appropriateness in the stroke population.

Patient-reported outcome measures (PROMs) have been used for many years to gain insights into a patient's view of their physical symptoms, their functional abilities and their perception of their overall psychosocial wellbeing in relation to their health status (Black 2013, Black & Jenkinson 2009, Bottomley et al. 2019). As a result, in both research and clinical practice, an assessment of a person's QOL is most often made using these questionnaire based tools (Snyder et al. 2013, Reeves et al. 2018). The term 'patient-reported' is included in the description of these outcome measures to denote one important feature – the tool is used to allow the person to make a self-evaluation or

assessment of their own satisfaction, well-being and happiness (Aaronson 1988, Higginson & Carr 2001). Where a person is unable to complete these questionnaires, for example due to changes in cognition or communication, it may be suitable for the tool to be completed by a significant other or nominated proxy (Hilari et al. 2007, Robertson et al. 2017).

In the dysphagia population, PROMs are widely used to explore the impact of dysphagia on QOL and to evaluate the effectiveness of treatment and intervention approaches. At present, there are upwards of 30 tools currently published and available in the literature (Patel et al. 2017). A key consideration for any clinician or researcher in the selection of which PROM to use, is the quality of the tool. This judgement is most often made with consideration for its underlying psychometric properties, including its reliability and appropriateness for use within a given clinical population. However, another important consideration in the selection of an appropriate PROM, is the content and focus of the tools themselves i.e. what aspects of the person's experience do the items in the tool consider and assess (Carr & Higginson 2001, Cieza & Stucki 2005). Unless a PROM truly and comprehensively incorporates the perspective of the person or clinical population for which it is intended, then it is unlikely to differ significantly from traditional measurement tools (Trujols et al. 2013).

The ICF framework has been successfully used in previous studies to evaluate the comprehensiveness and suitability of the content of outcome measures that are used in both healthcare research and clinical practice (Tschiesner et al. 2008, Brockow et al. 2004, Wallace et al. 2019, Nund et al. 2019). As described in detail in Chapter 1, the ICF

framework can be used to describe a person's experience of health by considering four key components – 'Body Functions', 'Body Structure', 'Activities and Participation' and 'Environmental Factors'. By mapping the content of selected PROMs to the various components and categories within the ICF, an evaluation of the scope and breadth of a tool or outcome measure can be made (Threats 2007).

In more recent years there has also been a move towards the development of core outcome sets (COS) in healthcare research. A COS recommends, through consensus, the minimum set of outcomes that should be considered and measured in research concerned with specific conditions and populations (Williamson et al. 2012). In an attempt to support this movement, the Core Outcome Measures in Effectiveness Trials (COMET) initiative subsequently developed a detailed taxonomy that can be used in the analysis and classification of specific outcome measures – The COMET Taxonomy (Dodd et al. 2018) (Appendix 25). This taxonomy comprises four core areas and a total of 38 different outcome domains. Similar to studies that have used the ICF, by mapping a given PROM to the COMET Taxonomy, potential gaps and limitations in the content of a specific tool or outcome measure can be highlighted (Harman et al. 2017).

At present, this research team does not know of any PROM that has been specifically designed for use in the stroke population with dysphagia. As a result, both researchers and clinicians are limited to using a PROM that has been designed with a generic dysphagia population in mind and that may or may not have been validated for use with those who have had a stroke. In order to triangulate the findings from the studies

reported in Section 3 of this thesis, this study aims to identify the range of PROMs that are currently in common use in dysphagia research following stroke.

Once identified, it is likely that the psychometric properties of these PROMs will have been previously addressed and reviewed in the literature (Speyer et al. 2014, Patel et al. 2017). Therefore, this study aims to explore the content of these tools using both the ICF framework and the COMET Taxonomy. In doing so, the appropriateness and relevance of the information that is gathered and analysed by these tools can then be considered.

7.3 Methods – Stage 1: Scoping review

7.3.1 Study design

The first stage of this study involved conducting a scoping review to identify and select PROMs that are commonly used in dysphagia RCTs following stroke. This scoping review was guided by the Preferred Reporting Items for Systematic Review and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al. 2018) (Appendix 26) and the methodological framework outlined by Arskey and O'Malley in 2005 (Arskey & O'Malley 2005).

The protocol for the scoping review was prospectively published in November 2020, on the COMET database. The protocol can be accessed at comet-initiative.org/Studies/Details/1748 and a copy is available in Appendix 27.

7.3.2 Eligible studies

Published studies were included if they reported on a RCT which examined the effectiveness of a named dysphagia intervention in the stroke population. For the purpose of this study, a RCT was defined as ‘a trial in which subjects are randomly assigned to one of two groups: one (the experimental group) receiving the intervention being tested, and the other (comparison or control) receiving an alternative (conventional) treatment’ (Kendall 2003, p.164). Furthermore, the study had to refer to at least one measure of swallowing performance or swallowing-related outcomes.

Studies were excluded if they included paediatric participants i.e. <18 years of age, or if the text was not available in the English language. Where conference abstracts were deemed to report on the same data as a published original paper, the published paper was given preference and the abstract was counted as a duplicate.

7.3.3 Search strategy

A comprehensive electronic search strategy was developed in conjunction with Trinity College Dublin librarians. This search strategy included terms that were thematically related to stroke, dysphagia and randomised controlled trial. The search was completed on December 13th 2020. Five databases were searched from inception to this date: CINAHL, The Cochrane Database, EMBASE, Web of Science and PubMed. A sample of the search strategy that was used is available in Appendix 28.

7.3.4 Data extraction

All studies identified following the electronic search were uploaded to the online Covidence platform (www.covidence.org) to support the screening and selection process. Using this platform, the title, abstract and full-text of relevant studies was reviewed independently by both the lead researcher and the research supervisor. Any discrepancies that arose were discussed in detail and a consensus was reached regarding their selection.

Once study review and screening was completed, the relevant data was extracted and inputted onto a data extraction sheet, which was developed on Microsoft Excel. On this data extraction sheet, the details of each study were listed alphabetically, alongside their basic characteristics (i.e. year published, intervention) and the specific outcome measures that were used. All of the outcome measures referenced across the selected studies were then extracted and listed, and duplicates were removed. The remaining list of outcome measures was screened. On screening, those measures which did not meet the relevant inclusion criteria were excluded from further analysis.

The initial screening phase was completed to ensure that the outcome measure was relevant to the specific population being studied. Therefore, the outcome measures were only accepted if they:

- a) Directly evaluated swallowing, or
- b) Directly evaluated stroke but had at least one item that evaluated swallowing.

Following the initial screening phase, the list of outcome measures were reviewed once again to ensure that the measure could be deemed to be a PROM. In order to achieve this, the following additional criterion was applied:

- a) The measure had to have at least one item that sought feedback or information directly from the person with dysphagia.

The final list of identified PROMs was then reviewed and screened one last time. The purpose of this final screening phase was to ensure that the PROMs could be deemed to be in common use, and that they were capable of providing some level of meaningful data. Similar to other studies which have explored the content of outcome measures in this way (Tschiesner et al. 2008, Nund et al. 2019), this was achieved by applying two final criteria. The remaining PROMs were only accepted if:

- a) They were used by at least two different author groups (signifying its use as a common outcome measure), and
- b) If there was at least some published data available to support their psychometric properties.

7.4 Methods – Stage 2: Qualitative analysis of content

The second stage of this study involved the mapping of each identified PROM to both the ICF and the COMET Taxonomy for Outcome Measures.

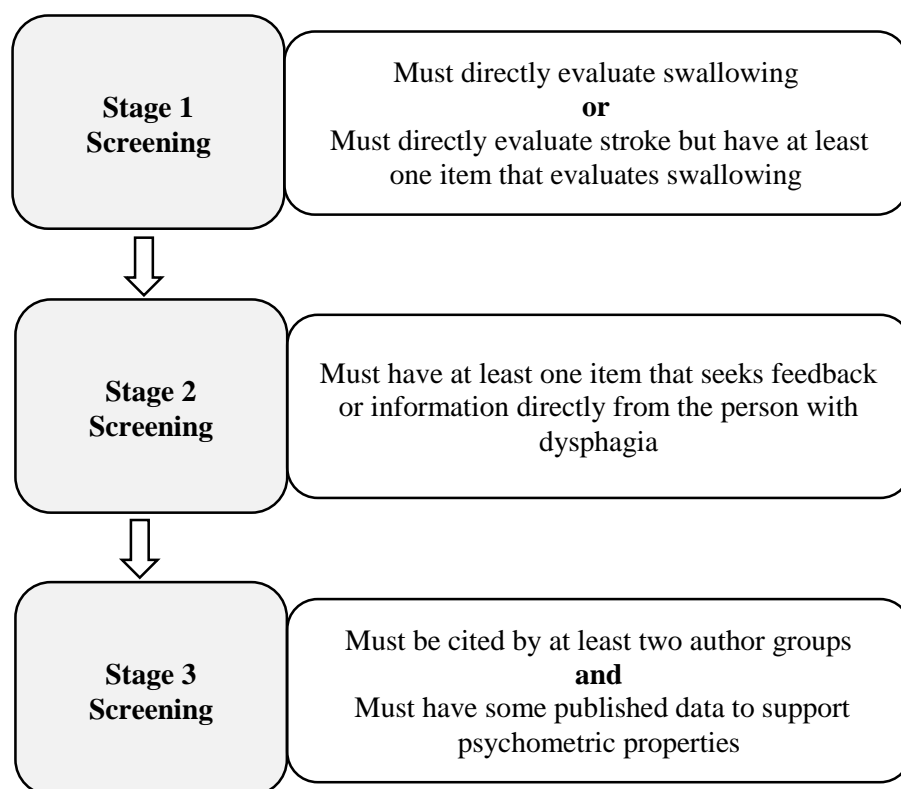


Figure 7.1: Overview of outcome measure screening process

7.4.1 ICF mapping process

In order to complete the ICF mapping process, individual measurement items or domains within each PROM were listed and considered individually. The key concepts in each item/domain were then extracted and mapped to the most suitable ICF category. This mapping exercise was guided by previously used and well-established coding rules (Stucki et al. 2002, Cieza & Stucki 2005). A summary of these coding rules is available in Table 7.1.

Table 7.1: ICF coding rules

NUMBER	RULE
1	Become familiar with the structure and concepts within the ICF prior to completing a mapping exercise
2	Link each item to the most precise ICF category
3	If the content of a concept is not explicitly named in the ICF category, document this content separately
4	Do not use the ‘unspecified’ categories in the ICF, instead link the concept to the related higher level category
5	If there is not enough information regarding the concept to link it to an ICF category, document the concept as being ‘not defined’
6	If the concept is not contained in the ICF, but is clearly a personal factor, document the concept as ‘personal factor’
7	If the concept is not contained in the ICF but is not a personal factor, the concept should be documented as ‘not covered’
8	If the concept refers to a diagnosis of specific health condition, document the concept as ‘health condition’

By way of an example, the DHI (Silbergleit et al. 2012) is a 25 item patient-reported questionnaire. If the DHI was being mapped to the ICF, each of the 25 questions would be treated as an individual item. Each item would then be considered separately and the relevant concepts in the item extracted. For item three on the DHI – ‘I’m embarrassed to eat in public’ – the extracted concepts would be ‘embarrassment’ and ‘eating in public’. These two concepts would then be linked to the most relevant categories within the ICF. ‘Embarrassment’ would be linked to ‘e460 – Societal attitudes’, which is listed within the ‘Environmental Factors’ component of the framework. By comparison ‘eating in public’ would be linked to ‘d920 – Recreation and leisure’, which is listed within the ‘Activities and Participation’ component.

The ICF mapping process was completed by the lead researcher and was independently reviewed by the research supervisor. Any disagreements were discussed and a consensus decision was reached.

7.4.2 COMET taxonomy mapping process

In mapping the identified PROMs to the COMET Taxonomy, each item or domain within the PROM was again considered individually. The principal concept within each item was determined and this concept was then mapped to the taxonomy. The descriptive information provided for each core area and outcome domain within the COMET Taxonomy was used to guide the mapping process.

Again, using the same example from the ICF Mapping Process, the third item on the DHI (Silbergleit et al. 2012) – ‘I’m embarrassed to eat in public’ – would be mapped to the core area ‘Life Impact’. Within this core area, the item would be further mapped to ‘Social functioning’. By way of comparison, item number 11 on the DHI, ‘I eat less because of my swallowing problem’, would be mapped to the core area ‘Physiological/Clinical’ and the outcome domain ‘Metabolism and nutrition outcomes’.

The COMET Taxonomy mapping process was completed by the lead researcher and was reviewed independently by the research supervisor. Any disagreements were discussed and a consensus decision was reached.

7.5 Results – Stage 1: Scoping review

7.5.1 Study selection

Electronic database searching resulted in the identification of 4,095 articles. Following removal of duplicates, 3,049 articles were screened for inclusion. Following title and abstract screening, 2,788 articles were removed, leaving 261 articles to be assessed for eligibility. 151 more articles were excluded following full text review, leaving 110 articles which were included in the final review (Figure 7.2).

7.5.2 Outcome measure selection

From the 110 articles that were included in the final review, 30 distinct outcome measures were identified following the initial screening process. Each of these outcome measures either a) directly evaluated swallowing or b) directly evaluated stroke outcomes but had at least one item that was related to swallowing.

On further screening, 22 of these outcome measures were subsequently excluded as they did not contain at least one item which sought feedback or information directly from the person with dysphagia i.e. they were not classified as a PROM. Of the remaining eight outcome measures, six were excluded as a) at least two groups of authors did not cite them, or b) there was no published data available to support their psychometric properties.

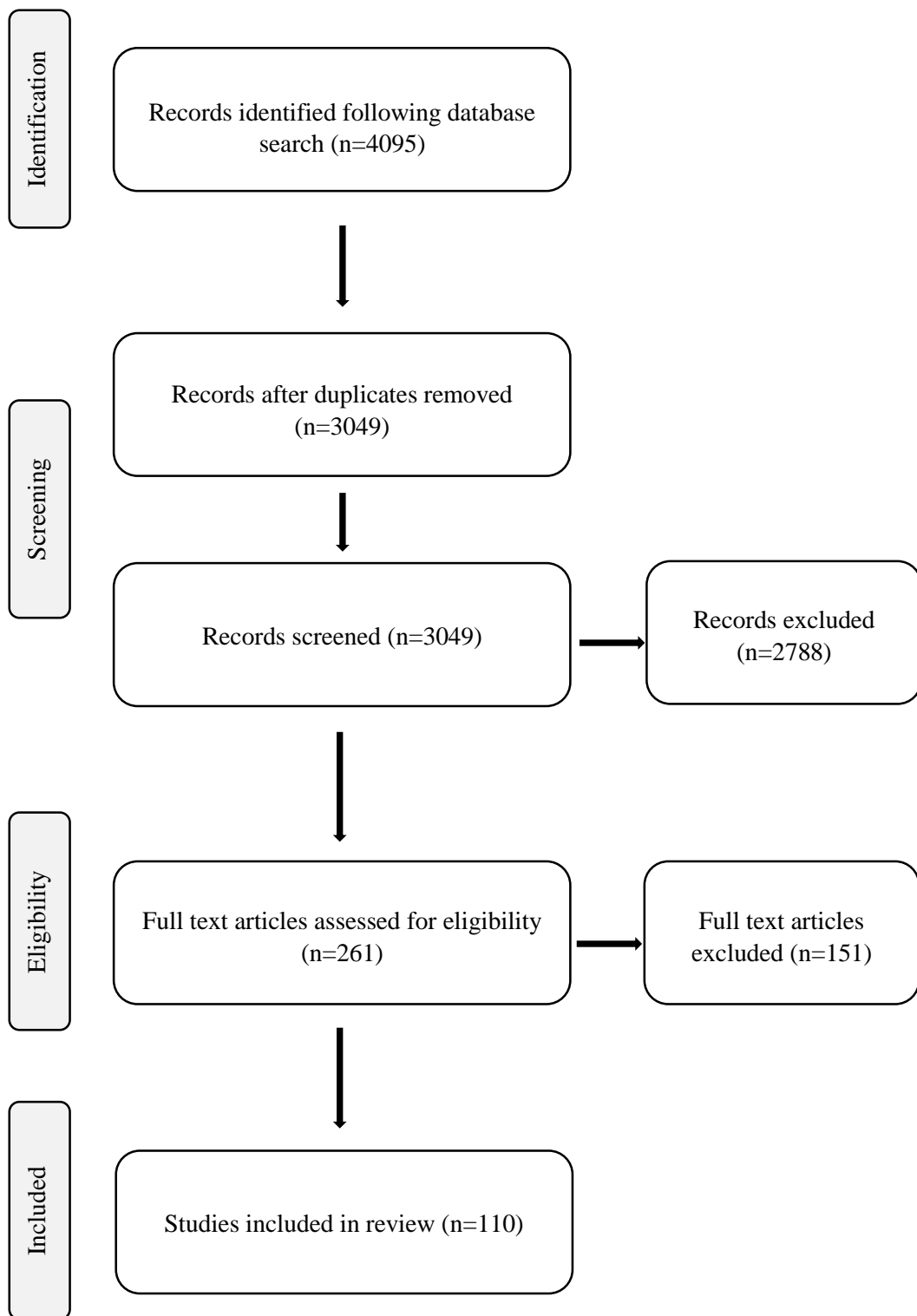


Figure 7.2: PRISMA flow diagram

This resulted in the selection of two PROMs – the Swallowing Quality of Life Questionnaire (SWAL-QOL) (McHorney et al. 2002) and the Eating Assessment Tool (EAT-10) (Belafsky et al. 2008). The SWAL-QOL was cited as an outcome measure in ten clinical trials, while the EAT-10 was cited in two clinical trials. Therefore, 12 of the total 110 articles that were screened included a commonly used PROM to evaluate the effectiveness of the intervention under investigation.

7.6 Results – Stage 2: Qualitative analysis of content

7.6.1 ICF mapping process

The two identified PROMs that were included in the qualitative analysis, consisted of 54 individual items that required conceptualisation and mapping. On review, 7 of these items were subsequently excluded as they did not relate directly to swallowing (e.g. SWAL-QOL Item 43 – In the last month how often have you had trouble staying asleep). These items were therefore not included in the identification and mapping of relevant concepts.

Consideration of the remaining 47 items resulted in the identification of 85 individual concepts. Seven of the 85 concepts were subsequently excluded as they could not be directly linked to the ICF. These concepts included factors relevant to swallowing such as ‘frustration’, ‘caution’ and ‘apathy’, but as they are not currently classified under the ICF, they could not be included.

The remaining 78 concepts mapped to 14 different ICF categories. 36% (n=5) of these concepts related to ‘Body Functions’, 7% (n=1) related to ‘Body Structures’ and 57% (n=8) related to ‘Activity and Participation’. No concepts in either PROM related to ‘Environmental Factors’. The most commonly identified ICF category across both PROMs was ‘b510 – Ingestion Functions’, with 35% (n=27) of concepts related directly to this category.

The SWAL-QOL represented 53 of the 78 concepts that were mapped to the ICF. The majority of these concepts (n=32, 60%) were related to ‘Body Functions’ i.e. the physiological functions of the body systems. The remaining concepts (n=21, 40%) were related to ‘Activities and Participation’ i.e. the person’s ability to complete a task and/or be involved in a life situation.

By comparison, the EAT-10 represented a more even spread of concepts across the ICF, with 52% (n=13) of concepts related to ‘Body Functions’ and 44% (n=11) related to ‘Activities and Participation’. The EAT-10 contained one concept that was mapped to ‘Body Structures’ i.e. the anatomical parts of the body.

7.6.2 COMET taxonomy mapping process

As previously outlined, the two PROMs included in the qualitative analysis consisted of 54 individual items. Again, 7 of these items were excluded as they did not relate directly to swallowing, meaning that 47 items were included in the mapping process.

Of these 47 items, 27 mapped to the core area ‘Life Impact’. Within this area, the most commonly mapped domain was ‘Emotional functioning/wellbeing’. The other 20 items mapped to the core area ‘Physiological/Clinical’. Within this area, the most commonly mapped domain was ‘Gastrointestinal outcomes’.

The SWAL-QOL represented 37 of the items that were mapped to the COMET Taxonomy. Of these 37 items, 57% (n=21) were mapped to the core area ‘Life Impact’ with the most common outcome domain within this core area being ‘Emotional functioning/wellbeing’ (n=13, 62%). The remaining 16 items were mapped to the core area ‘Physical/Clinical’ with ‘Gastrointestinal outcomes’ being the most common outcome domain mapped within this area (n=9, 56%) (Table 7.3).

The EAT-10 represented the other 10 items that were mapped to the COMET Taxonomy. Of these 10 items, 60% (n=6) were mapped to the core area ‘Life Impact’ and 40% (n=4) were mapped to the core area ‘Physical/Clinical’. The items within the EAT-10 demonstrated a relatively even spread across the outcome domains that were mapped (Table 7.4).

Table 7.2: Results of outcome measure screening process

OUTCOME MEASURE AND NO. OF TIMES CITED IN ARTICLES	SEEKS FEEDBACK FROM PERSON WITH DYSPHAGIA	CITED BY AT LEAST TWO AUTHOR GROUPS	PUBLISHED PSYCHO-METRIC DATA AVAILABLE
Clinical Dysphagia Scale (n=1)	×	-	-
Cough Reflex Grading Score (n=1)	×	-	-
Dysphagia Handicap Index (DHI) (n=1)	✓	-	-
Dysphagia Severity Rating Scale (n=6)	×	-	-
Eating Assessment Tool (EAT-10) (n=2)	✓	✓	✓
EuroQOL-5 Dimension (EQ-5D) (n=1)	✓	-	-
Functional Oral Intake Scale (FOIS) (n=16)	×	-	-
Generic QOL Inventory (GQOL-74) (n=1)	✓	-	-
Kubota Toshio Swallow Test (n=4)	×	-	-
Lip Force Test (n=1)	×	-	-
Mann Assessment of Swallowing Ability (MASA) (n=5)	×	-	-
Modified Mann Assessment of Swallowing Ability (MMASA) (n=2)	×	-	-
Numerical Rating Self-Report Scale (n=1)	✓	-	-
Penetration Aspiration Scale (PAS) (n=30)	×	-	-
Patient Self-Perception Score (n=1)	✓	-	-
Parramatta Hospitals Assessment of Dysphagia (PHAD) (n=1)	×	-	-
Repetitive Saliva Swallowing Test (n=2)	×	-	-
Royal Brisbane Hospital Outcome Measure for Swallowing (RBHOMS) (n=2)	×	-	-
Standardised Swallowing Assessment (SSA) (n=10)	×	-	-

Swallow Function Scoring System (n=2)	×	-	-
Swallowing Quality of Life Questionnaire (SWAL-QOL) (n=10)	✓	✓	✓
Timed Water Swallow Test (n=1)	×	-	-
Videofluoroscopic Dysphagia Scale (VDS) (n=8)	×	-	-
Visual Analogue Scale (n=1)	✓	-	-
Visual Analogue Satisfaction Scale (n=1)	×	-	-
Volume Viscosity Swallow Test (n=1)	×	-	-
Water Drinking Test (n=1)	×	-	-
Water Intake Test Score (n=1)	×	-	-
Water Swallow Test (n=6)	×	-	-
Watian Drinking Water Test (n=1)	×	-	-

Table 7.3: SWAL-QOL mapped to ICF and COMET Taxonomy

ITEM	ICF CONCEPT	ICF COMPONENT	ICF CHAPTER	ICF CATEGORY	COMET CORE AREA	COMET OUTCOME DOMAIN
Dealing with my swallowing problem is very difficult	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Emotional functioning/ wellbeing
	Burden	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
My swallowing problem is a major distraction in my life	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Emotional functioning/ wellbeing
	Burden	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
Most days, I don't care if I eat or not	Eating	Activities and Participation (d)	5 Self-care	D550 Eating	Physiological/ Clinical	Metabolism and nutrition outcomes
	Apathy	Unable to categorise				
	Appetite	Body Functions (b)	1 Mental functions	B130 Energy and drive functions		
It takes me longer to eat than other people	Eating	Activities and Participation (d)	5 Self-care	D550 Eating	Life Impact	Physical functioning
	Time Taken	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
I'm rarely hungry anymore	Appetite	Body Functions (b)	1 Mental functions	B130 Energy and drive functions	Physiological/ Clinical	Metabolism and nutrition outcomes

It takes me forever to eat a meal	Eating	Activities and Participation (d)	5 Self-care	D550 Eating	Life Impact	Physical functioning
	Time Taken	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
I don't enjoy eating anymore	Eating	Activities and Participation (d)	5 Self-care	D550 Eating	Life Impact	Emotional functioning/ wellbeing
	Pleasure	Activities and Participation (d)	9 Community, social and civic life	D920 Recreation and leisure		
How often in the last month, have you experienced choking with eating food?	Choking	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system	Physiological/ clinical	Respiratory, thoracic and mediastinal outcomes
	Eating	Activities and Participation (d)	5 Self-care	D550 Eating		
How often in the last month, have you experienced choking when you take liquids?	Choking	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system	Physiological/ clinical	Respiratory, thoracic and mediastinal outcomes
	Drinking	Activities and Participation (d)	5 Self-care	D560 Drinking		
How often in the last month, have you experienced having thick saliva or phlegm?	Saliva management	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/ clinical	Gastrointestinal outcomes
How often in the last month, have you experienced gagging?	Gagging	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system	Physiological/ clinical	Respiratory, thoracic and mediastinal outcomes

How often in the last month, have you experienced drooling?	Saliva management	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced problems chewing?	Chewing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced having excess saliva and phlegm?	Saliva management	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced having to clear your throat?	Management of phlegm/secretions	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced food sticking in your throat?	Food sticking	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B280 Sensation of pain	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced food sticking in your mouth?	Food sticking	Body Functions (b)	2 Sensory functions and pain	B280 Sensation of pain	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced food or liquid dribbling out of your mouth?	Oral control	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/clinical	Gastrointestinal outcomes

How often in the last month, have you experienced food or liquid coming out your nose?	Nasal regurgitation	Body functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/clinical	Gastrointestinal outcomes
How often in the last month, have you experienced coughing food or liquid out of your mouth when it gets stuck?	Expectoration of food/liquid	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system	Physiological/clinical	Respiratory, thoracic and mediastinal outcomes
Figuring out what I can and can't eat is a problem for me.	Navigating swallowing difficulties	Activities and participation (d)	1 Learning and applying knowledge	D177 Making decisions	Life Impact	Emotional functioning/wellbeing
It is difficult to find foods that I both like and can eat	Limited choices	Activities and participation (d)	1 Learning and applying knowledge	D177 Making decisions	Life Impact	Social functioning
I fear I may start choking when I eat food	Choking	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system	Life Impact	Emotional functioning/wellbeing
I worry about getting pneumonia	Worry/Anxiety	Activities and participation (d)	2 General tasks and demands	D240 Handling stress and other physiological demands	Life Impact	Emotional functioning/wellbeing
	Pneumonia	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system		

I am afraid of choking when I drink liquids	Worry/Anxiety	Activities and participation (d)	2 General tasks and demands	D240 Handling stress and other physiological demands	Life Impact	Emotional functioning/ wellbeing
	Choking	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system		
	Drinking	Activities and Participation (d)	5 Self-care	D560 Drinking		
I never know when I am going to choke	Unpredictability	Unable to categorise			Life Impact	Emotional functioning/ wellbeing
	Choking	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system		
My swallow problem depresses me	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Emotional functioning/ wellbeing
	Impact on mental health	Unable to categorise				
Having to be so careful when I eat and drink annoys me	Caution	Unable to categorise			Life Impact	Emotional functioning/ wellbeing
	Frustration	Unable to categorise				
I've been discouraged by my swallowing problem	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Emotional functioning/ wellbeing
			1 Mental functions			

	Motivation	Body Functions (b)		B130 Energy and drive functions		
My swallowing problem frustrates me	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Emotional functioning/ wellbeing
	Frustration	Unable to categorise				
I get impatient dealing with my swallowing problem	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Emotional functioning/ wellbeing
	Frustration	Unable to categorise				
I do not go out because of my swallowing problems	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Social functioning
	Social Impact	Activities and Participation (d)	9 Community, social and civic life	D920 Recreation and leisure		
My swallowing problem makes it hard to have a social life	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Social functioning
	Social Impact	Activities and Participation (d)	9 Community, social and civic life	D920 Recreation and leisure		
My usual work or leisure activities have changed because of my swallowing problem	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine system	B510 Ingestion functions	Life Impact	Role functioning
	Change in normal routine	Activities and Participation (d)	2 General tasks and demands	D230 Carrying out daily routine		

Social gatherings (like holidays or get-togethers) are not enjoyable because of my swallowing problem	Social gatherings	Activities and Participation (d)	9 Community, social and civic life	D920 Recreation and leisure	Life Impact	Social functioning
My role with family and friends has changed because of my swallowing problem	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Role functioning
	Familiar Roles	Activities and Participation (d)	7 Interpersonal interactions and relationships	D770 Intimate relationships		

Table 7.4: EAT-10 mapped to ICF and COMET Taxonomy

ITEM	ICF CONCEPT	ICF COMPONENT	ICF CHAPTER	ICF CATEGORY	COMET CORE AREA	COMET OUTCOME DOMAIN
My swallowing problem has caused me to lose weight	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/ Clinical	Metabolism and nutrition outcomes
	Lose Weight	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B530 Weight maintenance functions		
My swallowing interferes with my ability to go out for meals	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Social functioning
	Go out for meals	Activities and Participation (d)	9 Community, social and civic life	D920 Recreation and leisure		
Swallowing liquid takes extra effort	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Physical functioning
	Drinking	Activities and Participation (d)	5 Self-care	D560 Drinking		
	Effort	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
Swallowing solids takes extra effort	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Physical functioning

	Eating	Activities and Participation (d)	5 Self-care	D550 Eating		
	Effort	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
Swallowing pills takes extra effort	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Physical functioning
	Medication	Activities and Participation (d)	5 Self-care	D570 Looking after one's health		
	Effort	Body Functions (b)	2 General tasks and demands	D230 Carrying out daily routine		
Swallowing is painful	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Physiological/ Clinical	General outcomes
	Painful	Body Functions (b)	2 Sensory functions and pain	B280 Sensation of pain		
The pleasure of eating is affected by my swallowing	Eating	Activities and Participation (d)	5 Self-care	D550 Eating	Life Impact	Emotional functioning/ wellbeing
	Pleasure	Activities and Participation (d)	9 Community, social and civic life	D920 Recreation and leisure		
	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions		

When I swallow, food sticks in throat	Food sticking	Body Functions (b)	2 Sensory functions and pain	B280 Sensation of pain	Physiological/clinical	Gastrointestinal outcomes
	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions		
	Throat	Body Structures (s)	3 Structures involved in voice and speech	S330 Structure of pharynx		
I cough when I eat	Cough	Body Functions (b)	4 Functions of the cardiovascular, haematological, immunological and respiratory systems	B450 Additional functions of the respiratory system	Physiological/clinical	Respiratory, thoracic and mediastinal outcomes
	Eating	Activities and Participation (d)	5 Self-care	D550 Eating		
Swallowing is stressful	Swallowing	Body Functions (b)	5 Functions of the digestive, metabolic and endocrine systems	B510 Ingestion functions	Life Impact	Emotional functioning/wellbeing
	Stressful	Activities and Participation (d)	2 General tasks and demands	D240 Handling stress and other physiological demands		

Table 7.5: Frequency of ICF categories

ICF CATEGORY	TOTAL NO. OF TIMES IDENTIFIED/ FREQUENCY	NO. OF TIMES IDENTIFIED IN SWAL-QOL/ FREQUENCY	NO. OF TIMES IDENTIFIED IN EAT-10/ FREQUENCY
b510 – Ingestion functions	n=27, 35%	n=18, 34%	n=9, 36%
b450 – Additional functions of the respiratory system	n=10, 12%	n=9, 17%	n=1, 4%
d550 – Eating	n=8, 10%	n=5, 9%	n=3, 12%
d230 – Carrying out daily routine	n=8, 10%	n=5, 9%	n=3, 12%
d920 – Recreation and leisure	n=6, 8%	n=4, 8%	n=2, 8%
b280 – Sensation of pain	n=4, 5%	n=2, 4%	n=2, 8%
b130 – Energy and drive functions	n=3, 4%	n=3, 6%	0
d560 – Drinking	n=3, 4%	n=2, 4%	n=1, 4%
d240 – Handling stress and other physiological demands	n=3, 4%	n=2, 4%	n=1, 4%
d177 – Making decisions	n=2, 3%	n=2, 4%	0
b530 – Weight maintenance functions	n=1, 1%	0	n=1, 4%
d570 – Looking after one’s health	n=1, 1%	0	n=1, 4%
d770 – Intimate relationships	n=1, 1%	n=1, 2%	0
s330 – Structure of pharynx	n=1, 1%	0	n=1, 4%

Table 7.6: Frequency of COMET Taxonomy outcome domains

COMET TAXONOMY OUTCOME DOMAIN	TOTAL NO. OF TIMES IDENTIFIED/ FREQUENCY	NO. OF TIMES IDENTIFIED IN SWAL- QOL/ FREQUENCY	NO. OF TIMES IDENTIFIED IN EAT-10/ FREQUENCY
Emotional functioning/wellbeing	n=15, 32%	n=13, 35%	n=2, 20%
Gastrointestinal outcomes	n=10, 21%	n=9, 24%	n=1, 10%
Respiratory, thoracic and mediastinal outcomes	n=6, 13%	n=5, 14%	n=1, 10%
Social functioning	n=5, 11%	n=4, 11%	n=1, 10%
Physical functioning	n=5, 11%	n=2, 5%	n=3, 30%
Metabolism and nutrition outcomes	n=3, 6%	n=2, 5%	n=1, 10%
Role functioning	n=2, 4%	n=2, 5%	0
General outcomes	n=1, 2%	0	n=1, 10%

7.7 Discussion

7.7.1 Overview of findings

The results of this study suggest that patient perspectives and priorities are not being routinely considered in dysphagia clinical trials following stroke. Of the 110 studies included in this review, just over 10% (n=12) included a commonly used and validated PROM in the evaluation of the effectiveness of the intervention under examination. Indeed, only 17% (n=19) of studies included any measure of patient perception, regardless of validity, reliability or common use. Of the 12 studies that did include a PROM, the two measures that were used in these studies – the SWAL-QOL (McHorney et al. 2002) and the EAT-10 (Belafsky et al. 2008) – are both generic dysphagia assessment tools that were developed with a general dysphagia population in mind.

The SWAL-QOL was cited in 10 of the 12 RCTs, which included a PROM. This may not be surprising, given the sound psychometric properties reported in the literature and the validation of its use in many dysphagia populations (Timmerman et al. 2014, Patel et al. 2017). However, the feasibility of the SWAL-QOL has long been questioned in the literature, given that the person with dysphagia must make a rating on a 5 point scale and different instructions are given for different sections throughout the tool. As a result, the accessibility of the tool may prove particularly difficult for persons with cognitive, communication and/or other literacy challenges (Zraick et al. 2012, Lemmens et al. 2013, Simpelaere et al. 2017). This issue becomes especially relevant in persons presenting with dysphagia following stroke, given the wide range of concomitant impairments including aphasia that this group can and do present with (Flowers et al.

2013, Stipancic et al. 2019). Indeed, these challenges in the use of the SWAL-QOL were highlighted in the findings reported in Section 3 of this thesis, with the SLT participants specifically highlighting the SWAL-QOL as being particularly cumbersome and not suitable for use in clinical practice in persons following stroke.

By comparison, the EAT-10 may be relatively quick and easy to administer, with only 10 items which the person with dysphagia is required to rate on a scale of 0 to 4 (Speyer et al. 2014). Alongside its use as a PROM, numerous studies have shown the ability of the EAT-10 to be used a screening tool to detect dysphagia and aspiration in some clinical groups (Cheney et al. 2015, Rofes et al. 2014, Arslan et al. 2017). However, the psychometric properties of the EAT-10 have recently been questioned in the literature (Cordier et al. 2017, Wilmskoetter et al. 2019a). Furthermore, it has been suggested that the EAT-10 may lack sufficient depth and detail to track and demonstrate changes in the person's perception of their swallowing problem (Wilmskoetter et al. 2019a). The authors of the tool acknowledge that in order to achieve ease in administration and use, it was necessary to limit the depth and breadth of the items that were assessed (Belafsky et al. 2008). As a result, items that specifically assess the social, emotional and functional impact of dysphagia were omitted. Therefore the very use of the EAT-10 in the assessment of psychosocial wellbeing and QOL is questionable.

Beyond the use and feasibility of the two PROMs that were highlighted following the scoping review, the qualitative analysis of these PROMs also suggested some important findings. When the identified concepts within the SWAL-QOL were mapped to the ICF, the majority of items were related to 'Body Functions', suggesting that the

outcome measure focuses mainly on the physiological aspects of the swallow process. However, all of the other concepts within the measure were related to the ‘Activities and Participation’ chapter within the ICF framework. This suggests that the measure also recognises the restrictions that dysphagia can place on a person’s involvement in everyday activities and day-to-day life situations.

A notable gap within the SWAL-QOL however, was the lack of consideration for ‘Environmental Factors’. Within ‘Environmental Factors’, the ICF considers the impact of important concepts such as relationships and support structures, familial and societal attitudes, social policy, and health service delivery. It is widely recognised that a significant link exists between dysphagia and social isolation (Pizzorni 2017). Furthermore, the findings from the two studies reported in Section 2 of this thesis, demonstrate the significant impact that ‘Environmental Factors’ has on the experiences of both persons living with long-term dysphagia following stroke and those living with dysphagia during the stroke rehabilitation journey. The absence of any item that can be linked to the Environmental Factors chapter of the ICF, suggests that the SWAL-QOL may not be holistic enough to consider the complex and wide-ranging impact that dysphagia can have in this population.

A similar gap in content was evident when the EAT-10 was mapped to the ICF. Again, the items in this measurement tool represented categories in both the ‘Body Functions’ and ‘Activities and Participation’ chapters, and also included one concept that was mapped to ‘Body Structures’. However, the lack of consideration for and inclusion

of items that could be linked to ‘Environmental Factors’ was noteworthy, with no item in the EAT-10 mapped directly to this chapter of the ICF.

When both the SWAL-QOL and the EAT-10 were mapped to the COMET Taxonomy, only two of a possible five core areas were represented – ‘Physiological/Clinical’ and ‘Life Impact’. However, given that these are PROMs, this is to be expected, as the other core areas within the COMET Taxonomy – ‘Death’, ‘Resource Use’ and ‘Adverse Events’ – are not suitable to be rated by the person with dysphagia. Of note, within the core area of ‘Life Impact’, the outcome domain ‘Role functioning’ was only mapped twice – both times within the SWAL-QOL. Again, this suggests that both of these outcome measures may not be giving enough consideration to the impact that dysphagia can have on a person’s role and function within society.

In order to ensure that the perspectives, experiences and priorities of persons with dysphagia following stroke are fully considered in both research and clinical practice, the findings of this study suggest that the development of a stroke-specific dysphagia PROM may be necessary. Consideration of the findings from Section 2 in this thesis, suggests that this measurement tool should include a broad range of assessment items that equally target ‘Body Functions’, ‘Activity and Participation’, and ‘Environmental Factors’. Furthermore, any PROM should ideally be developed in collaboration with the clinical population for which the measure is intended to be used, otherwise the relevance and appropriateness of the tool cannot be guaranteed (Testa & Simonson 1996, Staniszevska et al. 2012). If a PROM specific to the stroke population with dysphagia is to be developed, then the breadth and depth of the assessment items which are included will

need to be balanced with accessibility and feasibility, given the challenges in assessment that were reported by the SLT participants in Section 3 of this thesis, and the likelihood that persons with dysphagia following stroke may also present with some level of cognitive and/or communication difficulties.

Finally, it is worth noting that the findings of this study, suggest that dysphagia research following stroke is currently lacking a uniform and consistent approach to outcome measurement in general. A total of 30 outcome measures were identified in the first stage of the scoping review. Beyond the Penetration-Aspiration Scale (Rosenbek et al. 1996), which was cited 30 times, there was significant heterogeneity in the other measures that were included. Consideration should therefore be given to the development of a core outcome set for dysphagia research following stroke, with this core outcome set including a stroke-specific dysphagia PROM.

7.7.2 Methodological considerations

There are known limitations in the use of the ICF to map the content of outcome measure tools. Firstly, a number of concepts may not be classified under the current version of the framework and so may need to be excluded (Nund et al. 2019). In order to mitigate the impact of this on the findings of the study, a second framework was also used – the COMET Taxonomy. The use of both frameworks in the mapping exercise ensured that all relevant assessment items were accounted for and also offered a level of data triangulation. Similar gaps in the identified PROMs were highlighted when mapped to both frameworks and so this strengthens this finding.

Secondly, limitations in the inter-rater reliability of mapping outcome measures to the ICF have been recognised in the literature (Starrost et al. 2008, Chen et al. 2016), with similar biases and nuances in interpretation likely to have occurred in mapping the tools to the COMET Taxonomy outcome domains. A certain level of subjectivity and interpretation is required in the development of concepts from assessment items. Further subjectivity and interpretation can exist in linking these concepts to a relevant ICF chapter and category. For example, when considering item number 5 in the EAT-10 – ‘Swallowing pills takes extra effort’ – the concept of pills was mapped to the ‘Activities and Participation’ component, the ‘Self-care’ chapter and the category ‘Looking after one’s health’, as it was interpreted that pills in this context was related to the activity of taking medication and the person’s ability to do this. However, if the concept of pills had been taken in isolation, without consideration for the context in which the concept was phrased, it may have been mapped as ‘Products or substances for personal consumption’ under the ‘Environmental Factors’ component of the framework.

In order to minimise the impact of bias and interpretation, the study would have been strengthened if a larger number of researchers had completed the mapping process independently, with disagreements discussed until consensus reached. If this approach was taken, the reliability of the mapping process could also have been evaluated statistically by computing percentage exact agreement scores for example. However, the timeline and resources for completion of the study restricted what was possible.

7.8 Conclusions

This study described a scoping review and qualitative analysis that identified and evaluated two PROMs that are currently in common use in dysphagia clinical trials following stroke. The findings of this study highlight the lack of priority that current research gives to the evaluation and measurement of psychosocial wellbeing and QOL in intervention studies. The findings of this study also highlight the lack of a suitable stroke-specific dysphagia PROM which comprehensively assesses the wide-ranging and broad experiences of this clinical population. The development of a suitable and appropriate patient-reported measurement tool for use in those with dysphagia following stroke is warranted.

CLINICAL ASSESSMENT TOOLS FOR EXPLORING PSYCHOSOCIAL WELLBEING AND QUALITY OF LIFE IN DYSPHAGIA FOLLOWING STROKE: SUMMARY OF FINDINGS FROM SECTION 4

- Clinical trials on dysphagia intervention in the stroke population fail to recognise the importance of considering psychosocial wellbeing and QOL as a relevant outcome measure.
- If and when QOL is included as an outcome in dysphagia clinical trials, there are a limited number of PROMs currently being used in the research to evaluate this aspect of care.
- The PROMs that are commonly in use have been designed and validated for the general dysphagia population and are not specific to the needs of those persons living with dysphagia following stroke.
- The SWAL-QOL is one of these commonly used PROMs – this tool poses significant difficulties for the stroke population with dysphagia, given its length and the complexity of the language and instructions that it includes.
- Although not a QOL measure, the EAT-10 is also in use – the underlying psychometric properties of this tool have been questioned, alongside the breadth of the content that is covered within the tool.
- When mapped to the ICF, neither the SWAL-QOL nor the EAT-10 have any assessment items which explore the impact of ‘Environmental Factors’ on the person’s experience of dysphagia.
- When mapped to the COMET Taxonomy, both the SWAL-QOL and the EAT-10 demonstrate a lack of appreciation for the impact that dysphagia has on a person’s role and function within society.
- A stroke-specific dysphagia PROM is necessary to support clinical practice and ongoing research in the dysphagia population.
- Consideration should also be given to the development of a core outcome set in dysphagia intervention studies following stroke – QOL should be included in this minimum data set and measurement of that outcome must be considered.

SECTION 5: DISCUSSION

Chapter 8: Integration of findings

8.1 Summary of study findings

The importance of considering psychosocial wellbeing and QOL following stroke is increasingly recognised (Sumathipala 2012). However, research in this area, particularly for persons with dysphagia, remains scarce. This thesis presented exploratory research into psychosocial wellbeing and QOL in the stroke population with dysphagia. This was achieved by exploring three key areas – the experiences of persons with dysphagia following stroke, the beliefs, attitudes and practice patterns of SLTs when working in this clinical area, and the assessment tools that are commonly used to evaluate psychosocial wellbeing and QOL. Five studies were completed in the exploration of these areas.

Section 2 presented two studies which explored the impact of dysphagia on QOL following stroke. In Chapter 3, autobiographical stories recounting the authors' experiences of the stroke rehabilitation journey were analysed using IPA. The importance of early education and reassurance, and individualised approaches to assessment and management are highlighted, with the findings also demonstrating the significant social and emotional consequences of dysphagia during this time. In Chapter 4, the experiences of persons with long-term dysphagia following stroke were explored. Data was collected using one-to-one interviews with study participants and was analysed using IPA. The findings of this study highlighted variations in service delivery and care pathways for this clinical group and demonstrated the need for ongoing and regular access to SLT in the months and years following a stroke.

In Section 3, the current clinical practice patterns of SLTs when addressing and supporting QOL in dysphagia following stroke were explored. In Chapter 5, an international survey study with SLT participants was reported. The findings of this study established the significant variations and inconsistencies that currently exist in clinical practice in this area, and outlined a number of challenges to supporting QOL specific to the stroke population. These challenges were further explored in an international focus group study which was presented in Chapter 6. The findings of this focus group demonstrated the unique complexities faced by SLTs when working in this clinical area, with a lack of clinical resources and professional consensus on assessment and management approaches reported as significant contributory factors.

Finally, Section 4 presented a scoping review which explored the use of PROMs in evaluating psychosocial wellbeing and QOL in clinical trials on dysphagia intervention following stroke. The results of this study, which are presented in Chapter 7, suggest that psychosocial wellbeing and QOL is not consistently considered as an outcome measure in stroke-related dysphagia research. Furthermore, the two PROMs that were identified as being in common use – the SWAL-QOL and the EAT-10 – are unlikely to meet the needs of both the person with dysphagia and the SLT working in this clinical area.

8.2 Integration of study findings

As described in Chapter 1, the theoretical framework of this thesis is that our understanding of the experiences of persons with dysphagia following stroke, our clinical

practice in this area, and future research priorities and professional development needs are all interlinked. Therefore, on completion of all five studies, it was important to integrate the findings of each, towards the development of new knowledge and understanding regarding the area under investigation.

As outlined in Chapter 2, the triangulation protocol developed by Farmer and colleagues was adapted and used to integrate the findings of the five research studies completed as part of this thesis (Farmer et al. 2006). Using this protocol, the findings from Section 2 (the experiences of persons with dysphagia following stroke), Section 3 (current SLT clinical practice) and Section 4 (the inclusion of PROMs in stroke-related dysphagia clinical trials) were integrated. This integration process resulted in the development of eight overarching or meta-themes. Following assessment for convergence of these themes across the study findings, there was agreement across two themes, partial-agreement across three themes and dissonance/disagreement across the remaining three themes (Table 8.1).

Table 8.1: Convergence coding matrix

META-THEME	CONVERGENCE CODE
Assessment of psychosocial wellbeing and quality of life	D
Importance of goal-setting	PA
Intervention planning	PA
Uncertainty regarding prognosis	AG
Withdrawing active rehabilitation	PA
Access to services	AG
Prioritising psychosocial wellbeing and quality of life	D
Influence of environmental factors	D

AG = agreement, PA = partial agreement, D = dissonance

8.2.1 Assessment of psychosocial wellbeing and quality of life

The findings from Section 3 of this thesis suggest that SLTs feel psychosocial wellbeing and QOL should be routinely assessed and considered in clinical practice. However, assessment in this clinical area is described as particularly challenging. Many different assessment approaches are described, with just over half of the participants in the survey study reporting formally assessing QOL on a routine basis.

The SLT participants reported that it was difficult to find the time to complete a QOL assessment as the limited tools that are available are reported as being time-consuming and not user-friendly. As a result, informal observations and subjective judgements regarding QOL are often the only assessments that are being made, with the majority of participants describing the use of case history details and observations of the patient as their primary means for assessing psychosocial impact and QOL. Given the subjective nature of both of these approaches, their consistent use both between and amongst SLTs, would have to be questioned. When the SLT participants did report using formalised or objective tools, such as rating scales or specific QOL assessments, there was little consensus regarding the most appropriate tools to use. Furthermore, participants reported that a lack of clinical and best practice guidelines to support if, how, and when QOL should be assessed, further compound the challenges that they face.

By comparison, the results from the scoping review presented in Section 4 suggest that the assessment of psychosocial wellbeing and QOL is not considered as a priority outcome measure in dysphagia RCTs following stroke. This may go some way towards explaining the significant challenges that the SLTs report in the assessment of QOL

during the stroke rehabilitation journey. The finding that the majority of dysphagia clinical trials following stroke do not routinely consider the assessment of psychosocial wellbeing and QOL may be contributing to both the lack of international recommendations available to guide clinicians, and the challenges reported by the SLT participants in this thesis. When these studies do consider QOL, the PROMs that are commonly used may pose difficulties for use in the stroke population, who so often present with co-occurring communication and/or cognitive changes (Flowers et al. 2013, Stipancic et al. 2019). Furthermore, when considered in the context of the findings from Section 2 in this thesis, the items that are considered and assessed in these PROMs are unlikely to be comprehensive enough to fully capture and explore the experiences of the person with dysphagia following stroke.

8.2.2 Importance of goal-setting

The findings from Section 2, demonstrate the importance of goal-setting towards both motivation and well-being in persons with dysphagia following stroke. Throughout the stroke rehabilitation journey, persons with dysphagia describe how even though some goals may have appeared trivial or inconsequential to others, they marked significant milestones in their stroke recovery when these goals were met or achieved. For persons with long-term dysphagia following stroke, they describe the positive impact that ongoing goals and hopes for the future has on overall wellbeing.

With regards SLT practice in this area, goal-setting was described as being a particularly challenging aspect to dysphagia management, when considering psychosocial wellbeing and QOL following stroke. Significant variations were seen in

the SLT participants' approaches, with the most obvious difference being whether or not the person with dysphagia was included in the process. For some of the SLT participants they felt it was integral to include and have input from both the person with dysphagia and their family/carers. These participants felt that with this inclusionary approach, the person with dysphagia is likely to be more engaged and motivated, as the goals for care are personally relevant to them.

For other SLT participants their experience has been that the person with dysphagia is often more comfortable with having their goals and priorities for care decided for them by their healthcare worker. As a result, they were unlikely to spend time discussing and setting goals with the person with dysphagia. Furthermore, these participants reported that developing personalised and individual goals is a challenging aspect to the care that they provide. It may be worth considering if these variations in the approaches to goal-setting are linked to the challenges and inconsistencies that were reported in the assessment process. If a comprehensive and appropriate assessment and understanding of the priorities and aspirations of the person with dysphagia is not developed, it will subsequently be very difficult to set meaningful and suitable intervention goals (Sugavanam et al. 2013, Plant et al. 2016).

For persons with cognitive and communication difficulties who present with post-stroke dysphagia, the SLT participants described the extra time required if they attempt to include the person in assessment, goal-setting and intervention planning. They described the added layer of complexity involved, with the limited use of formal QOL assessment tools in this population again acknowledged. As a result, the SLT participants

reported that their options for assessment are limited to observations or discussions with the person's family and carers. A lack of clinical time was cited as a significant challenge in addressing psychosocial wellbeing and QOL in general, and so this challenge becomes even greater when working with those who require additional support to engage in this process.

As the authors of the autobiographical accounts progressed through their stroke rehabilitation journey they described how they often became more involved in both setting their own goals and negotiating their own management plans. This increasing assertiveness often coincided with the person with dysphagia taking 'risks' and demonstrating 'non-compliance' with oral intake recommendations made by their SLT or other healthcare worker. With regards this 'risk-taking' behaviour, the SLT participants discussed how persons with dysphagia who place a higher priority on QOL, are more likely to be 'non-compliant' with oral intake recommendations. The SLTs reported understanding the person's motivation for not following these recommendations but described how it conflicts with their priority for intervention, which is to maintain safe nutrition and hydration.

There was also a suggestion from the SLT participants that when persons with dysphagia are 'non-compliant' with SLT recommendations regarding oral intake, it can often be due to a lack of understanding of the risks that are involved. Interestingly, the findings from both the autobiographical accounts and the interviews with persons with dysphagia following stroke, suggested that the participants in these studies knowingly engage in these behaviours. Furthermore, the persons with dysphagia in this thesis

reported that their motivation for taking these risks is to improve or enhance their psychosocial wellbeing and QOL. If SLTs had the opportunity, and the appropriate clinical tools to develop a shared understanding of the specific priorities and goals of the person with dysphagia, then these confusions and misunderstandings regarding ‘non-compliance’ may not be so commonplace (Kleinsinger 2010, King & Ligman 2011).

8.2.3 Intervention planning

Beyond goal-setting, the SLT participants reported differing approaches to intervention and management strategies. For some participants they questioned what they can actually offer the person with dysphagia, other than to facilitate active rehabilitation. For other participants they described a role in sign-posting the person with dysphagia to appropriate voluntary and support agencies for psychosocial support.

The SLT participants reported a lack of knowledge as a contributing factor, which they linked to both a lack of research and best practice guidelines. However, it is also worth considering that without an objective and robust assessment process, it will be extremely difficult for any clinician to discuss and set personally relevant goals and subsequent intervention plans with the person with dysphagia following stroke. Furthermore, it will be difficult to quantify any improvement in psychosocial wellbeing and QOL following management and intervention. Therefore, the lack of appropriate stroke-specific QOL assessment tools may be further contributing to the challenges faced by SLTs when they attempt to set goals and associated intervention plans.

Throughout their rehabilitation journeys, the authors of the autobiographical accounts describe a number of individualised compensatory strategies they have developed towards supporting their ability to have their preferred food and drinks with increased comfort and safety. This trial and error in the development of individualised compensatory strategies was also seen in the interviews completed with persons with long-term dysphagia following stroke, with one participant in the interview study describing the positive influence that his SLT had on his confidence in trialling new food and drinks with these compensatory strategies. A number of the authors of the autobiographical accounts also reference support they had from healthcare workers in developing these strategies.

However, none of the SLT participants in this thesis referenced the development of individualised approaches to eating and drinking preferred ‘high-risk’ foods as an approach to supporting QOL in this clinical group. Of note, participants in the international focus group reported that the individualised and personal approach that is often needed when supporting QOL in dysphagia following stroke, was one of the specific challenges to clinical practice in this area.

If persons with long-term dysphagia following stroke can access ongoing SLT, the participants in the interview study reported that there would be multiple benefits, including supporting their ability to cope with and manage their day-to-day dysphagia associated symptoms, ongoing education and advice, and regular re-assessment of their swallow function for signs of improvement. However, the priorities for intervention

reported by the SLT participants for persons with long-term dysphagia following stroke are less clear.

Although the SLT participants reported they were more likely to prioritise QOL in this group, the importance of maintaining swallow safety and adequate nutrition and hydration was still noted. If and when active rehabilitation is concluded, many of the SLT participants indicated that psychosocial wellbeing and QOL would then become a clear priority for care for this clinical group, however, only a small number of SLT participants reported that they would likely keep the person open and active on their clinical caseload. The SLTs suggest that these variations can be due to either differences in service policies and care pathways, or to differences in individual therapists' approaches to long-term management. Interestingly, the SLT participants reported that education and training would not be a priority for intervention, even though advice and ongoing information was reported as being particularly important for the persons living with dysphagia.

8.2.4 Uncertainty regarding prognosis

The autobiographical accounts analysed in Chapter 3 recount the extreme anxiety and panic the authors experienced when they first realised the extent of their swallowing difficulties. A lack of understanding and uncertainty further compounds these feelings of fear and alarm, and the authors recall how they begin to question very early on what their potential for recovery and expectations for the future should be.

On discussing these concerns regarding recovery and prognosis with their healthcare workers, the authors describe feelings of frustration and anger. For some

authors they felt the prognosis they were given was overly optimistic, for others they reported feeling their healthcare workers were not being optimistic enough. Interestingly, in the interviews completed with persons living with long-term dysphagia following stroke, the participants also discussed the impact that these early discussions regarding prognosis and expectations for recovery subsequently had on their experience of the stroke rehabilitation journey. These participants reported they were unprepared for the possibility that they would have long-term difficulties with swallowing following stroke, as they feel it was never explicitly discussed with them.

An interesting challenge reported by the SLT participants in this thesis was the unpredictability of the stroke trajectory, the stroke rehabilitation journey and expectations for recovery. In particular, the participants discussed the validity of their management recommendations and the lack of clarity they often have regarding a person's specific rehabilitation potential and associated swallow risk. The participants felt that the timeframe and expected rehabilitation gains for persons with dysphagia following stroke can be ambiguous, and so for this reason it can be difficult to know if and when to begin to consider QOL. Again, the SLTs report that the lack of clarity they have regarding the stroke journey becomes particularly obvious when they compare their management in stroke to their management in other clinical populations, such as those with progressive neurological diseases and head and neck cancer.

To demonstrate the specific challenges experienced in this area, the SLT participants referenced particular examples where they felt that gaps in their clinical knowledge made their management of QOL particularly challenging. Participants

discussed persons with dysphagia who were consistently ‘non-compliant’ with oral intake recommendations but who never developed aspiration pneumonias or other associated complications. The SLT participants described how they had been proven wrong in these scenarios and that this resulted in subsequent challenges when explaining to the person with dysphagia their rationale for recommending restrictions in oral intake.

The participants also referenced the acknowledged gaps in the evidence base for certain dysphagia rehabilitation and compensatory strategies (Cohen et al. 2016, Bath et al. 2018, Jones et al. 2020), and how they felt this influenced the adherence of the person with dysphagia. Again, the SLT participants described challenges in defending the restrictions they might suggest on the types of food and drink a person can take, when the SLTs themselves are not fully convinced of the appropriateness of their recommendations.

8.2.5 Withdrawing active rehabilitation

Variations and inconsistencies were seen when the SLT participants reported on their decision making regarding the withdrawal of active rehabilitation. Again, there was no clear consensus amongst participants as to if and when active rehabilitation should be concluded. Clear discrepancies in how SLTs are approaching this aspect of care were evidenced throughout both the survey study and the focus group. For some participants, ongoing active rehabilitation continues indefinitely, whereas for others, they may make a decision to withdraw rehabilitation within the first 3 months following stroke.

Despite living with dysphagia for many years after their stroke, the participants in the interview study all report ongoing hope for improvement in their dysphagia symptoms – a finding that was also reported in the one other study which has been published in this area (Helldén et al. 2018). Despite not being linked in with SLT services on an ongoing basis, two of the three participants report independently completing ongoing dysphagia rehabilitation exercises. Although ongoing exercise has been advocated towards minimising the impact of detraining on swallow function (Burkhead et al. 2007, Oh 2015), without appropriate remote supervision and regular review, the appropriateness and accurate execution of these dysphagia rehabilitation exercises would have to be questioned. The discussions that were had with these persons with dysphagia regarding prognosis, expectations for ongoing recovery, and the reason for withdrawing active rehabilitation are unclear. However, considering the reports from the SLT participants regarding both the difficulties in decision-making regarding the withdrawal of active rehabilitation and the low priority placed on education and information, it could be hypothesised that patient participation in these discussions was minimal.

Of note, the participants in the interview study discuss the positive impact that continued hope for improvement has on their mental health and well-being. Interestingly, the SLT participants in this thesis acknowledge that ongoing therapy may have a positive impact on the QOL of persons with dysphagia, but believe that those persons who are more accepting of their difficulties have a better QOL. This suggests an interesting divergence in the perspectives of the persons with long-term dysphagia and the SLT participants in this thesis.

8.2.6 Access to services

The SLT participants in both the international survey study and the international focus group described the impact that limitations in service delivery structures have on their ability to address and support psychosocial wellbeing and QOL in persons with dysphagia following stroke. In particular, the participants referred to both the lack of follow-up and variations in services for persons with long-term difficulties with swallowing. Throughout the interviews with persons with long-term dysphagia following stroke, the variations in the SLT services that are available are clear. Furthermore, the interview participants feel they have to continually fight and advocate for access to these services. Although the interview participants were all discussing their experiences of the Irish healthcare service, the participants of Helldén's Swedish based study, reported similar findings, suggesting this may be an international experience (Helldén et al. 2018).

Although the SLT participants acknowledged the positive contribution that voluntary organisations and agencies can play, they feel that the absence of ongoing stroke-specific MDT input for persons with dysphagia following stroke, significantly affects what can be offered by SLTs towards assessing and supporting psychosocial wellbeing and QOL. There was a suggestion from some of the participants that QOL issues are more likely to become a priority for persons with dysphagia when they return home, and that unfortunately this is the time when services are likely to be least available to them.

The SLT participants also discussed the impact that moving through various services can have on the person with dysphagia. Throughout the stroke journey the person

is likely to have input from acute teams, inpatient rehabilitation teams, specialist community rehabilitation teams and general community follow-up healthcare professionals. As a result, the SLT participants felt this has an impact on the consistency and quality of care that can be provided.

Finally, the SLT participants reported challenges in MDT working when it comes to addressing and supporting QOL in dysphagia following stroke. In particular, the participants discussed the impact of the widely recognised lack of psychology services (Intercollegiate Stroke Working Party 2016, Stroke Alliance of Europe 2017) on their ability to meet the holistic needs of these persons with dysphagia. Additional to this, the participants felt that MDT members are not always fully cognisant of the significant impact that dysphagia can have on QOL. As a result, they felt that support for QOL as a priority for care is not always evident when it comes to team discussions regarding intervention planning and management decisions for persons with dysphagia.

8.2.7 Prioritising psychosocial wellbeing and quality of life

The findings from Section 2 demonstrate the significant impact that dysphagia has on psychosocial wellbeing and QOL throughout the stroke journey. This impact is evident from the earliest days post stroke, throughout the rehabilitation journey, and continues for persons living with long-term swallowing difficulties. Although the SLT participants in this thesis acknowledged that QOL should be a priority of care for assessment and intervention in persons with dysphagia following stroke, there was a lack of consensus as to when QOL should be addressed. For some participants they felt that QOL should be acknowledged and addressed throughout all stages of the stroke journey. For other

participants, they reported that the sub-acute rehabilitation stage and/or the point at which the person returns home were more appropriate, as they felt this was when the person was most likely to be aware of the impact of their dysphagia on QOL.

Of note, the SLT participants reported that QOL in the acute stages following stroke poses significant challenges. There was general agreement amongst the participants that the acute stage post-stroke was the time during which they were least likely to address QOL, as the majority of SLT participants felt it is most appropriate to focus on maintaining swallow safety and adequate nutrition and hydration. Furthermore, the SLT participants reported that for most people with dysphagia, their swallowing difficulties are often temporary and some level of recovery is expected. With an expected recovery in swallow function, the SLT participants reported they do not necessarily prioritise psychosocial wellbeing and QOL in their dysphagia management at this stage. Interestingly, although the SLT participants in the international focus group discussed the importance of patient education and training in supporting QOL, the SLT participants in the international survey ranked education and training as the lowest priority goal in the acute stages following stroke. Given the experiences reported by the participants in the autobiographical study, an emphasis on education, advice, and information sharing, with both the person with dysphagia and their family in the early stages following stroke, may go some way towards alleviating the significant anxiety and fear that is commonly experienced (Azizi et al. 2020).

Although the majority of SLT respondents in the survey study agreed with the definition of QOL that was proposed by the WHO, there was debate regarding the

definition amongst the participants in the SLT focus group. Participants had differing opinions as to whether QOL was solely linked to eating and drinking despite an acknowledged aspiration risk, or whether it was a wider management concept that involved incorporating the wishes of the person with dysphagia throughout the assessment and therapy process. The SLT participants discussed how the lack of clarity regarding what is meant by QOL, affects both their assessment and therapy approaches and can lead to difficulties in prioritising treatment goals. The participants reported that their confusion regarding the definition of QOL becomes more apparent when they compare their practice when working in stroke, to their practice with other patient populations, in particular those with progressive neurological conditions.

For persons with progressive and life-limiting conditions, the SLT participants in this thesis felt that the management of psychosocial wellbeing and QOL is much clearer, as the priorities for care are apparent to all involved i.e. the person with dysphagia, the SLT and the wider MDT. Considering this it could be proposed that the confusion reported by the SLT participants does not necessarily lie with the definition of QOL itself, but rather with the priority or weighting that QOL should be given in the stroke population. The finding that the SLT participants felt dysphagia is more likely to impact the QOL of persons with progressive neurological conditions and head and neck cancer, than persons with stroke, may support this hypothesis. The lack of emphasis on QOL as an important outcome in dysphagia clinical trials following stroke may also be a contributing factor.

8.2.8 Influence of environmental factors

The ICF defines ‘Environmental Factors’ as the ‘physical, social and attitudinal environment in which people live and conduct their lives’ (WHO 2002, p.10). In doing so, the framework acknowledges the important role that family and carer support networks, the perceived position of the person within their community, and access to services and systems including healthcare, has on their experience of their health condition.

The findings from Section 2 in this thesis highlight the significant impact of ‘Environmental Factors’ on the experiences of persons with dysphagia following stroke. The important role of caregivers, family, and friends is demonstrated, the impact of societal attitudes on the person’s motivation to attend and engage in social and celebratory events involving food and drink is clear, and the significant impact that access to consistent and long-term healthcare services can have is apparent.

The SLT participants in Section 3 further acknowledge the role that ‘Environmental Factors’ play in psychosocial wellbeing and QOL in this clinical group. The importance of including family and caregivers where possible throughout their assessment and management of dysphagia is discussed, while the SLTs who participated also believe that persons with robust and healthy support networks are less likely to experience the negative impacts of dysphagia following stroke. Alongside caregiver supports, the SLTs recognise the importance of social re-integration in living well following stroke and in doing so acknowledge the likely impact that dysphagia and dysphagia-related symptoms will have on the person’s ability to achieve this. Finally, the

SLT participants are very aware of the significant inconsistencies and limitations that currently exist in the service delivery models available for persons with dysphagia following stroke, particularly for persons living with long-term swallowing disorders. The participants discuss how these inconsistencies and limitations impact the quality of the service that they are able to offer, and subsequently the experiences of the person living with dysphagia.

By comparison, the findings from the qualitative analysis completed in Chapter 7 show that ‘Environmental Factors’ are not explicitly considered in the PROMs that are commonly being used in dysphagia clinical trials in the stroke population. As a result, alongside limitations in the feasibility of their use in the stroke population, these tools are not considering all of the factors that will impact the person’s experience of this phenomenon.

8.3 Quality of life - a universal challenge

Alongside the themes that were developed following the integration of the study findings outlined above, it is also important to note that the assessment and management of QOL in dysphagia is likely to pose challenges for SLTs across all clinical populations. The findings from the first section of the international survey, which looked at the assessment and management of psychosocial wellbeing and QOL more generally in the dysphagia population, demonstrated similar inconsistencies and variations in approaches to assessment and intervention. The participants were dissatisfied with the amount of

clinical time they could allocate to supporting QOL generally, and they highlighted gaps in professional knowledge, clinical resources, and MDT working as specific challenges in this area. Furthermore, the assessment and management of QOL is known to pose challenges in clinical groups who do not present with dysphagia. Similar research in persons with aphasia, dysarthria and palliative care needs has highlighted gaps in the knowledge base, a need for QOL specific resources, and the lack of time available to clinicians to address this important aspect of care (Collis & Bloch 2012, O'Reilly & Walshe 2015, Northcott et al. 2017).

With that being said, this thesis sought to explore QOL specific to the stroke population with dysphagia. In doing so, the particular challenges associated with this clinical group have been highlighted. For the person with dysphagia, they face a complex journey, from the acute and sudden onset of their symptoms, through to navigating a complex and somewhat unpredictable stroke rehabilitation journey, and for some the prospect of living with long-term difficulties with eating and drinking. For the managing SLT, they understand and appreciate the importance of considering psychosocial wellbeing and QOL, but face uncertainty regarding when and how to assess and what intervention approaches may be suitable. This uncertainty is compounded by difficulties in predicting the stroke rehabilitation journey, limitations in service delivery structures, co-occurring cognitive and communication deficits in the person with stroke, and a lack of specific research in this area. The findings of this thesis highlight a number of key areas for consideration in clinical practice, and highlight a number of priorities for future research in this area.

8.4 Conclusions

This chapter considered the overall findings of the research studies that were completed as part of this thesis. When the findings from all five studies are integrated, a number of themes relevant to the experience and management of psychosocial wellbeing and QOL in dysphagia following stroke are generated. These themes allow new understandings and knowledge to be developed, and can be used to inform both clinical and research priorities for the future.

Chapter 9: Strengths, limitations and recommendations

9.1 Introduction

The findings of this thesis have a number of implications for both clinical practice and future research priorities. In order to frame the overall impact of these findings, it is important to firstly consider the quality of the research that was undertaken.

Given that the methodology used in this thesis was primarily qualitative in nature, the concept of trustworthiness and its use in evaluating the quality of qualitative research will be introduced. Consideration will then be given to the steps that were taken throughout this thesis, to enhance the trustworthiness of the studies that were completed. Consideration will also be given to opportunities that were missed and the limitations of the research. Finally, recommendations for both future clinical practice and future research priorities will be made.

9.2 Trustworthiness in qualitative research

Trustworthiness in qualitative research is used to establish the level of confidence that one can have in the data collection and analysis procedures that have been adopted (Polit & Beck, 2014). Similar to the use of validity and reliability in quantitative research, a number of specific criteria should be considered when determining the degree of trustworthiness of a qualitative study (Connelly 2016). The four criteria first suggested by Lincoln and Guba back in 1985, are still widely accepted by many qualitative

researchers as being the most appropriate. These criteria include credibility, transferability, dependability and confirmability (Lincoln & Guba 1985). In 1989, the authors added a fifth criterion – authenticity (Guba & Lincoln 1989).

Table 9.1: Criteria for ensuring trustworthiness in qualitative research

CRITERIA	DESCRIPTION	TECHNIQUES
Credibility	Findings are well explained, trustworthy and reliable	Triangulation; reflexive journaling; peer de-briefing; alignment of research methodologies
Transferability	Findings may have relevance to other settings	Detailed and thick description of both participants and research methods
Dependability	Methods are appropriate, coherent and reproducible	Triangulation; detailed and thick description; audit trail
Confirmability	Findings accurately reflect the views of the participants	Audit trail; reflexive research diary; consideration for researcher positionality
Authenticity	Research is genuine, worthwhile and impactful	Reflexive diary; thick description; impactful dissemination of findings

9.3 Developing trustworthiness in this research

The specific strengths of the individual studies completed as part of this thesis were discussed in the relevant study chapters. With consideration for Lincoln and Guba’s five criteria (Lincoln & Guba 1985, Guba & Lincoln 1989), this section will discuss a number of high-level methodological steps that were additionally taken throughout the research process, towards developing the overall trustworthiness of the research findings.

9.3.1 Methodological congruence

The principle of methodological congruence demands that there is harmony and alignment across a study's research purpose, research questions, paradigm, methodological approach, and data and collection methods. Orientation across these important elements in the design of a study contribute to the overall credibility of the study's results (Badu et al. 2019).

In the planning of this thesis, careful consideration was given to the selection and use of each of the components that would make up the overall research design. Following the adoption of a research paradigm which aligned with the ontology and epistemology of the researcher, a methodological approach was chosen. As discussed in Chapter 2, this methodological approach met the overall aims of the study, and complimented the chosen research paradigm. A range of data collection and analysis methods were then chosen. Again, each of these methods aligned closely with the research paradigm and methodological framework, and also fulfilled the aims of the study. Finally, a description of the rationale for the use of, and the strengths and limitations of each of these research parameters was provided.

9.3.2 Thick description

Thick description has been used for many years in qualitative research towards developing the overall trustworthiness of a study's findings. Thick description can be defined as a dense or intensive account which provides the reader with significant detail regarding context, actions and/or experiences (Krostjens & Moser 2018).

- *Methods:* In this thesis, a thick description of the data collection and analysis methods is provided in each relevant study chapter. This description includes specific details on the development of data collection methods and how they were used when interacting with the participants of the study. The description also includes step-by-step details describing the analysis of the data collected. This level of description contributes to the overall dependability of the studies that were completed.
- *Findings:* Thick description is used throughout the reporting of the findings of each study. Direct quotes from study participants are used in the relevant chapters, to evidence the detailed accounts provided of their experiences and perspectives. The use of thick description in this way contributes to the overall credibility and confirmability of the study's findings.

9.3.3 Minimising researcher bias

In all research, one of the biggest potential threats to the quality of a study's findings, is the impact of researcher bias. Researcher bias can be defined as the influence the researcher may have, either intentional or unintentional, on the overall results or findings of a study. Although some degree of prejudice is present in nearly all published studies (Pannucci & Wilkins 2011), researchers should always be aware of possible sources of bias and should take the necessary steps towards minimising the impact of this bias on data collection and analysis (Smith & Noble 2014). In qualitative research, these steps may include the use of a reflexive diary and/or the use of an audit trail (White et al. 2012)

- *Reflexive Diary:* A reflexive approach to qualitative research is now widely

recognised and accepted in the academic world (Barrett et al. 2020). Where previously qualitative researchers would have been encouraged to ‘bracket’ their preconceived assumptions and previous experiences in the process of data analysis, conscious acknowledgement of these values and their potential impact is now encouraged (Ortlipp 2008). As a result, the use of a reflexive diary has now become common practice in many qualitative studies. In order to contribute to the confirmability of the overall findings of this study, a reflexive diary was kept by the lead researcher throughout the data collection and analysis phases, and also during the process of writing the relevant discussion chapters. A sample extract from this reflexive diary can be found in Appendix 29. This reflexive diary included the thoughts and reflections of the researcher as the relevant themes and categories were developed from the data, including references to potential biases based on past experiences and perspectives where appropriate. The use of a reflexive diary in this way, contributes to the overall confirmability of the study’s findings (Krostjens & Moser 2018).

- *Audit Trail:* An audit trail is a detailed description of the steps taken by the researcher during the data collection and analysis phase, towards the development and reporting of the study’s findings. In this way, audit trails are records of what was done in an investigation. The purpose of an audit trail is to clearly demonstrate the steps taken by the researcher and the associated decisions made. According to Lincoln and Guba (1985), an audit trail is comprised of six categories of information. These six categories of

information and details of where they can be found in the reporting of this thesis are outlined in Table 9.2.

Table 9.2: Details of audit trail, adapted from Lincoln & Guba 1985

CATEGORY	LOCATION
Raw data e.g. transcripts	Extracts of transcripts from studies presented in Appendices
Data reduction and analysis products e.g. identified themes and data summaries	Examples of data analysis procedures presented in Appendices
Data reconstruction and synthesis products e.g. structure and development of over-arching categories from themes	Examples of data analysis procedures presented in Appendices
Process notes e.g. descriptions of methods, procedures and rationale and/or details on improving trustworthiness of study	Process notes presented in methods section of each study Details on trustworthiness provided in Chapter 9
Information about intentions and disposition e.g. Reflexive Diary	Extract from reflexive diary presented in Appendix 29
Instrument development information including pilot forms and revisions	Details presented in methods section of each study

9.3.4 Minimising participant bias

Participant bias, also known as subject bias, is the tendency that participants may have, to act or respond in a way that they feel the researcher wants them to, or in a way that corresponds with what the researcher may be looking for. The presence of participant

bias can threaten the credibility of a study's findings (Pannucci & Wilkins 2010). A number of steps were taken in this study to minimise the potential impact of participant bias.

- *Data Collection Tools:* Throughout this study, the collection of data was guided by specially designed data collection tools, including interview protocols and a survey study. This systematic approach to the collection of information from participants contributed to the overall trustworthiness of the study. The use and presentation of an audit trail in this study, contributes to the overall transparency and objectivity in the development of the study's findings. This in turn contributes to the overall confirmability of the study (Cutcliffe & McKenna 2004). In the interviews completed with persons with dysphagia following stroke, and in the focus group with internationally based SLTs, interview protocols were developed to guide the questions asked by the lead researcher. The use of these interview protocols ensured that the questions asked by the lead researcher, and the direction of the conversation, remained relevant to the overall aims of the study. Furthermore, these interview protocols also provided important cues for the researcher, with regards the phrasing and wording of particular questions. This was important to ensure that the questions posed were open-ended, neutral and not leading in any way for the participants (Castillo-Montoya 2016). Finally, although the lead researcher allowed the participant to 'lead' the conversation in so far as was possible, the interview protocol also provided a loose structure with regards the topics that should be covered, ensuring all key areas were addressed and

discussed with each participant. In the design of the survey questionnaire tool, similar considerations were taken into account. Neutral, open-ended questions were asked throughout. For questions where the participant had to give a closed answer or where they were asked to make a selection from a list, they were also given the opportunity to add additional qualitative comments or thoughts, again ensuring that the data collected was representative of the participant's true opinions and perspectives.

- *Study Information:* The information given to participants prior to partaking was carefully considered with regards the potential for introducing participant bias. At all stages throughout the data collection phase, participants were informed and reassured that the information they provided was entirely confidential and would not impact their ongoing care in anyway. Furthermore, participants were only given as much information as was necessary, regarding the overall aims of the research study. For example, in the survey and focus group studies, the studies were described as an exploration of SLT beliefs and practices when working with QOL in dysphagia. No additional and unnecessary information regarding the aims of the wider researcher project was provided. Providing this information may have introduced a priming effect where participants subsequently and perhaps inadvertently, provided information and experiences which they felt supported the overall research aims.

9.3.5 Triangulation

The purpose of triangulation in qualitative research is to increase the credibility of the final results. Triangulation involves the use of multiple approaches in the investigation of a particular area of study, in order to strengthen the quality of the findings (Polit & Beck 2014).

- *Data Triangulation:* Data triangulation, which involves the use of multiple data sources, is used throughout this study. In the exploration of the experiences of persons with dysphagia following stroke, both autobiographical accounts and one-to-one interviews are used. The findings of these studies are further triangulated with previous research studies completed in the area, which have made use of both focus group interviews and participant surveys. In the exploration of the clinical practice patterns and needs of the SLT profession in this area, both a survey questionnaire and a focus group interview are used. The combination of these methods contributes to the overall credibility of the findings which were developed.
- *Investigator Triangulation:* Investigator triangulation involves the use of two or more researchers throughout the study process. The inclusion of a second researcher in the process of data collection and analysis reduces the risk of researcher bias, contributing to the credibility and confirmability of the study's findings (Pannucci & Wilkins 2010). In this thesis, the research supervisor contributed to investigator triangulation in a number of ways. In the analysis of the qualitative data gathered throughout, the research

supervisor reviewed and analysed random samples of the data to verify the emerging categories and themes being developed. Furthermore, in the facilitation of the SLT focus group interview, the research supervisor supported data collection by acting as an observer and note-taker, and by posing additional questions towards the end of the interview, that may have been overlooked by the lead researcher.

9.4 Limitations and missed opportunities

It has been suggested that a good quality qualitative study should not only provide a detailed description of the data collection and analysis methods used, but also a reflection and honest discussion on the particular limitations of the study, and how this may have impacted on the overall findings (Elo et al. 2014). The specific limitations of the individual studies completed as part of this thesis were discussed in the relevant study chapters. With consideration for Lincoln and Guba's five criteria (Lincoln & Guba 1985, Guba & Lincoln 1989), this section will recognise and discuss the higher-level limitations associated with this research.

9.4.1 Participant selection

Participant selection in qualitative research is most often purposeful in nature (Patton 2002). Where possible, qualitative researchers often aim to recruit a relatively homogenous group of participants, for whom the research question or topic will be particularly significant or meaningful. In doing so, the researcher is maximising the

richness of the information that is collected and the concepts that are subsequently developed (Palinkas et al. 2015). Where appropriate and possible, a level of purposeful sampling was used throughout this thesis. However, it was recognised early on that recruitment and access to participants might be limited. Therefore, there was a pragmatic approach to the criteria used to guide the selection of participants.

In the interview study completed with persons with long-term dysphagia following stroke, the three persons who participated represented varying levels of dysphagia severity and differences in both cognitive and communication abilities. Although these characteristics contributed to the breadth of the information that was gathered and the variety of experiences that were described, the variation seen will have impacted the transferability of the findings. The recruitment of a more homogenous group, using selection criteria with more specific detail regarding the oral intake and cognitive/communication status of participants may have been more desirable. Alternatively, the recruitment of a larger number of participants using the criteria outlined in this thesis, would have also strengthened the findings. However, as previously noted, access to these participants proved extremely difficult.

Similarly, in the international SLT focus group study, the credibility and transferability of the findings would have been strengthened, if it had been possible to be more selective regarding participant recruitment. For this study, it may have been more desirable to hold a number of focus groups, each comprised of SLTs working in different clinical areas e.g. an acute care focus group, an inpatient rehabilitation focus group and a community care focus group. This would have allowed a more detailed and in-depth

exploration of the challenges specific to each stage in the stroke rehabilitation journey. Again, difficulties in participant recruitment, alongside time constraints for completion of the study, limited what was possible.

9.4.2 Participant description

One of the key characteristics of high quality qualitative research is the use of thick description throughout, and this should apply where possible, in the description of the characteristics of the study participants. The transferability of the findings of this study would have been strengthened if additional information regarding the participants was available and had been collected (Korstjens & Moser 2018).

In the autobiographical study, the information regarding the participants' characteristics was limited to what was available within the texts themselves. It was therefore not possible to gather consistent relevant information from each participant, such as age, presence and impact of cognitive changes, and/or the level of family and caregiver support.

Information regarding the level of family and caregiver support may also have been relevant to the persons with long-term dysphagia who participated in the interview study. Furthermore, for the participants in both the autobiographical study and the interview study, further information regarding their general level of dependence on family/caregivers and their wider care needs following their stroke would have contributed to the context of the data collected, and therefore contributed to the overall transferability of the findings.

9.4.3 Member checks

At the outset of this thesis, the background, experiences and beliefs of the lead researcher were clearly outlined and discussed. It was acknowledged that a certain level of bias in the development of the research findings was unavoidable, given the inherent role of the lead researcher throughout the data collection and analysis phases. A number of steps were taken towards minimising the impact of this bias including the use of a reflexive diary and an audit trail. However, the inclusion of some level of member checking would have further contributed to this process. Member checking is a method that is often used in qualitative research towards minimising researcher bias and thus improving the overall trustworthiness of the study findings (Birt et al. 2016). Member checking commonly involves sharing a brief overview of the study findings with the research participants, for the purpose of inviting feedback and validation.

Although it would not have been possible with the autobiographical study, for the interviews with the persons with long-term dysphagia following stroke, a short synopsis of the findings could have been shared with the participants. This may have been a synopsis of the findings of the study as a whole, where each participant would ideally have been able to recognise some of their own experiences and perspectives in the overall findings. Alternatively, each participant could have been offered a bespoke synopsis of the findings of their own interview transcript. This option may have been more suitable for this study, particularly for the person who was reported as having a cognitive impairment. Similarly, in the international SLT focus group, a simple member check

using the findings that were developed following data analysis may have been relatively easy to complete and would have strengthened the overall trustworthiness of the study.

9.4.4 Patient and public involvement (PPI)

Finally, PPI in healthcare research is becoming increasingly important, with recognised benefits for the overall trustworthiness, relevance and quality of the associated research findings (Harrison & Palmer 2015, Russell et al. 2020). There were a number of missed opportunities for incorporating PPI throughout this thesis.

The inclusion of a PPI advisory group at the outset of this project, would have allowed collaboration with persons with experience of living with dysphagia following stroke throughout the research design process, and also in the interpretation of the subsequent research findings. In particular, a PPI advisory group could have played a significant role in the development of the interview guide and other relevant materials used in the one-to-one interviews with persons living with long-term dysphagia following stroke. Advice and consultation regarding the structure, content, and facilitation of these interviews would also have been possible. Furthermore, a PPI advisory group could have been involved in the analysis and validation of the findings from both the autobiography study and the one-to-one interview study. This could have been completed in lieu, or alongside, the use of member checks as outlined previously.

Finally, the PPI advisory group might have been particularly useful for supporting the recruitment of persons for the one-to-one interview study. Recruitment proved extremely difficult. Insights from and collaboration with a PPI advisory group might have

resulted in suggestions for accessing and reaching potential participants, which had not been considered by the research team alone.

9.5 Recommendations for clinical practice

Having considered the quality, strengths, and limitations of the research that was undertaken as part of this thesis, two key recommendations for ongoing clinical practice can be made. These recommendations focus on the assessment of psychosocial wellbeing and QOL in the stroke population with dysphagia, and considerations in the management of this vulnerable clinical group.

9.5.1 Assessment of quality of life

The findings of this thesis support the need for clinicians to regularly and consistently assess and consider psychosocial wellbeing and QOL in persons with dysphagia following stroke. Furthermore, this assessment should be completed throughout the stroke journey, as the experiences and perspectives of the person with dysphagia are likely to change and evolve with time. Regular re-assessment is important to document changes, and to ensure that the person's priorities are encompassed throughout the wider management plan.

The development of a stroke-specific QOL assessment tool would allow standardised and reliable assessments to be made, and would ensure that the specific priorities and needs of the stroke population are considered and captured. Until a bespoke

assessment tool is developed, clinicians should carefully consider the measures that are being used to explore and evaluate QOL.

The majority of tools that are currently available will likely explore symptom burden and the ability of the person to participate in day-to-day activities. However, SLTs should be aware that there are other aspects specific to the stroke population that may not be addressed by these generic tools – namely the impact that the person’s dysphagia has on important relationships in their life, the availability of carer and informal supports, and the overall societal impact of their dysphagia. Furthermore, consideration will need to be given to the specific cognitive and communication needs of the person with dysphagia, and the influence this may have on their ability to participate in a formal assessment process.

In the absence of a suitable clinical assessment tool, it will be useful for SLTs to consider and reflect on the findings from the studies in this thesis, which explored the experiences of persons with dysphagia following stroke. By considering these findings, SLTs may be able to frame semi-structured discussions with the person following stroke, which explore many of the key areas relevant to the potential impact of dysphagia on their day-to-day lives and overall psychosocial wellbeing. Although it may not be possible to quantify these discussions and objectively track potential progress, it will go some way towards ensuring the priorities of the person with dysphagia are considered and incorporated into management plans whenever possible.

9.5.2 Supporting and managing quality of life

The SLT participants described significant challenges in determining appropriate intervention strategies when attempting to support and manage QOL in this patient group. A number of suggestions for clinical practice can be proposed when the findings from the studies which explored the experiences of persons with dysphagia are considered.

Firstly, intervention should be guided by a robust assessment process which involves both informal observations and clinical reasoning, alongside an appropriate, holistic, and validated assessment tool. Secondly, intervention priorities should be based on the findings of this assessment, as psychosocial wellbeing and QOL is subjective and individual to the person. The support and management of QOL should be considered throughout the patient journey and alongside rehabilitation and/or impairment focused interventions. The importance of supporting and managing psychosocial wellbeing and QOL should also be considered in the development of stroke services and the allocation of resources and staffing, particularly for persons with long-term dysphagia.

More specifically, clinicians need to fully recognise the importance of education and information sharing when working with persons with dysphagia following stroke, and the impact that this can have on their overall QOL and wellbeing. This is particularly important in the acute and rehabilitation stages following stroke. Prioritising education and training throughout the stroke journey can support the person with dysphagia in feeling a sense of control and autonomy with regards their dysphagia management. It may also contribute to empowering the person with dysphagia in the self-management of their condition as early as possible. Although the importance and benefits of including the

person who has had a stroke in the goal-setting rehabilitation process is widely recognised (Plant et al. 2016, Lloyd et al. 2018), it needs to be reiterated here. Where possible, SLTs should use the findings from a robust QOL assessment process to guide in-depth discussions and collaborative goal-setting, ensuring the patient and/or their caregivers are as involved in the process as possible.

Throughout the stroke rehabilitation journey and for persons with long-term dysphagia following stroke, there are a number of intervention goals that can be considered which may target QOL and psychosocial wellbeing. The SLT can play a key role in supporting the development of individualised eating and drinking plans, and compensatory swallowing strategies. Many of the persons with dysphagia in this thesis discussed the importance of trialling and experimenting with different foods and textures in an attempt to maximise the variety and choice of food and drinks they can manage. For those persons who had support from an SLT in doing so, they discussed the positive impact this had on both their confidence and motivation.

Additionally, for persons with long-term dysphagia following stroke, the importance of regular ‘check-ins’ with the person with dysphagia needs to be recognised. Many of the SLT participants reported discharging the person with dysphagia from their caseload if or when active rehabilitation has ended. However, offering the person with dysphagia a regular follow-up appointment, for example, every 6 months, would provide an opportunity for regular re-assessment of swallowing function, discussion and troubleshooting around the day-to-day management of the person’s dysphagia and a review of ongoing intervention goals.

9.6 Recommendations for future research

Alongside recommendations to support clinical practice, the findings of this thesis also highlight a number of areas that should be given priority in future research. There are four key priorities, which primarily focus on the assessment of psychosocial wellbeing and QOL in the stroke population with dysphagia, and further development of our understanding of the impact of dysphagia in this clinical group.

9.6.1 Development of a dysphagia quality of life assessment tool

The findings of this thesis highlight the need for a QOL assessment tool that is specific to the stroke population with dysphagia. The use of such a tool will be instrumental in ensuring that the experiences, perspectives, and priorities specific to this clinical population are captured and considered. The development and routine use of such a tool would allow for a reliable, valid and consistent evaluation method to support intervention planning and the identification of appropriate and meaningful QOL goals. Such a tool would also provide SLTs and persons with dysphagia with an objective option to measure progress and change, and would support SLTs in quantifying the impact of the services they deliver; particularly if/when active rehabilitation has been discontinued.

Consideration should be given to a tool that can be modified for use with persons with cognitive and/or communication deficits and if possible, a shortened version should be made available for use in the acute care setting. The use of a large scale modified Delphi study might be a suitable methodology to ensure that both patient and clinician priorities and experiences are considered and included in the development of this tool.

Reference should also be made to previous research which has explored and reported on the experiences of this clinical group. Considering the findings of this thesis it could be suggested that such a tool should include the following:

1. In relation to the ICF 'Body Function' component:
 - a) Consideration of the physical symptoms associated with dysphagia with a particular reference to saliva management.
 - b) Consideration of a wide range of associated emotions including anxiety and frustration.

2. In relation to the ICF 'Activities and Participation' component:
 - a) Consideration of the person's ability to fulfil their desired role within their family and/or community.
 - b) The impact of dysphagia on the person's desired social life.
 - c) How 'in control' and independent the person feels in managing their dysphagia on a day to day basis.

3. In relation to the ICF 'Environmental Factors' component:
 - a) Consideration of both formal and informal supports and if these supports are meeting the needs of the person with dysphagia.

- b) The person's level of satisfaction with the availability and relevance of dysphagia healthcare services.
4. Other considerations not captured in the ICF:
- a) How informed the person with dysphagia feels regarding their ongoing dysphagia care and management plan.
 - b) How satisfied the person with dysphagia feels regarding their ongoing dysphagia care and management plan.

9.6.2 Development of a core outcome set to include quality of life

The findings of this thesis suggest that psychosocial wellbeing and QOL are not routinely considered as an outcome in dysphagia clinical trials in this clinical population. The significant impact that dysphagia can have in the stroke population is clearly demonstrated. Furthermore, the SLT participants report on the importance of addressing psychosocial wellbeing and QOL when possible, but report significant challenges in knowing how and when to do so.

If QOL was consistently considered in the evaluation of interventions in dysphagia management following stroke, it would be possible for clinicians and persons with dysphagia to make more informed decisions regarding priorities for treatment. Furthermore, information regarding the potential impact of interventions on QOL may be useful in advocating for the availability of ongoing services for persons with long-term dysphagia following stroke.

The findings of this research support the need for a core outcome set in dysphagia research following stroke, which includes psychosocial wellbeing and QOL. The development of a stroke-specific QOL assessment tool would be a useful addition to a core outcome set in this area, as it would further compliment attempts to standardise the information that is measured and reported in these studies.

9.6.3 Further development of the evidence base

Although the findings of this thesis contribute to our understanding of the impact of dysphagia on psychosocial wellbeing and QOL in the stroke population, there is a need for ongoing research in this area. Further qualitative studies using varying methodologies, data collection, and data analysis methods would be useful. These studies should focus on and include different time points along the stroke rehabilitation journey. Furthermore, a range of studies are required where detailed purposive sampling criteria are used to ensure that the experiences and perspectives of persons with varying dysphagia presentations, varying clinical characteristics, and varying backgrounds are included.

Future research should also explore the perspectives of family members and caregivers. Although not explicitly addressed in this thesis, the findings did demonstrate the significant change in familial relationships, the new roles required of family and close friends and the potential impact of these supports on the overall experience of the person with dysphagia following stroke. A small number of studies have already looked specifically at this area (Tseng et al. 2016, Davis et al. 2021), but again a wider range of studies with varying methodologies and sampling criteria are required to build on and triangulate these findings.

With additional research in the area, the use of a meta-synthesis approach, involving the review and integration of findings from multiple qualitative studies, would allow the development of high level and detailed theories to represent the impact of dysphagia on psychosocial wellbeing and QOL in this vulnerable patient group. With a greater understanding of the needs of this clinical group, more targeted and appropriate assessment and intervention approaches can then be developed.

9.6.4 Development of a consensus statement

While the evidence base to support the assessment and management of psychosocial wellbeing and QOL is still evolving, the development of a clinical consensus statement may go some way towards guiding clinical practice. In contrast to clinical care guidelines, which are based on robust and high quality research, consensus statements are developed with consideration for the existing evidence base alongside expert opinion (Jacobs et al. 2014). Although a consensus statement may not be able to make explicit recommendations to guide clinical practice, it may address some of the inconsistencies and shortfalls in the quality of care that is currently being provided.

9.7 Unique contribution of this thesis

This thesis contributes to the existing literature on the holistic management of dysphagia following stroke, by highlighting the importance of considering psychosocial wellbeing and QOL in this clinical group, and demonstrating the current complexities that exist in the clinical management of this area. This was achieved by qualitatively exploring

the experiences of persons living with dysphagia following stroke, current clinical practice patterns and beliefs of SLTs working in dysphagia management following stroke, and the inclusion and content of PROMs in dysphagia clinical trials in the stroke population.

This thesis includes the first study which has explored the experiences of persons living with dysphagia during the stroke rehabilitation journey. This study is also unique in that it is the first study that has used autobiographical accounts as the data source for exploring the impact of dysphagia in a clinical group. Although the experiences of persons living with long-term dysphagia following stroke was previously explored by Helldén et al. in 2018, this thesis includes the first study which has used an interpretative methodology to investigate this area. In doing so, this study strengthened the findings reported by Helldén and colleagues, while also demonstrating for the first time, the impact of dysphagia on the person's self-identity and perception of themselves within their community. The findings of both of the studies completed as part of this thesis, make a significant contribution to our understanding of the experiences of this clinical group, which have been under-represented in the literature to date.

This thesis documents for the first time, the current clinical practice patterns of SLTs when addressing psychosocial wellbeing and QOL, both in the general dysphagia population, and with specific reference to those with dysphagia following stroke. Furthermore, this thesis includes the first study which has explored the facilitators and barriers to SLT clinical practice in this area. In doing so, the significant variations and inconsistencies in current practice patterns are demonstrated and complexities unique to

the psychosocial support of persons with dysphagia following stroke are highlighted. The findings of these studies allow future professional development priorities towards enhancing the quality of care provided to this clinical group to be highlighted.

Finally, this thesis includes the first investigation into the inclusion of PROMs in dysphagia clinical trials following stroke. The findings of this study clearly demonstrate the lack of priority given to patient reports in dysphagia RCTs in the stroke population. Importantly, the qualitative analysis completed as part of this study highlights the lack of an appropriate PROM to explore the wide-ranging and complex impact of dysphagia following stroke. The need for the development of a stroke-specific QOL assessment tool is demonstrated, alongside the inclusion of QOL as part of a core outcome set for stroke-related dysphagia intervention research.

By systematically integrating the findings from the studies completed as part of this thesis, new knowledge and understandings regarding the wider area of study were generated. In particular, differences and similarities in the priorities of persons with dysphagia following stroke, and SLT clinicians working in this area are clearly revealed. These new understandings highlight important recommendations for clinical practice and future research priorities.

9.8 Overall conclusions

The dysphagia journey for persons following stroke is complex. The perspectives and experiences of the person with dysphagia can change and evolve as they progress through this journey and the support of the SLT is key throughout. Unfortunately, SLTs report significant challenges in the assessment and management of QOL in dysphagia following stroke, primarily due to a lack of stroke-specific clinical tools, the absence of clear clinical guidelines to support practice, and a paucity of research in this area. Furthermore, dysphagia clinical trials in the stroke population fail to recognise psychosocial wellbeing and QOL as an important outcome measure when evaluating the impact of interventions in this vulnerable clinical group.

The development of a stroke-specific QOL assessment tool for dysphagia will be an important priority for future research. The availability of such a tool will allow the priorities of the person with dysphagia following stroke to be clearly highlighted and considered in clinical practice, will address a number of the clinical challenges reported by SLTs practicing in this area, and will be useful for inclusion as a core outcome measure in dysphagia intervention studies following stroke.

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Appendix 1: References to quality of life and dysphagia in stroke guideline documents

COUNTRY	GUIDELINE TITLE	AUTHOR	YEAR	REFERENCE TO DYSPHAGIA AND QOL
UK	Stroke Rehabilitation in Adults	National Institute for Health and Care Excellence (NICE)	2013	No reference to QOL in dysphagia
SCOTLAND	Management of Patients with Stroke: Rehabilitation, prevention and management of complications, and discharge planning	Scottish Intercollegiate Guidelines Network (SIGN)	2010	No reference to QOL in dysphagia
SCOTLAND	Management of Patients with Stroke: Identification and management of dysphagia	Scottish Intercollegiate Guidelines Network (SIGN)	2010	<ul style="list-style-type: none"> • “Most dysphagia resolves within the first few weeks, but in some cases it may persist, with resulting long term consequences for nutrition management and psychosocial adjustment” (page 1) • “There is a paucity of data on health outcomes from the patient’s perspective, such as quality of life and patient satisfaction. Some attempts are now being made to redress this with the use of quality of life questionnaires and patient focused outcome measures” (page 20) • “Healthcare professionals should be aware of the importance of the social aspects of eating. An inability to eat normally may affect patient morale, lead to feelings of isolation and could contribute to clinical depression” (page 20) • Recommendations for Research: “the exploration of the patient’s experience of dysphagia and its relation to quality of life after stroke.” (page 24)

UK	National Clinical Guideline for Stroke	Royal College of Physicians (RCP)	2016	<ul style="list-style-type: none"> • “People with persistent swallowing problems may avoid eating in social settings and thus lose the physical and social pleasures connected with food and drink” (page 85) • “Further trials are ongoing, but more are likely to be needed as current evidence on efficacy is limited, including details on the timing of interventions after stroke and the intensity of the intervention. Outcomes should focus on freedom from tube feeding, quality of life and the duration of treatment effect” (page 85)
US	Guidelines for the Early Management of Patients with Acute Ischemic Stroke	American Heart Association/American Stroke Association	2018	No reference to QOL in dysphagia
AUSTRALIA	Clinical Guidelines for Stroke Management	Stroke Foundation	2017	No reference to QOL in dysphagia
IRELAND	Council for Stroke National Clinical Guidelines and Recommendations for the Care of People with Stroke and Transient Ischaemic Attack	Irish Heart Foundation	2010	<ul style="list-style-type: none"> • “An inability to eat and drink normally may affect patient morale, lead to feelings of isolation and could contribute to clinical depression. Healthcare professionals should be aware of the importance of the social aspects of eating and drinking” (page 69)
CANADA	Canadian Stroke Best Practice Recommendations, Acute Stroke Management: Prehospital, Emergency Department and	Heart and Stroke Foundation	2018	No reference to QOL in dysphagia

	Acute Inpatient Stroke Care			
CANADA	Canadian Stroke Best Practice Recommendations, Rehabilitation, Recovery and Community Participation following Stroke Part One: Rehabilitation and Recovery following Stroke	Heart and Stroke Foundation	2019	No reference to QOL in dysphagia
CANADA	Canadian Stroke Best Practice Recommendations, Rehabilitation, Recovery and Community Participation following Stroke Part Two: Transitions and Community Participation following Stroke			<p>General reference (not dysphagia specific):</p> <ul style="list-style-type: none"> • “Changes in quality of life measured at regular intervals during recovery and participation, and reassessed when changes in health status or other life events occur (e.g., at 60, 90- and 180-days following stroke” (page 23, 31, 41, 47)

Appendix 2: ‘Triangulation protocol’, adapted from Farmer et al. 2006

STEP	DESCRIPTION
1: Sorting	Sort main findings from each study/section into similar categories that address the area of interest. Determine areas of both overlap and divergence.
2: Convergence coding	Identify the themes from each study/section. Compare these themes to determine degree of convergence across studies/sections. Characterise the type of convergence: <ul style="list-style-type: none"> • Agreement: Full agreement between studies/sections on the elements of comparison • Partial Agreement: There is partial agreement between studies/sections on the elements of comparison • Silence: Only one study or section addresses the theme, and it is silent across the other studies/sections • Dissonance: There is disagreement between the studies/sections on the element of comparison
3: Convergence assessment	Determine a global level of assessment of the level of convergence
4: Completeness assessment	Compare the themes from each study/section to enhance completeness of united set of findings and identify differences in scope or coverage
5: Researcher comparison	Compare the assessments of convergence and completeness across multiple researchers
6: Feedback	Feedback triangulated results to research team or stakeholders

Stroke: It couldn't happen to me

Margaret Cromarty (2008)

Chapter 2

p8

"Perhaps the worst thing about my predicament was the fact that I had no control over anything. (...) Feeding was taken care of through the nasogastric tube and weeks later by the gastrostomy."

Chapter 5

p20

"I could watch the proceedings in the kitchen through the big open hatchway. I could see my daughters busying themselves with the platters of food and later the dirty dishes. I, of course, could take no part, but could only lie and watch."

Chapter 6

p22

"With horror I thought that this was the end of my leisurely breakfasts, reading the newspaper, when the house was empty and quiet. (...) Gone too, the happy afternoons and evenings preparing a meal for friends and loved ones and sharing it with them. So much that made up the fabric of my life had disappeared, almost literally overnight."

p28

"Back in the Intensive Care Unit the Dietician had calculated the number of calories per day I needed and I received these in the form of two types of disgusting and smelling liquid. These were pumped into my stomach via a nasogastric tube, as eating and drinking were out of the question. This was my meat and two vegetables and it was washed down with the required amount of water."

p29

"The tube was anchored to the nose with sticking plaster and that in itself was uncomfortable – in addition to giving one the look of an elephant, the 'trunk' dangling down in front of one's face."

Chapter 7

p34

"Coughing was a tremendous problem for many months following the stroke, and to a lesser extent it still is. Of course there are those who would not regard it as such. A strong cough reflex helps protect the airway – that being a most important consideration, and an obsession of

anaesthetists, physiotherapists, speech and language therapists and nurses. To me, the cough was a real trial; causing discomfort, worry and worst of all for me, embarrassment.”

p35

“There was no big family roast lunch. (...) No sticky chocolate for tea”

“I was not eating at this stage so chocolate eggs were out of the question for me. Instead Iain came up with the idea of giving me, of all things, two small soft toy bears.”

Chapter 8

p48 – 49

“I was sitting up (after a fashion) and I couldn’t send the saliva backwards to my throat (my tongue didn’t work), nor swallow it automatically (that didn’t work properly either) so out it came. I felt mortified. I hate to think what it looked like. I thought if I ignored it, it might go away. Of course it didn’t. I dribbled like a teething baby. Visiting friends came armed with boxes of tissues. Someone was constantly wiping my face. I wanted to hide it.

Chapter 9

p64

“The swallowing mechanism wasn’t working properly. Another function that we all take for granted. Until it goes wrong. I started taking a great interest in what is involved in swallowing, asking exactly what movements are involved so that I could copy and concentrate on each one.

“I was dismayed to be told that with all but the thickest liquid some had trickled down towards my lungs. I was not closing off my airway, so there was constant danger that I might choke. Great caution had to be exercised with my food and drink, and this was policed by the speech therapist.”

Chapter 10

p68

“For several months, food was absent from my life. Food that we would recognise as such that is.”

p69

“Being tube fed, and therefore having substances deposited straight into my stomach, meant that I avoided tasting things. This was a definite advantage in the case of the liquid feed. It smelled vile, and on the unfortunate (but mercifully rare) occasions that I burped and regurgitated a little, tasted even worse.

“I longed for the taste of something sharp and refreshing in my mouth. I craved a drink of grapefruit juice – my usual breakfast drink. But I couldn’t open my mouth. Even if I could have done, my swallowing was haphazard and unreliable. There was every chance that any liquid I swallowed would end up not in my stomach, but in my lungs.

p70

“This was highly unorthodox, even dangerous, so we kept it a secret from the staff to begin with. I did not want to be stopped. Particularly when my sister started bringing me little bottles of ready mixed gin and tonic to put in my syringe. It was lovely to have a refreshing taste in my mouth, and as for the gin and tonic – that was a real treat.”

p71

“She was horrified that I was drinking ‘straight’ fruit juice (I kept quiet about the gin and tonic!) Tactfully, she pointed out that for swallowing safety, fluids should be thickened (with a proprietary, supposedly tasteless powder). Meanwhile she suggested that I should start with something the consistency of yoghurt, taken off a spoon.”

“Iain or the girls used to spend the whole day with me and they would bring themselves a packed lunch which they ate at my bedside. What delights lurked inside those plastic picnic boxes! Sandwich fillings which I would have previously thought mundane or outrageous became tantalising. The look of pained registration with which I watched my family tuck in caused much amusement and not a little sheepishness on their part. Even the hospital food became attractive. I was tormented by the tempting smells emanating from the trolleys, which regularly arrived on the ward. I craved a plate of chips, a good stew; even boiled fish would have been acceptable. But I was stuck with my fruit yoghurt or chocolate mousse, which is what I preferred.”

“I had no idea what a complicated business eating is. It is one of the many functions of daily life that we all take for granted. I was affronted that it was no longer an automatic process.”

p72

“At first, it could take twenty minutes to eat half a pot of mousse. The girls took their turn feeding me, and with remarkable forbearance they and Iain would give me ‘eating practice’ every day. They endured chocolate spray in their faces, down their clothes, and all over their hands and arms as I spat, coughed, choked and dribbled my way through the pot. They endured it stoically, even cheerfully. I was ashamed. This was disgusting.”

“On many occasions when I was being fed by one of the nurses I would become so embarrassed by the mess I was making that I would only attempt a few mouthfuls.”

“But inside I was squirming with embarrassment. I found the mess I made and the coughing and spitting that I did, very hard to take.”

p74 – 75

“I craved normal food. What I wouldn’t have given for a chip! At suppertime the other patients had sandwiches. Sandwiches with fillings such as chicken salad, prawn and mayonnaise, cheese and tomato. Never before had such things been so attractive. But they were not for me. I wasn’t allowed them.”

“It seemed that I was constantly receiving dire warnings of the consequences of trying to eat unsuitable food. Choking was predicted and aspiration pneumonia threatened. ‘Dangerous’ foods were expressly forbidden. I felt like a recalcitrant toddler. This was reinforced by the fact that I had to be fed.”

p77

“Mealtimes resembled a battlefield. To my chagrin, and acute embarrassment, I was unable to behave with anything like the decorum I deemed appropriate. I expected to be able to eat without thinking; it had always been an automatic process. But I still coughed and spat and dribbled. I was mortified. But I covered my embarrassment by laughing; my mess at mealtimes was treated as a huge joke.”

“I had to be fed, and while I was having pureed food, fed with a spoon. I had a bib around my neck. I felt like a baby; and I was treated like a child: “You can’t have this” “You’re not allowed that.” How I hated that! Yet I played along, I laughed.”

“However, one day I flipped. It was reactive. A member of staff made a flippant and dismissive remark to me in front of the other patients, all assembled for their meals. I was angry. But I felt powerless (...) I burst into tears. It was all I could do – although I didn’t contrive it.”

p78

“Feeding someone is a skilled task, a skill frequently underestimated (...) I didn’t realise this until I was on the receiving end of it. How vulnerable we are when we are unable to feed ourselves.”

p80

“I took risks with what I ate from the start. Risks, that is, in the eyes of the professionals; I never tried anything I didn’t think I could cope with.”

Chapter 12

p92

“Weekends at home were something more than we had dared hope for. They gave me a degree of freedom, and I felt I was a ‘proper’ member of the family again. In addition, I could try out things I ‘wasn’t allowed’ – to eat or to do – in the rehabilitation centre. I had been craving chips for as long as I could remember – well before I could eat at all – but they were deemed too difficult for me to chew and swallow. So one day when I was at home, we had fish and chips for supper. What a treat! It took a large amount of tomato ketchup to make them moist enough to manage, but I had fantasized long enough; I was determined not to miss out.”

Chapter 15

p115

“I can now go to restaurants – my table manners have improved sufficiently and I am no longer so self-conscious about being fed in public – and the theatre. I have even started hosting a charity coffee evening.”

“And I can drink everything unthickened – even water, which was forbidden as it use to make me choke.”

Preliminary Analysis of extracts from:

‘Stroke: It couldn’t happen to me’ – Margaret Cromarty (2008)

<i>Extract</i>	<i>Reflections</i>	<i>Emerging Theme</i>
“Perhaps the worst thing about my predicament was the fact that I had no control over anything. (...) Feeding was taken care of through the nasogastric tube and weeks later by the gastrostomy.”	Lack of control	Control
“I could watch the proceedings in the kitchen through the big open hatchway. I could see my daughters busying themselves with the platters of food and later the dirty dishes. I, of course, could take no part, but could only lie and watch.”	Feeling isolated and left out of social situations around mealtimes	Social Exclusion
“With horror I thought that this was the end of my leisurely breakfasts, reading the newspaper, when the house was empty and quiet. (...) Gone too, the happy afternoons and evenings preparing a meal for friends and loved ones and sharing it with them. So much that made up the fabric of my life had disappeared, almost literally overnight.”	Importance of food/drink in life before - structure and social connections Now different - changed, feeling separated from same	Relationship with food/drink
“Coughing was a tremendous problem for many months following the stroke, and to a lesser extent it still is. Of course there are those who would not regard it as such. A strong cough reflex helps protect the airway – that being a most important consideration, and an obsession of anaesthetists, physiotherapists, speech and language therapists and nurses. To me, the cough was a real trial; causing discomfort, worry and worst of all for me, embarrassment.”	Persistence of symptoms Discomfort associated with symptoms Disagreements with healthcare staff	Living with symptoms Relationships with healthcare staff
“There was no big family roast lunch. (...) No sticky chocolate for tea”	Feeling left out of celebrations as unable to partake in food/drink aspect - no meaning any longer	Social Exclusion
“I was not eating at this stage so chocolate eggs were out of the question for me. Instead Iain came up with the idea of giving me, of all things, two small soft toy bears.”	Feeling left out of celebrations as unable to partake in food/drink aspect - no meaning any longer	Social Exclusion
“I was sitting up (after a fashion) and I couldn’t send the saliva backwards to my throat (my tongue didn’t work), nor swallow it automatically (that didn’t work properly either) so out it came. I felt mortified. I hate to think what it looked like. I thought if I ignored it, it might go away. Of course it didn’t. I dribbled like a teething baby. Visiting friends came armed with boxes of tissues. Some one was constantly wiping my face. I wanted to hide it.	Lack of control Vulnerability Reliance on others Child/baby like references Embarrassment associated with symptoms	Control Vulnerable Reliance on others Living with Symptoms - embarrassment
“The swallowing mechanism wasn’t working properly. Another function that we all take for granted. Until it goes wrong. I started taking a great interest in what is involved in swallowing, asking exactly what movements are involved so that I could copy and concentrate on each one.	Things taken for granted before, now realise the importance	Greater appreciation now
“I was dismayed to be told that with all but the thickest liquid some had trickled down towards my lungs. I was not closing off my airway, so there was constant danger that I might choke. Great caution had to be exercised with my food and drink, and this was policed by the speech therapist.”	Requiring monitoring and supervision Not making progress as quickly as would have liked Ongoing dangers associated with food/drink	Restrictions Progress - the future Living with symptoms - risk
“For several months, food was absent from my life. Food that we would recognise as such that is.”	Different from the norm - not food we would usually recognise	Social exclusion

Listing of Preliminary Themes Developed from each Transcript

In the Blink of an Eye	Locked In	Out of the Darkness	Pressed but not Crushed	Running Free	Stroke - It couldn't happen to me	The Diving Bell and the Butterfly	My Year Off	Stroke This	When Lightning Strikes
Control	Adjusting	Living with symptoms	Coping strategies	Living with symptoms	Control	Living with symptoms	Living with symptoms	Living with symptoms	Reliance on others
Living with Symptoms	Control	Adjusting	Relationship with food/drink	Progress/The Future	Social exclusion	Progress/The Future	Relationship with food/drink	Restrictions and Supervision	Control
Adjusting	Living with symptoms	Progress/The Future	Progress/The Future	Vulnerability	Relationship with food/drink	Greater appreciation	Coping strategies	Control	Living with symptoms
Coping strategies	Greater appreciation	Reliance on others	Control	Reliance on others	Living with symptoms	Relationship with food/drink	Peer Support		Views of others
Vulnerability	Progress/The Future	Social inclusion	Reliance on others	Control	Relationships with professionals	Coping strategies			
Progress/The Future	Taking risks	Setbacks	Vulnerability	Relationship with food/drink	Vulnerability	Reliance on others			
Greater appreciation	Vulnerability	Coping strategies	Living with Symptoms	Adjusting	Reliance on others	Views of others			
Relationship with food/drink	Relationship with food/drink	Relationships with professionals	Social exclusion	Cravings	Greater appreciation	Adjusting			
Social exclusion	Reliance on others	Greater appreciation	Adjusting	Greater appreciation	Restrictions and Supervision	Social importance food/drink			
Restrictions and Supervision	Social inclusion	Control	Motivating factors	Taking risks	Progress/The Future	Social exclusion			
Taking risks		Social exclusion	Re-integrating	Relationships with professionals	Cravings	Setbacks			
Peer Support		Taking risks	Self management	Social exclusion	Taking risks				
Relationships with professionals		Self-mangement	Social inclusion	Coping strategies	Relationships with family				
Social inclusion				Self-management	Adjusting				
				Re-integrating	Re-integrating				
				Setbacks					

Clustering of Preliminary Themes towards Development of Final Themes

Physical Consequences	Society	Adjusting and Coping	Process of Recovery	Changed relationships	Control
Living with Symptoms	Social Exclusion	Coping Strategies	Progress/The Future	Relationship with Food/Drink	Loss of control
Becoming familiar with symptoms	Re-integrating into society	Self-Management	Setting and achieving goals	Relationship with family	Reliance on others
	Views of others		Setbacks	Relationship with professionals	Regaining control

Appendix 4: Interview study ethical approval



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

30/01/2018

Application Academic Year 2017/18
Applicant: HT 23 (2016/17 TT66) Moloney, Jennifer
Title of Research: Exploring the psychosocial impact of chronic dysphagia in stroke

Dear Jennifer,

Your submission for ethics approval for amendments to the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Saturday, 12 June 2021, and has been approved.

Best wishes,

A handwritten signature in black ink, appearing to read 'Saeed'.

Professor John Saeed

Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

06/07/2016

Application Academic Year 2015/16

Applicant: TT66 Jennifer Moloney

Title of Research: Exploring the psychosocial impact of chronic dysphagia in stroke.

Dear Jennifer,

Your submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Wednesday, 06 July 2016, and has been approved in full. We wish you the very best in your research activities.

Best wishes,

Dr Lorna Carson
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences



Dear Jennifer,

I refer to your email below and attachment that sets out the clarity requested by the PCRC. I wish to formally approve your research application, on behalf of the Primary Care Research Committee.

In relation to the approval decision you will note that the PCRC protocol requires that the Primary Care Research Committee will have sight of the final draft report prior to publication and that their opinion will be considered in relation to the publication, in particular items that may have a bearing on the HSE's reputation, a copy of the protocol is available if required.

I would like to take this opportunity to wish you well with your research.

Kind regards,

Shirley Keane.
On behalf of Chair, Primary Care Research Committee.

Shirley Keane,
Business Planning and Development Manager,
Office of Head of Planning, Performance and Programme Management,
Primary Care Division.

Tel: 091 775922
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Email: shirley.keane@hse.ie
Eircode: H91 N973

Appendix 5: Interview study and focus group study reporting checklist

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Interview Study	Focus Group Study
Domain 1: Research team and reflexivity			
<i>Personal Characteristics</i>			
1. Interviewer	Which author/s conducted the interview or focus group?	p.113	p.169
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	BSc	BSc
3. Occupation	What was their occupation at the time of the study?	SLT	SLT
4. Gender	Was the researcher male or female?	Female	Female
5. Experience and training	What experience or training did the researcher have?	p.71-75	p.71-75
<i>Relationship with participants</i>			
6. Relationship established	Was a relationship established prior to study commencement?	No	No
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	No information	No information
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p.71-75	p.71-75
Domain 2: study design			
<i>Theoretical framework</i>			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 115	p.170
<i>Participant selection</i>			
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p.111	p.168
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	p.112	p.168

12. Sample size	How many participants were in the study?	p.114	p.170-171
13. Non-participation	How many people refused to participate or dropped out? Reasons?	None	None
Setting			
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	p.115	p.169
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	p.115	No
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	p.115	p.170-171
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p.113	No
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	p.114	P.170
20. Field notes	Were field notes made during and/or after the interview or focus group?	During	During
21. Duration	What was the duration of the interviews or focus group?	p.115	84 mins
22. Data saturation	Was data saturation discussed?	N/A	N/A
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No	No
Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	One	One
25. Description of the coding tree	Did authors provide a description of the coding tree?	p.116	p.172
26. Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data	Derived from the data
27. Software	What software, if applicable, was used to manage the data?	Not used	Not used
28. Participant checking	Did participants provide feedback on the findings?	No	No
Reporting			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes p.116-126	Yes p.172-189
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes	Yes

Appendix 6: Interview study recruitment poster

SWALLOWING DIFFICULTIES FOLLOWING STROKE?

We would like to talk to you!

We are looking for adults living with swallowing difficulties as a result of a stroke, to participate in a PhD study being run by Trinity College, Dublin.

The aim of our study is to develop a greater understanding of the impact of your swallowing difficulties on your everyday life.

The findings of this study will inform the quality of future healthcare services provided in this area.



Who? You must be over 18, and currently living with swallowing difficulties as a result of a stroke at least 12 months ago

Where? At a time, date and place that suits you best

What's involved? Up to two face to face interviews with the researcher, where you will have the opportunity to discuss the impact of your swallowing difficulties on your everyday life

How long will it take? No longer than one hour for each interview

How will my information be protected? Any information you provide will be completely confidential and anonymised and stored in Trinity College, Dublin.

Interested?

Find out more by contacting Jennifer Moloney – Principal Investigator

Email: jemolone@tcd.ie Phone: 086 1047 001



Appendix 7: Interview study gatekeeper information leaflet



Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

Project Title: Understanding the psychosocial impact of chronic dysphagia in stroke; a qualitative exploration

Jennifer Moloney, PhD Candidate – Principal Investigator
Dr Margaret Walshe, Associate Professor in Speech and Language Therapy – Supervisor

Dear colleague,

My name is Jennifer Moloney. I am a Speech and Language Therapist currently completing my PhD degree in the Department of Clinical Speech and Language Studies, Trinity College Dublin, under the supervision of Dr Margaret Walshe.

The aim of the research study associated with my PhD, is to develop a greater understanding of the psychosocial impact that chronic swallowing difficulties may have on the lives of persons who have had a stroke. It is planned that the findings of this study will contribute to the future holistic care and management of these persons.

I am writing to you to invite you to act as a gatekeeper for the purpose of participant recruitment in this study. If agreeable, your participation will involve you displaying the attached recruitment poster in your clinic waiting area.

Participants in this study will be required to take part in an individual interview with me, the Principal Investigator, where we will have the opportunity to discuss the impact of their swallowing difficulties on their everyday lives. I have outlined the broad participant criteria below and I have also included a copy of the Participant Information Leaflet for further information.

Participants must:

- Be over 18 years of age
- Be living in the community, either independently or with formal supports
- Present with oropharyngeal dysphagia as a result of stroke which requires the use of modified diet and fluids or a full Nil Per Oral status
- Be at least 12 months post stroke

- Be able to provide verbal and written consent
- Be capable of participating in an interview with or without communication supports

If you would like any further information, or if you are interested in participating in this study as a gatekeeper, please contact me using the following details:

Telephone: 086 1047 001

Email: jemolone@tcd.ie

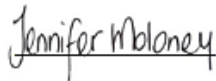
Alternatively, you may wish to contact my supervisor, Dr Margaret Walshe, Assistant Professor in Speech and Language Pathology, using the following details:

Telephone: 01 896 2382

Email: walshema@tcd.ie

Many thanks for your time.

Sincerely,



Jennifer Moloney

This study has been approved by the Faculty Research Ethics Committee in Trinity College Dublin. Nothing in this document restricts or curtails your rights.

Appendix 8: Interview study participant information leaflets



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The University of Dublin

Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

PARTICIPANT INFORMATION LEAFLET

Project Title: Understanding the psychosocial impact of chronic dysphagia in stroke; a qualitative exploration

You are invited to participate in a research study which is being carried out in the area of swallowing difficulties as a result of stroke. This research is being conducted by:

Jennifer Moloney, PhD Candidate
Speech and Language Therapist

What is the purpose of this research study?

The aim of this study is to gain a greater understanding of the impact that swallowing difficulties may have on the day to day lives of persons who have had a stroke. It is hoped that the findings of this study will help to inform the future care and support of these persons.

What is involved in the study?

I would like to meet with you to discuss in detail your experiences of living with swallowing difficulties following a stroke. During this interview, I would like to learn about how your swallowing difficulties have impacted you and may ask questions about your opinions and feelings and the changes there have been in your day to day life since your stroke.

This interview will be arranged for a time, date and location that suits you best and will last for approximately 60 minutes. Following this, you may be invited to participate in a second shorter interview at a later date, where we will have the opportunity to discuss some of your experiences in more detail.

Our discussions will be audio-taped and later transcribed. You are welcome to a copy of the final transcript if you wish. All information that could identify you will be removed from the transcript and your identity will not be disclosed to anyone outside of this study. All information gathered will be stored in a locked secure location or on a password protected computer. Once transcribed, all of the audio-tapes will be destroyed.

Are there any benefits or risks to participating?

There is no immediate benefit to you for participating in this study, but your feedback will be used to help inform the care and support of persons living with similar difficulties in the future.



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In the unlikely event that the topics raised in our discussions cause upset to you, you will be offered appropriate follow-up support.

Please be assured that if you do not wish to participate in this study, your current or future service provision will not be affected. You may withdraw from this study at any time.

Who can I contact for further information?

If you would like any further information, or if you are interested in participating in this study, you or a family member can contact me using the following details:

Telephone: 086 1047 001

Email: jemolone@tcd.ie

Alternatively, you may wish to contact my supervisor, Dr Margaret Walshe, Assistant Professor in Speech and Language Pathology, using the following details:

Telephone: 01 896 2382

Email: walshema@tcd.ie

Thank you for taking the time to read this information leaflet.

This study has been approved by the Faculty Research Ethics Committee in Trinity College Dublin. Nothing in this document restricts or curtails your rights.



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Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

PARTICIPANT INFORMATION LEAFLET

Introduction

My name is **Jennifer Moloney** and I am a **Speech and Language Therapist**.

I am researching the **impact of swallowing difficulties** on persons who have had a stroke.



The Research

I would like to meet with you to discuss your **opinions and experiences of living with swallowing difficulties**.





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The University of Dublin



The meeting should take about **60 minutes** and I may invite you to a second meeting for further discussion.



The meeting will be audio recorded.



Your identity will be protected.

NO
THANKS!

You can change your mind at any time if you no longer want to be involved.

For further information, you or a family member can contact me using these details:



086 1047 001



jemolone@tcd.ie

Appendix 9: Interview study aide memoire



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The University of Dublin

Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

AIDE MEMOIRE

Project Title: Understanding the psychosocial impact of chronic dysphagia in stroke; a qualitative exploration

In order to prepare for our conversation, you may find it helpful to consider and reflect on some of the suggestions listed below.



- The early stages following your stroke – how you felt, what your hopes, expectations and fears were

- Your first understanding of your difficulty swallowing – your early experiences of it

- How or when you came to realise that you may have a long term difficulty with swallowing – what did this mean for you?

- How your difficulty with swallowing has changed your life – what have the implications been for you and for others close to you

- What has been helpful to you in this time – what has made things more difficult

- Anything else that you feel is important to you and would be helpful to share

Appendix 10: Interview study consent form



Trinity College Dublin
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The University of Dublin

Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

PARTICIPANT CONSENT FORM

Project Title: Understanding the psychosocial impact of chronic dysphagia in stroke; a qualitative exploration

Jennifer Moloney, PhD Candidate – Principal Investigator

Dr Margaret Walshe, Associate Professor in Speech and Language Therapy – Supervisor

Overview of Study

I am invited to participate in a research study which is being carried out by Jennifer Moloney and Dr Margaret Walshe. The aim of this research study is to gain a greater understanding of the impact of chronic swallowing difficulties in persons who have had a stroke. This research study has been approved by the Faculty Research Ethics Committee in Trinity College Dublin. I have read and understand the associated Patient Information Leaflet.

Overview of my Participation

I understand that my participation in this study is voluntary and that I can withdraw at any time without any consequence of any kind.

I understand that by participating in this study, I will be partaking in an individual interview with the Principal Investigator where I will be asked to discuss the impact that my swallowing difficulties have on my day to day life. This interview will be approximately 60 minutes in length and will be held at a place of my convenience. I may be asked to participate in a second shorter follow-up interview at a later date. Participation in this second interview is also voluntary.

The information gathered in my interview will be used to inform the future service delivery and care of persons living with chronic swallowing difficulties after stroke.

Confidentiality

I understand that my interview(s) will be audio-recorded and later transcribed. It has been explained to me that these recordings will be stored on an encrypted and/or password protected device and destroyed once transcribed. It has been explained to me that any identifying information will be removed from the transcripts of my interview(s) and I will be assigned a pseudo-name to protect my identity. I can request a copy of my interview(s) transcripts if I wish. In the unlikely event that I become upset or distressed in the course of the interview I will be offered the appropriate supports.



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Following completion of this study, the information collected will be stored for 5 years in a locked filing cabinet in Trinity College Dublin. It will then be destroyed by Dr Margaret Walshe, the supervisor of this study.

Participant Declaration and Signature

I am satisfied that I understand what my participation in this study involves. I am aware that I can withdraw from this study at any time without any consequences of any kind. I have been given a copy of the Patient Information Leaflet and this Consent Form to keep.

Signature of Participant

Date

Principal Investigator Declaration and Signature

I believe that the above participant has given informed consent to participate in this study.

Signature of Principal Investigator

Date



Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

PARTICIPANT CONSENT FORM

Project Title: Understanding the psychosocial impact of chronic dysphagia in stroke; a qualitative exploration

The Study

I understand that this study is being carried out by **Jennifer Moloney** and **Dr Margaret Walshe**.



Please mark/circle

I understand that the **goal** of this study is to **explore** the **impact** of **swallowing difficulties** on everyday life after a stroke.



Please mark/circle

What is involved?

I understand that I will be taking part in a **one to one interview** with **Jennifer Moloney**.



Please mark/circle



I understand that we will be discussing the impact that my swallowing difficulties have on my life.



Please mark/circle

I understand that the interview will be approximately 60 minutes in length.



Please mark/circle

I understand that the interview will be held at a place of my convenience.



Please mark/circle

I understand that I may be asked to participate in a shorter follow-up interview at a later date.



Please mark/circle



Important Information

I understand that my interview will be audio-recorded and transcribed.



Please mark/circle

I understand that my identity will be protected throughout.



Please mark/circle

I know that I can change my mind at any time if I no longer want to be involved.

NO
THANKS!



Please mark/circle



Participant Declaration and Signature

I understand what is involved in this study.

I agree to participate in this study but know that I can withdraw at any time.

I have been given a copy of the Participant Information Leaflet and this Consent Form to keep.



Please mark/circle

Signature of Participant

Date

Principal Investigator Declaration and Signature

I believe that the above participant has given informed consent to participate in this study.

Signature of Principal Investigator

Date

Appendix 11: Interview study guide

1. Time of/Early Stages following Stroke

Tell me as much as you can remember about the time you had your stroke

What were you thinking and feeling at that time?

What were your hopes or expectations?

What were your fears?

2. Onset of Swallowing Difficulty & Rehabilitation

When did you first realise you had difficulty swallowing?

What was your understanding of your swallowing difficulty at the time?

What were your thoughts and feelings at the time?

Who was involved at the time? How were they involved?

Tell me what you remember about the Speech and Language Therapist.

Tell me about what rehabilitation you've had for your swallowing.

What has been your impression of this rehabilitation?

Have you had any particularly positive or negative experiences you'd like to share?

When you look back at your rehabilitation to date, are there any events that stand out in your mind?

3. Long-Term Difficulty Swallowing

When did you come to realise you might have a long term difficulty with swallowing?

How did you come to realise that?

What were your thoughts and feelings at the time?

Who was involved? How were they involved?

Was there anything or anyone that you found supported you at this time?

Was there anything or anyone that made this time for you more difficult?

4. Impact of Stroke Generally

Tell me about a typical day for you before you had your stroke.

Tell me about a typical day for you now.

What does a good day mean for you?

What does a bad day mean for you?

What has been the biggest change in your life following your stroke?

What do you miss most about your life before your stroke?

What positive changes have occurred in your life since your stroke?

Are there any important lessons you've learned since having your stroke?

5. Impact of Difficulty Swallowing

What has been the biggest change in your life because of your difficulty swallowing?

Has your difficulty with swallowing impacted anybody else close to you? How?

What helps you to manage your difficulty swallowing on a daily basis?

What makes managing your swallowing difficulty more difficult?

What is the most challenging thing about your difficulty swallowing?

Who has been most helpful to you in managing your difficulties with swallowing? How has he/she been helpful?

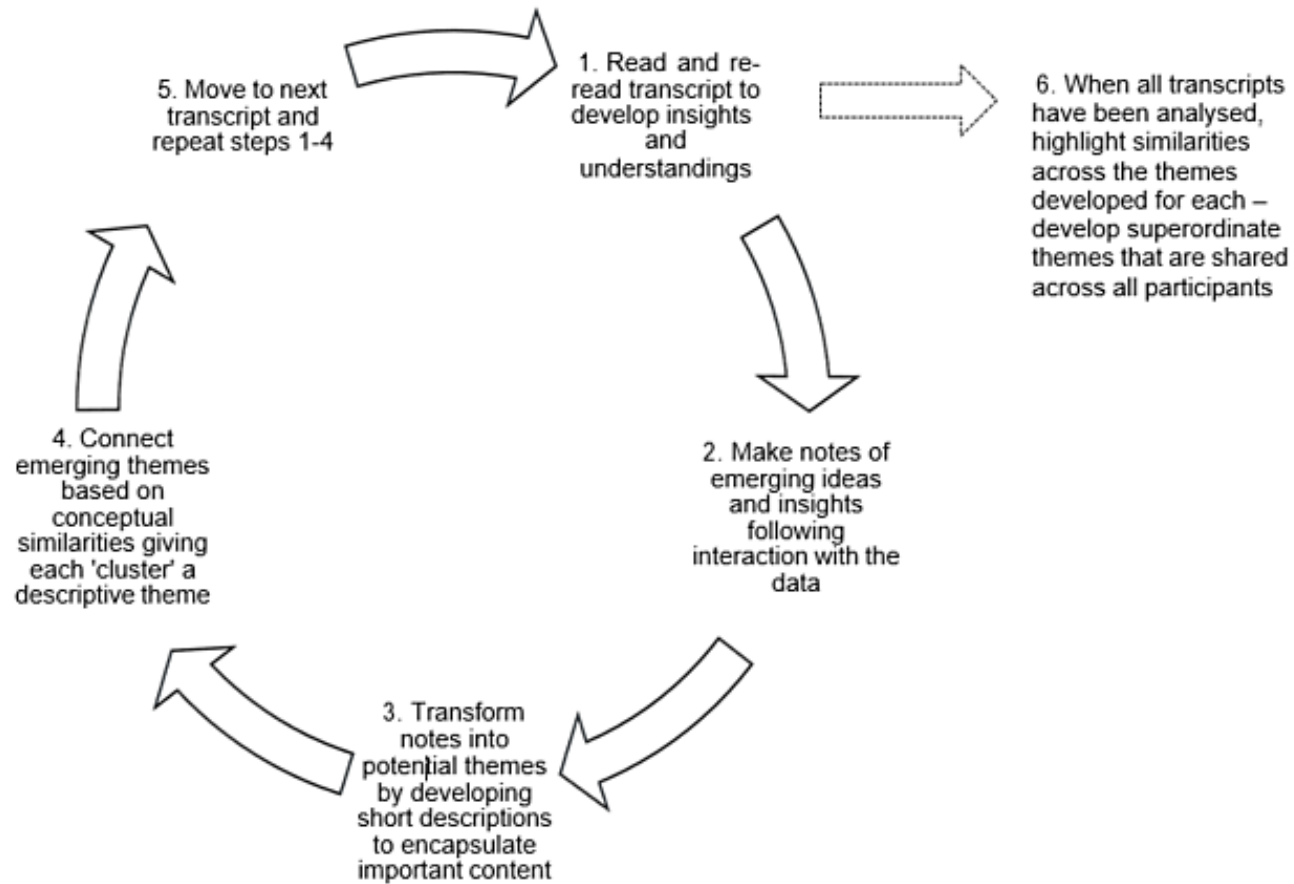
6. Closing Questions

When you think about the future, where do you see yourself in a years time, in 5 years time?

What advice would you give to somebody else in a similar situation?

Is there anything else you think it would be important for me or for others to know?

Appendix 12: Steps involved in Interpretative Phenomenological Analysis (IPA)



Appendix 13: Interview study data analysis sample

Extracts from interview with Pat when discussing secretion management

<i>Transcript Extracts</i>	<i>Reflections</i>	<i>Emerging Theme</i>
I have a lot of secretions in my mouth too and I'm not able to move the secretions because the tongue doesn't move them in my mouth, so they stay there and it's always full.	Impact of physical symptoms and persistence of same	Physical symptoms
The secretions in my mouth are a major problem so I have patches on to try and dry up the saliva.	Attempts to manage symptoms; Secretion management a priority for Pat	Symptom management
He used to get injections every 3 months and then we'd come home and we used to put patches on to try and get the balance right. Mind you he's not getting the botox injections now due to Covid. So we try and work out as best we can with the patches.	Trying to make do with options for symptom management; Impact of Covid on healthcare services; Figuring it out themselves	Coping with symptom management; Healthcare services; Trial and error
If I have too many patches I dry up and I'm too dry and if I'm too dry then it's uncomfortable. Sometimes I get it wrong and more times I don't and more times we do.	Trial and error; No clear approach or formula; Figure out as you go along	Trial and error
I needed to speak to you today, so I had my patches on early in the morning so that they could dry me up for the call, and then I have to replace them.	Preparing in advance; Lack of spontaneity; Need to have a clear routine to support plans	Importance of routine
You're constantly having to keep an eye on it. If I don't need as many patches, maybe half, we can manage that. Sometimes we've learned that I don't need that many patches.	Learning as you go along through trial and error	Trial and error
We try to do our best.	Coping by figuring it out by themselves	Coping with symptom management; Healthcare services; Trial and error
I have the suction machine here beside me and we use that when we need it.	Options for management of symptoms; As needed	Symptom management
Yes and oral hygiene would be a huge thing. That would be very important. You have to have that, otherwise things won't go as normal as you like, you have to have a routine.	Routine and importance of same towards coping with symptoms	Importance of routine; Coping

List of Preliminary Themes Developed from each Transcript

Ben	Tom	Pat
Limitations and Variations	Social-Identity	Hope for the future
Knowing the System	Self-Identity	Social-Identity
Hope for the Future	Daring to Hope	Importance of Routine
Daring to Hope	Hope for the Future	Trial and Error
Importance of Routine	Limitations and Variations	Symptom Management
Symptom Management	Knowing the System	Knowing the System
Self-Identity	Symptom Management	
Social-Identity	Trial and Error	
	Importance of Routine	

Clustering of Preliminary Themes towards Development of Final Themes

Coping	Identity	Hope	Interactions with Healthcare Providers
Trial and Error	Self-Identity	Daring to Hope	Limitations and Variations
Importance of Routine	Social-Identity	Hope for the Future	Knowing the System
Symptom Management			

Appendix 14: Survey study ethical approval



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

14/03/2017

Application	Academic Year 2016/17
Applicant:	HT36 Moloney, Jennifer
Title of Research:	The beliefs and practices of Speech and Language Therapists regarding quality of life issues in dysphagia management

Dear Jennifer,

Your revised submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, today Tuesday 21st February 2017, and has been approved in full. We wish you the very best in your research activities.

Please note that on completion of research projects, applicants should complete the End of Project Report Form and submit one signed hard copy to the School Office as well as an electronic copy (slcsc@tcd.ie).

Best wishes,

A handwritten signature in black ink, appearing to read 'Saeed'.

Professor John Saeed

Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Scoil na nEolaíochtaí Teangeolaíochta,
Urrabhra agus Cumarsáide,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

School of Linguistic, Speech &
Communication Sciences,
Trinity College,
Dublin 2, Ireland

T 353 (0)1 896 1660
slcsc@tcd.ie
www.tcd.ie/slcscs

Appendix 15: Survey study reporting checklist

A Consensus Based Checklist for Reporting of Survey Studies (CROSS)

Developed from:

Sharma A. et al. (2021). A Consensus-Based Checklist for Reporting of Survey Studies (CROSS). *J GEN INTERN MED*. <https://doi.org/10.1007/s1166-021-06737-1>

Title and Abstract	State the word 'survey' along with a commonly used term in title or abstract to introduce the study's design.	p.137
	Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussions and conclusions.	p.137-138
Introduction and Background	Provide a background about the rationale of study, what has been previously done, and why this survey is needed.	p.138-140
Purpose/aim	Identify specific purposes, aims, goals or objectives	p.140
Study Design	Specify the study design in the methods section with a commonly used term.	p.141
Data collection methods	Describe the questionnaire e.g. number of sections, questions, names of instruments used.	p.141-142
	Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure and reference links.	N/A
	Provide information on pretesting of the questionnaire, if performed. Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting and the level of similarity of demographics between pre-testing participants and sample population.	p.141
	Questionnaire, if possible, should be fully provided	Appendix 16
Sample characteristics	Describe study population including eligibility criteria for inclusion and exclusion	p.142-143
	Describe the sampling techniques used. Specify the location of sample participants whenever cluster sampling was applied.	p.142
	Provide information on sample size, along with details of sample size calculation	N/A
	Describe how representative the sample is of the study population particularly for population-based surveys.	N/A
Survey administration	Provide information on modes of questionnaire administration including the type and number of contacts and the location e.g. outpatient room, online.	p.142
	Provide information on survey's period.	p.143
	Provide information on the entry process.	p.142
Study preparation	Describe any preparation process before conducting the survey e.g. advertising the survey.	p.142

Ethical considerations	Provide ethical approval for survey if obtained, including informed consent, institutional review board approval, Helsinki declaration and good clinical practice.	p.141
	Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorised access.	p.143
Statistical analysis	Describe statistical methods and analytical approach. Report the software that was used for data analysis.	p.143-144
	Report any modifications of variables used in the analysis, along with reference.	N/A
	Report details about how missing data was handled. Include rate of missing items, missing data mechanism.	N/A
	State how non-response error was addressed.	N/A
	For longitudinal surveys, state how loss to follow-up was addressed.	N/A
	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample.	N/A
	Describe any sensitivity analysis conducted.	N/A
Respondent characteristics	Report numbers of individuals at each stage of the study. Consider using a flow diagram where applicable.	p.144 & p.152
	Provide reasons for non-participation at each stage if possible.	Not possible
	Report response rate, present the definition of response rate or the formula used to calculate.	Unable to determine
	Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions.	N/A
Descriptive results	Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes.	p.145 & p.152
Main findings	Give unadjusted estimates and if applicable confounder-adjusted estimates.	N/A
	For multivariable analysis, provide information on the model building process, model fit statistics and model assumptions.	N/A
	Provide details about any sensitivity analysis performed. If there are considerable amounts of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset.	N/A
Limitations	Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design.	p.162-163
Interpretations	Give cautious overall interpretation of results, based on potential biases and impressions and suggest areas for future research.	p.159-162
Generalisability	Discuss the external validity of the results	N/A
Role of the funding source	State whether any funding organisation has had any roles in the survey's design, implementation and analysis.	N/A
Conflict of interest	Declare any potential conflict of interest.	N/A
Acknowledgements	Provide names of organisations, persons that are acknowledged along with their contribution to the research.	N/A

Appendix 16: Survey tool

Many thanks for taking the time to complete this survey. This survey is completely anonymised and you will not be required to provide any identifying information. It should take approximately 10 minutes to complete.

* 1. Please indicate your consent to participate below.

I understand that my completion of this survey indicates my consent to participate.

Demographic Information

2. In what country did you obtain your primary degree in Speech and Language Therapy?

- Ireland
- United Kingdom
- Australia
- New Zealand
- Canada
- United States
- South Africa
- Singapore
- Other (please specify)

3. In what country are you currently practising as a Speech and Language Therapist?

- Ireland
- United Kingdom
- Australia
- New Zealand
- Canada
- United States
- South Africa
- Singapore
- Other (please specify)

4. How many years postgraduate experience do you have working as a Speech and Language Therapist?

- 1-3
- 4-6
- 7-9
- 10+
- 20+

5. In what setting do you primarily practice as a Speech and Language Therapist?

- Acute Hospital
- Inpatient Rehabilitation
- Residential Setting
- Outpatient Clinics
- General Community Based Service
- Specialist Community Based Service
- Private Practice
- Other (please specify)

Definitions and Beliefs

6. For the purpose of this study, the following WHO definition of 'Quality of Life' (QOL) will be used: ***"An individual's 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. It 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."*** Does this definition accurately summarise your understanding of the term 'QOL'?

- Yes
- No
- Somewhat

Additional Comments:

7. According to Farri et al (2007, p.85), ***"dysphagia is a disorder which has a negative influence on the patient's life, severely affecting quality of life, both the social and emotional aspects"***. Please indicate your level of agreement or disagreement with this statement.

Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Additional Comments:

8. ***'Dysphagia outcomes will strongly impact a person's overall health and well being'*** Please indicate your level of agreement or disagreement with this statement.

Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Additional Comments:

9. In your own opinion, please rank the patient populations below from 1 – 5. 1 being those most likely to experience poor QOL as a result of dysphagia, 5 being the population least likely to experience poor QOL as a result of dysphagia.

<input type="text"/>	Progressive Neurological Conditions
<input type="text"/>	Stroke and Acquired Brain Injuries
<input type="text"/>	Dementia
<input type="text"/>	Head and Neck Cancer
<input type="text"/>	Other

Current Practice in QOL Management

10. What proportion of your caseload includes persons with dysphagia?

- 0-20%
- 21-40%
- 41-60%
- 61-80%
- 81-100%

11. As a rough estimate, what proportion of your clinical time do you spend managing or supporting QOL issues in persons with dysphagia?

- 0-20%
- 21-40%
- 41-60%
- 61-80%
- 81-100%

Additional Comments:

12. Are you satisfied with the amount of clinical time you can currently allocate to managing or supporting QOL issues in persons with dysphagia?

- Yes
- No
- Somewhat

Additional Comments:

13. How do you gather information regarding the impact that dysphagia has on the QOL of the persons you work with? Please be as specific as possible. (Tick all that apply)

Case History

Observations

Rating Scales

Specific Assessment Tools (Please Specify)

14. Generally, is this information routinely gathered as part of your assessment protocol?

Yes

No

Somewhat

Additional Comments:

15. What do you feel, if any, are the **facilitators** to effective clinical practice in the management of QOL in persons with dysphagia?

16. What do you feel, if any, are the **barriers** to effective clinical practice in the management of QOL in persons with dysphagia?

Training and Education

17. How confident do you feel in managing QOL for persons that you work with who have dysphagia?

Extremely Confident

Very Confident

Somewhat Confident

Limited Confidence

Not Confident at all

18. Do you feel your pre-qualification Speech and Language Therapy training prepared you adequately to work with QOL issues in the dysphagia population?

- Yes
 No
 Somewhat

Additional Comments:

19. Have you engaged in post-qualification training (e.g. conferences, course days, third level education) in the area of QOL issues in dysphagia?

- Yes
 No
 If 'Yes' please briefly outline details below:

Stroke Specific Questions

20. Do you currently work with persons who experience dysphagia as a result of stroke?

Yes

No

Stroke Specific Questions

21. How knowledgeable do you feel with regards the specific QOL issues relevant to dysphagia in the stroke population?

Extremely Knowledgeable	Very Knowledgeable	Somewhat Knowledgeable	Limited Knowledge	Not Knowledgeable at all
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. In your own opinion, please rank the basic goals of **acute** dysphagia management in the stroke population below from 1 – 5. 1 being the most important, 5 being the least important.

<input type="text"/>	Education and Training
<input type="text"/>	Maintenance of adequate nutrition and hydration
<input type="text"/>	Quality of Life
<input type="text"/>	Safety (i.e. preventing aspiration)
<input type="text"/>	Other

23. In your own opinion, please rank the goals of **long-term** dysphagia management in the stroke population below from 1 – 5. 1 being the most important, 5 being the least important.

<input type="text"/>	Education and Training
<input type="text"/>	Maintenance of adequate nutrition and hydration
<input type="text"/>	Quality of Life
<input type="text"/>	Safety (i.e. preventing aspiration)
<input type="text"/>	Other

24. At what stage in the person's journey following stroke, do you feel it is most appropriate to address QOL issues associated with their dysphagia?

- Acute
- Subacute Inpatient Rehabilitation
- Community-Based Rehabilitation
- Once improvement in swallow function has plateaued
- At all stages

Additional Comments:

25. What, if any, do you feel are the **facilitators**, specific to the stroke population, which impact on the management of QOL issues in dysphagia?

26. What, if any, do you feel are the **barriers**, specific to the stroke population, which impact on the management of QOL issues in dysphagia?

27. Generally, how long following a person's stroke do you feel it is appropriate to withdraw dysphagia rehabilitation therapy, if little or no progress in swallowing function has been made?

- 0-3 months
- 3-6 months
- 6-9 months
- 9-12 months
- 12-18 months
- 18-24 months
- 2 years+

Additional Comments:

28. If it has been agreed that further improvement in swallow function is unlikely, how likely are you to keep the person 'open' and 'active' on your caseload?

- Extremely Likely
- Likely
- Somewhat Likely
- Unlikely
- Very Unlikely

Additional Comments:

29. If it has been agreed that further improvement in swallow function is unlikely, what do you believe are the priorities, if any, for ongoing Speech and Language Therapy input? 1 being the highest priority, 5 being the least priority.

<input type="text"/>	Education and Training
<input type="text"/>	Maintaining adequate nutrition and hydration
<input type="text"/>	Quality of Life
<input type="text"/>	Safety (i.e. preventing aspiration)
<input type="text"/>	Other

30. What do you feel are the main QOL issues facing persons living with long-term dysphagia following stroke?

Closing Comments

31. Are there any final comments you would like to make regarding QOL issues in the management of the dysphagia population in general?

Appendix 17: Survey study data analysis sample – Thematic Analysis (TA)

Example of noting of important features in the responses

Q24 What, if any, do you feel are the facilitators, specific to the stroke population, which impact on the management of QOL issues in dysphagia?

#	RESPONSES	DATE
1	client directed outcomes	4/18/2017 11:24 AM
2	The acute onset can make the QOL issues more apparent to everyone involved, making it more likely to be assessed and addressed	4/13/2017 4:28 PM
3	family support confidence that family/ staff will keep patients mouth clean/ pre from bacteria so for example free water protocol could be trialled	4/12/2017 10:00 AM
4	Experienced therapists working with patients - open to counselling re; choices/ risks and benefits / QOL . Consistency of staff so patients can freely discuss / build relationship	4/7/2017 1:11 PM
5	supportive environment with others having an understanding of the impact of dysphagia on the individual	4/6/2017 10:54 AM
6	Having a family support system.	4/6/2017 9:23 AM
7	teamwork, educating other team members re dysphagia	4/4/2017 10:11 PM
8	mdt's	4/4/2017 12:52 PM
9	team approach family contact	4/3/2017 10:15 AM
10	Spontaneous improvements benefit their dysphagia status and in turn their QOL	4/2/2017 4:01 PM
11	establishment of specific community rehab teams for stroke/ MDT working, timely service and education, Good support from voluntary agencies (Stroke association), potential scope for improvement which gives person motivation / hope	3/31/2017 2:38 PM
12	carer support	3/31/2017 9:43 AM
13	Spontaneous recovery - the hope that there may be improvement in swallow function	3/31/2017 9:07 AM
14	good team working, access to medical advice and dietetic involvement	3/31/2017 8:50 AM
15	SLT focus on preventing aspiration above all else?	3/31/2017 8:43 AM
16	Frank and open discussion regarding the impact of dysphagia with the pt and the family/carers to establish pt's wishes and needs involving the pt in decision making regarding their dysphagia management and rehab	3/30/2017 5:02 PM
17	Patient having communication skills that support the discussion. Patient having a family/friend support system. Good mobility (e.g. for posture)	3/30/2017 10:05 AM
18	Swallow screening, MDT knowledge/ buy-in to role of SLT with stroke population, MDT joint working, likelihood of receiving intensive SLT rehab post stroke, access to objective assessments e.g. VFSS or FEE's, time, intensity of intervention, collaborative goal setting.	3/30/2017 9:42 AM
19	Improvements in swallow function can be made quite quickly which allows time during the acute stage and inpatient rehabilitation stage to address quality of life factors Patients who do not have any cognitive deficits- easier to address QOL Family involvement and support	3/30/2017 9:29 AM
20	a team recognition of the importance of these issues (catering, HCAs, Nurses, AHPs) a consultant/GP who is on board with QOL issues Understanding & confidence in treating the issue by the treating SLT	3/30/2017 9:15 AM
21	Often they can be quite medically well	3/30/2017 8:13 AM
22	Same as previously mentioned	3/30/2017 7:18 AM
23	Adherence to treatment	3/29/2017 7:55 PM
24	A complete analyse of current problems.	3/29/2017 4:26 PM
25	as per previous facilitators question with	3/29/2017 2:00 PM

Example of code generation and sorting into themes using these features

SLT Characteristics	Service Delivery/Configuration	Multidisciplinary Team	Patient Factors	Stroke Trajectory
SLT Experience	Timely service	Teamwork	Patient communication skills	Acute onset
Understanding of impact	Objective assessments	Team approach	Good mobility	Spontaneous improvements
Educating others	Intensive rehab	Team recognition	No cognitive deficits	Scope for improvement
Understanding and confidence			Medically well/stable	
Preventing aspiration			Family involvement	

Appendix 18: Focus group ethical approval



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

25/06/2018

Application Academic Year 2017/18

Applicant: TT75 Moloney, Jennifer

Title of Research: Quality of Life in Chronic Dysphagia following Stroke: A Focus
Group Study.

Dear Jennifer,

Your revised application for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Tuesday 1st May 2018, and has been approved in full. We wish you the very best in your research activities.

Please note that on completion of research projects, applicants should complete the End of Project Report Form and submit one signed hard copy to the School Office as well as an electronic copy (slcsc@tcd.ie).

Best wishes,

A handwritten signature in black ink, appearing to read 'Saeed'.

Professor John Saeed

Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Appendix 19: Focus group recruitment advertisements

WANTED!

Focus Group Participants Needed

Who are we?

- We are a group of researchers based in the Department of Clinical Speech and Language Therapy, Trinity College, Dublin, Ireland.
- We are interested in developing the clinical supports available to Speech and Language Therapists working with persons who have dysphagia following stroke.

Who are we looking for?

- We are looking for Speech and Language Therapists with an interest in quality of life issues in dysphagia following stroke.
- We would like to hear more about your experiences of working in this area.
- We are particularly interested in barriers and facilitators to effective practice in supporting quality of life in this clinical group and suggestions or ideas you might have towards further supporting clinical practice in this area.

What's involved?

- We are inviting you to participate in a 60 minute focus group which will be scheduled during the 8th Annual ESSD Congress in Dublin, Ireland.
- It is anticipated that each focus group will have 6-8 participants.
- During the focus group, you will be invited to share your experiences and opinions in the area under study.
- The focus group will be audio-recorded.
- Tea, coffee and light refreshments will be provided.

For further information or to express an interest in participating in this study, please contact the Principal Investigator, Jen Moloney – Email: sltfocusgroup@gmail.com



Research Participants Wanted

Are you working as a **Speech and Language Therapist**?

Do you have an interest in **quality of life** issues in **dysphagia** management following **stroke**?

Would you be interested in participating in a **short focus group** during the upcoming ESSD Conference in Dublin?

If so, we would love to hear from you!

For more information please contact

Jen Moloney – PhD Candidate, Trinity College Dublin

Email: sltfocusgroup@gmail.com



Appendix 20: Focus group participant information leaflet



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

PARTICIPANT INFORMATION LEAFLET

Supporting quality of life issues in dysphagia following stroke: An international focus group study of Speech and Language Therapy practice

Jennifer Moloney, PhD Candidate – Principal Investigator

Dr Margaret Walshe, Associate Professor in Speech and Language Therapy

We would like to invite you to participate in our research study. Before you decide if you would like to participate, you should understand fully why the research is being done and what it would involve for you. Please take the time to read the following information carefully and share it with others if you wish. If you have any questions or would like more detail, please get in touch. Choosing not to take part in this research will not disadvantage you in any way.

What is this study about?

This study is part of a larger PhD research project which is exploring the assessment and management of quality of life issues in chronic dysphagia following stroke. As part of this larger project we would like to know more about the current perspectives of international Speech and Language Therapists (SLTs) working in this important clinical area. We would also like to know more about what you perceive to be the current facilitators and barriers to effective practice in this area.

What will taking part involve?

Taking part in this research study will involve participating in an open group discussion with 5-7 other Speech and Language Therapists. This group discussion will be facilitated by the Principal Investigator and will focus on your experiences of working with quality of life issues in persons with chronic dysphagia following stroke.

The group discussion will be scheduled to run during the Annual Congress of the European Society of Swallowing Disorders which is being held in Dublin from the 25th to the 29th September 2018. It will be held in a meeting room at the venue of the Congress (i.e. the Aviva Stadium, Dublin) and the exact time and date will be confirmed depending on participant availability.

The group discussion will last approximately 60 minutes. There are no right or wrong answers in a discussion of this kind – we are simply interested in your experience and opinions.

Will taking part be confidential?

The group discussion will be audio-recorded using a dictaphone which will be encrypted. Following the discussion, this recording will be transcribed by the Principal Investigator. Each participant will be given a pseudonym at the time of transcription and any potential identifying information will be removed. Your participation in this study will not be disclosed to anyone, but there is the possibility that another member of the group may know or recognise you.

We may use direct quotes from you in reports or publications related to this study. If so, these quotes will be attributed to your pseudonym and will not include any identifying information.

The audio-recordings will be destroyed directly following transcription. Any hardcopy records of the transcripts, which will not have any identifying information, will be stored in a locked filing cabinet in the Department of Clinical Speech and Language Studies, Trinity College, Dublin. Any electronic copy files of the transcripts will be stored on an encrypted and password protected storage device.

You will be given the opportunity, at the end of the group discussion, to indicate whether or not you would like a copy of the final transcript.

How will the information I provide be used?

The transcripts of the group discussion will be qualitatively analysed. Common themes and factors across group participants will be identified. The findings will contribute to the wider research project which aims to explore the assessment and management of quality of life issues in chronic dysphagia following stroke. The findings of this study may also may be written up independent of this wider research project and be published in a peer-reviewed academic journal.

What if I want to withdraw from the study?

If you agree to take part in this study, you can choose to withdraw at any point.

What do I do now?

If you are interested in participating in this study, or if you have any further questions, please contact:

Jennifer Moloney, Principal Investigator Email: jemolone@tcd.ie

or

Dr Margaret Walshe, PhD Supervisor Email: walshema@tcd.ie

Appendix 21: Focus group protocol



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

FOCUS GROUP PROTOCOL

Supporting quality of life issues in dysphagia following stroke: An international focus group study of Speech and Language Therapy practice

1. Welcome Address
 - a. Introduction of facilitator and explanation of role
 - b. Explain general purpose of discussion
 - c. Explain presence and purpose of audio recording equipment
 - d. Explain structure of focus group and duration, allow suggestions for any ground rules
 - e. Review house keeping information
 - f. Review data collection, storage and confidentiality
2. Participant Consent
 - a. Review of consent forms
 - b. Allow time/space for questions and clarifications
 - c. Signing and collection of consent forms
3. Begin Data Collection
 - a. Invite brief introductions from each participant
 - b. Opening questions
 - c. Main questions
 - d. Closing questions, comments and remarks
4. Post-data Collection
 - a. Acknowledge and thank participants
 - b. Offer 'sign-up' sheet where participant's can request copy of transcripts

} *See below

*Opening Questions:

- What are the main quality of life issues you come across in this clinical group?

Main Questions:

- What are the main facilitators to effective clinical practice in this area?
- What are the main barriers to effective clinical practice in this area?
- Are there any specific clinical tools or resources that would further support your clinical practice in this area?

Closing Questions:

- Is there anything further you would like to add or discuss?

Appendix 22: Focus group consent form



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Trinity College Dublin – School of Linguistic, Speech and Communication Sciences

PARTICIPANT CONSENT FORM

Project Title: Supporting quality of life issues in dysphagia following stroke: An international focus group study of Speech and Language Therapy practice

Jennifer Moloney, PhD Candidate – Principal Investigator

Dr Margaret Walshe, Associate Professor in Speech and Language Therapy

- I agree to participate in the above named focus group, facilitated by Jennifer Moloney, Principle Investigator and PHD Candidate, Trinity College Dublin
- I have read the Participant Information Leaflet related to this study
- I fully understand the aims of this study and what my taking part involves
- I agree to have the focus group audio-recorded so that it can be later transcribed
- I am fully aware that I will remain anonymous in the reporting of any data related to this study
- I am fully aware that data collected will be stored anonymously, safely and securely
- I am fully aware that I am not obliged to answer any question, but that I do so at my own free will
- I am fully aware that I can withdraw from the focus group at any point, but that any data provided up to that point cannot be withdrawn from the study

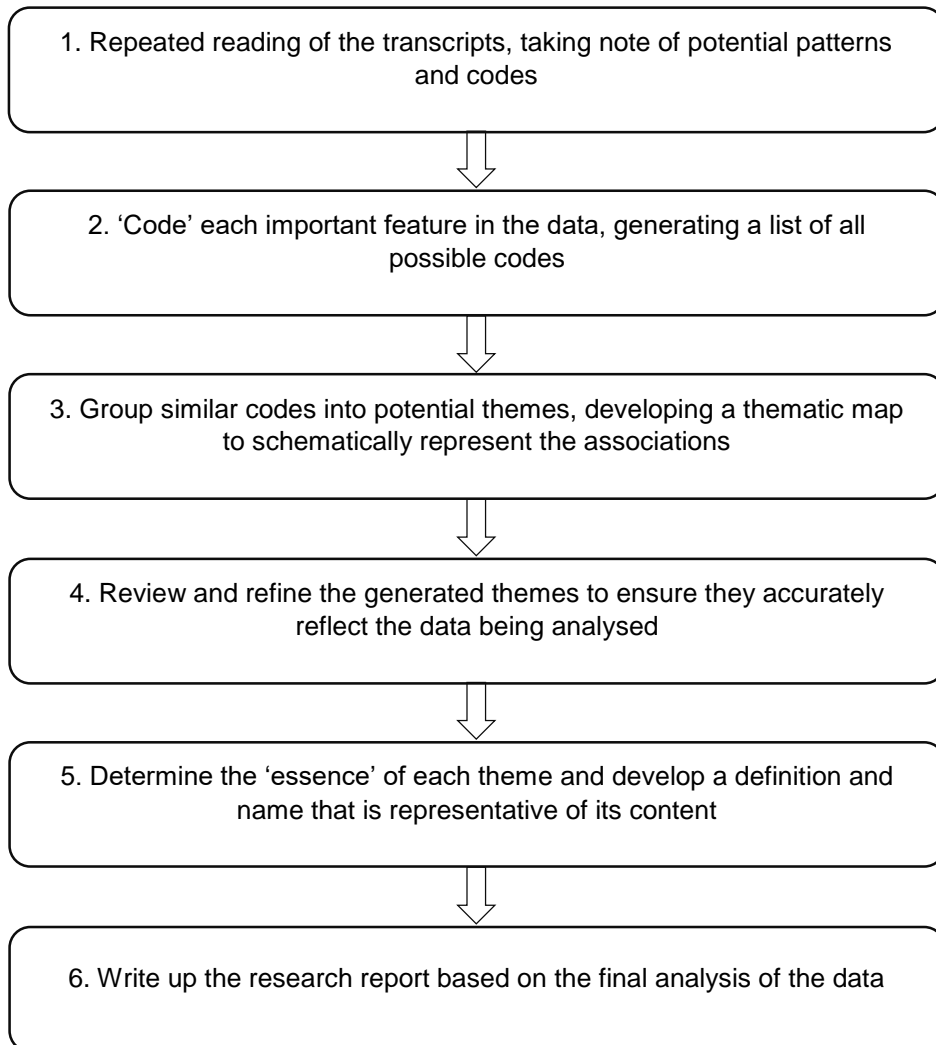
Participant's Printed Name and Signature

Date

Principal Investigator's Printed Name and Signature

Date

Appendix 23: Steps involved in Thematic Analysis (TA)



Appendix 24: Focus group data analysis sample

Example of noting of important features in the transcript

31 know what kind of things come to mind and what types of issues do these people face in
32 your experience and what kind of issues do you come up against in your clinical setting?
33 I guess, I mean from my experience in Singapore, quality of life is not something that
34 you immediately think about when you're managing patients, there's just so many things
35 to settle, with medical care for example. Rehabilitation is so important and swallow
36 rehabilitation is so important that it's not a thing that we often address. And I think for
37 the people there they don't usually think about quality of life either, it's just more for
38 survival and recovery, back to work. That's more important but yeah I guess quality of
39 life comes in aswell, in the work setting aswell, yeah, but we don't really touch a lot on
40 that.
41 R: Okay, I wonder is that similar in other places?
42 P10: Yeah, I was just going to agree with what you said there. Working on a stroke ward,
43 people are usually so shocked with everything that is happening and their whole world
44 has changed that they whether they also have a swallowing difficulty or not, often isn't a
45 major question. I think it's mostly with patients that primarily have dysphagia as their
46 main clinical problem and if they ambulatory and can speak, those are the ones that I feel
47 there is an instant issue around quality of life and dysphagia. With the others it's more
48 like it's underneath all of the other topics.
49 P4: I think a quite interesting topic we are often discussing is short term quality of life and
50 long term. If there are discussions around don't PEG or whatever it is because it his
51 quality of life to be able to drink but that's a more immediate quality of life and you have
52 to think about the consequences of that and long term you don't want the patient to be
53 sick because that's not quality of life. I think that's a bit spectrum and we're not always
54 talking about the same I feel in clinic when you're talking about quality of life.
55 R: Okay that's interesting there's a big difference in what people define quality of life as and
56 what you are saying is that in the acute stages especially that it might not be the main
57 priority.
58 P8: Yeah I think coming from community and the primary care side I'm definitely coming at
59 it from a very different angle and really quality of life is always considered. You're always
60 weighing up the risks a lot more and you do definitely have that discussion that it is their
61 decision at the end of the day if they want to implement your recommendations. Once

Comparing priorities in acute vs community
QoL a priority in community and primary care (vs acute)
Depending on where the dysphagia ranks compared to other changes
In acute stages, still dealing with shock/change. ∴ QoL not NB.

Community is time to consider
QoL, can make decisions
62 they're aware, yeah, I feel like it's more about the education so that they can make the
63 decision based on what they feel will impact on their quality of life the most and they've
64 gone through their acute experience and they've gone through their rehab. They know
65 that they're no longer in shock about what's just happened, they're trying to figure out
66 what's attainable for them now.
67 P11: I think it's only when they get back into their normal routine, you know their normal
68 social routine that they really feel the consequences of having dysphagia. Definitely if you
69 go into a restaurant, café, or whatever it might be suddenly you're very limited in what
70 you can have, you can no longer participate as well as you could have been. Where as in
71 the hospital, you just want to stay well and stay alive, it doesn't matter what you have to
72 do in order to do that but when you get home then your priorities kind of shift.
73 P5: Yeah I think in the community the idea that your priorities changing a lot, and after,
74 when you get the referral, if they're a long time post stroke, to get the referral that makes
75 you turn up on their door step, one of the reasons is that they're currently not happy
76 with their quality of life after dysphagia and yes things like I don't want to have thickener
77 any more what can I do or I want to be able to cook and taste the things that I'm
78 cooking for my family because my role really changed and yeah being able to go out for
79 coffee with friends, and all of those things really add up and we've got a different role of
80 problem solving to fit in with them which is what it should be any way, being patient-
81 centred, but it does change a lot for us in the acute like you're saying when you just want
82 to keep them safer. Role is different in acute versus community
83 R: Any other thoughts on that? (...) There seems to be a very obvious difference in terms
84 of priority in acute versus community just from what you're saying and I know you
85 mentioned that in acute care, you know, medically that might take precedence alongside
86 all of the other things you have to worry about. But I wonder are there any other factors
87 that you think maybe get in the way of focussing on quality of life in acute care?
88 P5: I don't know if it gets in the way of quality of life but I've had a bit of experience on an
89 acute stroke ward and everyone has got their own priorities and all the different MDT,
90 somebody is worried about this bit, and somebody is worried about this bit and this bit
91 and sometimes it all gets separated even though it shouldn't be and quality of life, it
92 could fall into so many different categories it's hard to just solve that one.

QoL becomes an issue when they get home
Comparing priorities among MDT members in acute - QoL gets lost.

Impact of communication deficits.

93 R: Okay

94 P10 And I think also patients with additional language impairment, it can be hard to find out

95 in terms of what their life has been and what they'd like to go back to, it can be difficult

96 P11: I think that's where the family comes in, in terms of making decisions right there and

97 then, they might say that they prioritised their quality of life over, let's say an NG or

98 PEG insertion, they're willing to take the risk but we don't know if that person would

99 wish to go down that route, you just have to go with the family

100 P1: I think it's also part of it too, to assess what their goals are, everyone has different goals,

101 the patient has different goals, the family has different goals and it's probably different to

102 my goals and what the physicians goals are and then that way you can really target your

103 assessment and rehabilitation to meet their goals and even maybe you know they might

104 want to eat a certain type of consistency or a certain food and you can then assess that in

105 your videofluoro even and you're working towards that in your rehab or whatever it is.

106 Maybe that's their quality of life. - Importance of addressing patients specific goals.

107 R: Okay, and we might even stick with that and move into when you are assessing the

108 impact of dysphagia in a person following stroke. How do you go about doing that? And

109 even thinking wider of whether or not the person decides to eat and drink at risk,

110 thinking about the whole impact that dysphagia has on their life. How would you go

111 about judging that or making conclusion about that or assessing it clinically?

112 P3: I think it's not something that we formally assess. And I mean I think it comes back to

113 what is meant by quality of life and how we define that. And I'm actually now thinking I

114 actually don't know how I would define it you know it's like I think it's different. Is it

115 feeding at risk or is it the provision of therapy or is it you know focussing on patient

116 centred goals. I think quality of life is really poorly defined and sometimes it's put into a

117 box of risk feeding and patients are on thickener and they just like take thin liquids and

118 you can say on well that's quality of life but sometimes I don't know in our patient group

119 from our insights I think sometimes the provision of therapy might add to their quality

120 of life but I think in terms of assessment yeah I don't know.

121 P5: I think in the head and neck, the head and neck population you would use the SWAL-

122 QOL and the MD and all sorts of things but am in stroke no

123 P9: I think in stroke I use the SWAL-QOL and the MD

Importance of family involvement

What is QOL? risk feeding vs therapy vs patient centred goals

459 be their priority versus your priority versus the patient's priority. If it's a nursing home

460 for example, the priority of the carers, the nurses.

461 NT: So would you agree, would the consensus be that stroke is a different group, or is there a

462 spectrum? - What does QOL mean?

463 P3: I think it depends aswell on your view of quality of life, I think if it's a black and white

464 model it just applies regardless. I think if you see quality of life as just adhering to your

465 patient's goals then I think it just applies across the board. But I think with those

466 progressive neurological disorders like dementia or Parkinson's you might have more,

467 more of a conservative approach or maybe like with patients with MND, where their life

468 expectancy is limited you might, their goals are different, but you also understand that

469 they may view it a bit different. - Difference vs progressive patients

470 P10: And I think with stroke, it's also a question about timing, so I think I would working on

471 a stroke ward, I would think quality of life, I wouldn't guide my decisions so strongly by

472 what the patients wishes are at that moment because there's just so many things that

473 have to be considered that if I follow a patient's wishes I'm really bringing him into a

474 huge risk. So I think that there is a huge difference for me aswell. Are they really acute

475 and I sort of have the feeling that it's really just overwhelming, they just sleep, they don't

476 want all of that. They never wanted to be on a tube and it's just this horror scenario and

477 if they say you know I don't like that or whatever, then I would try to convince them a

478 lot more aggressive as compared to someone that's two or three years post onset and

479 where the future is a bit different than with my patient that's just a couple of hours post

480 onset when I think tomorrow everything could be really different so it's, the focus is

481 managing to get you there. I think that really is a huge difference in stroke versus other

482 populations with dysphagia. - stroke trajectory - priority - sleep stroke journey

483 P5: I would think that stroke is like a separate group in that respect but it's also the setting,

484 has a big impact. So even it would make a different to my decision or as you were saying

485 how much at that moment in time the patients priorities of quality of life is taken into

486 consideration or at the forefront. But if they're in a very good care home and changing

487 their mind about what they want to eat and drink versus if they're in an acute location or

488 versus on their own in their own home and trying to cook things. - Different over populations.

Impact of setting on Tx priorities

Example of code generation and sorting into themes using these features

Potential Codes
Competing priorities in acute (QOL vs Recovery/Rehab)
Differing perspectives on what QOL means
QOL as a priority in acute vs community
Role in acute different to community
QOL - Risk feeding and/or patient centred goals and/or provision of therapy
Patient priorities shift during stroke journey
Impact of setting on treatment goals
Stroke vs persons with progressive conditions
QOL in stroke not as important as in other conditions
What does QOL mean?
Competing MDT priorities in acute - where does QOL fit?

Refined Codes
Competing priorities in acute setting
Definition of QOL
Acute vs Community Setting
Stroke vs Other Populations
Changing nature of QOL

Codes sorted into Themes	
What is QOL?	QOL as a priority in Stroke Care
Definition of QOL	Competing priorities in acute setting
Changing nature of QOL	Acute vs Community Setting
	Stroke vs Other Populations

Appendix 25: The COMET Taxonomy

Core area	Outcome domain	Explanation
Death	1. Mortality/survival	Includes overall (all-cause) survival/mortality and cause-specific survival/mortality, as well as composite survival outcomes that include death (e.g. disease-free survival, progression-free survival, amputation-free survival)
Physiological/ clinical	Physiological/clinical 2. Blood and lymphatic system outcomes 3. Cardiac outcomes 4. Congenital, familial and genetic outcomes 5. Endocrine outcomes 6. Ear and labyrinth outcomes 7. Eye outcomes 8. Gastrointestinal outcomes 9. General outcomes 10. Hepatobiliary outcomes 11. Immune system outcomes 12. Infection and infestation outcomes 13. Injury and poisoning outcomes 14. Metabolism and nutrition outcomes 15. Musculoskeletal and connective tissue outcomes 16. Outcomes relating to neoplasms: benign, malignant and unspecified (including cysts and polyps) 17. Nervous system outcomes 18. Pregnancy, puerperium and perinatal outcomes 19. Renal and urinary outcomes 20. Reproductive system and breast outcomes 21. Psychiatric outcomes 22. Respiratory, thoracic and mediastinal outcomes 23. Skin and subcutaneous tissue outcomes	<p>Physiological/clinical outcomes include measures of physiological function, signs and symptoms, as well as laboratory (and other scientific) measures relating to physiology, and are categorised according to the underlying cause/body system.</p> <p>“General disorders” includes those affecting the whole body and cannot be attributed to a certain body system (e.g. fatigue, chills, flu like symptoms, malaise, anorexia, pain (unspecified, not associated with a particular body system), fever (not attributable to infection), anthropometric measures (e.g. weight), “global” measures, “symptoms” (not associated with a particular body system), “physical health”, fitness).</p> <p>Pain outcomes are categorised according to underlying cause or body system or within the “General symptoms” category (if non-specific).</p> <p>Laboratory parameters (for example, from blood samples) and scientific measures (for example, pharmacokinetic outcomes) should be classified within the physiological domain that captures the reason for the assessment (rather than within the “blood and lymphatic system” category, for example).</p> <p>Psychiatric outcomes include all those relating to mental health conditions and associated behaviours (e.g. addictions and behavioural problems).</p> <p>Pregnancy, puerperium and perinatal domain extends to outcomes relating to</p>

Core area	Outcome domain	Explanation
	24. Vascular outcomes	breastfeeding and weaning. Outcomes relating to neoplasms include those related to non-solid and solid tumours.
Life impact	Functioning 25. Physical functioning 26. Social functioning 27. Role functioning 28. Emotional functioning/wellbeing 29. Cognitive functioning	Impact outcomes Physical functioning: impact of disease/condition on physical activities of daily living (for example, ability to walk, independence, self-care, performance status, disability index, motor skills, sexual dysfunction, health behaviour and management) Social functioning: impact of disease/condition on social functioning (e.g. ability to socialise, behaviour within society, communication, companionship, psychosocial development, aggression, recidivism, participation) Role functioning: impact of disease/condition on role (e.g. ability to care for children, work status) Emotional functioning/wellbeing: impact of disease/condition on emotions or overall wellbeing (e.g. ability to cope, worry, frustration, confidence, perceptions regarding body image and appearance, psychological status, stigma, life satisfaction, meaning and purpose, positive affect, self-esteem, self-perception and self-efficacy) Cognitive functioning: impact of disease/condition on cognitive function (e.g. memory lapse, lack of concentration, attention); outcomes relating to knowledge, attitudes and beliefs (e.g. learning and applying knowledge, spiritual beliefs, health beliefs/knowledge)

Core area	Outcome domain	Explanation
	30. Global quality of life	Includes only implicit composite outcomes measuring global quality of life
	31. Perceived health status	Subjective ratings by the affected individual of their relative level of health
	32. Delivery of care	Includes outcomes relating to the delivery of care, including <ul style="list-style-type: none"> • adherence/compliance • patient preference • tolerability/acceptability of intervention • withdrawal from intervention (e.g. time to treatment failure, reason for stopping therapy) • appropriateness of intervention • accessibility, quality and adequacy of intervention • patient/carer satisfaction (emotional rather than financial burden) • process, implementation and service outcomes (e.g. overall health system performance and the impact of service provision on the users of services)
	33. Personal circumstances	Outcomes relating to patient's finances, home and environment
Resource use	Resource use 34. Economic 35. Hospital 36. Need for further intervention 37. Societal/carer burden	Economic: general outcomes (e.g. cost, resource use) not captured within other specific resource use domains Hospital: outcomes relating to inpatient or day case hospital care (e.g. duration of hospital stay, admission to ICU) Need for further intervention: outcomes relating to medication (e.g. concomitant medications, pain relief), surgery (e.g. caesarean delivery, time to transplantation) and other procedures (e.g. dialysis-free survival, mode of delivery) Societal/carer burden: outcomes relating to financial or time implications on carer or society as a whole (e.g. need for home help, entry to institutional care, effect on family income)

Core area	Outcome domain	Explanation
Adverse events	38. Adverse events/effects	Includes outcomes broadly labelled as some form of unintended consequence of the intervention (e.g. adverse events/effects, adverse reactions, safety, harm, negative effects, toxicity, complications, sequelae). Specifically named adverse events should be classified within the appropriate taxonomy domain above with an additional level of categorisation which identifies that this outcome is being considered as an adverse event.

Appendix 26: Scoping review study reporting checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	p.197
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	p.197-198
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	p.199-202
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	p.201-202
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	p.202
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	p.202-203
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	p.203
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	p.380-381
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	p.203-204
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	p.204
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	p.204
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	P.204-205

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	p.208-209
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	p.208-209
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	p.213-214
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	p.213-214
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	p.227-231
Limitations	20	Discuss the limitations of the scoping review process.	p.231-232
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	p.233
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JB I = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).

Appendix 27: Scoping review protocol

Swallowing outcome measures in the stroke population: A scoping review

Background: Speech and language therapists report that the assessment of quality of life in persons with swallowing difficulties following stroke is a difficult process. This may be because the tools that are currently used to assess outcomes in the stroke population with dysphagia, do not accurately capture the significant psychosocial challenges faced by this group.

Objectives: The aim of this study is to identify and then compare the content of tools commonly used to assess dysphagia in the stroke population, using both the International Classification of Functioning Disability and Health (ICF) and the COMET Outcome Classification Taxonomy as a reference.

Design: A scoping review based on Arksey & O'Malley (2005) methodological framework.

Data sources: An electronic search of databases will be completed (PubMed, CINAHL, EMBASE, Web of Science, Cochrane).

Review methods: All identified studies will be screened by reading of titles, keywords and abstracts. Articles deemed eligible for inclusion will be read in full prior to analysis.

Contributors

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Supervisor: Dr Margaret Walshe, Associate Professor, Clinical Speech and Language Studies, Trinity College Dublin

Further Study Information

Current Stage: Ongoing

Date: November 2020 - March 2021

Funding source(s):

Health Area

Disease Category: Rehabilitation

Disease Name: Stroke

Target Population

Age Range: 18 - 120

Sex: Either

Nature of Intervention: N/A

Stakeholders Involved

- None

Study Type

- Systematic review of outcome measures/measurement instruments

Method(s)

- Literature review

Scoping Review methodological framework.

Data sources: An electronic search of databases will be completed (PubMed, CINAHL, EMBASE, Web of Science, Cochrane).

Review methods: All identified studies will be screened by reading of titles, keywords and abstracts. Articles deemed eligible for inclusion will be read in full prior to analysis.

Appendix 28: Sample of scoping review search strategy

CINAHL Search Strategy

1. S1 (MH "Cerebrovascular Disorders") OR (MH "Basal Ganglia Cerebrovascular Disease+") OR (MH "Carotid Artery Diseases+") OR (MH "Cerebral Ischemia+") OR (MH "Cerebral Vasospasm") OR (MH "Intracranial Arterial Diseases+") OR ((MH "Intracranial Embolism and Thrombosis")) OR (MH "Intracranial Hemorrhage+") OR (MH "Stroke") OR (MH "Vertebral Artery Dissections") OR (MH "Stroke Patients") OR (MH "Stroke Units")
2. S2 TI (stroke or poststroke or post-stroke or cerebrovasc* or brain vasc* or cerebral vasc or cva or apoplex) or AB (stroke or poststroke or post-stroke or cerebrovasc* or brain vasc* or cerebral vasc or cva or apoplex)
3. S3 TI ((brain or cerebr* or cerebell* or vertebrobasil* or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or middle cerebral artery or MCA* or anterior circulation or posterior circulation or basilar artery or vertebral artery) N5 (ischemi* or ischaemi* or infarct* or thrombo* or emboli* or occlus*)) OR AB ((brain or cerebr* or cerebell* or vertebrobasil* or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or middle cerebral artery or MCA* or anterior circulation or posterior circulation or basilar artery or vertebral artery) N5 (ischemi* or ischaemi* or infarct* or thrombo* or emboli* or occlus*))
4. S4 TI ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli* or putaminal or putamen or posterior fossa or hemispher*) N5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*)) OR AB ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli* or putaminal or putamen or posterior fossa or hemispher*) N5 (haemorrhage* or hemorrhage* or haematoma* or hematoma* or bleed*))
5. S5 S1 OR S2 OR S3 OR S4
6. S6 (MH "Deglutition") OR (MH "Gagging")
7. S7 (MH "Deglutition Disorders")
8. S8 TI ((swallow* or deglutit* or dysphag*) N3 (disturbance* or disorder* or difficult* or dysfunction* or impair* or condition* or abnormal* or damage* or injur*)) OR AB ((swallow* or deglutit* or dysphag*) N3 (disturbance* or disorder* or difficult* or dysfunction* or impair* or condition* or abnormal* or damage* or injur*))

9. S9 TI ((swallow* or deglutit* or dysphag*) N3 (scale* or screen* or checklist* or assess* or exam* or identif* or recogni* or evaluat* or diagnos* or detect* or hazard or risk or test)) OR AB ((swallow* or deglutit* or dysphag*) N3 (scale* or screen* or checklist* or assess* or exam* or identif* or recogni* or evaluat* or diagnos* or detect* or hazard or risk or test))
10. S10 S6 OR S7 OR S8 OR S9
11. S11 MH Random Assignment or MH Single-blind Studies or MH Double-blind Studies or MH Triple-blind Studies or MH Crossover design or MH Factorial Design
12. S12 TI ("multicentre study" or "multicenter study" or "multi-centre study" or "multi-center study") or AB ("multicentre study" or "multicenter study" or "multi-centre study" or "multi-center study") or SU ("multicentre study" or "multicenter study" or "multi-centre study" or "multi-center study")
13. S13 TI random* or AB random*
14. S14 AB "latin square" or TI "latin square"
15. S15 TI (crossover or cross-over) or AB (crossover or cross-over) or SU (crossover or cross-over)
16. S16 MH Placebos
17. S17 TI (((singl* or doubl* or trebl* or tripl*) N3 (blind* or mask*))) OR AB (((singl* or doubl* or trebl* or tripl*) N3 (blind* or mask*)))
18. S18 TI Placebo* or AB Placebo* or SU Placebo*
19. S19 MH Clinical Trials
20. S20 TI (Clinical AND Trial) or AB (Clinical AND Trial) or SU (Clinical AND Trial)
21. S21 S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20
22. S22 S5 AND S10 AND S21

Appendix 29: Sample extracts from reflexive diary

Originally hand-written – transcribed here to ensure legibility

REFLECTIONS FOLLOWING ONE-TO-ONE INTERVIEW WITH BRIAN, 09TH MAY 2017

- I wasn't prepared for the possibility that Brian would bring his wife in and out of the interview. This definitely interrupted the flow and I wasn't sure whether I should encourage her participation when she was there or continually refer back to Brian. Need to clarify this with MW and look at the relevant literature/ethical guidelines.
- I asked a lot of closed questions. Maybe this was the natural SLT coming out in me, automatically supporting his communication challenges. Maybe this was necessary and appropriate, but it may have also curtailed the information that Brian offered. Is this avoidable? Need to look back through the transcript and reflect on times where maybe I could have pulled back on use of closed questions and tried to open the conversation up more.
- Brian was very tangential and went off topic a lot. Was this as a result of something that I did/didn't do or was it linked to Brian's cognition – maybe a bit of both? I was very conscious of not being too directive when he did go off topic as I didn't want to take over and lead the conversation – but there was a lot of irrelevant information discussed. I need to find a balance here.
- I also need to do a better job of wrapping up/closing the interview. I feel it came very suddenly in this interview. It was difficult to find a natural close, again because the conversation was quite erratic at times and lacked structure. Again, maybe I should have taken more control at times. Another option might be to spend more time at the start of the interview discussing format/structure etc., but again, need to balance this with not leading too much.
- I was surprised to hear about Brian continually practicing rehabilitation exercises without regular input from a SLT. My initial reaction was to want to discuss in detail with Brian re: benefits/expectations etc. towards rationalising what he was doing – this is very clearly my bias and me with my SLT hat on!! It took a lot for me not to ask for more information about what exactly he was doing and why. Brian clearly has ongoing hope for improvement and maybe his ongoing practice of these rehabilitation exercises makes him feel like he has some level of control over this – similar to autobiographical accounts.

- I was also struck by the sense of ‘us versus them’ when Brian and his wife were talking about healthcare professionals and their time in hospital and rehab. In one sense this is a good thing as they weren’t afraid to voice when they were unhappy or when they felt let down and they were giving a truthful and honest representation of their experiences. But it’s also really disappointing to hear their frustration and disappointment. You get a sense that they felt and still feel abandoned and that they struggled to get consistent advice/support from all the different services that they accessed. As an SLT you are usually only involved in one part of the person’s journey, whether it’s during the acute stay, the rehab unit or community living – it was a real insight to hear how Brian’s differing experiences in all of these services resulted in an overall sense of a lack of cohesion and transfer of care.

RESEARCH MEMO FOLLOWING READING OF LITERATURE ON COPING STRATEGIES FOLLOWING STROKE, 19TH JUNE 2020

- Literature suggesting that individual’s response to their stroke can define the ‘impact’ of their disability on psychosocial wellbeing and QOL, more so than severity of symptoms or disability – ‘What is it within a person that allows them to cope?’
- Suggestion that most QOL assessment tools quantify or explore severity or frequency of symptoms, but does this really give a clear picture of ‘impact’ considering the above
- Should there be more focus on coping mechanisms and supports that are available – does this link with ‘Personal Factors’ in ICF and/or ‘Environmental Factors’
- How do you do that in a clinical setting - ? Giving people space and time to discuss their illness, use of Socratic questioning? How does that work, practically, in stroke population with potential cognitive and communication challenges?
- Can these research theories re: coping and adjusting following stroke be applied specifically to persons with dysphagia following stroke?

REFLECTIONS FOLLOWING CONFIRMATION REPORT VIVA, 6TH NOVEMBER 2018

- Glad to hear the positive comments and feedback re: my choice of methodology and the nuances in data collection and analysis, as this has been a real learning curve for me. Need to ensure that I continue to emphasise and demonstrate my reasoning for these approaches throughout the research process and in the write up of my final thesis.
- However, I think I need to make my theoretical framework more accessible as it took a bit of explaining and discussion – A visual diagram would help to show relationships and interactions between all arms of the thesis and how they link together.
- Really interesting line of questioning re: whether or not QOL and psychosocial wellbeing is even something that SLTs should have been involved in. I wasn't prepared for this (clearly as a result of my own bias in the area) and could have done better about defending it. I referred to findings from focus group which are yet to be fully analysed and findings from survey which demonstrate that SLTs feel they have a clear role in this area. But I could also have referenced stroke care clinical guidelines which recommend and state that QOL and psychosocial wellbeing is an important role for all healthcare staff. At the very least, SLTs need to be aware of the significant impact. Yes, we don't have specific formal training in the area – but maybe that is a professional development need? Again, this is alluded to by SLT participants in survey and focus group.
- Answering the 'so what' question – this will be a tricky one until we pull all the strands together, again if my theoretical framework was clearer then this might have been more obvious. Again, I could have done better here. I offered preliminary thoughts based on findings of individual studies so far, but these could change significantly when findings are integrated and considered as a whole– and I also don't want to pre-empt what might yet be developed from the findings. The development of a stroke-specific dysphagia QOL tool is already looking like an obvious next step but need to be sure this is clearly backed up in findings and conscious of the impact of my own personal experiences here.
- Overall, was a positive experience and a good opportunity to reflect on work to date, take stock of where project is at now and plan for the remaining work that still needs to be completed.