Applying Principles of Motor Learning to Dysphagia Rehabilitation

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Supervisor Certificate

I, Professor Kirrie Ballard, as primary supervisor of Ms Claire Layfield’s doctoral research program hereby certify that I consider her thesis ‘**Applying Principles of Motor Learning to Dysphagia Rehabilitation**’ to be acceptable for examination.

[redacted]

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Date: 31st July 2022

Statement Of Originality

I, Ms Claire Layfield, hereby declare that the work contained within this thesis is my own work and that all the assistance received in preparing this thesis and sources have been acknowledged, including work published with multiple authors. This thesis has not been submitted to any other university or institution as a part or a whole requirement for any degree or other purposes.

In addition, ethical approval from the University of Sydney Human Ethics Committee was granted for the studies presented in this thesis. Participants were required to read a participant information document and informed consent was gained prior to data collection.

[redacted]

Claire Layfield

Date: 31st July 2022

Declaration Of Completion

This is to certify that the thesis entitled '**Applying Principles of Motor Learning to Dysphagia Rehabilitation**' is submitted by Ms Claire Layfield in fulfilment of the requirements for the degree of Doctor of Philosophy and is in a form ready for examination.

[redacted]

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Abstract

Dysphagia or difficulty swallowing can be the consequence of numerous neurological and medical conditions. In mild forms individuals may be restricted in the types of foods and liquids they are able to consume, in its most severe form individuals are unable to consume any food or liquid orally and depend on direct nutrition to the stomach via a feeding tube. Dysphagia is associated with multiple adverse health outcomes including pulmonary complications, dehydration and malnutrition. Furthermore, the psychosocial impact of dysphagia is devastating. In most cultures, socializing with friends and family frequently involves enjoying a shared meal or drink and celebrations and holidays often have an accompanying feast. Imagine being unable to take part in family meals, sharing a coffee with a colleague or enjoying a celebratory feast...ever.

Swallowing is complex movement involving both volitional and reflexive components. Our understanding of the neural underpinnings of swallowing continues to evolve. Alongside this, our understanding of the motor control of swallowing is augmented. A related concept to motor control, is motor learning which refers to the mechanism underlying the ability to develop skilled movements. The role of motor learning has primarily been studied in neurologically intact individuals. Its application to rehabilitation has gained traction across allied health disciplines. In speech pathology, it has been explored most thouroughly in Motor Speech Disorders. Emerging evidence is arising in the clinical practice area of voice. The role of motor control and motor learning for swallowing and dysphagia rehabilitation has been recognised. To date, no research prospectively designing an intervention program grounded in principles of motor learning is available.

The overarching goal of this doctoral research program was to evaluate the potential benefit of applying the Principles of Motor Learning to dysphagia rehabilitation. In achieving this, an important objective was to present a multifaceted perspective on the current status of dysphagia rehabilitation and draw together conceptual, empirical, clinical and patient perspectives. This research program is motivated in clinical practice so translational research findings are paramount to its inception, development, implementation and dissemination.

1. Review the status of motor control for complex movements like swallowing and the implications of motor learning in neurologically injured populations. (Chapter 1)
2. Present a clinically oriented evidence-based review of intervention options for severe dysphagia following brainstem stroke. This chapter reports an evidence based response to a case based scenario based on the first participant in this study. (Chapter 2)
3. Review the literature investigating behavioural intervention for post stroke dysphagia through the lens of motor learning.(Chapter 3)
4. Develop an intervention protocol grounded in the practice and feedback principles of motor learning. (Chapter 4)
5. Report on outcomes of the intervention protocol using single case experimental design methodology to evaluate efficacy. (Chapter 5)
6. Interview and thematically analyse the perspectives of stroke survivors with chronic dysphagia who have completed the research led intervention program. (Chapter 6)
7. From this multifaceted perspective future directions and clinical implications are recommended.

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Publications And Presentations

Publications

Layfield & Ballard (2012) Dysphagia Rehabilitation following brainstem stroke: Clinical Outcomes. Abstract in *International Journal of Stroke,* 7, S1 1–74

Layfield, C., & Ballard, K. J. (2013). Evidence-based intervention options for chronic dysphagia following lateral medullary stroke, *Evidence-Based Practice Briefs,* 8(2), 1-13.

Conference Presentations

Layfield, C., Ballard, K. J., Clark, H. M., & O'Dwyer, N. (November, 2013). *The clinical application of motor learning principles to dysphagia rehabilitation*. Paper presented at 2013 ASHA Convention, Chicago, USA.

Layfield, Ballard, O'Dwyer, Clark & Anderson *"Onwards and Upwards" – Perspectives and experiences of stroke survivors with chronic dysphagia*. Conference: Asia Pacific Conference of Speech Language and Hearing,Taiwan October 2013

Layfield, C., Ballard, K. J., O'Dwyer, N. & Clark, H. M. (June, 2012). *Intervention outcomes for chronic dysphagia following brainstem stroke*: *A pilot study*. Poster at Speech Pathology Australia conference, Hobart, TAS.

Layfield, C., Ballard, K. J., O'Dwyer, N. & Clark, H. M. (June, 2012). *Applying principles of motor learning to dysphagia rehabilitation*. Oral presentation at Speech Pathology Australia conference, Hobart, TAS.

Notes On Style

This is a thesis that includes one publication. This paper represents chapter 2 of this thesis. This chapter is formatted according to the author instructions for *Evidence-Based Practice Briefs*. References for this chapter appear at the end of the manuscript version of the published paper in that chapter. References for the remaining chapters are provided at the end of the thesis. Aside from Chapter 2, this thesis is written in accordance with APA 6th Edition with Australian English spelling.

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Chapter 1.

1.1 Chapter Overview

This thesis reports the outcomes of a research project evaluating a treatment program for dysphagia rehabilitation within the frameworks of motor learning, neuroplasticity and strength-based training. The aim of this first chapter is to provide an overview of key concepts germane to this thesis. As the primary focus of this thesis, deglutition is introduced first, before describing the historical and current context of motor control theory and its important concepts related to swallowing. This is followed by a review of the central control of swallowing. Next dysphagia is introduced, before delineating some pertinent issues surrounding dysphagia rehabilitation. Theories of motor learning, neuroplasticity and strength-based training are then summarised. Finally, the complexities surrounding treatment dosage and intensity in behavioural intervention are introduced. The overall goal of this chapter is to introduce the reader to concepts that will be explored in more depth throughout the rest of the thesis.

1.2 Introduction to Deglutition

Swallowing, also known as deglutition, refers to the process whereby food is transported from the mouth or oral cavity to the stomach. Because of its effortless execution and seemingly simple function, the complexity of swallowing is frequently underestimated.

It involves the coordination of five separate anatomical areas: the oral cavity, nasopharynx, pharynx, larynx and oesophagus. It involves at least five of the twelve cranial nerves and more than 30 pairs of striated muscles. Although typical swallowing occurs with effortless fluidity, for diagnostic purposes, clinicians working with disordered swallowing typically divide the act of a single swallow into components. The most common description involves a functional division comprising three distinct phases: the oral phase, the pharyngeal phase and the oesophageal phase. Prior to this, an oral preparatory phase is reported which involves mastication (or chewing) and preparing the bolus to be swallowed. Each phase involves the precise and rapid sequence of coordinated movements. These movements, open and seal a succession of valves creating a series of pressure differentials enhancing bolus transport while maintaining airway protection. This finely calibrated coordination between the respiratory and digestive systems adapts across the lifespan. These interactions are governed by multiple neural networks extending from the cortex to the brainstem.

Peripheral physiology of deglutition is well established. Several sources offer overviews of the swallowing process (e.g. Cook, 2009; Dodds, Logemann, & Stewart, 1990; Logemann, Rademaker, Pauloski, Ohmae, & Kahrilas, 1998; Matsuo & Palmer, 2008; Robbins, Hamilton, Lof, & Kempster, 1992). These descriptions are more contemporary discussions, which stem from a long history in the medical and anatomical literature. There are also many more in-depth reports offering detailed analyses of various aspects of deglutition including: mastication and bolus propulsion (Matsuo & Palmer, 2013), coordination of respiration and deglutition (Martin-Harris et al., 2005; Martin-Harris & McFarland, 2013), pressure phenomena of both the oral phase (Shaker, Cook, Dodds, & Hogan, 1988; Siwiec & Shaker, 2013) and pharyngeal phase (Dodds et al., 1990), and the role of the upper oesophageal sphincter (UOS) (Ertekin et al., 2001; Lang & Shaker, 2000; Samuel & Shaker, 2013).

Currently, speech and language pathologists (SLPs) primarily work in the field of oro-pharyngeal dysphagia which occurs prior to the oesophageal phase. Accordingly, discussion about the oesophageal phase of swallowing goes beyond the scope of this thesis, however, there is a plethora of literature detailing the physiology of this (For a review see Mashimo & Goyal, 2006).

Central control of swallowing is also well established. Historically swallowing was believed to be largely involuntary, and thus mainly regulated by brainstem reflexes. Building on early work put forward by Doty (1968, 1976), research in this area has focused on developing models of neural circuitry within the brainstem to further explore its mediation of deglutition across its various phases (e.g. Bieger & Neuhuber, 2006; Jean, 1984, 2001; Lang, 2009; Miller, Bieger, & Conklin, 1997). It is now understood that swallowing necessarily involves nervous system connections at multiple levels. Developments in functional brain imaging have been integral in developing contemporary models of swallowing physiology which take account of the role of cortical and sub cortical regions with regard to swallow initiation and integration of sensory input (e.g. (Hamdy, 1996, 2003; Michou & Hamdy, 2009; Steele & Miller, 2010; Vasant & Hamdy, 2013) . This has generated opportunities for behavioural intervention of swallowing rehabilitation to be researched systematically.

Deglutition is a complex motor activity, organized by a neuronal network within the brainstem. Anatomically, brainstem control of swallowing involves several motor nuclei (V, VII, IX, X, XII) and two main groups of interneurons located throughout the brainstem in a disperate yet interconnected series of nuclei known as the reticular formation (RF). Physiologically, the dorsal and ventral regions of the medulla can be seen as functionally distinct regions of the neural network (Jean & Dallaporta, 2013)

The Nuclueus Tractus Solitarus (NTS) housed within the dorsal medulla is the primary sensory nucleus for the pharyngeal phase of swallowing, and receives afferent input from cranial nerves VII, IX, and X. The interneurons in the dorsal medullary region integrate input from the sensory neuclei and ascending cortical pathways. The synthesis of this input has a direct impact on the activation of the swallow response and triggers swallowing initiation and the shapes the temporo-spatial organisation of any given swallow. Accordingly, this ensures swallowing movements are tailored to each individual bolus.

The Nucleus Ambiguous (NA), is situated in the ventral region of the medulla. The NA is the primary motor nucleus for CN (IX, X and XI) and has interconnections with other motor nuclei involved with swallowing more generally including (V, VII, and XII). The ventral medulla also houses a group of interneurons. These receive the specifc execution commands for each swallow from the corresponding interneurons in the dorsal medulla and accordingly allocate motor activation to the various motor neurons involved in producing swallowing movements.

It has now been recognised that the cerebral cortex plays an important role in swallow initiation, processing sensory input and coordination of deglutition. Cortical and subcortical regions have been noted to influence various aspects of brainstem control of swallowing.
Pathways descending from the cortex to the brainstem can influence motor output to the swallowing musculature (Vasant & Hamdy, 2013).

The complexity of the neural circuits involved in swallowing allows for modulation from both peripheral and cortical pathways. This ensures that the functional flexibility of swallowing is optimised. Importantly in the present context, it also means that motor learning principles may be constructed to capitalise on these attributes of the neural network to improve swallowing when it becomes neurologically disordered.

1.3 Motor Control

1.3.1 Theories of motor control

The discipline of motor control and motor learning has significant potential for refining our understanding of deglutition and the nature of its disorders. Motor control theories have evolved over time as our understanding of neurophysiology has advanced. Accordingly, our understanding of deglutition and dysphagia have also evolved.

The earliest theories of motor control originated from the *Reflex Model*, attributed to Sherrington (1906) which proposed that, once initiated, movement was controlled by responses to sensory feedback from the peripheral nervous system in a series of reflex arcs. A model developed from the reflex chaining hypothesis, put forward by James (1890). This theory did not account well for the ability to modify movements in rapid response to a changing environment (Cobos, Sánchez, Garcıa, Vera, & Vila, 2002).

New developments in thinking led to *Hierarchical Theories* of motor control (J. A. Adams, 1971) which proposed that movement was controlled by the central nervous system and in a top-down manner from cortical centres throughout the nervous system. In contrast to the open loop hypothesis previous models had assumed, hierarchical theory incorporated a closed loop theory for some movements enabling a degree of control to be attributed to feedback of sensory information. Hierarchical models provided good impetus for changing views of motor control and learning however they could not account for two major issues: First, how is a new movement able to be generated (the novelty problem), and second, inefficiency in storage of motor plans (because of a need to store slight variations in the motor plan separately). If we take speech production as an example, although only a small subset of phonemes exist for any given language, actually huge variability is required to represent small differences across co-articulated sounds in speech. Similarly, if we consider deglutition, although the movements of swallowing have a consistent pattern, a wide array of bolus viscosities involving different timing and pressure dynamics are needed, to accommodate swallowing in everyday eating contexts.

Two competing theories arose from attempts to reconcile these problems. The first was motor schema theory, and the second was dynamic systems theory. *Motor Schema Theory,* originally put forward by Schmidt (1975), proposed two concepts diverging from those offered by previous hierarchical theories. The first is the notion of a generalised motor program, which offers a mechanism for storing the basic information program to control actions that have common characteristics, but still offering enough flexibility to account for environmental variables and allow for significant variation in how the action is produced. The second built on previous notions of cognitive schema. Schema describe patterns of thought or behaviour that organize categories of information and relationships between them. For the motor skills variant of a schema, Schmidt proposed that "the schema was a rule developed by practice and experience across a lifetime, which described a relationship between the outcomes achieved on past attempts at running a program and the parameters chosen on those attempts" (Schmidt, 2003). The development of these schema are an example of motor learning in the context of this theory.

Dynamic Systems Theory, is grounded in a more ecological framework and proposes an alternative theory to motor control. It argues that the prescriptive nature of motor programs does not take advantage of the intrinsic dynamics that either functionally or structurally shape the production of movement (Summers & Anson, 2009). Instead, dynamic systems theory argues that movement emerges as the result of a transient dynamic interaction of body systems and the environmental circumstances in which it operates. This is related to statistical learning concepts which are gaining popularity to explain learning in a variety of contexts. Movement patterns are governed by the dynamic interaction of structures and the properties of the particular environmental circumstance working together in a coordinated functional assemblage to achieve the motor goal. One differing feature of this view, asserts that these integrated dynamic interactions are self-organizing and function autonomously thereby reducing the role of the CNS in movement control. Functional synergies are developed naturally through practice and experience and help solve the problem of coordinating multiple muscles and joint movements at once (Roller, Lazaro, Byl, & Umphred, 2013). As such, this approach argues for a responsive and non-linear mechanism for motor learning and development. It argues patterns of skilled movements emerge from these dynamic interactions, and this allows for adjustment between the many degrees of freedom in the motor system, accounting for intersystem coordination.

These theories have formed the basis for much of the contemporary debate in the field of motor control and learning. As an account for the development and refinement of the discrete action of swallowing, schema theory makes intuitive sense and aligns with neurophysiological models of deglutition as well as behavioural learning perspectives and cognitive psychology models of memory and learning. Schmidt's work has led to clear well tested principles of motor learning and form the focus of the theoretical underpinnings of this thesis. Attempts at understanding deglutition within a motor control framework are in their infancy and are discussed next.

1.3.2 Important Concepts for the motor control of deglutition

Two important constructs are central to understanding the motor control of deglutition within the schema theory framework: the first is the notion of a *Generalised Motor Program (GMP),* and the second is the concept of a *Central Pattern Generator (CPG).*

A motor program can be defined as "A set of motor commands that is pre-structured at the executive level and that defines the essential details of a skilled action" (Schmidt & Wrisberg, 2008, p. 108). A *Generalised Motor Program (GMP)*, can be defined as a motor program for a class of actions. This GMP is stored in memory but, for execution to take place, a number of parameters must be specified for how the program will be executed on any given occasion. This overcomes both storage and novelty challenges that previous motor program models faced and provides the basis for the development of Schmidt's 1975 seminal schema theory model. For example, in speech, one GMP for producing /k/ is stored, but modified in the context of having a glide or vowel follow it (e.g. /kl/ or /ka/) or a nasal or vowel precede it (e.g. /nk/ or /ak/). In deglutition, a single GMP for swallowing is stored, which can be modified if drinking from a cup or a straw or a spoon or with variations in viscosity or bolus size. These factors adjust the parameters of the motor plan thereby altering its execution to meet the needs of any given bolus. If we consider a mealtime context, significant variation between the bolus size, texture, mode of delivery to the oral cavity occurs rapidly. Because the motor program is generalised, only small adjustments in the parametric specifications need to be made to alter the execution of the swallow so it is efficient and effective. As a result, an infinite number of execution options are available with one stored GMP.

A CPG, on the other hand is a neuronal ensemble within the CNS that works together to execute a motor program (Balaban et al., 2015). Movements governed by CPGs are typically genetically predetermined and have a rhythmic patterned output (e.g. locomotion, respiration, mastication). A general distinction made in the motor learning literature is that motor programs are responsible for learned skills which are developed over time with practice, whereas CPGs are responsible for repetitive movement patterns that are in some way prewired or genetically determined (Schmidt & Wrisberg, 2008, p. 117). Two characteristic signs of CPG movements are firstly that they often result in the repetition of movements in a rhythmic manner and second that the system returns to its starting condition when the process ceases (Roller et al., 2013). Balaban and colleagues (2015) emphasise that the function of CPGs should not be reduced to rhythm generators and assert that the means by which neurons are organised into a pattern-generating set is not clear.

It is now well established that deglutition is mediated by a CPG (e.g. Jean, 2001). Because swallowing involves purely non-volitional reflexive components, its mediation by a CPG is important. Without this there would be no mechanism for modulating reflex responses based on the phase of deglutition.

Overall movement patterns are determined by central commands either via the elicitation of GMPs or CPG movements which interact with sensory feedback to produce the final executed movement.

1.4 Introduction to dysphagia

Given the multi-dimensional nature of deglutition, the opportunity for breakdown across one or more systems mediating swallowing is abundant. Dysphagia occurs when there is an impairment (either in strength or timing or coordination) in any phase of the swallow and at any level of the nervous system. It is important to recognize at the outset that dysphagia is not a disease in and of itself but a symptom or cluster of symptoms of various structural, physiological or neurological impairments arising from a multitude of medical conditions.

Because of its etiological diversity, a wide variability in the presentation of swallowing difficulties exists. The Speech Pathology Australia Dysphagia Clinical Guidelines (2012) emphasize the broad scope of function that can be affected by dysphagia. These include sucking, controlling saliva, chewing, drinking, taking medications, and protecting the airway. Furthermore, dysphagia severity varies greatly between individuals. With mild dysphagia, individuals may have trouble swallowing large tablets or difficulty chewing. At the other end of the spectrum, individuals with the most severe swallowing impairments may require a tracheostomy as external intervention to protect the airway from saliva or food. Dysphagia may occur across the lifespan, for example dysphagia frequently occurs in children born with genetic disorders and also in elderly individuals with degenerative diseases. It may be transient or permanent, acute or chronic, and occur with either a sudden or gradual onset. It may affect one or more of the phases of swallowing: oral, pharyngeal or oesophageal.

A commonly reported complication of dysphagia is aspiration where material enters the airway below the level of the vocal folds. This may include saliva, prandial, refluxed gastric contents or vomit and less commonly foreign objects. Aspiration associated with dysphagia has been linked to asphyxiation and aspiration pneumonia which in severe cases may lead to death (Almirall, Cabre, & Clave, 2012; Chang et al., 2013; Langmore et al., 1998; Lanspa, Jones, Brown, & Dean, 2013; van der Maarel-Wierink, Vanobbergen, Bronkhorst, Schols, & de Baat, 2011). Further complications of dysphagia include dehydration or malnutrition (Crary et al., 2013; Davalos et al., 1996; Rofes et al., 2013).

1.4.1 Incidence, prevalence, and prognosis of dysphagia

It is very challenging to get accurate estimates of incidence and prevalence of dysphagia. Reports use varying definitions of dysphagia, limit incidence and prevalence reports to specific populations and use inconsistent assessment criteria to include or exclude participants in these reporting standards. The following discussion focuses on the complexities associated with the stroke population, the direct focus of this research project; however, it is acknowledged that similar intricacies have been highlighted in the literature across settings including residential care settings (e.g. Steele, Greenwood, Ens, Robertson, & Seidman-Carlson, 1997; Sura, Madhavan, Carnaby, & Crary, 2012), and acute hospital care (Cichero, Heaton, & Bassett, 2009) as well as across other populations such as head and neck cancer (Garcia-Peris et al., 2007), respiratory disease (Good-Fratturelli, Curlee, & Holle, 2000; Mokhlesi, Logemann, Rademaker, Stangl, & Corbridge, 2002), and progressive neurological disease (Takizawa, Gemmell, Kenworthy, & Speyer, 2016).

Nevertheless, accurately reporting the incidence and prevalence of dysphagia in the stroke population has posed a number of challenges to researchers. Within the stroke population, dysphagia has been reported to affect between 28%-81% of people after stroke depending on aetiology, specificity and timeframe of assessment (Martino et al., 2005). Martino et al. compiled and analysed an exhaustive list of references. Table 1.1 provides an illustration of a small subset of these studies to exemplify the wide disparity in reporting methods and consequent discrepancy in reported frequency of dysphagia.

It is well established that the presence of dysphagia following stroke is linked with adverse health outcomes. These include pulmonary complications (e.g. aspiration pneumonia), dehydration, and nutritional compromise. Acute stroke patients who experience aspiration pneumonia have a mortality rate at 30 days following stroke that is six times higher than those who do not (Katzan, Cebul, Husak, Dawson, & Baker, 2003). Primary and secondary dysphagia-related risks have been associated with increased length of hospital stay (Odderson, Keaton, & Mckenna, 1995). In one of the only population based longitudinal studies investigating the impact of the presence of acute dysphagia on long term stroke outcomes, found a significant association between acute dysphagia and the need for long term residential care at 5 years following stroke (Smithard, Smeeton, & Wolfe, 2007).

While the adverse health outcomes are serious, another obvious corollary is the psychosocial impact of dysphagia. Research has found an association between dysphagia and reduced mealtime enjoyment (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002) as well as impacting relationships with family, friends and carers (Kaatzke-McDonald, 2003). Dysphagia has been linked with reduced activity and participation levels (World Health Organization, 2001) and lower scores on quality of life measures (Logemann, Gensler, & Robbins, 2008) and depression (Holland et al., 2011). Perspectives of individuals living with dysphagia and its impact on their caregivers warrants further investigation in the literature.

TABLE 1.1 Range of definitions and assessment methods contributing to variable incidence reports of dysphagia in the stroke population

Reference	Report frequency of dysphagia	Participants	Aetiology	Evaluation methods	Timeframe of assessment	Definition of dysphagia
Meng, Wang, and Lien (2000)	81% (29/36)	36 consecutive patients	Brainstem stroke	Clinical evaluation and instrumental assessment	10-75 days post stroke	Various degrees in difficulty swallowing
Gottlieb, Kipnis, Sister, Vardi, and Brill (1996)	28% (exact n/N not reported)	180 consecutive patients admitted for stroke rehabilitation	All regions Single or multiple	Clinical evaluation (consistent with screening)	Patients were hospitalized 7-21 days prior to admission to rehabilitation. Unclear when assessment took place	Coughing on thin fluid bolus
Barer (1989)	29% (105/357)	357 patients	hemispheric	Clinical evaluation	On admission and within 48hrs of stroke	Delay or coughing on more than one occasion, or severity of dysphagia indicated the use of alternative hydration/nutrition
(Daniels & Foundas, 1999)	78% (42/54)	54 consecutive new acute strokes. All male. (Obtunded patients excluded)	All regions of the brain First stroke	Video fluoroscopy	Within 5 days of stroke onset	intermittent evidence of trace penetration into the laryngeal vestibule with immediate clearing and no significant clinical dysfunction - aspiration of more than one viscosity

Even within the well-defined aetiological group of stroke, the examples in Table 1.1 demonstrate the alternative approaches to defining and measuring dysphagia and the implications this has on incidence reporting. Martino and colleagues (2005) synthesized findings from 24 articles and made the following conclusions: First, incidence of dysphagia was reported as highest using instrumental assessment (Bours, Speyer, Lemmens, Limburg, & de Wit, 2009; Hind et al., 2009; McCullough, Wertz, & Rosenbek, 2001), and lowest when less comprehensive screening methods were employed (Daniels et al., 2015; Martino, 2012; Martino, Pron, & Diamant, 2000). And second, the incidence of dysphagia is lower following cortical stroke compared with brainstem stroke (Daniels & Foundas, 1999; Flowers, Skoretz, Streiner, Silver, & Martino, 2011). A key aim of these research efforts is effective management of acute dysphagia and optimization of clinical resources allocated to rehabilitation. Ideally, guidelines should determine which patients will be at risk of long term chronic dysphagia (and those who are likely to spontaneously recover) at the time of acute stroke admission.

Because of the complexities associated with acute stroke recovery, specific attention to the prognosis (and therefore the long-term incidence and prevalence) of dysphagia is justified. Smithard and colleagues (1997) tracked the course of swallowing changes in 121 consecutive acute stroke patients over the course of 4 weeks. Participants underwent both clinical and video fluoroscopic swallow study (VFSS). The authors reported identifying 61 patients (51%) with compromised swallowing on admission, on the basis of clinical evaluation. Of the 95 patients completing VFSS, there was evidence of below vocal fold (VF) aspiration in 21 patients (22%) on admission. At 4 weeks following stroke, 12 of the 81 patients (15%) who had follow up VFSS demonstrated evidence of aspiration indicating significant improvements in swallow function during this timeframe.

A second study attempting to address these issues followed the swallowing trajectory of 128 first time acute stroke patients over the first 6 months following stroke (Mann, Hankey, & Cameron, 1999). These authors found similar results to studies investigating the acute phase of stroke. As in the study by Smithard et al. (1997), participants completed both clinical and instrumental assessment during their acute admission. Clinical examination identified 65 (51%) patients with dysphagia on admission, identical findings to the earlier study. Their findings indicated 82 patients (64%) presented with dysphagia on VFSS. Of these, 28 patients (22%) presented with aspiration. However, 6 months later, 54 of the 67 patients available for repeat VFSS (42% of the original cohort) had persisting swallowing difficulties, and 17 (13%) presented with ongoing aspiration. These results do appear consistent with previous research findings, although it is difficult to make inferences about the fluctuations of new onset and persistent dysphagia within the cohorts.

Despite the high incidence of dysphagia reported at follow up by Mann et al. (1999), it remains unclear how much of a functional impact these swallow changes had. In addition to the VFSS findings, the authors also report that the majority of participants returning for follow up (97 of 112; 87%) had returned to their pre-stroke diet.

Daniels and Huckabee (2014, p. 17) outline five parameters required to determine the true incidence and recovery patterns associated with dysphagia. These are as follows:

1) Longitudinal study of consecutive stroke patients
2) A cohort of age-matched control participants from the general population
3) Instrumental swallowing assessment
4) Reliable definition and measurement parameters of dysphagia, which incorporate multiple factors including patient perception
5) Stability in findings across volume, consistencies and multiple trials

The authors assert that until large scale research accounting for these factors is replicated, determining the true incidence of dysphagia will stay intangible.

Despite the challenges in defining incidence in acute stroke and potential of resuming a pre-stroke diet, dysphagia remains linked with adverse health outcomes, survival rates and long-term dependency following stroke. For stroke survivors with persisting dysphagia, careful consideration of rehabilitation would be valuable. To date there has been an emphasis on compensatory management of dysphagia however there is increasing support for motor-based dysphagia rehabilitation. The growing body of research in dysphagia intervention is largely clinically driven. Literature guiding best practice regarding behavioural intervention for speech pathology is relatively sparse. A primary tenet of this thesis is that drawing from the wider literature base of motor control and learning will facilitate better design of effective motor-based intervention for motor-based disorders such as dysphagia. Before introducing some underlying theoretical concepts related to principles of motor control and learning and discussing these in relation to treatment intensity, some definitional issues regarding dysphagia rehabilitation are introduced.

1.5 Dysphagia Rehabilitation

The culmination of the neuroimaging and neuroplasticity findings led to a shift in perspectives about dysphagia rehabilitation. Prior to this time swallowing was largely considered reflexive and therefore not amenable to behavioural intervention. Consequently, clinical management of dysphagia had largely been compensatory up until this point. The early 1990s saw the beginning of some early clinical research reporting rehabilitative benefits of swallowing rehabilitation (Kahrilas, Logemann, & Gibbons, 1992; Kahrilas, Logemann, Krugler, & Flanagan, 1991; Logemann, 1991, 1994).

It is important to define several concepts relating to dysphagia management at this point. Firstly, the distinction between compensation and rehabilitation; and secondly the distinction between direct and indirect therapy.

1.5.1 Compensation vs Rehabilitation

Compensatory management of dysphagia relies on the implementation of strategies that provide an immediate but typically transient effect on the efficiency or safety of swallowing, whereas rehabilitation refers to intervention that, when provided over the course of time, is thought to result in permanent changes in the substrates underlying deglutition (i.e. changing the physiology of the swallow) (Gallaugher, Wilson, & Daniels, 2013, pp. 389-390).

This distinction is important but in clinical practice it may not be clear cut. If we are looking to improve someone’s swallowing so that they are able to return to eating and drinking an oral diet, then it will be important to aim to provide a rehabilitation program to facilitate this. Dysphagia leaves people susceptible to aspirating, which in turn can have adverse pulmonary complications. So while we are implementing this rehabilitation program, it may be necessary to rely on compensatory strategies such as texture modification, positional modifications or compensatory swallowing manoeuvres until such time as the risk of aspiration is mitigated.

1.5.2 Indirect vs direct intervention

The next distinction that is important to assert is the difference between direct and indirect intervention. Exercises aimed at improving neuromuscular control of a bolus that do not involve swallowing a prandial bolus are referred to from here as indirect intervention, while exercises which involve swallowing a prandial bolus will be referred to as direct intervention. There is some terminological uncertainty surrounding these terms as researchers have also used similar terms to define alternative intervention parameters. Within this thesis, these terms refer to the definitions outlined above.

If we return to our clinical example the notion of direct vs indirect therapy yields clinically meaningful differences for the individuals with dysphagia. If it is the case that someone is able to consume an oral diet with compensatory strategies without aspiration risk, then implementing a rehabilitation program using direct intervention will be more appropriate. It will yield better outcomes as it is more task specific, more salient, and will likely lead to better learning. If it is not the case that the person is able to consume any oral diet without aspiration risk, then the clinician should aim to use indirect therapy techniques to manage the clinical risks of working with someone who has an aspiration risk as a priority. This in turn means that little opportunity is available for practice, and no opportunity is available for practice outside the therapy session. To design effective interventions for dysphagia, a movement-based disorder, it is first essential to understand current theoretical concepts relation to principles of motor control and learning.

1.6 Motor Learning

1.6.1 Feedback and feed forward loops

Central mechanisms in motor learning are feedback and feed-forward loops. As a new movement is trialled, feedback is generated in so that the intended movement can be compared with the actual movement and error detected. This triggers an error correction signal that is fed back an integrated into refinements of the initial movement program so that it might be produced more accurately next time. Over time, with practice, the ability of the system to accurately predict the required movement parameters for the given conditions/context improves to a point where the movement can be executed with high accuracy even when feedback is not present. Feed-forward control models involve provision of preparatory incoming sensory information for an upcoming motor command. This facilitates detection and correction of movement errors and allows error anticipation (Schmidt & Lee, 2005, p. 128).

For swallowing, these processes are fundamental. Feedback and feedforward processes are important for responding to a particular consequence of a given bolus. Sensory feedback will allow for adjustments in relative timing and relative force of swallow: for example, in response to the spoonful of rice being hotter than expected or the ice cream being melted and liquid or icy and more solid. These adjustments in response to the given properties of a given bolus are known as feedback loops. Over time feedback allows prediction to become more accurate and motor learning occurs.

Feed-forward processes are especially important in reducing errors. Feed forward occurs in cases where the bolus has unexpected properties or does not match the predicted properties (e.g. eating something blindfolded, or eating a liquid filled chocolate when it was predicted to be hard). When this occurs an internal feed forward loop bypasses information provided by feedback and assumes an unexpected state). Humbert and German (2013) illustrate this well in their review of motor control of swallowing. A number of dental studies have also described these concepts with regard to bite pressure (Ottenhoff, Van Der Bilt, Van Der Glas, & Bosman, 1993; Ross et al., 2007) and animal models have also been used to provide empirical evidence supporting the idea of feed forward loops (Komuro et al., 2001).

1.6.2 Prediction/Anticipation

One mechanism that facilitates development of new motor skills is the ability to accurately predict or anticipate the consequences that any given set of parameters or circumstances will have on the outcome of the movement. Predictions necessarily occur prior to initiation of a movement. In the deglutition context a simple example is comparing the motor preparation for eating a spoonful of rice compared with a spoonful of ice-cream. These will be mediated in quite different ways quite predictably. Over time the refinement of predictions about the parameters associated with any given bolus lead to adaptation of movements, or learning.

1.6.3 Adaptation

Adaptation plays a central role in motor learning and promoting optimal motor function. It occurs as the feedback from multiple experiences over time compares feedback from the predicted state to the outcome of the movement goal. Over time refinements are made in the predictions. Several stages of the adaptation process have been identified. First the initial selection of the parameters refining the specific motor program (e.g. postural adjustments and preparatory set up to receive the bolus); second, modification of the motor program through sensory feedback during task performance; and finally subsequent assimilation of feedback over multiple trials to make adjustments.

Because adaptation is a form of motor learning that occurs as a result of ongoing experience, it is important for clinicians to be aware of adaptation as a form of motor learning and recognise the impact of having maladaptive learning taking place. For people with neurological injury, compensatory strategies in place to facilitate safety of oral intake may interfere with adaptive processes (Robbins et al., 2008).

Several studies have demonstrated positive adaptive changes to swallow physiology in response to perturbation and positional changes (Humbert et al., 2013; Humbert, Lokhande, Christopherson, German, & Stone, 2012; Wong, Domangue, Fels, & Ludlow, 2017).

Early studies reporting outcomes of a swallowing protocol investigating thermal application (icing) in patients with dysphagia of neurological origin indicated 'sensitisation' of swallowing (Lazzara, Lazarus, & Logemann, 1986). Several studies reported immediate changes to swallow function following thermal application, which lasted several swallows – these results may be early findings reporting adaptation in a disordered population (Lazzara et al., 1986; Rosenbek, Robbins, Fishback, & Levine, 1991; Rosenbek, Roecker, Wood, & Robbins, 1996). From a rehabilitation perspective, no longer term improvements were reported as a result of repeated exposure to this therapy method, but these findings do demonstrate adaptive change in response to altered swallowing conditions.

Maladaptation is an important consideration for clinicians working within the rehabilitation context. While rehabilitation can promote adaptive changes, intervention may also elicit maladaptive responses. Pascual-Leone, Amedi, Fregni, and Merabet (2005) raise the possibility that intervention may interrupt underlying restructuring of neural networks during the acute phase following neurological injury. Clinicians need to ensure that the rehabilitation techniques being employed optimise reorganisation rather than hinder inherent beneficial effects of spontaneous recovery. This has implications for the timing of therapy. Molfenter and Steele (2010) recommend monitoring for maladaptive changes occurring as a consequence of therapy.

1.7 Principles of Motor Learning

There has been extensive research investigating the most effective methods to stimulate long-term learning of new movement skills (cite some reviews on this – (e.g. G. Wulf, Shea, & Lewthwaite, 2010). The specific principles associated with robust motor learning outline a number of factors relating to practice and feedback. Practice is necessary for motor learning to occur. The way practice is structured can influence how successful this learning is.

It is important to note at the outset the distinction between performance and learning. Performance refers to change in the capability of a target movement during skill acquisition or practice. Learning refers to relatively permanent change in performance that occurs over time as a result of practice. Learning needs to be measured through retention and transfer tasks, not practice tasks. Variables that enhance performance may not be the same variables that enhance learning. Clinicians need to consider these factors in therapeutic practice and rehabilitation. Therapy needs to aim for retention of treatment gains after therapy has ceased, and generalization to related but untreated targets or environments. Generalization (transfer) to related but untreated targets or environments (e.g., outside of therapy room).

An overview of the principles of practice and feedback pertaining to the principles of motor learning are provided here. An application of these concepts with a specific focus to dysphagia rehabilitation is discussed later in chapter 3 (see pg 66-80).

Practice amount

The amount of practice undertaken plays an important part in the motor learning process. As a general structure feature, typically a larger amount of practice is associated with better learning than a small amount of practice. But, while it is intuitive to think that more practice is associated with more learning, the amount of practice interacts with a number of other practice parameters and so it is possible that optimising practice may reflect less overall practice.

Practice distribution

The way practice is distributed over time also plays an important role in the learning that occurs. It has long been established in both cognitive and motor domains that the temporal distribution of practice is important in the retention and generalisation of skills (L. Smith, 1974; Underwood, 1961). The motor learning literature reports that a practice schedule distributed over time leads to better learning. This is an important consideration in designing rehabilitation programs.

Practice variability

Variable practice refers to the context in which practice takes place. The options here are either constant practice (where the skill is practiced with the same context – e.g. repeated practice of 1 tsp puree) or variable practice (e.g. varying size, consistency and delivery of bolus would all lead to variable practice parameters in the swallowing rehabilitation context. It is clear that variable practice in this context is more representative of everyday eating. However, for clinicians working in dysphagia rehabilitation safety concerns may take priority. There are also considerations here around GMP and parameters for learning.

Practice schedule

The practice schedule refers to the design of the therapy tasks within the therapy session. The options here are blocked or random design. Blocked practice refers to a practice schedule where a skill is practiced in a repeated drill format and different targets are practiced in blocks. In this setting this could look like a block of X number of repetitions of effortful swallow followed by a block of X number of repetitions of tongue-hold manoeuvre etc… A random practice schedule alters the practice target in a random pattern. In this context an example may be X repetitions of swallow manoeuvers including effortful and tongue-hold manouvres in a randomized order. The benefit of randomized practice ensures that a different GMP needs to be produced on successive trials and that prediction for the upcoming trial is not possible.

Attentional focus

More recent constructs of the motor learning framework have introduced the concept of internal and external focus. The goal remains the same in both these conditions, ie to swallow without aspiration, however, with an internal focus the learner may concentrate on internal aspects of achieving the goal (e.g. tongue placement, hyo-laryngeal excursion), whereas if the learner has an external focus the focus will be on the outcome of the overall execution of the movement (I swallowed well enough to not aspirate).

Target complexity

Target complexity can be considered a difference between simple (part) movements or complex (whole) movements. From a clinical perspective, it makes sense to reduce the complexity of a target in order to reduce the demands on the learner and avoid unnecessary practice of established skills. From a motor learning perspective however, evidence suggests that in order to alter the GMP performing the overall goal may be necessary to improve motor control (Schmidt & Lee, 2005, p. 417). In dysphagia rehabilitation, there are a number of part practice protocols, including lingual strengthening, pitch glides targeting hyo-laryngeal excursion, as well as whole swallow manoeuvres – for example, effortful, tongue-hold, and Mendelsohn.

These targets are likely to interact with other practice parameters, and outcomes of the interventions need to be considered from a strength vs skill perspective as well as an acquisition vs learning perspective.

This concludes the introduction to principles of motor learning relating to practice structure. We now turn to feedback conditions. Feedback has received a good deal of attention in motor learning more generally (Shea & Wulf, 1999) and more specifically in the dysphagia rehabilitation setting (Bogaardt, Grolman, & Fokkens, 2009; Huckabee & Cannito, 1999; Humbert & Joel, 2012; Logemann & Kahrilas, 1990). Three specific conditions are of importance: The type of feedback; the frequency of feedback and the timing of feedback.

Feedback type

The type of feedback received is known to augment learning. Two types of feedback exist, fist the knowledge about performance (KP) which provides detailed feedback to the learner about various aspects of the movement (e.g. "next time I want you to focus on holding your tongue between your teeth until the swallow has been completed"). This type of feedback may include forms of biofeedback as well as clinician directed input. In contrast, knowledge of results (KR) can be considered feedback regarding the overall success of achieving the movement target (e.g. "that wasn't an effortful swallow'). Depending on the information provided, biofeedback can also provide KR. Both types of feedback can be considered beneficial, depending on the stage of learning.

Feedback frequency

How often feedback is received is known to impact learning. From a clinical perspective, often a high amount of feedback is provided to provide a motivating and supportive learning environment. In efforts to do this, the implications of frequency of feedback on motor learning may be overlooked. From a motor learning perspective, frequency of feedback can affect schema development. Somewhat counter-intuitively, provision of less frequent feedback has been shown to be beneficial for retention of skills and especially in the context of learning a GMP (Gabriele Wulf & Schmidt, 1989)

Feedback timing

The timing of feedback is also an important factor influencing motor learning. Feedback can occur concurrently (as in the case of tongue pressure strengthening, or sEMG) or it can occur following the completion of a movement. Concurrent feedback has been noted to increase external attentional focus which can lead to a more positive learning context. In order to support learning via intrinsic feedback mechanisms (i.e. adaptation) research has indicated that providing feedback several seconds after the completion of a movement is more beneficial than providing immediate feedback.

This concludes the introduction to motor learning principles. It is important to recognise from the outset that there are significant interaction effects between these practice and feedback principles and optimising the practice regime. This warrants consideration for each client. There are cases where clinical comorbidities, concerns regarding aspiration risk, and other individual client factors (e.g. cognitive status and motivation) will affect ability to participate in a motor learning regimen and degree or rate of response. It is important for clinicians to be aware of the optimal conditions for rehabilitation and the flexibility a framework like this allows, while also understanding the impact of selecting less than optimal practice and feedback structures.

There is a dearth of literature explicating and examining optimal treatment options for clinicians working within the specialist area of dysphagia rehabilitation. Drawing more generally from motor learning frameworks will assist in optimizing rehabilitation outcomes. These concepts are explored further throughout the remainder of this thesis: in relation to the existing dysphagia rehabilitation literature in chapter 3; with regard to intervention design in chapter 4; and then operationalised and applied to an intervention program in chapter 5.

While the focus of this thesis is the application of the principles of motor learning to dysphagia rehabilitation, these necessarily interact with other neurorehabilitation principles. Both the dichotomy between strength and skill training and issues around therapy dosage are worthy of discussion before moving on to more in-depth exploration of the principles of motor learning in the dysphagia rehabilitation context.

1.8 Additional Concepts in Neuro Rehabilitation

1.8.1 Neuroplasticity

A core concept in rehabilitation is *neuroplasticity*, or neural reorganisation following neurological injury. Compelling evidence now exists supporting this phenomenon. Kleim and Jones (2008) have outlined 10 principles of neuroplasticity. These relate to the amount, intensity, saliency, specificity, and timing of practice on a given skill, as well as the age of the learner and factors that affect the transfer of skill to new contexts. In a systematic examination of these principles in relation to swallowing and dysphagia rehabilitation, Robbins et al. (2008) identified a number of swallowing rehabilitation approaches with the potential to support neuroplastic change.

Research has highlighted variation in factors affecting post-stroke neuroplasticity, including time since stroke onset, intensity and type of therapy (Nudo, 2003; Nudo, Plautz, & Frost, 2001). Langhorne, Bernhardt, and Kwakkel (2011) identified two key elements of stroke rehabilitation that are particularly pertinent to inducing neuroplastic change, namely intensity of practice and specificity of the task used in therapeutic exercises.

1.8.2 Strength Training and Skill Training

A prominent issue in neurorehabilitation especially germane to the dysphagia rehabilitation context is strength-based training (SBT). Especially, it needs to be distinguished from skill training. Loss of strength is a major contributor to physical disability after stroke; therefore, where significant weakness exists, exercise designed to increase strength will be required to decrease disability (Canning, Ada, Adams, & O'Dwyer, 2004). While strengthening might be essential for rehabilitation, it may not lead to neuroplastic changes (Carroll, Riek, & Carson, 2001; Jensen, Marstrand, & Nielsen, 2005). This highlights the importance of measuring outcomes of motor learning retention and generalisation rather than performance. In the dysphagia rehabilitation context, two important review articles have explored the role of SBT (Burkhead, Sapienza, & Rosenbek, 2007; Clark, 2003).

By contrast, skill training has been demonstrated to generate adaptive reorganisation of the central nervous system (Kleim et al., 2002; Kleim, Barbay, & Nudo, 1998; Remple, Bruneau, VandenBerg, Goertzen, & Kleim, 2001). Nudo (2003) has shown that many skill-training mechanisms are also deployed in the relearning of motor skills and functional recovery. The findings of (Buonomano & Merzenich, 1998) and (Vigneau et al., 2006) support the findings of Nudo (2003) and demonstrate cortical neuroplasticity.

1.8.3 Intensity

A final important issue to be discussed with regard to behavioural intervention is intensity. In the context of behavioural intervention, defining and accurately measuring intensity is challenging. Before considering intensity further, the concept of therapy dose is introduced. Warren, Fey, and Yoder (2007) put forward a framework for exploring this concepts. They propose five distinct features of behavioural intervention that researchers and clinicians should aim to establish prior to conducting behavioural intervention based research (see Table 1.2). They assert this allows for more systematic comparison of the efficacy of alternative intervention designs.

Table 1.2 Components of therapy dosage proposed by Warren et al 2007

Concept	**Definition**
1. Dose	the number of properly administered treatment episodes during a single intervention period
2. Dose Form	the task/activity/context within which a treatment episode occurs
3. Dose Frequency	the number of times that a "dose of intervention" is provided per day or week.
4. Total Intervention duration	the total time period over which an intervention is delivered
5. Cumulative Intervention Intensity	the product of *dose* X *dose frequency* X *total intervention duration*. This provides a useful general indicator of overall intensity.

This framework provides a useful basis for intervention design and treatment comparison studies. All these aspects of intervention design do warrant detailed explication in order to minimise the influence of these factors on outcomes when examining treatment efficacy. For remediation of motor based behaviours, aspects of intervention grounded in PML and SBT may have been overlooked. The manipulation of intervention factors such as practice variability and feedback may influence intervention outcome irrespective of therapy dosage.

Linking this construct to models of strength based training also appears problematic. Behavioural intervention needs to be clearly distinguished from pharmacological models of dosage where it could be expected dose form may increase as intervention progresses. In fact, an important component of SBT is progressive overload which would lead to an undetermined but exponentially increasing practice target altering the dosage. (e.g. one client may commence an intervention dosage at 30 swallows per session and increase to 100 over the course of a six-week period, whereas another client may commence at 60 swallows and eventually get to 200 swallows per session over the course of therapy. The cumulative intervention dosage may be very different and the outcomes may be similar. Clearly there is a ceiling and floor to dose form which will influence intervention efficacy. It is important to acknowledge this as distinct from a set dosage per person implicit in this particular model.

Further exploration of intensity across the range of practice areas in speech pathology is offered in a dedicated special journal issue (E. Baker, 2012). Across this issue the general consensus was that treatment data guiding treatment intensity for SLP was lacking across all domains.

With specific regard to swallowing disorders, Logemann (2012) reviews the available randomized controlled trials available examining speech pathology intervention for dysphagia and concludes that from the available research therapy-dosage responses are not yet available for dysphagia. It is not surprising this review yielded few conclusions. By only including RCTs (of which there have been very few), the review overlooks promising smaller sample clinical outcome research. Secondly, the review is compromised by the complexities of the etiological heterogeneity of the various studies being reviewed. Thirdly, the author has not considered treatment intensity within a rehabilitation framework. For example, intensity of treatment is unlikely to be a factor necessary to consider in cases where compensatory strategies are the primary goal of intervention, which is frequently the case in acute care and in chronic care where individuals are unable to exert volitional control over their swallow. Because the end goal is to make oral intake safe, timely contact is essential for the management of aspiration risk but treatment intensity is unlikely to alter outcome of swallow physiology.

It is hoped that by drawing from the broader knowledge base of behavioural motor learning, some guidance surrounding optimizing therapy intensity for dysphagia rehabilitation may be possible.

1.9 Chapter Summary

The topics covered in this introduction draw together a range of important issues which raise a number of research questions which will be addressed in subsequent chapters.

1. How can the principles of motor learning influence intervention outcomes for people with chronic post stroke dysphagia?
2. How does motor learning within a rehabilitative context lead to changes in complex movements involving both volitional and involuntary components?

Chapter 2. Reviewing the evidence from a clinical perspective

2.1 Chapter overview

This chapter presents a case study and the challenge faced by clinicians working within an evidence based practice (EBP) framework. It presents the treatment of dysphagia following stroke from a clinical perspective, providing a clinical context for later discussions regarding the theoretical framework which also warrant consideration for this population. The clinical context is an important yet often overlooked aspect of clinical research. The translation of research to a clinical setting is essential for research to have a genuine clinical impact, but is not entirely straightforward. This chapter considers how existing research findings may be interpreted for clinical application, and informs the design of the research protocol developed in chapter4.

When designing protocols for research aimed at guiding evidence-based practice, it is important to take the limitations and conditions which exist in clinical practice into account. Three considerations with regard to research translation deserve special mention. First, the intensive nature of the therapy protocols outlined in research are typically not replicable in a clinical setting; second, research samples will likely be quite different from a typical clinical caseload; and third, the application of research findings based on a group means may not represent any specific clinical case.

First, treatment of participants in a research setting will likely be more resource intensive than a typical clinical setting permits. The Australian healthcare context offers two pathways to rehabilitation of this kind. In the public sector, rehabilitation is free, but logistical limitations and clinical availability are barriers to the implementation of resource- and time-intensive research-based protocols. Similarly, few can afford this type of intervention in the private sector. Clinicians are faced with the challenge of implementing best practice as indicated by research in modified ways, especially with regard to therapy schedules and dosage. Research aimed at informing and improving clinical practice needs to be designed so that application is feasible within the prevailing constraints of the health delivery system.

Second, participants in research programs are carefully selected with respect to inclusion criteria which typically include age, medical background history, and often language to participate in therapy among other factors. The research sample therefore often represents only a very small proportion of a clinician's caseload (even with the same primary diagnosis). Again clinician's must consider these individual differences when implementing 'best practice' because the majority of individuals on any given clinical caseload would be unlikely to meet inclusion criteria for a relevant research protocol.

Third, research results are typically generated from a sample in which the presented disorder varies substantially in severity. Results which compare the means, while important in guiding treatment protocols, necessarily ignore the individual differences in severity which may be recognised and captured through clinical judgement. In a sense, research findings offer statistical judgement; clinical judgement for an individual case is what the clinician brings to the design of an individual treatment strategy.

The following article reviews evidence of treatment of dysphagia following stroke from a clinical perspective, offering a step-by-step guide for clinicians translating evidence into clinical practice. The clinical scenario was developed from one of the case studies reported in later chapters.

Evidence-Based Intervention Options for Chronic Dysphagia Following Lateral Medullary Stroke

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Structured Abstract

Clinical Question: Are rehabilitation techniques more effective than compensatory strategies in improving swallow function and facilitating oral intake after a medullary stroke?

Method: A review of research comparing treatment outcomes between compensatory strategies and rehabilitative techniques for individuals with chronic dysphagia secondary to brainstem stroke was completed.

Study Sources: Cochrane Database of Systematic Reviews, Evidence Based Medicine Reviews, PubMed, MEDLINE, CINAHL, Social Sciences Citation Index (Web of Science), EMBASE, and speechBITE™

Search Terms: (Dysphagia OR Deglutition Disorders) AND (Lateral Medullary Stroke; OR Lateral Medullary Syndrome; OR Wallenberg Syndrome; OR brainstem stroke) AND (Therapy outcomes; OR treatment efficacy; OR rehabilitation; OR intervention; OR compensatory OR compensation)

Primary Results: Results from a review of the literature yielded only six articles which were detailed enough in their description to allow clinical replication. Of these only one represented an experimental group design of a high standard of evidence while the others comprised case series and case study designs. Results indicate positive outcomes for the use of both compensatory strategies and rehabilitation techniques. Most individuals make improvements in swallow physiology and functional oral intake status.

Conclusions: The majority of studies reviewed in this brief represent lower levels of evidence. Despite this, results do reflect positive clinical outcomes with benefits of both compensation and rehabilitation reported. Further, regular application of compensatory techniques may produce improvements to swallow physiology over time. The majority of patients appear able to return to some form of oral intake following therapy.

Clinical Scenario

Marianne is a 40-year-old female who went to the emergency room with acute shortness of breath, following a few days of symptoms consistent with an upper respiratory tract infection. On arrival, she presented with inspiratory stridor, a husky voice, coughing episodes, and haemoptysis (coughing up blood). Her oxygen saturation levels worsened and she was transferred to the intensive care unit (ICU).

Initially, Marianne was treated for supraglottitis. Later, an MRI indicated a left-sided (L) lateral medullary infarct (LMI), which was attributed to a vertebral artery dissection with associated thrombosis. While in the ICU, she required intubation to maintain her airway and then a tracheotomy. Her intensive care admission was complicated by an acute episode of aspiration pneumonia and oesophagitis. In the early days following her stroke, Marianne presented with many classical signs of LMI, also known as Wallenberg syndrome. Wallenberg syndrome is a cluster of symptoms that typically involves vestibulo-cerebellar signs and symptoms, sensory alterations, as well as bulbar muscle weakness can be seen in these cases.

Marianne’s balance was impaired, so she had difficulty sitting upright, with a tendency to fall to the left. She also was unable to stand and limb ataxia was present on the left. She complained of severe vertigo with associated nausea and vomiting. Cranial nerve assessment indicated impaired eye movements (nsytagmus). Her hearing on the right (R) side was impaired. She had significant sensory alterations to temperature and pain ipsilaterally in her L face and contralaterally in her R trunk and limbs. R-sided palatal movement was reduced and her gag reflex was absent bilaterally. Results from an endoscopic examination indicated a (L) vocal cord paralysis and consequent dysphonia. She was severely dysphagic, and relied entirely on a feeding tube (percutaneous endoscopic gastrostomy [PEG]) for nutrition.

When her medical condition stabilised, about 6 weeks later, Marianne was transferred to inpatient rehabilitation where she made significant gains. Her ocular and vestibular cranial nerve function improved. She re-established independence with all activities of daily living. Although her gait remained mildly ataxic, she was able to mobilise indoors without assistance and used a walker outdoors and for longer distances. Marianne finally returned home 12 weeks after her stroke.

Prior to her stroke, Marianne worked at a bank and was an active member of her local community. She also has two children. Now she is unable to participate in school, church, or community events because of her inability to eat and drink normally or swallow her saliva. Likewise, returning to work is not possible. She has had two episodes of pneumonia and several other chest infections since her stroke.

One year later, Marianne is referred to Leah an experienced clinician in the area of neuro-rehabilitation for ongoing follow up and management of her dysphagia. Marianne's severe dysphagia has persisted. She remains wholly dependent on her feeding tube for nutrition and she must cough her saliva to her mouth and then clear it by spitting into a facial tissue. She is keen to know if there is anything further that can be done to improve her swallow function and is very motivated to participate in therapy.

Leah reviews Marianne's history to date. Marianne has had therapy several times to help with her swallowing, but without success. Her dysphagia significantly affects her ability to participate in everyday activities and reduces her quality of life. Leah is guarded about Marianne's potential for rehabilitation. She contacted a number of colleagues to discuss her case. The general consensus was that in light of the severity of the dysphagia, her previous failed attempts at therapy and extended period of time since her stroke, the ability for Marianne to make significant therapeutic gains was limited.

Leah has decided to review the research literature for the best possible options for Marianne's ongoing speech pathology intervention. Specifically, she hopes to ascertain whether swallow rehabilitation is more or less effective than compensatory strategies for individuals following LMI, in order to guide her management.

Background

The Relationship between Brainstem Stroke and Dysphagia

Literature examining the relationship between brainstem stroke and dysphagia has generally focused on three topics: the role of the brainstem in swallow function, co-occurrence of brainstem pathology with dysphagia, and the nature of dysphagia following brainstem lesions.

Neural structures of the brainstem play a vital role in the coordination of swallowing networks. Lesions affecting the brainstem, in particular, the lateral medulla, are often associated with a clinical presentation of dysphagia. (For detailed overviews see Amirali, Tsai, Schrader, Weisz, & Sanders, 2001; Bieger & Neuhuber, 2006; Jean, 2001; Lang, 2009; Miller, 2008; Zald & Pardo, 1999).

Incidence of dysphagia associated with lateral medullary stroke varies. This can be primarily attributed to the range of evaluation techniques of dysphagia and the time-frame of the assessment. For example, Flowers, Skoretz, Streiner, Silver, and Martino (2011) report an incidence of dysphagia of 57% following lateral medullary stroke in the first 3 weeks following stroke; while Meng, Wang and Lien (2000) report an incidence rate of 22% of individuals with persisting severe dysphagia on hospital discharge (Meng, Wang, and Lien, 2000).

The most clinically relevant focus of the literature has been to ascertain the nature of dysphagia associated with lateral medullary stoke. This has significant implications for clinical intervention. Comparing the characteristics of recurrent cortical or subcortical strokes and first time brainstem strokes, Han, Chang, Lu, and Wang (2005) found predominantly pharyngeal phase breakdown in the brainstem cohort, while the cortical infarct group displayed more oral preparatory and oral phase difficulties. The brainstem infarct cohorts were significantly more likely to require nasogastric feeding at the time of video-fluoroscopy. Interestingly there were no significant differences between choking, impaired cough ability, aspiration or pneumonia rates. Han et al. reported that 100% of patients with brainstem infarct demonstrated residue in the pyriform sinuses. Consistent with this, a case series by Bian, Choi, Kim, Han, and Lee (2009) reported that common findings on video-fluoroscopy for patients with medullary infarcts include increased residue in the pyriform sinuses with associated post-swallow aspiration and impaired upper esophageal sphincter (UES) opening.

Using surface electromyography (sEMG), Crary and Baldwin (1997) compared temporal aspects of swallowing and peak sEMG electrical activity in patients with dysphagia following brainstem stroke and healthy age matched controls. Their results indicated that swallow attempts by the patients with dysphagia were characterized by increased muscle activity with more variable amplitude patterns occurring over a shorter interval of time. An analysis of the amplitude and temporal aspects of the swallow attempts from three electrode placements sites allowed for an interpretation of coordination. Not surprisingly the patients with dysphagia had significantly worse coordination compared with controls.

Comparing Compensation Strategies to Rehabilitation

It is important to differentiate between compensation and rehabilitation as therapy options for dysphagia. Huckabee and Cannito (1999) identify compensation as a strategy that temporarily alters the bolus or swallow to facilitate oral intake, but does not remediate the underlying swallowing impairment. In contrast, rehabilitation aims to improve the disordered swallow physiology in order to promote improved swallow function.

Historically, dysphagia management has relied heavily on compensatory strategies. However, there have been changes in the philosophy of treatment options for dysphagia. Until recently, swallowing was viewed as a reflex and therefore not considered suitable for behavioral remediation (Robbins et al., 2008). With advances in understanding the neural substrates underlying dysphagia, the componential nature of the swallowing sequence, and the neuromotor control of each component, swallowing rehabilitation has become theoretically feasible (Chicero, 2006; Robbins et al., 2008). In turn, more support for swallow rehabilitation is now being generated in the literature (Burkhead, Sapienza, & Rosenbek, 2007; Clark, 2003).

A related matter in rehabilitation is indirect versus direct therapy. Indirect therapy is meant to improve aspects of swallowing without introducing a prandial bolus. It is thought to be useful for patients at high risk of aspiration and attempts to improve the underlying constructs of swallowing physiology with minimal risk. Direct therapy involves optimizing swallow function with a bolus and can be used for individuals who are able to tolerate even small amounts of oral intake (Logemann, 1991, 1999).

Beneficial effects of both direct and indirect therapy have been reported for the target case in the current scenario. Neumann and colleagues investigated differences in outcomes between direct and indirect therapy for patients with diverse neurological deficits including brainstem infarct and achieved successful outcomes for both direct and indirect swallowing therapy. They found no differences in outcomes between the groups and no correlations between outcome success and lesion location (Neumann, 1993; Neumann, Bartolome, Buchholz, & Prosiegel, 1995).

Engaging in Evidence-Based Practice

There are various methods available to facilitate the implementation of evidence based practice (EBP) (e.g. Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996; Worrall & Bennett, 2001). In the current scenario, the SLP follows this 5-step method suggested by the Oxford Centre for Evidence Based Medicine (OCEBM):

1. Asking a focused question
2. Finding the Evidence
3. Critical Appraisal of the evidence
4. Making a decision
5. Evaluating the Performance

Asking a Focused Question

One strategy employed in EBP paradigms is directing and focusing a literature search by asking a specific and relevant clinical question. Frequently the PICO format is utilized; this question prototype outlines the patient/problem, the intervention, a comparison intervention, and the outcomes to be measured. By specifying a question in this way, a search of the literature will produce a succinct set of articles for review.

For our purposes, the SLP developed an answerable clinical question using the PICO format to assist her decision making: For people with chronic dysphagia following lateral medullary stroke, is swallow rehabilitation more effective than compensatory strategies to improve swallow function and facilitate oral intake?

Finding the Evidence

Leah employed several search strategies to ensure the most relevant literature was obtained. First she conducted a search for systematic reviews, next a database search, and finally a search of targeted journals.

First, as systematic reviews are considered the strongest level of evidence, an initial search of Cochrane Database of Systematic Reviews, Evidence Based Medicine Reviews and speechBITE ™ was conducted; this did not yield any systematic reviews related to lateral medullary stroke and dysphagia. There were, however, three systematic reviews that discussed dysphagia rehabilitation in relation to stroke more generally (Bath, Bath, & Smithard, 2000; Foley, Teasell, Salter, Kruger, & Martino, 2008; Geeganage, Beavan, Ellender, & Bath, 2012).

Next, a comprehensive search was undertaken of various readily available databases including: PubMed; MEDLINE via Ovid; CINAHL via ebscohost; Social Sciences Citation Index (Web of Science); EMBASE; SCOPUS and speechBITE ™.

Broadly speaking, the search terms were derived by the PICO question although slight differences in databases led to small changes in specific search terms. The SLP first searched for patient-related search terms including: Dysphagia AND (Lateral Medullary Stroke; OR Lateral Medullary Syndrome; OR Wallenberg Syndrome). Because of the limited sample generated following an initial search, the addition of brainstem stroke was added to the list of included etiologies. Following this, she combined these searches with the intervention and control search terms that included: therapy outcomes; treatment efficacy; rehabilitation; intervention; compensatory or compensation. This generated a total of 234 articles with 77 remaining after titles and abstracts were screened for articles meeting inclusion criteria and duplicates were removed.

Articles were included if they were peer-reviewed, written in English, published between 1950 and 2013, and reported therapy outcomes for people with dysphagia following lateral medullary stroke.

Articles were excluded if they reported data for participants with dysphagia from any etiology other than brainstem stroke, or if treatments studied were not readily available in speech pathology clinics (i.e., pharmacotherapy, transcranial magnetic stimulation, surgical intervention, acupuncture, and nutritional support as direct therapy).

After closer review, 70 articles were excluded because they did not have a treatment component or did not specify the therapy clearly enough for replication, or because the articles were diagnostic in nature. They aimed to either identify dysphagia as a primary impairment following brainstem stroke (Chua & Kong, 1996; Teasell, Foley, Doherty, & Finestone, 2002), characterize the nature of dysphagia associated with brainstem impairment (Bian et al., 2009; Crary & Baldwin, 1997), or correlate neuroanatomical lesions with clinical presentation of dysphagia and/or aspiration on video-fluoroscopy (H. Kim, Chung, Lee, & Robbins, 2000; J. S. Kim, 2003; J. S. Kim, Lee, Suh, & Lee, 1994; Kumral, Afsar, Kirbas, Balkir, & Ozdemirkiran, 2002; Kwon, Lee, & Kim, 2005).

Further, several other articles were excluded for the following reasons. First, one large group study compared outcomes of functional swallowing therapy across 208 patients with neurogenic dysphagia of varied causes, including 27 patients with Wallenberg's Syndrome (Prosiegel, Holing, Heintze, Wagner-Sonntag, & Wiseman, 2005). The authors reported that participants underwent swallowing therapy as per published protocols; however, details of the therapy received by each participant were not outlined and a wide array of therapy combinations is possible. This study could not be included in the critical appraisal as the contributing factors of each therapy to the outcomes remain unclear.

Second, Ozeki et al. (2012) reported outcomes for 34 patients participating in an inpatient rehabilitation program for dysphagia following brainstem infarct at least three months earlier. The therapy undertaken included 40–60 minutes of swallowing training by SLPs six days a week or management of eating style by nursing staff; pulmonary rehabilitation to strengthen cough and occupational therapy to improve performance in activities of daily living also were used. However, because of the ambiguous nature of the intervention in this study, it was not included in the critical appraisal.

Finally, there were several case reports that described an unusual presentation (Alstadhaug & Salvesen, 2007; Chen & Huang, 2008) or a more general course of recovery without details of therapeutic intervention following brainstem strokes (Finestone, Teasell, & Heitzner, 1999; Kruger, Teasell, Salter, Foley, & Hellings, 2007). As no explicit details of the intervention were provided in these studies, they were not included.

Figure 1 outlines the process of article selection including searching, screening, reviewing for eligibility and identifying the final set of articles for inclusion in review.

Critical Appraisal of the Evidence

For the clinical question in this scenario, the evidence was divided into articles reporting outcomes for compensation or rehabilitation of lateral medullary stroke. An overview of participant characteristics, swallowing strategies, and functional outcomes for reviewed articles appears in Table 1.

Compensation

Early research in this area compared swallow physiology with and without a head turn (to the weaker side) in six healthy volunteers and five individuals with LMI (Logemann, Kahrilas, Kobara, & Vakil, 1989). This technique aims to close the weak side of the pharynx and direct the bolus into the stronger side. Outcomes from video-fluoroscopy for the individuals who had sustained LMI indicated that all exhibited unilateral pharyngeal residue, pharyngeal residue in the pyriform sinuses on the affected side, a lower apex of the affected pyriform fossa, as well as reduced hyo-laryngeal excursion. With a head turn to the weaker side, upper esophageal sphincter (UES) opening diameter and the fraction of bolus entering the esophagus both increased significantly.

Logemann and Kahrilas (1990) followed up that earlier work with a case study of a 45-year-old female with severe and chronic dysphagia following medullary infarct. Over the course of 4 years, the patient was evaluated using video-fluoroscopy and progressed through a series of compensatory maneuvers [head-turn 12 months post onset (MPO), then supra-glottic swallow 36MPO and finally Mendelsohn maneuver at 45MPO]. At 60MPO, the patient's swallow function had improved sufficiently to enable return to oral intake and removal of her PEG. She remained free from adverse pulmonary complications for a further two years. The extent of swallowing therapy she received in the interim periods between evaluations is unclear, and such details would be of interest. Similarly, the necessity of continued use of swallowing maneuvers once the patient returned to oral intake is also not specified. This early study of swallow rehabilitation, however, provides evidence for swallowing being considered as a series of components that may be modified through systematic compensation. The authors suggest that the application of these compensatory techniques, if done regularly over extended periods of time, may lead to rehabilitation of swallow physiology to some extent.

Tsukamoto (2000) provided a brief case report confirming the findings of Logemann et al. (1989). Specifically two objective imaging techniques, video-fluoroscopy and computed tomography (CT), revealed that a head turn to the weaker side resulted in closure of the hemipharynx. Further, the use of additional CT imaging allowed the exact location of the closure, (above the level of the pyriform sinuses) to be established. Although this case report suggested that the head turn technique was potentially beneficial to individuals with dysphagia secondary to LMI, no discussion of aspiration or functional eating outcomes in this case was reported.

Most recently, Kanai et al. (2009) reported the course of recovery of a 54-year-old male with left LMI. Various indirect swallow therapies, including cold stimulation, effortful swallow, Mendelsohn Maneuver, Shaker method, and Masako method were initially employed. A cough strengthening exercise consisting of two sets of three voluntary coughs also was introduced. The authors used scintigraphy to monitor the presence of contrast in the lungs after the ingestion of a teaspoon sized bolus and followed by a voluntary cough (similar to the supra-glottic swallow maneuver). They observed the immediate presence of aspirated material in the larynx and pulmonary regions; however, 10 minutes later these areas were clear of aspirate and the voluntary cough appeared effective in expelling aspirated material from the lungs. Seven weeks following his stroke, the participant commenced daily direct therapy using this technique. The participant commenced with 1/3 teaspoons of jelly for practice, the amount increasing over 2 weeks when he commenced therapy with all types of pureed (paste like) foods. Eleven weeks post stroke he increased his intake to 3 pureed meals a day and 6 MPO he resumed 100% oral intake. Due to the reliable use and efficacy of the cough-swallow strategy, despite still demonstrating aspiration on video-fluoroscopy at 9 MPO, he was able to continue oral intake without any adverse health outcomes.

Rehabilitation

Two articles describe case series designs whereby swallow rehabilitation was undertaken and evaluated with individuals with chronic dysphagia secondary to brainstem stroke (Crary, 1995; Huckabee & Cannito, 1999).

First, Crary (1995) administered a direct rehabilitation program with the aim of increasing pharyngeal strength of swallow, duration of hyo-laryngeal excursion and UES opening, as well as improving coordination. The protocol included sustained posture swallow, humming to check vocal quality post swallow and cough to clear residue, if present. An additional biofeedback component using sEMG was utilized to provide patients with information on strength and duration of swallow. The proposed therapy schedule commenced with daily therapy for three weeks and then various schedules following this. One of six participants had a variable therapy schedule from the outset and was unable to complete the intensive phase. Outcomes were determined by functional improvements in ability to eat and drink, changes in swallowing physiology as measured by sEMG, and a post treatment questionnaire 18–24 months following completion of the treatment program. Results indicated that all participants improved with swallow physiology measures. Five of the six were able to resume full oral intake without non-oral supplementation, and no adverse health outcomes were identified up to 24 months post-treatment.

Second, Huckabee and Cannito (1999) aimed to replicate and extend Crary's (1995) work. Outcomes for ten participants with chronic dysphagia resulting from brainstem injury (either infarct or surgery) were evaluated from a retrospective file audit. All participants undertook an intensive 5-day treatment program that included two 1-hour therapy sessions per day, plus a home practice program. Rehabilitation exercises comprised regular repetitions of effortful swallow and Mendelsohn Manouver. Masako maneuver and head lifting or Shaker maneuver also formed part of rehabilitation programs for some patients. Again varying therapy schedules occurred after this. Two modes of biofeedback were employed with this group of patients. The first used sEMG with submental electrode placement to provide feedback to the patients about electrical activity for the muscles innervated during hyo-laryngeal excursion (supra-hyoid muscle group). This allowed for both visual and auditory feedback on strength and timing of swallow with various rehabilitative maneuvers having different target patterns. The second mode of feedback involved the use of acoustic feedback of sounds transmitted during cervical auscultation, in particular to monitor breath-swallow coordination. Outcomes were clearly documented for pre-treatment, after 10 therapy sessions (i.e. the intensive first week); six months post therapy and a final outcome taken one to four years later. Outcomes were systematically collected across participants and included a scale for functional outcomes related to nutritional intake, swallowing severity scale ratings based on video-fluoroscopy, and changes to pulmonary symptomology prior to and following treatment. Significant improvements were found with the means of nutritional route; at the commencement of therapy all participants were fully dependent on tube feeding, following the intensive first week of therapy all participants had commenced some form of oral intake, at six months post therapy seven out of ten participants no longer required supplemental nutrition. All participants improved on a swallowing severity scale. Though six of the ten had reported previous health complications associated with likely aspiration, no patients reported pulmonary complications following therapy.

Shaker et al. (2002) also reported findings from a randomized controlled trial with 27 patients dependent on enteral nutrition secondary to poor UES opening. Many of the diagnostic studies discussed above reported this feature in dysphagia associated with LMI. Seven of the participants in this study had sustained brainstem strokes. The therapy protocol was well specified and involved a home practice program of isometric and isotonic head lifting. The participants were required to complete three head lifts held for 1 minute with 1 minute break in between followed by 30 repetitions of head lifting. These exercises were completed three times a day for a period of six weeks. Overall results were promising for all participants. For the seven participants who had sustained brainstem infarcts, findings were consistent with other studies in terms of outcomes. All seven were at least partially dependent on tube feeding for nutrition at the commencement of therapy and all were able to resume oral intake after completion of the program. It should be noted that three of the seven were still in the acute stage of recovery (less than 2 weeks post stroke) the others were all greater than 4MPO.

Summary of findings

For the seven articles included in the review, four focused on compensation and three focused on rehabilitation. There was a total of 31 participants with sample sizes ranging from 1-10, for one study 7 participants were extracted from a larger cohort based on etiology. Participants from the four articles investigating compensatory strategies all had diagnoses of LMI, while the participants from the rehabilitation studies had broader diagnoses of brainstem stroke or neurological lesion associated with tumor compression or surgical resection in the brainstem. Of the 31 participants six had sustained their strokes less than four weeks prior to entering their respective research programs. The remaining participants ranged from 4-84 months post neurological injury.

Clinical outcomes are extremely positive where 26 out of 31 participants demonstrated functional improvements to swallow physiology. It should be noted that results may be skewed as a result of publication bias or the tendency of authors to submit and journals to publish articles with positive outcomes rather than those proving null hypotheses or reporting limited clinical outcomes (For review see Hopewell, Loudon, Clarke, Oxman, & Dickersin 2009).

Evaluation of the Evidence

For many research methodologies, rating scales exist to allow clinicians to verify the methodological quality of research. For example; the PEDro–P scale rates randomized controlled trials and non-randomized group comparison studies (Tate et al., 2004), whereas the Single Case experimental design (SCED) scale facilitates methodological rating of experimentally controlled single case studies (Tate et al., 2008). Despite the availability of such tools, the majority of research generated by this PICO question is low-level evidence that does not lend itself to rating on published scales. Robey (2004) outlines a five-phase model for clinical outcome research. Within this model, Phase I research includes "case studies, discovery-oriented single subject studies, small group pre-post studies, and retrospective studies" (p. 404), much of which characterizes the studies reviewed here. Although the level of evidence may be considered low by some standards, it does signify the the early stage of research within this specific area of clinical interest.

As an alternative, Logemann (1987) outlines a number of criteria for examining interventions focused on disordered swallowing. These include the use of objective assessment to quantify treatment outcomes; the standardization of assessment and therapy procedures; the homogeneity of patient groups in terms of etiology, nature of dysphagia, and stage of disease progression; and well-defined, detailed treatment protocols. For the purposes of this brief, the articles selected were rated on these indices, as shown in Table 2.

These data clearly highlight the lack of high-level evidence available for the current clinical scenario. It also illustrates the methodological components of this collection of articles by showing that all articles used objective assessment as one of the primary outcomes; four of seven described uniform replicable assessment and treatment procedures; and three of the four group studies had well defined participant cohorts with homogeneous groups.

Making a Clinical Decision

Having completed her literature search and appraisal, the SLP is cautious about generalizing the findings of these results too broadly. However, she does note that characteristics of one of the case studies overlaps significantly with her patient, and the majority of patients mentioned in the literature demonstrated improved swallow function and many were able to return to oral feeding. Leah also knows it will be important to carefully collect data to ensure her intervention can be effectively evaluated following completion of the therapy program. It will be important to document frequency of therapy sessions, intensity of treatment during sessions, the exact treatment protocol used and variations as they arise and to confirm any clinical improvements with objective assessment following therapy. She feels well-prepared for her upcoming initial assessment appointment and confident in her plans for Marianne.

Conclusion

The majority of studies reviewed in this brief represent lower levels of evidence. Despite this, results do reflect positive clinical outcomes. Positive effects of compensation and rehabilitation are noted. The recurrent implementation of compensatory techniques may produce a rehabilitative effect producing improvements in functional swallow outcomes. The majority of patients appear able to return to some form of oral intake following therapy. This review supports the use of an initial intensive therapy schedule and, as well, that the use of biofeedback using sEMG may be beneficial.

These finding s are consistent with broader principles of neuro-rehabilitation including those of neuroplasticity (Robbins et al., 2008) and strength-based training (Burkhead et al., 2007; Clark, 2003) as well as principles of motor leraning (Schmidt & Lee 2005).

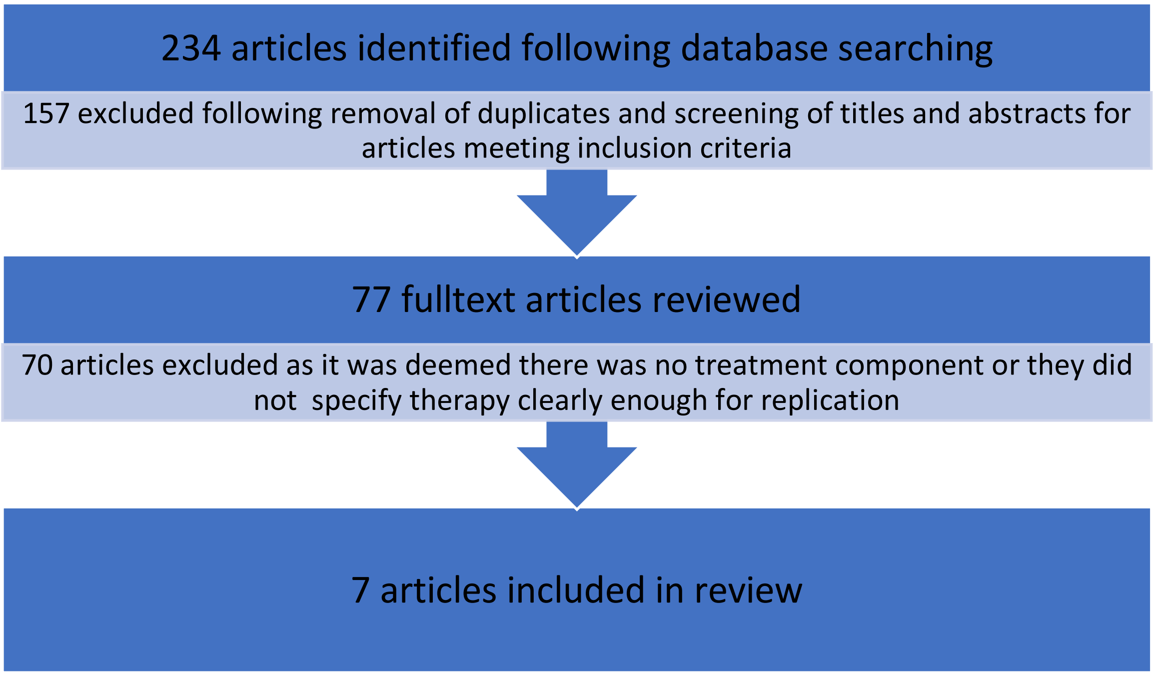

Figure 1. Flow diagram outlining the process of article selection

Table 1 Details of participant characteristics, swallowing strategy, and functional outcomes for reviewed articles

Reference	Strategy Type	Strategy	Participants	Etiology	MPO	Clinical Outcomes
Kanai et al. (2009)	Compensation	After ingestion of bolus 1-2 voluntary coughs to clear aspirated prandial.	1	LMI	< 1 month	At 9 months post stroke participant was able to resume oral intake for all nutrition with voluntary cough following each mouthful and likely texture modification.
Logemann and Kahrilas (1990)	Compensation	Head turn, supraglottic swallow, Mendelsohn maneuver.	1	LMI	4-60	At 60 MPO participant was able to resume oral diet for all nutrition
Logemann et al. (1989)	Compensation	Single intervention using head turn strategy on videofluoroscopy.	5	LMI	< 1 month	Improved UES opening and increased quantity of bolus swallowed
Tsukamoto (2000)	Compensation	Single intervention using head turn strategy on CT.	1	LMI	1	No outcomes regarding oro-pharyngeal functional or nutritional status reported
Crary (1995)	Rehabilitation	Swallow bolus using sustained posture technique, following swallow hum to check vocal quality, cough to clear residue if required, re-swallow. sEMG biofeedback was provided to participants following each swallow attempt.	6	Brainstem stroke	5-54	At 18-22 months post therapy 5/6 participants were able to resume oral intake for all nutrition.
Huckabee and Cannito (1999)	Rehabilitation	Regular repetitions of effortful swallow and Mendelsohn maneuver. Masako maneuver and head lifting or Shaker maneuver also formed part of rehabilitation programs for some patients. sEMG and acoustic feedback were employed.	10	7/10 Brainstem stroke 3/10 tumor compression and/or resection	8-84	4/7 brainstem stroke patients and 3/3 surgical patients were able to resume oral intake for all nutrition although most required texture modification at 6 months post therapy.
Shaker et al. (2002)	Rehabilitation	Progressive isotonic head lifting exercise regime.	7 (total of 27)	Brainstem stroke (various etiologies)	3/7 <1 4/7 >4	All 7 participants with brainstem stroke were able to resume oral intake following treatment

MPO – months post onset
LMI – Lateral Medullary Infarct
CT - Computed Tomography
sEMG – Surface Electromyography

Table 2. Research design, level of evidence, and methodological evaluation for treatment outcome studies generated by this PICO question.

Reference	**Design**	**Level of Evidence**[1]	**Desirable Features of Treatment Studies in Oral-Pharyngeal Dysphagia**[2]			
			Objective Assessment Employed	**Uniform and replicable Assessment Procedures Employed**	**Groups were homogeneous**	**Treatment protocol specified**
Shaker et al. (2002)	[3] Randomized Controlled trial PEDro-P scale rating = 6/10	Level 2	YES Video-fluoroscopy	YES Assessment procedure well described	NO Chronic and acute patients with various etiologies of dysphagia BUT same disordered aspect of swallow (reduced UES opening)	YES Treatment protocol clearly described
Logemann et al. (1989)	Case Series	Level 4	YES Video-fluoroscopy	YES Assessment procedure well described	YES 5 individuals with chronic dysphagia post LMI Also 6 health controls	YES Single intervention of head turn strategy
Crary (1995)	Case Series	Level 4	YES Video-fluoroscopy	NO Post treatment assessment procedures not uniform or systematically reported	YES 6 individuals with chronic post stroke dysphagia resulting from brainstem stroke > 5MPO	YES Treatment protocol clearly described
Huckabee and Cannito (1999)	Case Series	Level 4	YES Video-fluoroscopy	YES Assessment procedure well described	YES 10 participants with chronic post stroke dysphagia secondary to brainstem stroke or surgery > 8MPO	YES Treatment protocol clearly described
Tsukamoto (2000)	Case Study	Not rated	YES Video-fluoroscopy and Computed tomography	NO Not described	NA	NA Assessment only

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2.2 Chapter Summary

This chapter can be seen as a tutorial for clinicians wishing to translate available evidence into clinical practice based on the presentation of a specific case. This is what researchers expect clinicians to do, but extrapolating intervention protocols and modifying them on a case-by-case basis to suit changes in presentation of the case or to fit constraints imposed by the nature of the clinical setting is complex.

One of the fundamental motivations for the development of this research project was to bridge the gap between research and clinical practice. From a clinical perspective it is essential to understand the constraints governing methodologically robust research. Equally, from a research perspective it is essential to understand the demands and pressures of clinical practice. One aim of this research study was to empirically evaluate an intervention protocol which would be feasible in the current Australian context.

Bearing these considerations in mind, the next chapter discusses dysphagia rehabilitation from a motor learning framework in an effort to improve the current understanding of how behavioural intervention may be improved. Next, the assessment and intervention protocol developed for this research project is described in detail (see Chapter 4). Following this, quantitative and qualitative outcomes from a series of case studies are presented and the implications of this research are discussed (see Chapter 5).

NOTE: This article was written in 2012, one of the first articles in this doctoral research program. A supplementary search was conducted (June 2022) to see if there was potential to update this research review. There were many more articles on dysphagia rehabilitation, which is promising for future progress in the area. However, the search was replicated as per the specific

PICO question in the original study and consequently there were no new articles meeting the criteria of the PICO question specified.

Chapter 3. Motor learning in post-stroke dysphagia rehabilitation

3.1 Chapter Overview

This chapter discusses the dysphagia rehabilitation context and then reviews literature regarding behavioural interventions for dysphagia through the lens of the PML framework. This chapter builds on chapter 1 which introduces theoretical concepts of PML and chapter 2 which highlights the clinical need for further understanding and evidence to guide clinicians in the selection and implementation of behavioural intervention for swallowing disorders.

First this chapter, outlines the evolution of the rehabilitation context and provides the current setting for dysphagia rehabilitation context. Next it discusses three distinct, but salient concepts associated with neurorehabilitation; neuroplasticity (3.3.1), principles of motor learning (3.3.2) and strengths based training (3.3.3). It goes on to discuss the complexities of swallowing as a movement with both volitional and reflexive components. Importantly for this thesis, the implications of this multidimensional movement in relation to motor learning in dysphagia rehabilitation are outlined.

Finally it reviews the current available literature in dysphagia rehabilitation with reference to the PML framework.

3.2 Changing context for dysphagia rehabilitation

Deglutition is a complex motor behaviour involving volitional initiation of movement and a reflexive component. Attempts at understanding deglutition within a motor control framework are still in their infancy. A proliferation of neuro-imaging studies in the late 1990s shifted contemporary understanding of neural control of deglutition (Daniels & Foundas, 1999; Hamdy et al., 1998; Hamdy, Rothwell, Aziz, & Thompson, 2000; Kim, Chung, Lee, & Robbins, 2000; Mosier & Bereznaya, 2001; Mosier, Liu, Maldjian, Shah, & Modi, 1999; Mosier, Patel, et al., 1999; Zald & Pardo, 1999). Consequently, theories of the motor control of swallowing shifted from serial hierarchical models of control to multilevel heterarchical models of organisation (Mosier & Bereznaya, 2001). It is now well established that deglutition is a dynamic process with multiple volitional components initiated at the level of the cerebral cortex, and subsequently mediated via neural networks throughout the CNS in a multidimensional fashion, through the peripheral nervous system (PNS) and with reflexive components (Michou & Hamdy, 2009; Vasant & Hamdy, 2013).

These same advances in neuroimaging also generated a large body of research investigating neuroplasticity following stroke (Johansson, 2000; Kleim & Jones, 2008; Nahum, Lee, & Merzenich, 2013). Since then, the discipline of motor learning has made a significant impact in rehabilitation practice. It is now established that motor learning occurs during spontaneous recovery, as well as in response to rehabilitation (Krakauer, 2006). This point warrants consideration when reflecting on timing and acuity of symptoms following stroke.

Research by led by Boyd and Winstein has highlighted the influence of various factors on implicit motor learning following stroke including the nature of the task, stroke severity and stroke location (e.g. Boyd, Quaney, Pohl, & Winstein, 2007; Boyd & Winstein, 2001, 2003, 2004a, 2004b, 2006). A systematic review of the benefits of implicit compared with explicit motor learning following stroke reported that both implicit and explicit learning strategies were equally effective following stroke (Kal et al., 2016). The authors stated that methodological challenges within the research corpus meant that it was difficult to draw reliable conclusions.

Much research in the motor control and learning literature aims to illustrate important theories and concepts through empirical research. The majority of this research has focused on the upper and lower limbs, because of the well-established models around limb movement control and the straightforward nature of the movements at hand. Thus, extensive research has been conducted examining motor learning of upper and lower limbs following neurological injury (For review see Van Peppen et al., 2004). Much less experimental research has focused on complex movements, as in the case of swallowing. Deglutition has a less typical movement sequence initiated volitionally, followed by completely involuntary reflexive phases. Humbert and German (2013) highlighted the transformative impact that a solid theory of motor control for swallowing could have on individuals with dysphagia. Efforts have been made to elucidate a theory of motor control by using perturbations to observe adaptive responses during deglutition (Humbert et al., 2013; Humbert et al., 2012; Mosier, 1997), but these are still in their infancy.

It has now also been established that individuals with chronic motor impairment following stroke can exhibit functional motor improvements well beyond the historical motor recovery plateau (Page, Gater, & Bach-y-Rita, 2004). It is important to acknowledge at the outset that the type of therapy here needs to be well considered. In order to achieve positive rehabilitation outcomes, therapeutic practice needs to be explicit and theoretically grounded.

3.3 Important concepts in neurorehabilitation

3.3.1 Neuroplasticity

Compelling evidence now exists supporting neuroplasticity or neural reorganisation following neurological injury. Importantly for clinicians working in rehabilitation, this reorganisation can take place long after the initial acute neuroprotective period and this reorganisation is likely to be widespread across neural networks not localised to the area surrounding the damaged neural tissue (Nudo, 2003). Hamdy and colleagues confirmed that this occurs in the cortical swallowing centres following stroke (Hamdy, 2003; Hamdy, Aziz, Thompson, & Rothwell, 2001; Hamdy et al., 2000). Neuroplasticity is thought to be a primary mechanism of motor improvement following stroke (Jones et al., 2009), however it should also be noted that improvements in functional outcomes may occur independently of detectable neural changes (Teasell, Bayona, & Bitensky, 2005).

Kleim and Jones (2008) have outlined 10 principles that influence neuroplasticity. These relate to the amount, intensity, saliency, specificity, and timing of practice on a given skill, as well as the age of the learner and factors that affect the transfer of skill to new skills and contexts. In a systematic examination of these principles in relation to swallowing and dysphagia rehabilitation, Robbins et al. (2008) identified a number of swallowing rehabilitation approaches with the potential for stimulating neuroplastic change. One challenge with the implementation of systematic research on neuroplasticity is the need to test for neural change pre- and post-intervention. For clinicians working in rehabilitation, this option is not readily available. Behavioural measures are a more clinically feasible measure of progress in everyday clinical contexts.

Research has highlighted variation in factors affecting post-stroke neuroplasticity, including time post-stroke onset, intensity and type of therapy (Nudo, 2003; Nudo et al., 2001). Langhorne et al. (2011) identified two key elements of stroke rehabilitation that are particularly pertinent to inducing neuroplastic change, namely intensity of practice and specificity of the task used in therapeutic exercises.

3.3.2 Principles of Motor Learning

The principles of motor learning (PML) hold much promise for providing a basis for intervention design and therapy dosage within the dysphagia rehabilitation context. These principles are well established in the field of motor development and have been applied to the rehabilitation context (Krakauer, 2006; Kwakkel, Kollen, & Lindeman, 2004).
In parallel work spanning several decades, a set of behavioural principles have been identified that facilitate (re)learning of skilled movements such as sports, manual tasks and speech production (Schmidt & Lee, 2005, p 302; Maas et al., 2008). Neuroimaging, in particular fMRI, has demonstrated the validity of theoretically-grounded behavioural treatments in promoting neural change (Richards, Stewart, Woodbury, Senesac, & Cauraugh, 2008). The prescription of behavioural treatments in stroke survivors has been highlighted as an area requiring further research (Cramer & Riley, 2008; Jones et al., 2009). The principles of motor learning offer well-defined and well-tested methods for applying motor-based behavioural intervention in rehabilitation programs which are well aligned with the principles of neuroplasticity. This allows clinicians to confidently measure behavioural changes occurring as the result of therapy as proxy measures for neuroplastic change. This can only occur in the context of PML. As discussed later, there is limited evidence for the reorganisation of the motor cortex in the context of peripheral strength training.

PML promote long-term retention of learned motor skills through a structured practice and feedback approach. The goal is long-term *retention* of skills after training has ended and *generalisation* of training effects to untrained skills and contexts. This is distinct from motor *performance*, observed within a training session, which can be enhanced in the short term with alternative designs of practice and feedback. This distinction is important for clinicians to recognise because improving within-clinic performance does not necessarily improve retention and generalisation of learned skills. Therefore, rehabilitation needs to measure retention and generalisation of skills rather than performance. One challenge with this is the scarcity of studies that report long-term outcomes for patients. If the goal is to measure generalisation and retention of learned skills, then long-term outcomes need to be evaluated. It is important to note at this point that some PMLs are thought to facilitate learning of GMPs and some to facilitate learning to control parametric variation.

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3.3.3 Strength-based Training (SBT)

A final prominent issue in neurorehabilitation and especially germane to the dysphagia rehabilitation context is strength-based training (SBT). Loss of strength is a major contributor to physical disability after stroke; therefore, where significant weakness exists, exercise designed to increase strength will be required to decrease disability (Canning et al., 2004). For clinicians, this makes intuitive sense; however, a review of progressive resistance strength training following stroke reported preliminary evidence for improving musculoskeletal impairment following stroke but no conclusive support for the generalisation of strengthening to limitation of activity and participation (Morris, Dodd, & Morris, 2004).

The literature draws a distinction between strength, endurance and power. Strength refers to the "ability to produce large forces in short bursts"; endurance refers to the "ability to produce small sustained or repeated forces"; and power refers to the "ability to produce force at high speeds" (Clark, 2003, p 403). These are pertinent to the deglutition context where strength may be necessary for bolus transfer; endurance is required to sustain deglutition over the course of the meal; and power may be needed for high velocity movements to manage low viscosity boluses. Another important SBT concept is the notion of detraining, where either SBT ceases and deconditioning or detraining takes place (similar to the use it or lose it concept), or strength is maintained through other functional tasks so SBT is no longer required (Baker, Davenport, & Sapienza, 2005).

In the dysphagia rehabilitation context, two important review articles have explored the role of SBT (Burkhead et al., 2007; Clark, 2003). These reviews outline several principles corresponding to SBT regimes: adaptations to training including improving strength and endurance as well as de-training effects; resistive loading; repetition and volume of practice; and specificity. More recently Langmore & Pisegna (2015) have offered a critique of the effectiveness of exercises designed to rehabilitate dysphagia and concluded that only a minority of commonly employed exercises are effective in the long term. This highlights the importance of measuring outcomes of motor learning retention and generalisation rather than performance.

The idea that dysphagia can be treated through exercises designed to strengthen components of the swallowing process has a long history among therapists (Stathopoulos & Duchan, 2006). This notion is based on the premise that swallow dysfunction is grounded in peripheral weakness in the oro-pharyngeal musculature that controls deglutition. There is a growing body of literature reporting links between oro-pharyngeal musculature strength and swallowing outcomes in clinical populations (Robbins et al., 2007). Dysphagia clinicians who ground their rehabilitation approaches in strength-based frameworks argue that strength training improves both peripheral weakness and promotes reorganisation of neural circuitry through the repeated execution and refinement of complex movement patterns. There is currently no definitive literature providing support for this notion. Further, evidence from limb literature indicates that resistance training alone does not result in changes to the organisation of the motor cortex (Carroll et al., 2001; Jensen et al., 2005).

It is evident that experience-dependent neuroplasticity, PML and SBT principles overlap. All emphasise the need for a high volume of repeated practice that is task specific. The literature in the fields of PML and SBT provide us with a range of protocols for applying these principles specifically to (re)learning of skilled movements, with the central goal of functional improvements that can enhance activity and participation of the individual in daily activities. Next, the focus is placed on the PML framework, which provides the largest body of evidence for behavioural (re)training aiming to enhance long-term retention and generalisation of complex skilled movements. The theory behind PML is briefly reviewed and their relevance to the post-stroke rehabilitation is considered. What remains less clear is the impact of each individual principle of motor learning, and their interaction with each other and other rehabilitation principles, such as neuroplasticity, SBT and skill training.

3.4 Schema theory of motor control and learning

Deglutition is complex and dynamic. To be effective in its goal it requires a precise cascade of finely calibrated movements under volitional and reflexive control and integration of several organ systems. Grounding our knowledge of deglutition within a broader theoretical context may be helpful to further our understanding of motor control and motor learning in the dysphagia rehabilitation context. An applicable theory of motor control and learning is *Schema Theory*.

A primary tenet of schema theory is the generalised motor program (GMP; Schmidt, 1975, 2003; Schmidt & Lee, 2005). A GMP can be thought of as a stored representation of a movement that, once initiated, results in the production of a coordinated movement sequence (Schmidt & Lee, 2005). It is a set of motor commands that can be set up prior to the initiation of movement in a manner which allows some variation in the specific realisation of the movement (Keele, 1968). Some features of the GMP are held constant, including the sequence of events, and the relative timing and force of the movement pattern across the set of effectors involved. Initiation and accurate execution of the movement then relies on the specification of parameters, allowing variations of absolute force and timing within the GMP. This allows for variation in the expression of the movement executed without requiring individual motor programs for similar actions. Depending on the goal of the movement, parameters can be adjusted which alter the overall timing, force and muscle activation to execute the movement (Schmidt & Lee, 2005). A general class of movements can therefore be mediated by a single GMP, with the specific outcome determined by the parametric specification.

In order for GMPs to be effective in mediating internal and external circumstances, instructions about precise actions must be encoded. Schema theory assumes this encoding is represented in memory in the form of schemas. These relate past experiences of similar actions involving the same GMP. Updating can occur on a continuing basis.

Two types of schemas may be distinguished: a recall schema and a recognition schema. These both have implications for practice in the rehabilitation context. The recall schema retrieves the GMP for a class of actions and predictions are made to adjust to the given set of circumstances in which the action is to be performed for a particular movement goal. The recognition schema is a mechanism that incorporates feedback about the expected properties of the movement outcome. Over time, predictions are adjusted and movements become more accurate. Similarly, over time with practice, the recall schema is more easily retrieved and more accurately calibrated.

3.5 Schema theory of motor learning for swallowing

Swallowing breakdown can occur across any of the phases of deglutition. Impairment can comprise weakness, poor sequencing or poor timing of the events involved in swallowing. Thus it can be associated with the GMPs that are specifying patterns of movement at each phase

and/or the parameterisation of these GMPs to accommodate different rate, amplitude, and force of movement required to accommodate variations such as bolus size or viscosity.
The invariant features of GMPs, such as the relative timing of the movement pattern across the effectors involved, or the sequence of events, are well exemplified in swallowing. The timing of swallow events that occur during each phase of swallowing are reported in numerous studies (Cook et al., 1989; Hiiemae & Palmer, 1999; Mendell & Logemann, 2007; Pouderoux, Lin, & Kahrilas, 1997). A wide array of norms pertaining to normal swallowing movements now exist and have been reviewed by Molfenter and Steele (2012).

The sequence of swallow events is also well documented. Substantial variability in measurement definitions and outcomes exist within this literature, posing challenges for clinicians and researchers. The anatomical and physiological relationships between phases of the swallow necessarily impose a succession of some movements in relation to another. However, some variability in the exact sequence of events is present across and within individuals (Kendall, 2002; Leonard, Kendall, McKenzie, Gonçalves, & Walker, 2000; Logemann et al., 1998; Mendell & Logemann, 2007; Molfenter, Leigh, & Steele, 2014). For example, the aging swallow has been associated with less sensitivity to bolus volume threshold compared to a younger population, demonstrating variability across populations (Shaker et al., 1994).

Bolus volume and viscosity are external stimuli that can determine the parameters necessary for the GMP to be executed. They alter overall timing and force of swallowing but do not alter the relative timing or sequence of the swallow. For example, in order to maintain airway protection during swallowing, the apnoeic period predictably increases with increased bolus volume (Martin, Logemann, Shaker, & Dodds, 1994; Preiksaitis, Mayrand, Robins, & Diamant, 1992). In the same way, increased bolus viscosity has been demonstrated to show predictable changes to patterns of swallow physiology. High viscosity delays oral and pharyngeal bolus transit and prolongs and increases UES opening (Dantas et al., 1990).

In addition, deglutition and respiration are coordinated throughout the swallow. Different patterns of breath-swallow synchrony occur during various phases of the swallow (Martin-Harris et al., 2005; Martin-Harris, Brodsky, Price, Michel, & Walters, 2003; Martin et al., 1994; Matsuo, Hiiemae, Gonzalez-Fernandez, & Palmer, 2008; Palmer & Hiiemae, 2003; Pitts et al., 2013; Sawczuk & Mosier, 2001). Different GMPs are utilised for these different phases, and these GMPs must be executed in a specific sequence to move the bolus from the oral cavity to the pharynx safely. It is well established that there is considerable variation in the relationship between anatomical structure and hyoid and laryngeal movements (Molfenter & Steele, 2011). Wong et al. (2017) provide recent empirical evidence that an internal schema adapts hyo-laryngeal movements during swallowing to facilitate upper airway protection across a range of pre-swallow head positions.

In what follows, literature pertaining to dysphagia rehabilitation is reviewed with a view to exploring the use of PML, specifically practice and feedback as rehabilitation strategies. The focus in this section is to review evidence from the growing body of literature on dysphagia rehabilitation that may be underpinned by the principles of motor learning. Where possible, the literature that this review draws from has its basis in rehabilitation of dysphagia of neurological origin. Where this is not possible, research pertaining to swallowing in healthy populations will be used.

3.6 Application of PML to dysphagia rehabilitation

The historical focus of dysphagia management has relied heavily on compensatory rather than restorative strategies (Rumbach, Coombes, & Doeltgen, 2017). However, more recently a number of exercise-based therapy techniques have been proposed to improve the underlying physiology of swallowing in both normal and disordered swallowing.

The principles of motor learning describe a series of principles relating to the structure of practice and the design of feedback. Where relevant, links with associated rehabilitation concepts will be presented. Different principles may be applied to target different aspects of swallow physiology. PML may be applied either to facilitate modification of GMPs or to modify parametric settings. Some rehabilitation strategies purely focus on training aspects of the parametric settings to alter swallow physiology, whereas others lend themselves more readily to improving the overall GMP.

3.6.1 Structure of practice

Practice forms the basis of experience-dependent motor learning. Six principles of motor learning are specified in the motor learning framework: practice amount, practice distribution, practice variability, practice schedule, attentional focus and target complexity. Each of these is discussed with reference to the dysphagia rehabilitation literature, before turning to the structure of feedback and its best application for motor learning.

Practice Amount

Practice amount refers to the number of trials of movement practice. This is a somewhat nebulous concept in the area of behavioural intervention because precise measures of therapy dosage are not well reported in intervention studies (Warren et al., 2007). This is true in the case of dysphagia rehabilitation as well as other areas of speech pathology (Baker, 2012; Carnaby, Hankey, & Pizzi, 2006; Eastwood, Madill, & McCabe, 2015; Maas et al., 2008; Kaipa & Peterson, 2016).

From a motor learning perspective, increased practice amount leads to improved motor learning and generalisation because increased practice allows more opportunities to refine motor movements, enhancing the recall and recognition schemas of the practised motor program (Maas et al., 2008). There appears to be a general consensus in the rehabilitation research that more practice leads to improved outcomes (Kwakkel, 2006; Langhorne, Wagenaar, & Partridge, 1996). For dysphagia specifically, there is some preliminary research indicating that more intervention time leads to improved outcomes compared with less time (Brunner, Skeat, & Morris, 2008). However, it is important to recognise the interaction of practice amount with other PMLs, such as intensity and distribution of practice, and ensure that the amount of practice is optimised.

There are very few articles reporting practice amount or number of trials in the swallowing rehabilitation literature. An early study systematically investigating the impact of practice amount was conducted by Rosenbek and colleagues (1998). The researchers compared intensity of tactile-thermal application in patients with stroke-induced dysphagia. This intervention aims to promote pharyngeal sensation in order to trigger the pharyngeal swallow more rapidly. Patients were randomly assigned to receive 150, 300, 450, or 600 trials of thermal application over the course of two weeks. None of these intensities offered improved performance over another. The study represents one of the only studies to systematically investigate the impact of varying amounts of intervention; however, the absence of a comparative no-treatment condition renders the findings difficult to interpret.

Vickers et al. (2013) specifically investigated practice amount in 20 participants with persisting dysphagia following stroke. The intervention involved individually tailored exercises. Throughout the program, a record of the total number of repetitions of each exercise was recorded. The intervention period ranged from 4 to 52 days and the cumulative frequency intensity ranged from 363 to 10 704 trials, representing an average of 172 trials per day. As the authors suggest, the amount of practice varied considerably between participants and high rates of practice were not directly correlated with improved outcomes. One possible explanation for this is the known interactions of practice amount with other PMLs including practice variability, practice schedule and feedback structures, which were not controlled in this study. Carnaby-Mann and Crary (2008) reported outcomes from a mixed-aetiology case-series of 6 participants (3 of whom had stroke-induced dysphagia) employing the McNeill Dysphagia Therapy Program (MDTP). They reported an average of 45 swallows (SD = 27) per session over 12-15 one-hour sessions. Results were promising with 4/7 participants transitioning from non-oral to oral diets and maintaining their outcomes at 3 months post treatment. In a subsequent study (Carnaby-Mann & Crary, 2010), the same authors compared the MDTP with traditional therapy with biofeedback and reported the mean number of swallows per session as 91 compared with 32 respectively. Results indicate a significant improvement for the MDTP over traditional therapy with adjunctive biofeedback. Although the intervention varied between programs, one factor that may have contributed to these improved outcomes was the consistent application of increased practice amount. Importantly, the authors explicitly applied SBT principles including repetition (total number of swallows), load (which they define as bolus type where increased viscosity of bolus is indicative of increased load), frequency of swallows, and specificity of training.

While practice amount is considered a separate principle to progressive loading, it is likely that these two principles are related. SBT practice amount is a dynamic concept whereby clinicians evaluate a therapeutic practice amount as a starting point and over time increase the amount, and possibly its distribution, to progressively manipulate (over)load. The challenge with using bolus viscosity as a form of load is that viscosity cannot go beyond a solid food consistency and for many people thicker consistencies are easier to swallow compared with fast-moving fluids. Hence, there is not necessarily a linear relationship between viscosity of natural foods and load.

In addition, viscosity would interact with other factors such as bolus size. This highlights the importance of considering whether one is targeting the overall GMP for a swallowing movement pattern or parameterisation (e.g. force or amplitude of movement) in training. By employing PML, the overall schema and GMP can be targeted for practice by focusing on the full swallowing manoeuvre; while targeting specific control of parameter variation may improve peripheral strength, rate, and flexible control of different food/liquids.

Practice Variability

Practice variability is an important concept in the motor learning framework. Practice may occur in a constant or variable context. When practice focuses on a single aspect of the movement (or targets a single parameter), it can be considered constant (e.g. a series of effortful swallows aimed at consistently reaching a set level of perceived effort). If the practice includes retrieval of the motor program where different parameters are specified each time, practice is considered variable (e.g. a series of swallow manoeuvres which involve a different set of initial conditions each time).

Variable practice is thought to improve the GMP by providing experience with an array of initial conditions or movement predictions, the associated sensory consequences and the movement outcomes, thereby strengthening the schema for any given movement (Schmidt & Bjork, 1992). Furthermore, variable and constant practice schedules have been found to affect different aspects of learning differently. Consistent with the idea that variable practice improves the overall GMP, Lai, Shea, Wulf, & Wright (2000) found that variable practice improved the relative timing of a movement whereas constant practice improved the absolute timing. Lai and colleagues further explored the role of practice variability in an experiment that offered a combination of constant and variable practice over two practice schedules. The authors found that constant practice followed by variable practice yielded the best outcomes. They propose that initial constant practice allowed the learners to focus on practising the relative timing of a movement without having to recall a newly-specified schema each time. Once the motor program is established, then variable practice will optimise longer-term learning.

In the dysphagia rehabilitation context, many of the well-specified intervention protocols rely on SBT models. Oftentimes these programs do not incorporate variable practice into their training schedules; rather, they focus on training a single parameter setting (e.g. maximum force) to improve swallowing physiology.

The head lift manoeuvre, originally proposed by Shaker and colleagues (1997), is a six week isotonic-isometric training regime aimed at improving strength in the suprahyoid muscles, thereby improving hyo-laryngeal excursion and UES opening (Easterling, 2017). Research has indicated benefits of this training protocol in elderly (Shaker et al., 1997) and heterogeneous clinical populations (Logemann et al., 2009; Shaker et al., 2002). The clinical trials exploring the efficacy of the head lift manoeuvre report positive changes to swallow physiology immediately post therapy. Although these studies included stroke patients, it is difficult to make population-specific claims on the basis of these findings as the time post-stroke varied considerably. For example, spontaneous recovery effects cannot be ruled out for some patients. Within a motor learning framework, these exercises can be considered as constant practice, since the focus of the exercise is repeated practice of head lifting throughout the therapy session. The head lift manoeuvre fits best within a SBT regime with its aim being to impart change to a specific aspect of the swallow (i.e. UES opening). As such it does not alter the overall GMP or parametric control for swallowing. It may indirectly provide peripheral strength allowing recommencement of swallowing to take place (thereby resuming the GMP for swallowing) and at this point, adaptive processes may facilitate overall swallowing improvements. One possible link between SBT and motor learning may be that SBT gives the motor plan access to a greater range of parametric settings where beforehand peripheral weakness meant these options were inaccessible.

Another example of an intervention that is gaining traction in the deglutition context is respiratory muscle strength training (RMST). This approach is again grounded in a strength-based framework. It is based on the premise that improved ability to generate adequate subglottic pressure benefits swallow physiology by facilitating airway protection during the apnoeic period. Further recruitment of the suprahyoid muscles during use of the RMST has been demonstrated via electromyographic (EMG) investigation (Wheeler, Chiara, Sapienza 2006). RMST does not have a standardised dosage but within the speech pathology domain, protocols typically run for 4-5 weeks (Sapienza & Wheeler, 2006). This approach has recently been trialled in the sub-acute post-stroke dysphagia population by Park et al. (2016). These researchers randomly allocated 27 participants to either RMST or a sham therapy. The therapy dosage for both groups in the study was 25 trials daily, 5-days per week, for 4-5 weeks. During training, less than a 1-minute break was provided after each trial, with consideration for muscle fatigue and dizziness. Results indicated improved activity of the supra-hypoid muscles for the experimental group. All participants showed some improved outcomes on the Functional Oral Intake Scale (FOIS; Crary, Mann, & Groher, 2005) and the PAS (Rosenbek, Robbins, Roecker, Coyle, & Wood, 1996). With regard to swallowing outcomes, the only between-group difference related to PAS scores for liquids, where the experimental group demonstrated more improvements than the control group. In light of the overall improvements across both groups, it is likely that a number of participants were still making improvements associated with spontaneous recovery. Timing of post-treatment outcome measures is not reported in this study and RMST is susceptible to detraining effects (Baker et al., 2005) so it is unclear whether the improvements made in this study were maintained beyond the immediate post-treatment period. This intervention protocol also fits purely within the SBT paradigm and may not take into account the links between SBT, motor learning and neuroplastic change.

Lingual strengthening is another treatment approach grounded in SBT. Tongue pressure resistance training has been demonstrated to improve lingual strength in older healthy adults (Robbins et al., 2005). The link between lingual strengthening programs and swallowing outcomes has also been demonstrated in the post-stroke dysphagia population (Kim et al., 2017; Robbins et al., 2007). These studies report various therapy distributions and report different structures of practice.

Robbins and colleagues (2007) report findings from 10 participants with post-stroke dysphagia who used the Iowa Oral Performance Instrument (IOPI) to work on lingual strengthening. Participants completed 10 repetitions (alternating between anterior and posterior tongue bulb placement) three times a day, three days a week, for an eight week period, with a cumulative intensity of 720 trials (Robbins et al., 2007). Results indicated increased pressure generation and improved airway protection during swallowing, despite not practising swallowing. Several of the participants in this study were one month or less post-stroke and so may have been experiencing some additional benefits of spontaneous recovery. It was not possible to extract the specific data from the subset of participants who were more than 12 weeks post-stroke and thus less influenced by spontaneous recovery. Outcome measures were collected at a single baseline point and so it is not possible to ascertain stability of baseline performance. Also, performance was probed immediately after treatment but not beyond this point, making it difficult to ascertain the long-term effects on functional swallowing skills and safety.

In a larger more recent study by Kim et al. (2017), a total of 35 individuals with stroke-induced dysphagia undertook a conventional swallowing therapy program with or without an adjunctive lingual strengthening program. Limited details are available regarding the conventional therapy program. The authors indicated that it comprised thermal tactile stimulation, facial massage and various manoeuvres. In the lingual strengthening program, participants also completed 30 repetitions of isometric lingual resistance training with IOPI (randomly sequenced between anterior and posterior tongue bulb placement). Both therapy programs ran for five days a week for four weeks. The cumulative intensity for lingual strengthening was 600 trials (Kim et al., 2017). Results indicated overall improvements in PAS scores with no differences between groups for this measure. Significant group differences were reported for lingual strength and on the Videofluoroscopic Dysphagia Scale (VDS; Han, Paik, Park, & Kwon, 2008). The range of stroke onset time was not specifically reported; however, large standard deviations in the mean stroke onset time indicate that at least some of the participants were in the acute phase at the commencement of treatment. Again, no long-term effects on functional swallowing skills and safety, which would indicate motor learning, were reported in this study.

Again, the intervention of Kim et al. (2017) is an application of SBT and the practice schedule can be considered constant rather than variable. An important distinction between tongue pressure resistance training compared with head lift manoeuvre and RMST is the task-specific nature of the training activity for swallowing. The movement underlying this intervention forms part of the oral phase of swallowing. Training this aspect of deglutition directly targets parametric control of swallowing by focusing on improved force. This task demonstrates how interventions grounded within SBT models can lead to improved motor learning and subsequent neuroplastic change. However, it should be noted that this is not always the case as can be seen with head lift and RMST outlined above.

Practice Schedule

Of all the principles of motor learning, practice schedule has received the most attention in the general motor learning literature. Two practice schedules are often compared, namely blocked and random schedules. It is important to be clear from the outset that practice schedule is quite different from practice distribution and therapy dosage. Practice schedule refers to the schedule of items practised within any given session, whereas practice distribution refers to how practice is distributed across time and forms one component of therapy dosage.

Within the training or therapy session, random practice refers to a practice schedule that is not predictable for the learner. Each trial requires the learner to recall and execute a different GMP or adjust the parameter(s) for a given GMP. For example, if three swallow manoeuvres were being practised, the participant would be cued on which one to produce immediately prior to execution and the order would be randomised. Blocked schedules refer to schedules where all the trials for a given motor program are practised consecutively. Blocked practice frequently improves performance within the session and is, therefore, clinically very intuitive. However, there is now considerable evidence supporting the use of random practice to enhance longer-term learning

In rehabilitation of limb movement after stroke, the evidence is consistent with the general motor learning findings. Studies report a benefit of random practice over blocked practice (Hanlon, 1996). Very little attention is paid to the practice schedule in dysphagia rehabilitation. For the most part, blocked rather than random practice is employed (Logemann & Kahrilas, 1990; McCullough et al., 2012; McCullough & Kim, 2013; J. S. Park, Oh, Chang, & Kim, 2016; J. W. Park, Kim, Oh, & Lee, 2012). Currently few treatment comparison studies exist and optimising outcomes for patients remains clinically challenging.

Attentional focus

Previous research from the limb literature has reported improvements in motor performance when the focus of attention is drawn to the outcome of the movement (external focus) rather than the musculature performing the movement (internal focus) (Wulf, 2013; Wulf & Prinz, 2001). This finding has been attributed to the constrained action hypothesis, which postulates that focussing attention internally involves a conscious effort to analyse and control movement, which undermines implicit motor learning processes (McNevin, Shea, & Wulf, 2003; G. Wulf, McNevin, & Shea, 2001). The authors argue that an external focus of attention, on the outcome or effect of the movement, thereby promotes and refines automatic motor control processes. These findings have been extended to lingual strengthening tasks (Freedman, Maas, Caligiuri, Wulf, & Robin, 2007). The direct link between attentional focus and deglutition, especially in the dysphagia rehabilitation context, has not been explicitly explored. Nevertheless, there is a longstanding history of employing biofeedback in dysphagia rehabilitation (Bogaardt et al., 2009; Crary, Carnaby, Groher, & Helseth, 2004; Huckabee & Cannito, 1999; Logemann & Kahrilas, 1990) and stroke rehabilitation more generally (Nelson, 2007). If the participants' focus of attention is on the biofeedback output, usually a visual display of some aspect or outcome of movement, then this could convincingly be argued to be an external focus of attention. It could, however, be argued that some forms of biofeedback stimulate more internally focused attention by encouraging evaluation of the aspects of movement that generated the visual display (e.g. muscle tension or positioning of oral structures). Either way, biofeedback has been shown to have some positive effects for swallowing rehabilitation compared with other areas of stroke rehabilitation (Nelson, 2007). This is discussed in section 3.5.2 below which specifically reviews feedback.

Target Complexity – whole vs part practice

Deglutition is a motor skill requiring the sequencing and integration of multiple movements, some of which are under volitional control and some of which are reflexive. Clinically, it is intuitive to focus intervention first on subparts or lower level components of a more complex movement or movement sequence, in order to facilitate improvement in an overarching target goal. This ensures practice is directed towards the areas of the movement that are causing most concern while minimising time and attention on aspects of movement which may be optimal. Although clinically intuitive, this does not necessary align with optimising intervention outcomes from a motor learning perspective.

The motor learning literature highlights two perspectives that warrant consideration in determining the value of designing motor skill practice interventions in a whole or part format. An early suggestion regarding decisions to employ part or whole strategies for teaching and learning of motor skills is grounded in a hypothesis put forward by Naylor and Briggs (1963), which suggested that the benefits of part compared with whole practice depended on the movements' complexity (i.e. cognitive demands and number of components) and organisation (i.e. how the components of the task are related). Similarly, working within a schema theory framework, Schmidt and Wrisberg (2008) suggested that the decision regarding whole or part practice should be based on task classification. Tasks are classified as discrete, serial or continuous. Discrete movements are those which have multiple components but with well-defined beginning and end points and fixed sequences (i.e. those governed by a GMP), whereas serial tasks consist of a series of movements occurring in a sequential order, while continuous movements refer to those which are repetitive in nature.

Deglutition can be considered highly organised and also meets the criteria for a discrete skill. Both perspectives advocate for the benefits of whole practice for highly organised or interdependent motor skills. This implies that interventions to remediate dysphagia focusing on whole swallow manoeuvres rather than part swallow, or interventions focused on underlying subsystems, would lead to improvements in the overall GMP for swallowing. Conversely, interventions targeting partial manoeuvres of swallowing (e.g. head lift or tongue hold) might alter swallow physiology and dynamics by improving peripheral strength of swallowing muscles, rather than targeting a specific GMP as advocated by motor learning theorists.

3.6.2 The Dimensions of Feedback

An important aspect of rehabilitation for clinicians is the role of feedback and the influence it can exert on client performance and also learning. It is important for clinicians to recognise that intrinsic feedback mechanisms may be compromised in the post-stroke population compared with a non-neurologically injured population (Van Vliet & Wulf, 2006) and, therefore, extrinsic feedback may be more influential.

Feedback is often provided intuitively by clinicians in the therapeutic context, but there are several principles available to guide feedback more systematically. Schema theory outlines three aspects of augmented feedback which enhance motor learning: feedback type, feedback frequency and feedback timing (Schmidt & Lee, 2005, pp. 330-351). These concepts will first be considered within a broad motor learning context and then applied to post-stroke dysphagia rehabilitation.

Feedback type

Feedback about practice outcome can provide the learner with knowledge of the results (KR) of the target movement (either it was correct or not achieved). In contrast, feedback which specifically addresses the nature of the performance and how to improve the individual trial is known as knowledge of performance (KP). Both these forms of feedback can be effective in enhancing skill acquisition and improving performance. It is generally accepted in the motor learning literature that KR enhances long-term learning and retention of skills once the target for practice is known. There is some evidence to support the idea of providing KP in cases where there is unreliable internal representation of the goal (Newell et al 1990). Maas and colleagues (2008) argue that KP may be more beneficial in the early stages of therapy (to establish an accurate and reliable internal representation), whereas KR may be more beneficial at later stages where learners can accurately evaluate their own practice.

Feedback frequency

Feedback frequency refers to how often feedback is provided to the learner. Research has indicated that both relative frequency (percentage of trials on which KR is given) and absolute frequency (total number of times feedback is provided) are important for learning. Varying relative feedback frequency necessarily affects absolute feedback frequency. Research attempting to elucidate the optimum feedback frequency schedule has reported that increasing feedback frequency (or KR) promotes parameter learning (Wulf, Schmidt, & Deubel, 1993). In a follow up study, Wulf, Lee, & Schmidt (1994) found support for a dissociation between parameter learning and enhancing the overall GMP. The authors provided empirical evidence that the provision of reduced relative KR (at 50% frequency) promoted GMP learning and did not affect parameter learning. Surprisingly, this indicates that reducing the relative frequency of feedback does not diminish learning and may actually enhance it.

Feedback timing

The timing of feedback is also an important factor influencing motor learning. Augmented feedback can occur concurrently with or following the completion of a movement. Wulf & Shea (2004) have argued that providing feedback too early may interfere with information processing required to optimise intrinsic feedback processes, by reducing the reliance on memory retrieval needed for learning. This in turn hinders development of error-detection and refinement of motor skills. The delay period before providing feedback is meant to enhance intrinsic motor learning processes while the period following the provision of augmented feedback is thought to facilitate GMP refinement.

The role of feedback in dysphagia rehabilitation

The provision of augmented feedback by clinicians has obvious implications for rehabilitation outcomes. Augmented feedback as described in the motor learning literature has not been specifically investigated in a dysphagia rehabilitation context, but it warrants consideration in the design and implementation of the intervention.

The use of biofeedback has a longstanding history in dysphagia rehabilitation and there are several options available to facilitate positive rehabilitation for individuals with dysphagia. Preliminary research has investigated the use of VFSS (Logemann & Kahrilas, 1990), computed tomography (CT; Tsukamoto, 2000) and scintigraphy (Kanai et al., 2009) as methods of providing feedback to individuals who have undertaken rehabilitation for post-stroke dysphagia. These studies employed techniques which typically are considered diagnostic and limited by clinical practice as modalities for therapeutic feedback mechanisms.

A number of other feedback modalities are being utilised more regularly as biofeedback methods to facilitate swallowing rehabilitation. These include sEMG (for review see Bogaardt et al., 2009), lingual strengthening using the IOPI (for review see Adams, Mathisen, Baines, Lazarus, & Callister, 2013), and more recently ultrasound (e.g. Huang, Hsieh, Chang, Chen, & Wang, 2009).

Feedback presents a real challenge for the dysphagia rehabilitation clinician. Schemas develop over time in response to intrinsic feedback mechanisms. For people with dysphagia arising from sensorineural processing deficits, especially those who silently aspirate, it is unclear if an accurate internal representation is achievable. Because the internal feedback mechanisms are inconsistent with physiological swallow presentation, the breakdown may be at the level of internal feedback. In these circumstances, facilitating a motor plan that allows for safe swallowing may be more challenging, as there is a risk of reinforcing maladaptive swallowing processes.

3.7 Chapter Summary

A salient question that underlies the premise of this thesis is whether and how impairments of GMPs and parametric specifications within GMPs affect swallow physiology, and how principles of motor learning can be utilised by clinicians to facilitate rehabilitation. Deglutition relies on a highly integrated set of GMPs involving volitional and reflexive components across multiple systems. The circumstances are complex when these are compromised because of neurological impairment. Clinicians faced with remediating swallow function in these circumstances have little evidence to guide their selection and implementation of interventions. One method of overcoming this shortfall is to draw from the broader motor learning literature.

The purpose of this chapter was to first outline the theoretical relevance of several models of rehabilitation including neuroplasticity, strength-based training and motor learning. And second, review some of the current trends in the dysphagia rehabilitation literature and evaluate their foundations within these frameworks.

The dysphagia rehabilitation interventions discussed in this chapter all show promising outcomes for at least some stroke survivors with chronic dysphagia. The evidence points strongly towards therapies grounded in SBT models but the mechanisms underlying the reported improvements may be different. Individuals with peripheral weakness as a primary deficit in swallow function may respond well to a purely strength-based training approach to therapy. For others, damage from stroke to the neural circuitry involved in swallowing will lead to impairments involving higher-level motor programming rather than peripheral muscle weakness.

The link between SBT and motor learning and neuro-plasticity is complex. The principles of motor learning offer well-defined and well-tested methods for applying motor-based behavioural intervention in rehabilitation programs which are well aligned with the principles of neuroplasticity. The role of SBT paradigms in relation to promoting neuroplastic change is less clear.

There are some circumstances where SBT will only facilitate peripheral strength improvements, which are susceptible to detraining effects and will not promote generalisation of strength to functional activities. However, there are circumstances where SBT may facilitate motor learning, firstly in the context where strength can be considered as a precursor to re-establishment of a motor plan, and secondly where SBT strategies also target parametric settings, with improved strength providing access to increased options of parameter specification to be deployed in execution of the motor plan.

Overwhelmingly, current rehabilitation strategies target purely peripheral weakness or parametric settings rather than improving recall or retrieval or updating GMPs to fit a new set of peripheral circumstances. In order that SBT acts as a functional outcome facilitator, it is essential to consider other aspects of intervention design in order to promote positive rehabilitation outcomes. Depending on the condition being treated, it will sometimes be more appropriate to target GMPs even though this may be more challenging in rehabilitation design. Targeting these underlying issues with therapy fit for purpose may in fact lead to improved treatment selection and implementation by clinicians, and positive rehabilitation outcomes for their clients.

To date there have been no interventions that explicitly address these issues and ground intervention design within a PML framework, thereby enabling evaluation of the efficacy of this concept. The next chapter details an assessment and intervention protocol developed specifically to address these ideas.

Chapter 4. Assessment and Therapy Protocol

This chapter documents the protocols used in the assessment and therapy sessions and explains their content and structure. It also discusses the associated literature. This provides the rationale for the selection of assessment procedures and the development of the therapy program.

4.1 Eligibility

To be eligible, a number of inclusion and exclusion criteria were specified. Participants were screened to ensure they met inclusion criteria and were otherwise eligible for participation. The inclusion criteria comprised:

- presence of oral and/or pharyngeal dysphagia secondary to stroke, as diagnosed by the referring professional
- aged between 18 – 80 years
- fluent English speakers prior to stroke
- at least 12 weeks following stroke; ability to initiate voluntary swallow within one minute
- no more than mild cognitive/receptive language impairment determined by testing with Mini Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), with a threshold score of 23.

Participants with a diagnosis of additional progressive disease or a history of head and neck cancer, surgery or radiotherapy were excluded. Participants required a statement from their GP or specialist confirming they met eligibility criteria and were medically stable and able to participate in a rehabilitation program. Specific criteria included no chest pathology for 4 weeks prior to commencement of the program, no known barium allergy and no pacemaker or implanted electrodes. All had valid consent. This was in accordance with ethics approval.

4.2 Assessment Protocol

Eligible participants were asked for further information regarding background medical history, social history and current circumstances using a case history questionnaire. Participants then undertook a comprehensive assessment of the nature and extent of dysphagia to determine baseline stability of dysphagia and to measure progress over the course of the research program.

This study uses a single case experimental design (SCED) to evaluate intervention efficacy. Multiple baseline assessment measures were obtained for a subset of measures. To satisfy the SCED requirement for multiple baselines across participants, participants completed between 3 and 5 baseline measures to ensure stability of behaviours prior to treatment. These included measures for swallowing, speech and voice as well as respiratory related control measures that continued to be collected throughout and following treatment in order to maximise experimental control. In addition, a number of measures were collected in the pre- and post-treatment phases.

Pre-treatment measures were collected before treatment commenced. Baseline measures were collected over a two- to three-week period before treatment was initiated. Post treatment assessment was undertaken at three points: immediately following treatment conclusion, after four weeks, and after six months. Treatment was delivered in 6-week blocks. Some participants required two treatment phases. In these cases, the second phase of therapy commenced following a four-week therapy break. An overview of the assessment schedule can be seen in table 4.1. Specific assessment measures and their rationales are detailed below.

Table 4.1. Overview of assessment measures and data collection timepoints.

	Pre-treatment Assessment						**Within Treatment Assessment Probes**						**Post treatment Measures**		
	Pre-Tmt	BL1	BL2	BL3	BL4	BL5	Tmt1	Tmt2	Tmt3	Tmt4	Tmt5	Tmt6	Post Tmt1	Post Tmt2	Post Tmt3
Swallowing measures															
VFSS	✓													✓	
MASA		✓											✓	✓	
100 ml sip test		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
FOIS		✓											✓	✓	✓
Speech and Voice Measures															
Diadochokinesis (DDK)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Maximum Phonation Time (MPT)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	

Note. Tmt – treatment; BL – baseline; VFSS – videofluoroscopic swallowing study; MASA – Mann Assessment of Swallowing Ability (Mann 2002); FOIS – Functional Oral Intake Scale (Crary et al 2005);

4.2.1 Pre and Post treatment measures

Mann Assessment of Swallowing Ability (MASA). The MASA (Mann, 2002) evaluates oropharyngeal function in the stroke population. This assessment provides an overall dysphagia rating as well as an aspiration risk rating. These measures clearly translate into clinical profiles and provide specific information about change in swallowing function.

It is well established that clinical bedside assessments of swallowing are less accurate in identifying aspiration when compared to objective assessment (McCullough et al., 2005; McCullough et al., 2001). Significant variability exists in sensitivity and specificity of clinical bedside assessments or informal checklists of signs of dysphagia +/-aspiration. These variations can be attributed to methodological variations, including the underlying aetiological cause of the dysphagia, the time following hospital admission, the schedules of when each assessment are conducted and the type of instrumental assessment.

Despite the consistent (and obvious) finding that instrumental assessment is more accurate than clinical assessment, very little research to date has examined whether undergoing VFSS changes dysphagia management. In practice, many decisions regarding dysphagia management must be made on the basis of clinical bedside evaluation. Limitations regarding availability, clinical feasibility and suitability of patients for VFSS often influence clinical decision making surrounding instrumental assessment.

While various clinical bedside assessments are available, very few have been validated or undergone reliability testing. In an article comparing the MASA with blinded VFSS ratings, results indicated sensitivity of 73% and specificity of 89% for identification of dysphagia and a sensitivity of 93% and specificity of 63% for the identification of aspiration (Carnaby-Mann & Lenius, 2008).

With an awareness of the limitations of subjective clinical evaluation of swallowing and in conjunction with instrumental assessment measures, the MASA was employed to establish stable baseline measures of swallowing function pre-treatment and changes to the dysphagia measure and aspiration measure post-therapy.

Functional Oral Intake Scale (FOIS). The FOIS (Crary et al., 2005) assesses functional swallow outcomes. This scale specifically focuses on changes in abilities to consume oral intake and has also been psychometrically tested and proven to be a reliable, validated and sensitive test for measuring changes in functional swallow outcomes in the stroke population. For participants who relied on enteral feeding, changes to FOIS scores were made in collaboration with treating dietitians where the speech pathologist specified safest textures and the dietitian specified quantity of oral intake and enteral nutrition. A change in score of more than 2-points is considered clinically significant. One limitation of the FOIS is that it does not capture changes in texture modification beyond single and multiple consistencies. These changes, however, can lead to significant improvements in nutritional intake and quality of life (QoL). The level of texture modification with tube dependency is also not captured. Despite these limitations, this scale has frequently been employed since its development as an outcome measure for post stroke-dysphagia rehabilitation research (e.g. Bentim & Da Silva, 2009; Bogaardt et al., 2009; Permsirivanich et al., 2009). The FOIS was employed here, as well as changes to diet texture as outlined above.

Video fluoroscopic Swallow Study (VFSS). A 10-15 swallow protocol was employed using guidelines recommended by Logemann (1993a) and Steele, Barbon, and Namasivayam (2014). This allowed for standardisation of swallowing samples to be obtained across consistencies for each participant at all time points in the research program and ensured minimisation of radiation (Logemann, 1987). Table 4.2 outlines target swallows for each VFSS.

Table 4.2. Videofluoroscopic assessment protocol.

Fluids
An initial 1-3ml bolus of thin fluids to observe aspiration risk
Three 5ml boluses of thin fluids
If no evidence of aspiration, three 20-30ml boluses of thin fluids
100ml unregulated drink from cup
If aspiration occurs, aim for three 5ml boluses of thickened fluids as required
Solids
Three 5ml boluses of puree
Three tsp diced fruit or 10g biscuit

Analysis

Video-fluoroscopy is frequently cited as the gold standard assessment for swallowing (e.g. Tomic, Antonescu-Turcu, & Jacobs, 2013). All measures from VFSS were rated by experienced clinicians who were blind to the treatment hypotheses and the time-point of data collection, and who had not been involved with conducting assessments or the delivery of treatment. Various methods are available for measuring individual aspects of the deglutitive process, as well as whole swallow assessments derived from judgements of the componential features of the swallow. For the purposes of this study, VFSS analysis focused on clinical swallowing outcome measures including severity of aspiration.

Clinical Swallowing Outcome Measures

Measures of aspiration and residue are regarded clinically as functional swallow outcomes which impact on swallowing safety and efficiency (Logemann, 1993a). Changes in these parameters potentially allow for changes in end-point diet and pulmonary health, which in turn have flow-on effects for overall well-being, QoL, nutrition and hydration.

Aspiration

The Penetration–Aspiration Scale (PAS; Rosenbek, Robbins, et al., 1996) is a rating scale developed to systematise clinical interpretation of the presence (or absence) of material entering the airway. It rates movement of the bolus through the aero-digestive tract on an ordinal scale reporting eight levels of increasing risk of aspiration (depending on the flow and depth of the bolus and an individual's response to it). A score of less than 2 indicates a normal swallow and a score of 5 or higher indicates aspiration. This scale allows for changes to aspiration risk to be clearly documented throughout the course of the rehabilitation program. Since its development, this scale has frequently been used to measure penetration and aspiration risk in studies evaluating dysphagia (e.g. Lim, Lee, Lim, & Choi, 2009; Park et al., 2012; Robbins et al., 2007).

Quality of Life (QoL) Measures

In order to measure changes to QoL, the SWAL-QoL and SWAL–CARE were administered. These tools have been designed specifically to evaluate the impact of dysphagia on QoL and have documented validity and reliability (McHorney et al., 2002). Following pilot testing, the SWAL-QoL/SWAL-CARE measures were stopped because the results generated lower scores (associated with lower QoL) that were inconsistent with patient reports and clinical outcomes. It was thought that this situation may have been due to changes associated with commencing oral intake after previously being nil by mouth. Patients were reflecting on swallowing performance as being troublesome, whereas prior to treatment, there was no need to rely on swallowing and therefore it was not regarded as troubling. Therefore, measures of the dysphagia handicap index and the personal wellbeing index were added to the assessment protocol in order to measure change in swallowing QoL for subsequent participants. In addition, participants and their families were invited to participate in interviews to discuss the rehabilitation process and changes to swallowing, and the implications of this as a qualitative research project. (The outcomes from these interviews are reported and discussed in Chapter 6).

4.2.2 Baseline and experimental measures

In addition to the comprehensive assessment battery, the following set of outcome measures were collected across multiple baselines, weekly throughout the treatment phases, immediately following treatment, and 4 weeks following treatment.

Clinical swallow evaluation: 100ml swallow test

The primary outcome measure for this study was the 5-point rating scale for drinking 100ml of water without evidence of aspiration within 1 min of completing the task (see Table 4.3). The measure was taken weekly during the treatment phase to monitor change in functional swallowing between instrumental assessments. Similar types of scales have been used previously to report progress in dysphagia rehabilitation programs (Zheng, Li, & Liu, 2014).

Table 4.3. Rating scale for the modified timed 100ml swallow test.

1	Able to drink 100mls of water independently from cup without overt signs of aspiration within 1 minute
2	Able to drink 100mls of water independently from cup without overt signs of aspiration in > 1 minute
3	Able to drink 100mls of water within 1 minute without overt signs of aspiration with assistance or modifications (e.g. via spoon or adaptive equipment) without overt signs of aspiration
4	Overt signs of aspiration evident > 50mls (assistance/modifications as needed)
5	Overt signs of aspiration evident < 50mls (assistance/modifications as needed)

Note. Overt signs of aspiration included coughing, throat clearing, changes to vocal quality, changes to rate or effort of respiration.

“Water tests” (where the individual consumes a certain amount of water and observations are made regarding risk of aspiration and dysphagia) are a widely employed clinical technique used in conjunction with case information to determine functional swallowing status and the need for further objective assessment. Findings regarding their clinical utility have been equivocal and there has been significant variability in study methodology and participant characteristics, including aetiology and stage of disease progression. Variation in outcome measures makes comparing this research difficult.

Water tests have attracted criticism as a method that is not sensitive in detecting aspiration nor specific in ruling aspiration out (e.g. Garon, Engle, & Ormiston, 1996; Splaingard, Hutchins, Sulton, & Chaudhuri, 1988). The primary criticism is that despite detecting a large proportion of individuals who aspirate, these evaluations do not have the same accuracy as instrumental assessment, especially in the context of silent aspiration. These factors are often not considered in analyses evaluating the specificity of clinical swallow evaluations compared with instrumental assessments.

In a review of the literature of clinical swallow evaluations, Carnaby-Mann and Lenius (2008) highlighted issues that may bias the validity of assessment tools. Assessments with strong sensitivity and specificity will confirm or refute the presence of aspiration in the context of very mild and very severe (i.e. those who are likely to silently aspirate) cases. They point out that a large proportion of the results reporting findings for moderate cases of dysphagia may bias specificity, potentially leading to an overestimation of the validity of assessment tools.
In contrast, the literature supporting the clinical usefulness of water swallow evaluations emphasises its sensitivity in detecting individuals who may benefit from further instrumental investigation of swallow function. In particular, water swallow tests in combination with other criteria form the basis of several dysphagia screening tools (e.g. Martino et al., 2009). Indeed, initial validation for non-instrumental water swallow evaluations occurred in response to the impracticalities of administering VFSS on all stroke patients but recognising the vulnerability of aspiration risk in the stroke population (DePippo, Holas, & Reding, 1992). From there, efforts were made to refine these evaluations by combining other features including background history, cranial nerve and oral musculature observations and other impairments (e.g. dysphonia) thought

to be linked with aspiration (Daniels, McAdam, Brailey, & Foundas, 1997; McCullough et al., 2005), as a well as timing measures (Hughes & Wiles, 1996; Nathadwarawala, McGroary, & Wiles, 1994; Nathadwarawala, Nicklin, & Wiles, 1992). Clinical judgements made on the basis of a cluster of features appear to yield the best balance of sensitivity and specificity (Daniels & Huckabee, 2014). A large comprehensive study conducted at Yale University School of Medicine involving 3000 participants has indicated that passing water swallow evaluations allows for recommencement of oral diet and these findings have been broadened to now include a wide array of aetiologies (Suiter & Leder, 2008)

As yet, no optimal methods of tracking progress through therapy have been determined. In the current study, a 100ml water swallow test was used throughout the course of therapy in order to monitor change in functional swallow outcomes.

Control Measures

The design of this study included multiple baselines across behaviours as well as participants. The following tasks were used for the purpose of experimental control, as they were not expected to change as a result of the treatment protocol: diadochokinetic (DDK) rate, maximum phonation time (MPT) and vocal quality. An important property of control measures is that they have the capacity to change over time, are measurable, but are not expected to be affected by the therapeutic process. The measures chosen here were selected because of the probability of speech and voice disorders occurring as a consequence of stroke.

4.3 Treatment Protocol

A range of established therapeutic techniques have been deployed as interventions in this study. Three therapy manoeuvres (Effortful, Mendelsohn, and tongue hold (a.k.a. Masako)) were selected to be implemented into the PML-based therapy program. There are several reasons for their selection. First, their efficacy in neurologically impaired populations has been proven. These manoeuvres are known to improve swallowing in populations with neurological impairment and each manoeuvre specifically targets a different aspect of breakdown. Robbins and colleagues (2008) highlighted these manoeuvres for prioritisation for further research because of their potential for plasticity. Second, they have been selected on the basis of their potential to demonstrate motor learning. Finally, they are clinically feasible, an important consideration in the translation of research into a clinical setting. They form part of a clinician's therapeutic repertoire and no additional augmentative equipment is required. However, there may be evidence to support improved efficacy with adjunctive therapy modalities.

It is important to appreciate from the outset that the goal of this study was to explore the outcomes of an intervention protocol grounded in PML. As such, it was not the manoeuvres themselves that were critical, rather, the structure of practice was the key element of the intervention in this research study. Additionally, these manoeuvres were selected to reinforce methodological consistency and robustness. Consequently, they were chosen prior to clinical evaluation. In a clinical setting, by contrast, clinicians select therapeutic manoeuvres based on diagnostic evaluation of their client.

In what follows, the literature pertaining to stroke rehabilitation and the selected manoeuvres is reviewed. The research reviewed here relates specifically to the application of these manoeuvres in the post-stroke population. There has been some research exploring these manoeuvres in populations with other aetiologies (e.g. head and neck cancer). These studies are not discussed here as it is likely that motor learning will have different constructs depending on whether the disorder is neurological or structural in nature.

4.3.1 Specific manoeuvres employed in this research study

Effortful Swallow

Research has explored the impact of an effortful swallow on the swallowing physiology of adults in both the general population and those with dysphagia. Various measurement techniques have been employed and different aspects of swallow physiology have been focused on to assess the changes evoked by using the effortful swallow technique.

Early research highlighted the effortful swallow as a manoeuvre that increases posterior tongue base movement (Logemann, 1993b). Logemann reasoned that this increase in tongue base retraction should facilitate improved bolus clearance from the valleculae (Logemann, 1998). Indeed, there have been several studies investigating the role of the effortful swallow manoeuvre on the oral phase of swallowing. Research has emphasised the importance of the instructions used to elicit an effortful swallow and indicated that the equivocal results reported may be attributed to different instructions generating qualitatively different effortful swallows (Yeates, Steele, & Pelletier, 2010). Increased oral pressure has been found consistently in cases where the role of the tongue in effortful swallowing is emphasised and where instructions explicitly include the tongue (Fukuoka et al., 2013; Hind et al., 2001; Huckabee & Steele, 2006; Pouderoux & Kahrilas, 1995; Steele & Huckabee, 2007; Yeates et al., 2010). Additionally, one study also reported a non-significant trend towards reduced oral residue (Hind et al., 2001).

The majority of research has been dedicated to examining the impact of effortful swallowing on the pharyngeal phase of swallowing. In a series of three studies, Bulow and colleagues (Bulow, Olsson, & Ekberg, 1999, 2001, 2002) examined both video-fluoroscopic and manometric variables to evaluate the impact of several different swallow manoeuvres on swallow physiology in both healthy and disordered populations. Their aim was to further understanding of how swallowing manoeuvres alter swallow physiology in order to guide therapeutic rehabilitation of swallowing. In their first study, Bulow and colleagues (1999) examined effortful swallowing in healthy individuals and found a notable elevation of the hyoid prior to swallow initiation. This in turn influenced measures of swallowing in an unexpected way. While effortful swallowing may intuitively be thought to increase hyoid displacement, in this case hyoid displacement was reduced because of the adjustment to the pre-swallow positioning of the hyoid. The position of the larynx also elevated pre-swallow, thereby reducing hyo-laryngeal elevation. They posited that this early hyo-laryngeal elevation may facilitate safe transit of the bolus in disordered swallowing by early airway protective positioning of the larynx pre-swallow and by shortening the distance required for complete hyo-laryngeal excursion.

From the kinematic measures reported in these studies of Bulow and colleagues, it appears that the effortful swallow induces a significant difference between the distance of the hyoid and mandible pre-swallow, as well as significant differences in maximal laryngeal elevation and maximal hyoid movement. What remains unclear from these findings is whether the overall hyo-laryngeal excursion remains reduced (i.e. the pre-swallow plus during swallow movement cumulatively result in reduced movement) and what impact this may have in a disordered population. There are two possible interpretations here: early positioning of the larynx may facilitate airway protection, or as Huckabee and colleagues point out, this may reduce swallow efficacy (Daniels & Huckabee, 2014). Other researchers looking at kinematic measures of the pharyngeal phase in healthy populations have indicated greater displacement, velocity and duration of hyoid and laryngeal movements during effortful swallowing compared to normal swallowing (Jang, Leigh, Seo, Han, & Oh, 2015; Park, Kim, Oh, & Park, 2009). Similarly, Park and colleagues followed up their earlier research with studies investigating the impact of effortful swallowing in post-stroke dysphagia rehabilitation (with adjunctive NMES). Both studies provided support for the use of effortful swallowing as a facilitative manoeuvre for improving dysphagia following stroke (Park et al., 2009, 2012).

Research to elucidate the nature of changes in pharyngeal pressures during the effortful swallow also has been carried out in healthy populations. Results consistently indicate that effortful swallowing alters pharyngeal pressure at all levels of the pharynx (Hoffman et al., 2012; Huckabee, Butler, Barclay, & Jit, 2005; Huckabee & Steele, 2006; Pouderoux & Kahrilas, 1997; Takasaki, Umeki, Hara, Kumagami, & Takahashi, 2011; Witte, Huckabee, Doeltgen, Gumbley, & Robb, 2008). Despite this alteration of the timing of swallowing pressures, both durationally and sequentially, the impact on overall swallowing efficacy remains unclear.

There is much less research dedicated to exploring the impact of effortful swallowing in individuals with dysphagia. Pioneering research by Logemann and Kahrilas (1990) was a case study of a series of swallowing techniques in an individual following brainstem stroke and reported long-lasting benefits of practising effortful swallow. In two follow-up studies, Bulow et al. (2001, 2002) investigated the same manoeuvres in patients with moderate to severe pharyngeal dysfunction. The sample included eight patients, six of whom presented with dysphagia following stroke and two as the result of head and neck cancer. Five of the participants had frequent episodes of aspiration and three had delayed pharyngeal swallow initiation. With regard to effortful swallow, they reported similar preparatory positioning of the hyo-laryngeal complex. In support of the use of effortful swallow in a population of individuals with swallowing disorders, they reported that although effortful swallowing did not reduce the frequency of swallows leading to aspiration, it did significantly reduce the depth of contrast penetration into the larynx and trachea. They also reported that four of the eight individuals struggled with the technique because of weak lingual muscles and suggested that perhaps tongue strengthening prior to the initiation of effortful swallowing might be beneficial. Finally, they reported a non-significant result of effortful swallowing in altering peak intra-bolus pressure, or duration of this pressure when measured at the level of the inferior pharyngeal constrictor. This has important clinical ramifications as the authors suggested that swallowing manoeuvres may have the potential for decreasing pharyngeal pressure in the context of improved PES opening.

Mendelsohn

The Mendelsohn manoeuvre is another swallowing manoeuvre aimed at promoting airway protection, by maximising hyo-laryngeal excursion and prolonging the period of time that the hyoid complex stays at its peak height and anterior position. Some researchers have argued that it also prolongs the period of UES opening. As with the effortful swallow, the Mendelsohn manoeuvre was originally introduced as a compensatory strategy to facilitate safe transfer of the bolus through the pharynx (Daniels & Huckabee, 2014). In their case study, Logemann and Kahrilas (1990) found that repeated use of the Mendelsohn manoeuvre over time led to a rehabilitative effect on swallowing and improved overall swallow physiology, rather than just promoting safe transfer of the bolus. In the post-stroke population, the Mendelsohn manoeuvre has been used in conjunction with other manoeuvres and treatment modalities to promote functional improvements in swallowing for individuals with chronic dysphagia (Crary, 1995; Huckabee & Cannito, 1999).

Tongue hold (or Masako) manoeuvre

The final technique selected for this intervention program is the tongue hold manoeuvre (also known as the Masako manoeuvre). This technique was developed with the aim of improving base of tongue (BOT) to posterior pharyngeal wall (PPW) contact for patients who had undergone surgery for oral cancer. Research examining the impact of the tongue hold manoeuvre in a healthy population reported that the manoeuvre demonstrated a statistically significant anterior approximation of the PPW (Fujiu & Logemann, 1996). BOT and PPW approximation are integral in triggering the pharyngeal swallowing response. With repeated practice and the ability to promote peripheral muscle tissue strength, this manoeuvre is traditionally associated with strength-based training. Again, there have been no studies exploring the long-term outcomes for this manoeuvre. However, for populations that may require additional PWW strength to promote swallow efficacy, this manoeuvre may also lead to motor plan changes. Huckabee and Daniels (2014) highlighted that more research into the Masako is needed to determine its impact in a neurologically disordered rather than a structurally disordered population.

As can be seen from this literature review, effortful swallow has received the most attention to date. There is relatively less research on the therapeutic impacts of the Mendelsohn and Masako manoeuvres. More contemporary research investigating rehabilitation of deglutition frequently involves comparing a specific intervention with a "traditional therapy" comparison group. These three manoeuvres are often included in the traditional therapy comparison group, but as they are typically combined in an eclectic and individually-tailored manner, it is difficult to ascertain which (if any) manoeuvre may account for improved swallowing outcomes. Further, most research evaluating these techniques does not provide long-term outcomes or does not measure outcomes in a generalised context. It is therefore difficult to establish whether motor learning has taken place.

4.3.2 The Structure of Practice

As prefaced earlier in this section, the essential component of this intervention is its application of PML to dysphagia rehabilitation. The PML were introduced in chapter 1 section 1.7.4 and their theoretical basis was discussed with reference to the dysphagia rehabilitation literature in chapter 3 in section 3.5.1. The structure of practice forms an essential component of experience-dependent motor learning. The PML outline six practice principles: practice amount, practice distribution, practice variability, practice schedule, attentional focus and target complexity

Practice Amount

A *large amount of practice* leads to improved learning. The practice amount threshold required to generate improved swallowing outcomes is yet to be established. It is likely that this is individually determined and influenced by a number of factors. The intervention protocol aimed to continuously practice swallowing at the upper limit of the participant's ability in order to maximise the number of swallows per session. In line with principles of strength-based training, the number of swallows per session also progressively increased over the course of the intervention program (*progressive overload).*

Practice Distribution

A distributed practice schedule (rather than a massed practice schedule) is typically associated with improved motor learning (although see section 3.5.1.3). Participants attended three 1-hr therapy sessions a week for a period of six weeks. This likely promotes the practice required to facilitate motor learning. This distribution schedule is clinically feasible in the Australian healthcare context, although the number of sessions probably exceeds the norm for the treatment of chronic dysphagia patients in an outpatient setting. The practice distribution offered and the time within an individual therapy session dedicated to practice have the potential to optimise treatment intensity.

Practice Variability

Practice variability is a crucial aspect of training programs grounded within the motor learning framework. In this study it was achieved by varying bolus size, bolus consistency, and therapy manoeuvre within each therapy session. For each therapy target, manoeuvre, bolus size and bolus consistency were specified and varied each time. Practice variability is an under-reported aspect of therapy design in dysphagia rehabilitation. Anecdotal clinical reports frequently describe constant practice schedules. Including practice variability within the therapeutic design ensures that practice is more reflective of everyday eating. Nevertheless, there were some limitations in the practicalities of administering some aspects of the variable program for participants who remained at too high a risk of aspiration, in which case only the therapy manoeuvre was varied.

Practice Schedule

Another important aspect of the motor learning practice structure refers to the order of the delivery of each therapy practice task (in this case, each swallow). A randomised practice schedule has been linked with improved outcomes from a motor learning perspective. The current study employed a randomised schedule for each manoeuvre within the therapy session. Further, for participants able to undertake direct therapy, bolus size and consistency were also specified. Two levels of the therapy program were generated (one indirect and one direct) for each therapy session. Therapy manoeuvres, bolus size and type were all randomly allocated.

In order to mitigate aspiration risk within the session, several precautions were put in place. Therapy would commence at the safest consistency, specifically the level at which the participant did not demonstrate any overt signs of aspiration during VFSS. Throughout the therapy session, if 8/10 swallows were achieved without overt signs of aspiration, then therapy progressed to the next consistency and continued in a stepwise fashion. If evidence of aspiration occurred on 3/10 swallows, then therapy returned to the previous level. This allowed for advancement and regression through the therapy hierarchy in response to individual participants and the immediate circumstances of the therapy session. These precautions appear to be consistent with those outlined in previous therapy protocols for dysphagia rehabilitation (Barikroo & Lam, 2011; Carnaby-Mann & Crary, 2008). This stepwise progression is reported in table 4.4 below.

Table 4.4. Description of stepwise texture consistencies used in therapy.

Indirect Therapy
Saliva/lollipop/ice/<5ml water
Direct Therapy
Fluids
Water
Mildly thick (150)
Moderately thick (400)
Solids
Puree
Minced (1cm^2)
Soft
Full

Since the development of this protocol, the development of the international dysphagia diet standards initiative (IDSSI) has been developed (Cichero et al., 2013). These measures align with IDDSI standards.

Attentional Focus

The motor learning literature supports training programs that promote an external attentional focus. This is intuitive in training programs that have a highly visible external goal (the placement of a tennis serve, the result of a golf shot, shooting a basketball goal), but in the dysphagia rehabilitation context this is difficult to operationalise. One application may be the use of sEMG to focus on the outcome of a swallow, however further investigation is required to ensure that sEMG depicts true swallowing rather than suprahyoid contraction without deglutition. Furthermore, individuals with poor intrinsic feedback mechanisms and those who aspirate with reduced or no response are unlikely to be able to accurately focus on the successful outcome of any given swallow.

Target Complexity

The PML advocate for the practice of complex manoeuvres in preference to part movement manoeuvres once a basic motor plan has been established. Hence, the manoeuvres selected for implementation in this study all relied on whole swallowing rather than part swallow components.

Feedback considerations

The nature of the feedback provided within therapy or training sessions may influence the outcome of motor learning and warrants consideration when delivering therapy. During practice, providing feedback of overall results, delivered approximately half the time following a 3-5 second delay, is a strategy that supports motor learning. The study was designed to implement such a feedback schedule, however after pilot testing, it was recognised that this was not a valid intervention objective because unless invasive instrumental feedback techniques are employed, no reliable methods of identifying adequacy of swallow are currently available.

Table 4.5 provides an example of the randomly-generated therapy manoeuvres for each session. Both levels of swallowing ability are presented to allow for progression between direct and indirect therapy. Practice variability, practice schedule, target complexity and feedback frequency are all evident.

Table 4.5. Example of randomly-generated therapy manoeuvres for therapy sessions.

Treatment session – direct therapy	Feedback	Treatment session – indirect therapy	Feedback
Effortful 5ml		Effortful	Feedback
Effortful	Feedback	Mendelsohn	Feedback
Masako	Feedback	Mendelsohn	
Effortful 5ml	Feedback	Masako	
Effortful 5ml	Feedback	Effortful	
Mendelsohn 5ml		Effortful	
Masako	Feedback	Effortful	
Mendelsohn 10ml		Effortful	
Mendelsohn 10ml		Masako	Feedback
Effortful 5ml	Feedback	Masako	

4.4 Chapter Summary

This chapter provides a detailed overview and theoretical rationale for the intervention protocol. PML offer a set of practice and feedback principles guiding motor learning. To date, they have not been explicitly examined in the dysphagia rehabilitation context. This chapter outlines the application of the principles of motor learning in designing a prospective rehabilitation intervention protocol. Namely it incorporates practice principles of high volume of practice using a distributed schedule of appoinment sessions. Within each treatment session, practice principles of randomisation, variability, and target complexity are applied. Feedback principles are also considered. Consideration of rehabilitation principles of both the central and peripheral nervous system offers opportunities to discover more about the nature of swallowing difficulties and clinical options for guiding clinicians in the selection and implementation of dysphagia rehabilitation.

Chapter 5. The application of motor learning principles to dysphagia rehabilitation

Dysphagia, a disorder of swallowing function, has a significant impact on activity and participation outcomes following neurological injury. Dysphagia has been reported to affect between 27%-81% of people after stroke depending on aetiology, specificity and timeframe of assessment (Martino et al., 2005). Mann et al (1999) reported that 50% of individuals presenting with acute dysphagia immediately after having a stroke, will demonstrate persistent swallowing difficulties 6 months post stroke when reviewed on video-fluoroscopy.

It is well established that the presence of dysphagia following stroke is linked with adverse health outcomes including pulmonary complications (e.g. aspiration pneumonia), dehydration, nutritional compromise, as well as reduced activity and participation levels within the WHO-ICF framework and lower scores on quality of life measures (Logemann, Gensler, & Robbins, 2008). Schmidt et al (1994) reported aspiration pneumonia contributed to the death of 20% of stroke-survivors with dysphagia during the first year following stroke. Further, primary and secondary dysphagia related risks have been associated with increased length of hospital stay (Odderson, Keaton, & McKenna, 1995).

Despite this considerable incidence and the associated adverse health outcomes, evidence-based choices for rehabilitation of dysphagia following stroke remain elusive. This, in part, is due to changing professional attitudes in treatment options for dysphagia. Historically, swallowing was viewed as a reflex and therefore not considered suitable for behavioural remediation (Robbins et al., 2008). In light of this, dysphagia management has relied heavily on compensatory strategies (Lazarus, 2017). These techniques focus on providing a safe swallow strategy to overcome adverse effects of dysphagia and aspiration. In contrast, rehabilitative treatments aim to enhance the physiology of swallowing in order to improve airway protection and achieve normal oral intake (Easterling, 2013). For speech-language pathologists, limited research is available to guide treatment selection, or predict efficacy of treatment options of such rehabilitative approaches. Consequently, clinical practice falls back on compensatory techniques, which frequently have poor compliance and therefore associated pulmonary compromise, or health risks associated with maintaining adequate nutrition and hydration levels.

With advances in neuroimaging technologies, a proliferation of research into neuroplasticity and rehabilitation have emerged (Kleim & Jones, 2008). Rehabilitation efforts following stroke have received much attention with an emphasis in motor rehabilitation of limbs (Byl et al., 2003; Cheung, Tunik, Adamovich, & Boyd, 2014; Dimyan & Cohen, 2011; Frykberg & Vasa, **2015**)) and of speech motor control (Ballard et al., 2015; Ludlow et al., 2008).

Improved understanding of neural substrates involved in deglutition and the influence of research in neuroplasticity in rehabilitation has generated renewed interest in dysphagia rehabilitation (Malandraki, Johnson, & Robbins, 2011). Swallowing has been reconsidered and is now deemed to be at least partially responsive to behavioural rehabilitation (Easterling, 2017; Robbins et al., 2008; Speyer, Baijens, Heijnen, & Zwijnenberg, 2010; Wheeler-Hegland et al., 2009). Reviews highlight the need for increased empirical support evaluating the efficacy, effectiveness and efficiency of these techniques (Clark, 2003; Robbins et al., 2008). Further these reviews have emphasized the need for further research using high-quality controlled trials and using objective measures to validate treatment outcomes (Clark, 2003; Speyer et al., 2010).

Promising findings stemming from strength-based training approaches for dysphagia rehabilitation have been put forward (Burkhead, Sapienza, & Rosenbek, 2007; Clark, 2003; Clark, Lazarus, Arvedson, Schooling, & Frymark, 2009; Speyer et al., 2010; Steele, 2012). Researchers have suggested grounding treatment in theoretical principles, specifically experience dependent principles of neuroplasticity (Clark et al., 2009; Robbins et al., 2008); and more recently a growing interest in the application of principles of motor learning (Humbert & German, 2013; Zimmerman, Lazarus, & Malandraki, 2020).

Aligning with recommendations from these reviews, a dysphagia rehabilitation program based on the principles of motor learning was developed. Specifically, it employed swallowing manoeuvres that involve swallowing in its entirety, the randomisation and variability of swallowing manoeuvres and boluses, high levels of repetition, in a distributed practice schedule. (Details of the program development are seen in chapter 4).

The purpose of the current study was to conduct a Phase I efficacy trial investigating the implementation of a rehabilitation program incorporating principles of motor learning may be beneficial to chronic post-stroke dysphagia rehabilitation. A secondary goal of this study was to provide further evidence for a population that rarely receives direct attention in the literature or clinical pathways; the chronic post-stroke dysphagia population.

There is evidence to suggest that some individuals with chronic post stroke dysphagia are able to improve their swallow function in the longer term (Bath, Lee, & Everton, 2018; Bogaardt, Grolman, & Fokkens, 2009; Bulow, Speyer, Baijens, Woisard, & Ekberg, 2008; Carnaby-Mann & Crary, 2010; Crary, Carnaby, LaGorio, & Carvajal, 2012). Despite this, access to rehabilitation at this point is not readily available and carers and family members are faced with the burden of seeking ongoing treatment opportunities unassisted.

In order to ensure high quality control, a single case experimental design (SCED) methodology was employed to enhance methodological rigour. The experimental control in the study designs allows for valid inferences to be drawn regarding treatment effects for the individual being studied. It has been touted as a means of evaluating therapeutic efficacy by practicing clinicians (Kazdin, 2019). Their utility in rehabilitation populations has been emphasised (Graham, Karmarkar, & Ottenbacher, 2012; Krasny-Pacini & Evans, 2018).

To facilitate clinical translation of study findings, only outcome measures that are clinically accessible and feasible were utilised. The target population were individuals with chronic, severe dysphagia living in the community. Many individuals with severe dysphagia are discharged from formal rehabilitation with enteral nutrition without opportunity to have further swallowing assessment or participate in rehabilitation for swallowing at a later stage.

Dysphagia is associated with reduced social participation for stroke survivors and their carers; and increased carer burden (Helldén, Bergström, & Karlsson, 2018; Li et al., 2022; Robinson, Coxon, McRae, & Calestani, 2022). Improving swallowing function for this population has significant implications on health and well-being.

The current study evaluated whether a therapeutic intervention, grounded in PML, generates improved outcomes in swallowing efficacy. The following hypotheses were developed. Participation in motor-learning based dysphagia rehabilitation will

1) improve clinical swallowing outcomes on a modified 100ml timed water swallow test, measured using a 5-point scale quantifying volume, method of intake and overt signs of aspiration.
2) reduce dysphagia severity as measured by the Mann Assessment of Swallowing Ability (MASA; Mann, 2002).
3) improve functional oral intake as measured by the Functional Oral Intake Scale (FOIS; Crary, Mann, & Groher, 2005).

4) reduce incidence and severity of aspiration as measured by the Penetration-Aspiration Scale (PAS; Rosenbek, Robbins, Roecker, Coyle, & Wood, 1996).

As motor learning is thought to be specific to a skill, or group of related skills (Clark, 2012; Schmidt, Lee, Winstein, Wulf, & Zelaznik, 2018), it was also hypothesised that participation in motor-learning based dysphagia rehabilitation will not

5) alter performance on voice and speech tasks (i.e., maximum phonation time, and alternating and sequential syllable repetition tasks). These tasks have been included for experimental control.

5.1 METHOD

Ethics approval was obtained from the University of Sydney Human Research Ethics Committee, protocol number 2012/2020. Participants were recruited by flyer distributed via community based speech pathologists and medical specialists. All participants provided written informed consent.

5.1.1 Participants

Participants were 4 individuals (3 female; 1 male) aged between 40 – 76 years. All presented with severe dysphagia and were reliant on enteral feeding via percutaneous endoscopic gastrostomy (PEG) as a result of stroke. All participants met the following inclusion criteria: presence of oral and/or pharyngeal dysphagia secondary to stroke, as diagnosed by the referring professional; aged between 18 – 80 years; fluent English speakers prior to stroke; at least 6 months post–onset; ability to initiate voluntary saliva swallow within one minute; no more than mild cognitive/receptive language impairment determined by testing with the Mini Mental State Examination (MMSE), with a threshold score of 23/30; (Folstein, Folstein, & McHugh, 1975) and medically stable as per their managing medical team. In addition, participants were excluded if there was a diagnosis of additional progressive disease or a history of head and neck cancer, surgery, or radiotherapy. Participant characteristics are shown in table 1.

Table 1. Participant characteristics.

Participant	Gender	Age in Years	Months Post-Onset	Lesion type and location	Severity of Dysphagia	Mode of nutrition
1	Female	40	14	Left lateral medullary infarct	Severe	100% PEG
2	Female	56	36	Subdural haemorrhage + Bilateral cerebellar infarcts	Severe	100% PEG
3	Female	56	7	Bilateral cerebellar infarcts	Severe	100% PEG
4	Male	76	18	Right lateral medullary infarct	Severe	100% PEG

Note. PEG = Percutaneous Endoscopic Gastrostomy

5.1.2 Design

Single case experimental design (SCED), including multiple baselines across participants and behaviours, was employed (Krasny-Pacini & Evans, 2018) to conduct a Phase I test of the efficacy of the treatment approach (Beeson & Robey, 2006; Robey, Schultz, Crawford, & Sinner, 1999). A hallmark of SCED methodology is the repeated measurement of behaviours being targeted by the intervention. Participants underwent between 3 to 4 baseline assessments to evaluate variability of swallowing function. Following this, they received the experimental treatment for three 1-hour sessions weekly for 6 weeks (i.e., treatment Phase A). Participants then observed a 4 – 6 week therapy break, dependent on the participant’s schedule, where no intervention or other speech therapy was undertaken. At this point, another therapy block (Alvar, Hahn Arkenberg, McGowan, Cheng, & Malandraki, 2021;

Daniels, Corey, Fraychinaud, DePolo, & Foundas, 2006; Martin et al., 2007; Martin, Goodyear, Gati, & Menon, 2001; Robbins, 1999; Toogood et al., 2005; Zald & Pardo, 1999)The schedule of outcome measurements, assessing both the direct effects of treatment on swallowing function and control measures of voice and speech performance, are shown in below in table 2. The primary outcome measure was participants' scores on the modified timed water swallow test, which was completed at multiple baselines before treatment, then weekly throughout treatment and again immediately following treatment as well as again four weeks following intervention (a period where no intervention was undertaken). This effectively created a treatment withdrawal scenario, where the desirable outcome was maintenance of skill rather than return to baseline.

In addition to the primary outcome measure, a number of other measures were collected less frequently at key timepoints before and after intervention phases. These included a measure of dysphagia severity using the MASA; a more generalised measure of the ability to consume oral intake via the FOIS; and a measure of laryngeal aspiration and penetration of material using the PAS based on a single pre-treatment videofluoroscopic swallow study (VFSS) and a single post-treatment VFSS.

One means of augmenting experimental control is to measure a behaviour that is not being treated alongside the treated target behaviour. In this case, phonatory function (i.e., maximum phonation time for "ah"; MPT) and speech (i.e., sequential motion rate; SMR) were measured at baseline, weekly during treatment and at the same post treatment assessment points. Speech has previously been employed as a control measure alongside dysphagia intervention (Blyth, McCabe, Madill, & Ballard, 2017). These control measures were assessed at the same frequency as the primary outcome measure, to control for any incidental learning that may result from simple exposure to the assessment task.

In addition to the formal swallowing, voice and speech measures, participants were asked to report on any potentially adverse events at any time during the study (e.g., chest infection). No adverse events were reported.

Table 2. Schedule of outcome measurements assessing the effects of treatment Phases A and B on swallow function and control measures of voice and speech performance.

	Pre-Treatment (Phase A) (Repeated Measures and Pre/Post Outcome Measures)				**Weekly Probes (Repeated Measures Only)**						**Post-Treatment (Phase A) (Repeated Measures and Pre/Post Outcome Measures)**	
Timepoint	4 weeks				6 weeks						Immediately following Tmt Phase A	4 weeks following Tmt Phase A
	BL1	BL2	BL3	BL4	Tmt1	Tmt2	Tmt3	Tmt4	Tmt5	Tmt6	Ax2	Ax3
Consent	✓											
MMSE	✓											
Outcome Measures												
VFSS (PAS)	✓											✓
MASA	✓										✓	✓
FOIS	✓										✓	✓
Repeated Measures												
mTWST	✓	✓	✓		✓	✓	✓	✓	✓	✓		
AMR and SMR	✓	✓	✓		✓	✓	✓	✓	✓	✓		
MPT	✓	✓	✓		✓	✓	✓	✓	✓	✓		

	Pre-Treatment (Phase B) (Repeated Measures and Pre/Post Outcome Measures)	**Weekly Probes (Repeated Measures Only)**						**Post-Treatment (Phase B) (Repeated Measures and Pre/Post Outcome Measures)**	
Timepoint	Immediately prior to Tmt Phase B (approx. 6 weeks following Tmt Phase A)	6 weeks						Immediately following Tmt Phase B	At least 6 months following completion of treatment
	Ax4	Tmt1	Tmt2	Tmt3	Tmt4	Tmt5	Tmt6	Ax5	Ax6
Outcome Measures									
VFSS (PAS)								✓	
MASA	✓							✓	
FOIS	✓							✓	✓
Repeated Measures									
mTWST	✓	✓	✓	✓	✓	✓	✓	✓	
AMR and SMR	✓	✓	✓	✓	✓	✓	✓	✓	
MPT	✓	✓	✓	✓	✓	✓	✓	✓	

[a] Modified From Hughes and Wiles (1996); [b] Mann (2002); [c] Crary, Mann and Grober (2005); [d] Rosenbek, Robbins, Roecker, Coyle and Wood (1996).

5.1.3 Treatment Protocol

Participants attended therapy sessions three times per week for a period of six weeks. Therapy sessions were completed either in a university speech pathology clinic or at the participant's home, according to participant preference. Author CL provided all treatment sessions. All sessions were video recorded for later analysis of fidelity (see below). Dependent on participant ability, treatment began using either no bolus or using boluses varied in size (i.e., 0, 5, 10 ml) and consistency (i.e., fluid, solid) (see table 3).

Sessions followed a Principles of Motor Learning (PML) approach (Schmidt et al., 2018), with a pre-practice component and a practice component to each session. In pre-practice, participants were trained in the use of three swallow manoeuvres: effortful swallow, Mendelsohn manoeuvre, and tongue hold manoeuvre (i.e., Masako). These manoeuvres were selected prospectively, to align with the beneficial motor learning principles of high task complexity and specificity (Schmidt et al., 2018). That is, the swallow manoeuvres involve whole movement patterns rather than partial movements and matching the actual movements required for swallowing during daily eating and drinking, albeit with some potentially enhancing modifications. When needed, training involved clinician demonstration, cueing to shape more accurate execution, and verbal and visual (i.e., mirror) feedback. Consistent with the traditional PML approach, feedback during pre-practice was high frequency and provided knowledge of performance (i.e., information about why/how a response was correct or not). Once a participant had demonstrated at least two correct productions of all three manoeuvres with maximal cueing, they transitioned into the practice part of the session. Participants required minimal pre-practice following the first session of therapy.

In the practice phase of the treatment session, participants completed consecutive swallow trials of randomly presented manoeuvres. The sequences were prepared using the random generator on MS Excel and the clinician verbally presented the target. An example is provided in table 3. This served as the treatment protocol proforma for guiding the session, for clinical documentation, and for later scoring of fidelity. If participants were practising with a bolus, then a variable bolus size (including no – bolus as one variant) was also specified. The proforma also specified whether knowledge of results feedback (i.e., indication of correct / incorrect performance only) was to be provided. A sliding scale was used throughout training with higher frequency of feedback provided in the earlier intervention sessions, and decreasing frequency as participants became more experienced and proficient (Schmidt et al., 2018). Every 10 swallows, the bolus target alternated between fluids and solids. As such, the treatment incorporated practice principles of random (i.e., order of manoeuvres) and variable (i.e., bolus parameters) target selection in an effort to promote long-term learning (Schmidt et al., 2018).

The target number of swallows per session was incrementally increased over the 6 – week period; each participant formed their own criterion – referenced benchmark to progress from throughout therapy. This progressive increase in repetitions throughout the course of therapy is consistent with principles of strength-based training.

To minimize the clinical risk of aspiration during therapy sessions, the following precautions were employed. The starting level of therapy targeted the safest consistency, where the participant did not demonstrate any overt signs of aspiration. Throughout the therapy session, if 8/10 swallows were achieved without overt signs of aspiration then a progression to the next consistency was made; however, if evidence of aspiration occurred on 3/10 swallows, then a safer consistency was selected. This stepped procedure follows previous dysphagia rehabilitation protocols (Barikroo & Lam, 2011; Carnaby-Mann & Crary, 2008)

Table 3.3. Proforma used in treatment sessions, showing an example for a participant practicing with a bolus and a participant practising without a bolus.

Session #: ___	**Participant ID: ______**				**Date: ____**
OPTION 1: With Bolus	**Feedback**	**OPTION 2: No Bolus**	**Feedback**	**Aspiration (yes/no)**	**Comments**
Effortful 5ml		Effortful 0ml	Feedback		
Effortful 0ml	Feedback	Mendelsohn 0ml	Feedback		
Masako 0ml	Feedback	Mendelsohn 0ml			
Effortful 5ml		Masako 0ml			
Effortful 5ml	Feedback	Effortful 0ml			
Mendelsohn 5ml		Effortful 0ml			
Masako 0ml	Feedback	Effortful 0ml			
Mendelsohn 10ml		Effortful 0ml			
Mendelsohn 10ml		Masako 0ml	Feedback		
Effortful 5ml	Feedback	Masako 0ml			

5.1.4 Outcome Measures

Primary outcome measure.

Timed water swallow tests are commonly used to evaluate swallow function and provide a clear benchmark for normal swallowing (Hägglund, Karlsson, & Karlsson, 2022; Hughes & Wiles, 1996; Nathadwarawala, Nicklin, & Wiles, 1992). Normative data exists for healthy adults (Hägglund et al., 2022), and strong inter-rater reliability exists measuring both healthy controls and adults with acquired neurogenic dysphagia (Hughes & Wiles, 1996). They have been utilised in single case experimental design studies in neurogenic dysphagia (Jenks & Pitts, 2019). They have some limitations in their use for people who are unable to swallow thin liquids safely (Daniels, Huckabee, & Gozdzikowska, 2019, pp. 137-138). Consequently, a modified scale was developed to capture change in swallow function, while mitigating aspiration risks and is shown in table 4.

Table 4. The modified timed water swallow test utilised in this study.

Score	**Description of Swallowing Ability**
1	Able to drink 100mls of water independently from cup without overt signs of aspiration within 1 minute
2	Able to drink 100mls of water independently from cup without overt signs of aspiration in > 1 minute
3	Able to drink 100mls of water within 1 minute without overt signs of aspiration with assistance or modifications (e.g. via spoon or adative equipment) without overt signs of aspiration
4	Overt signs of aspiration evident > 50mls (assistance/modifications as needed)
5	Overt signs of aspiration evident < 50mls (assistance/modifications as needed)

Secondary outcome measures.

Three rating scales were used to measure functional clinical swallowing outcomes.

1. The Mann Assessment of Swallowing Ability (MASA; (Mann, 2002) rates 24 behaviours related to alertness, comprehension and motor control for swallowing to generate a dysphagia severity score out of 200 (170-200 = no abnormality, 149-169 = mild, 141-148 = moderate, <141 = severe). The MASA was employed to measure dysphagia severity and aspiration risk. Mann (2002) reported excellent inter-rater reliability for the MASA for both dysphagia and aspiration and excellent internal consistency. These findings have been corroborated by (Antonios et al., 2010).
2. The Functional Oral Intake Scale (FOIS; Crary, Mann, & Grober, 2005) is a 7-point scale indicating degree of dependence on enteral feeding and oral dietary restrictions (i.e., 1 to 3 indicates dependence on enteral feeding from total to supplementary, 4 – 5 indicates total oral intake from a single tolerated consistency through no restrictions). Crary et al. (2005) reported that inter-rater reliability for the FOIS is high, with perfect agreement on 85% of ratings.

3. The Penetration Aspiration Scale (PAS; Rosenbek et al., 1996) is an 8-point scale coding incidents of penetration or aspiration of bolus during clinical videofluoroscopy swallow study (VFSS; 1 indicates no entry of material to larynx, scores from 2 - 4 indicate material enters but is ejected, 5 - 8 indicate entry to/below the folds with some/no effort to eject the material). All data were scored from the VFSS recordings by an independent experienced speech-language pathologist, blinded to time point. Rosenbek et al (1996) reported strong inter-rater reliability of the scale.

These measures were selected as distinct but complementary evaluations of functional swallowing. The MASA reports on aspiration risk and swallowing severity; the FOIS describes ability and restrictions in oral intake; and the PAS reports the presence, depth and response to aspiration events from VFSS.

Control measures.

Objective acoustic measures of voice and speech were made. These included maximum phonation time for sustained “ah” across three attempts (MPT; sec) and average syllable repetition rate across three attempts at a sequential motion task (i.e., rapidly repeating the sequence “pataka”, reported in syllables/sec). Voice and speech samples were audio-recorded at 48 kHz sampling rate and 16-bit resolution using a Marantz (Kanagawa, Japan) PMD661 solid-state recorder, with AudioTechnica (Tokyo, Japan) ATM75 cardioid headset microphone placed 5 cm from the mouth. All data were scored from audio recordings by author CL using PRAAT analysis software (Boersma, 2011).

5.1.5 Data Analysis

Group level statistics were not possible due to the sample size in this Phase I trial. No analyses of statistical significance were undertaken. Clinical measures of the modified water swallow test, MASA, FOIS, and PAS have thresholds for the amount of change needed to declare a clinically significant change. Therefore, data were evaluated for whether these published criteria were met for each participant at each phase change.

Acoustic data were graphed over time per participant, and graphs inspected for changes in level or slope of trend lines and percent of non-overlapping data across each successive phase of the study (Kratochwill et al., 2013).

5.1.6 Treatment Fidelity

Therapy sessions were video-recorded and adherence to treatment protocols was measured for 20% of the sessions by an independent rater not involved with the study. Inter-rater agreement on administration of each step in the protocol (i.e., binary yes/no decision), including steps up/down in the task hierarchy and delivery of feedback based on participant performance, was >90% for all sessions scored.

5.1.7 Reliability

Twenty percent of the modified timed water swallow tests were rescored by an independent assessor, blinded to time point of assessment. As these measures use patient videos, it was not possible to blind the assessor to participant. Inter-rater point-to-point agreement between the independent assessor and primary scorer (CL) was 100%.

All VFSS videos were rescored, using the PAS, by an independent assessor who was blinded to the participants and timeframe of assessment. Inter-rater point-to-point agreement between the independent assessor and primary scorer (CL) was > 90%.

Inter-rater reliability of the MASA and FOIS are both reported to be high so only the first author collected these measures. Similarly, control measures (i.e., MPT and SMR) were only collected and measured by the first author as previous research has indicated a single rater provides highly reliable measurements.

5.2 RESULTS

Performance for the four participants over time on the primary outcome measure of the modified timed water swallow test is shown in Figure 1. Secondary measures of MASA, FOIS and PAS are shown in Figures 2 and 3. The control measures of voice and speech are shown in Figure 4.

5.2.1 Primary outcome measure

As shown in Figure 1, participants 1 and 3 both made significant improvements in swallow function. They both transitioned from presenting with overt signs of aspiration on <50mls of water via teaspoon (i.e., score of 5) at baseline to being able to drink 100mls of water from a cup independently without overt signs of aspiration (i.e., score of 1). Both reported this effect was maintained at 6 months following treatment. Participants 2 and 4 showed an improvement from a score of 5 in baseline to 4 during treatment (i.e., being able to tolerate >50mls of thin fluids via teaspoon before overt signs of aspiration); however, both returned to their baseline level post-treatment.

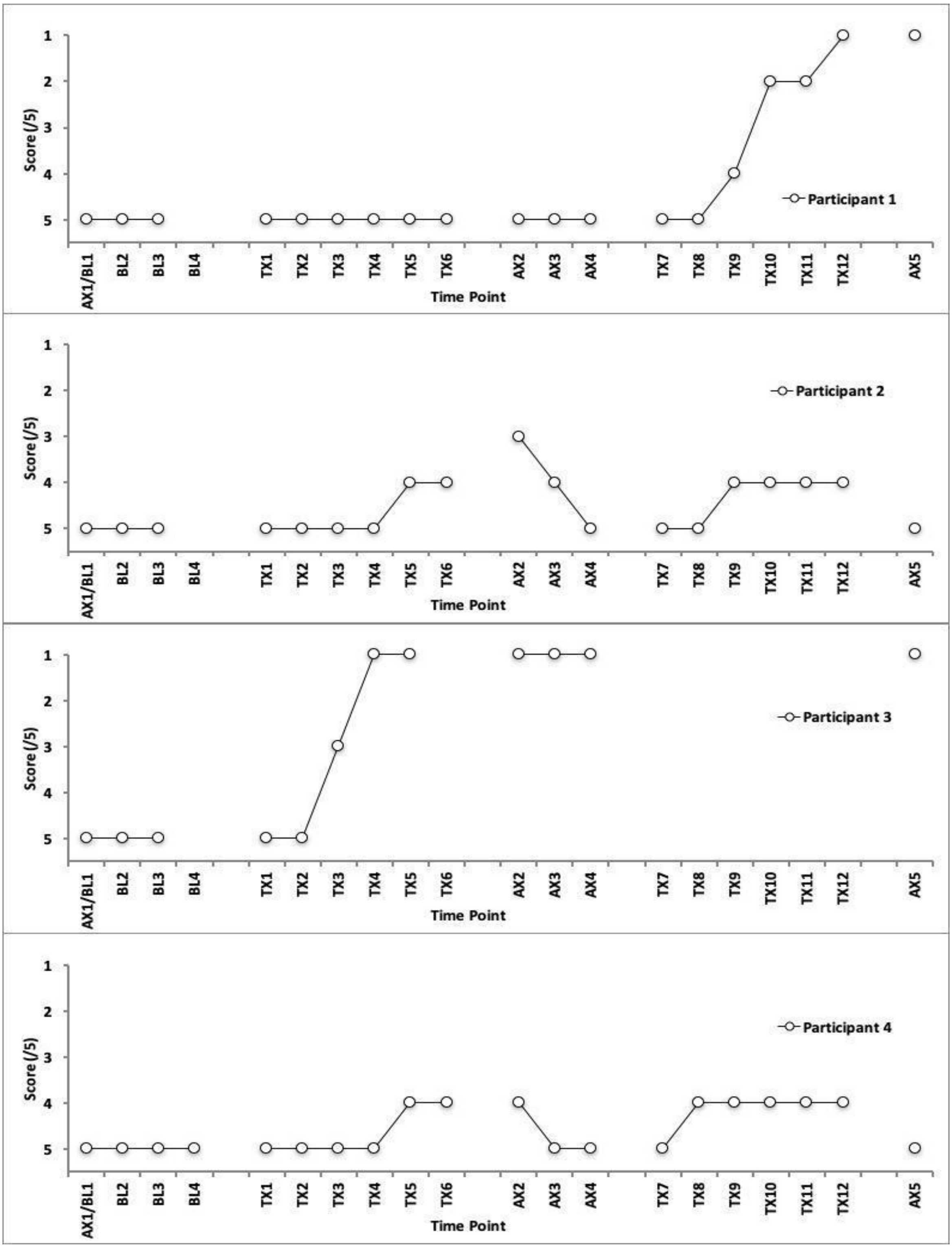


Figure 1. Performance of each participant on the primary outcome measure, the modified 100 ml timed water swallow test, across all study phases. Note that the measurement scale is reversed so that improvement (a *lower* score) is shown as a rising line. A score of 1 indicates all 100 ml was consumed independently via cup without overt signs of aspiration within 1 minute while a score f 5 indicates evidence of aspiration on <50ml via teaspoon. BL = baseline, TX = treatment probe, AX = pre- to post- treatment assessment points.

5.2.2 Secondary outcome measures

Mann Assessment of Swallowing Ability.

As shown in Figure 2 (left panel), all four participants presented with improvements on MASA scores associated with treatment. Participant 1 showed the greatest change in swallowing severity over the course of the study with pre-treatment MASA results falling in the severe dysphagia range (i.e., score of 122) and results immediately following the second treatment phase improving to the normal swallow range (i.e., score of 181). This represents an overall change of 55 points. Participant 2 made considerable progress throughout the study period, with scores shifting from the severe dysphagia range (i.e., score of 117) to the moderate dysphagia range (i.e., score of 161). This represents an overall score change of 44. Participant 3 progressed from a moderate pre-treatment score of 170 to a score within normal limits at 188; a range of 18 points. Participant 3 improved to the normal swallowing range in the least amount of time. Participant 4 made the least progress in terms of improving overall swallowing severity. Pre-treatment scores fell in the severe range (i.e., score of 129) to the moderate range (i.e., score of 145); a range of 16 points.

Functional Oral Intake Scale.

Changes to the FOIS are shown in Figure 2 (right column). At the commencement of the intervention program, all participants were receiving 100% of their nutritional intake via PEG. Participants 1, 2, and 4 were having no oral intake. Participant 3 was having spoonfuls of thickened liquids throughout the day of inconsequential nutrition. Previous research has defined clinical change as the transition from tube feeding to oral feeding (i.e., from levels 1-3 to levels 4-7) and the transition from restricted oral intake of one or two consistencies to an unlimited or minimally restricted diet (i.e., a change from levels 4-5 to levels 5-7) (McMicken, Muzzy, & Calahan, 2010).

Participants 1 and 3 showed considerable and sustained improvement on FOIS scores. They shifted 6 and 5 points, respectively, to both achieve a score of 1 by the end of the intervention program. Participant 1 required both intervention phases to make these improvements.

Participant 3 progressed more quickly and only needed a single intervention phase to achieve this. A score of 1 indicates that both were able to resume an unrestricted oral diet by the completion of the research project.

Participants 2 and 4 also improved on the FOIS measure, demonstrating an improvement of 1 point (i.e., from 7 to 6) following the completion of the first intervention block which then remained stable. Both were able to introduce small amounts of oral intake but continued to rely on PEG feeds for all their nutrition at the completion of the program. While a change of 2 or more points is considered clinically significant, the introduction of any oral intake at all having been nil-by-mouth for 36 and 18 months, respectively, is noteworthy.

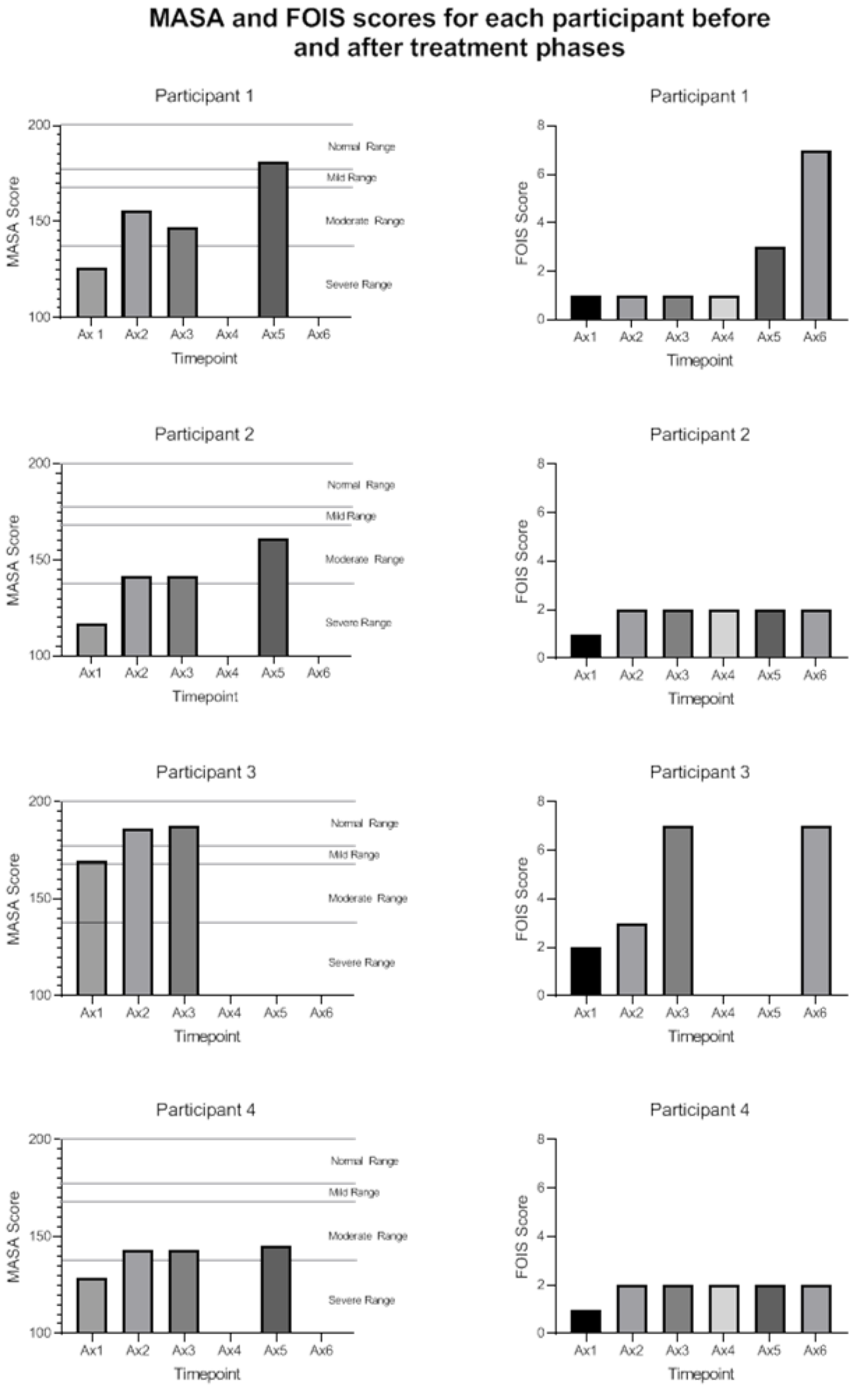


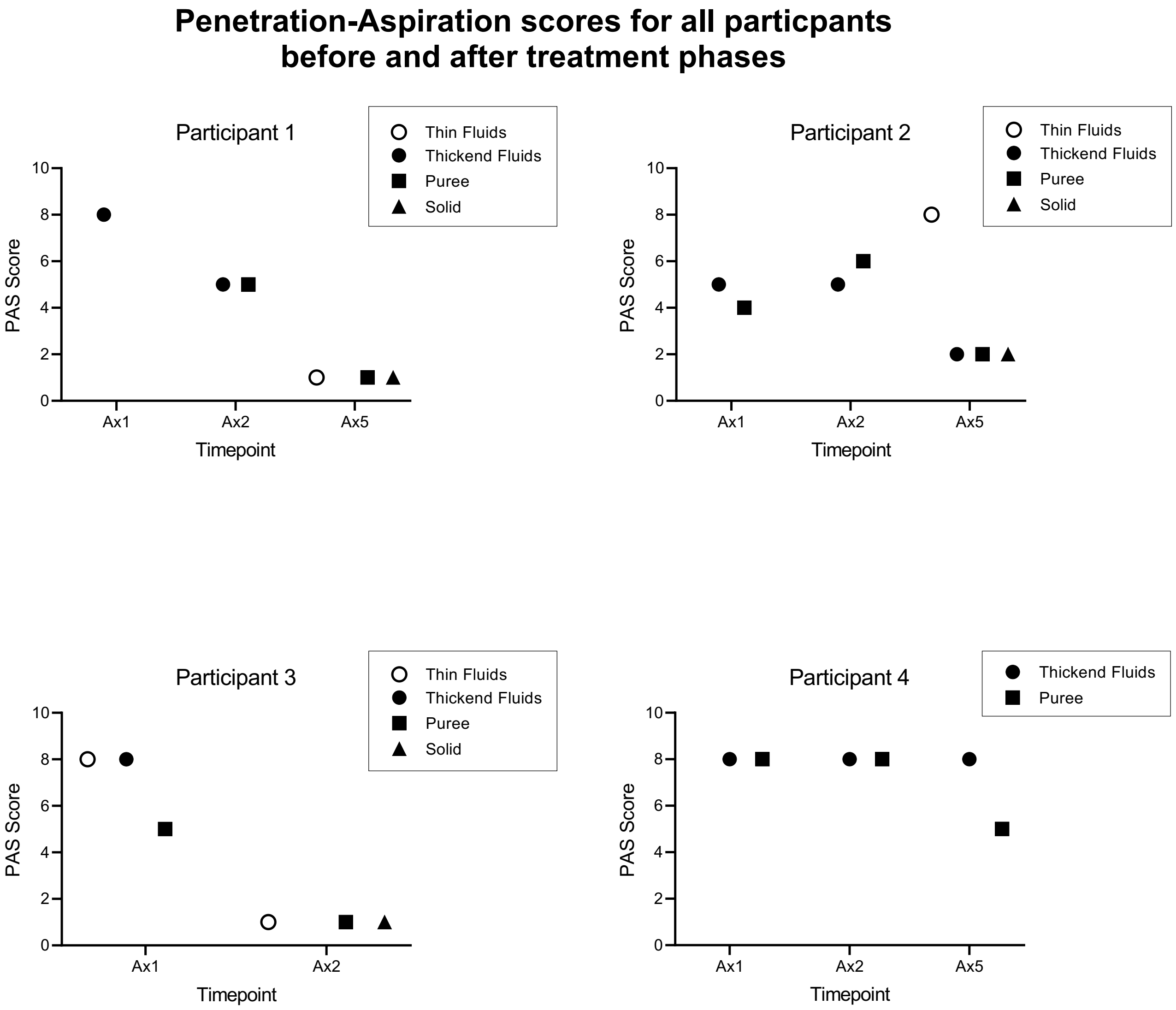
Figure 2. Scores on the MASA and the FOIS across baseline and assessment phases for each participant. Here, a *higher* score indicates better performance. AX1 = Pre-treatment / baseline, AX2 = immediately post-treatment Phase A, AX3 = immediately pre-treatment Phase B, AX4 = immediately post-treatment Phase B, AX5 = 4 weeks post-treatment Phase B.

Penetration Aspiration Scale.

Consistent with MASA and FOIS scores, participants 1 and 3 demonstrated improvements over the course of the intervention program. Initially, both scored 8 indicating deep aspiration of the bolus without a spontaneous effort to remove the bolus from the airway. For participant 1, only thickened fluids were trialled at assessment point 1 before the VFSS was terminated. Following the initial block of intervention, this individual demonstrated improvements in swallow function; however, both thickened fluids and puree both entered the airway to the level of the vocal cords, with residue remaining in the laryngeal vestibule following the completion of the swallow attempt or recording. Following the second phase of treatment, participant 1 displayed no signs of aspiration on thin fluids, puree or solids during the VFSS. Similarly, pre-treatment, participant 3 presented with deep aspiration and no attempt to remove the bolus for thin and thickened fluids. For puree consistencies, this individual presented with deep penetration; however, the bolus remained above the airway. Following a single treatment phase, there were no signs of aspiration or penetration on thin fluids, puree or solid bolus during the VFSS.

Participant 2 remained at risk of aspiration throughout the course of the treatment study, despite PAS scores indicating an improvement in swallow function following both treatment phases. This individual's score for thickened fluids maintained at level 5 (i.e., reaching the vocal folds) from pre- to post-treatment phase A, and improved further to level 2 following the treatment phase B. Status with puree was less clear, with scores indicating deeper aspiration following treatment than before treatment. Again, following treatment phase B, PAS scores reflected an improvement in swallow function and no aspiration for puree or soft solids. Deep aspiration with an ineffective clearing was observed for thin fluids at this stage. Despite overall improvements observed on the PAS, this participant remained at risk of aspiration because of significant post-swallow residue.

Lastly, participant 4 presented with deep aspiration on puree and thickened fluids both at pre-treatment and following the initial intervention phase. This individual continued to present with aspiration of thickened fluids and penetration of puree following the second treatment phase.



Penetration-Aspiration scores for all particpants before and after treatment phases

Participant 1

Participant 2

Participant 3

Participant 4

Figure 3. Scores on the PAS across pre-treatment and post-treatment assessment phases for each participant. Each participant was assessed on one thin liquid swallow and one puree swallow at each time point. Here, a *lower* score indicates better performance, with a score of 1 indicating no entry of material to the larynx and 8 indicating below the vocal folds with no effort to eject material. AX1= pre-treatment, AX2 = immediately post-treatment Phase A, AX5 = immediately post-treatment Phase B.

5.2.3 Control Measures

Data for the control measures of voice (i.e., MPT, left panel) and speech (i.e., SMR, right panel) for each participant are shown in Figure 4. Evidence for change attributed to the treatment would present as a clear change in level of performance at a phase change, and a clear change in slope of trend line across adjacent phases, and minimal percentage of overlapping data points across adjacent phases (Kratochwill et al., 2012). As seen in Figure 4, these criteria were not met for either MPT or SMR for any participant.

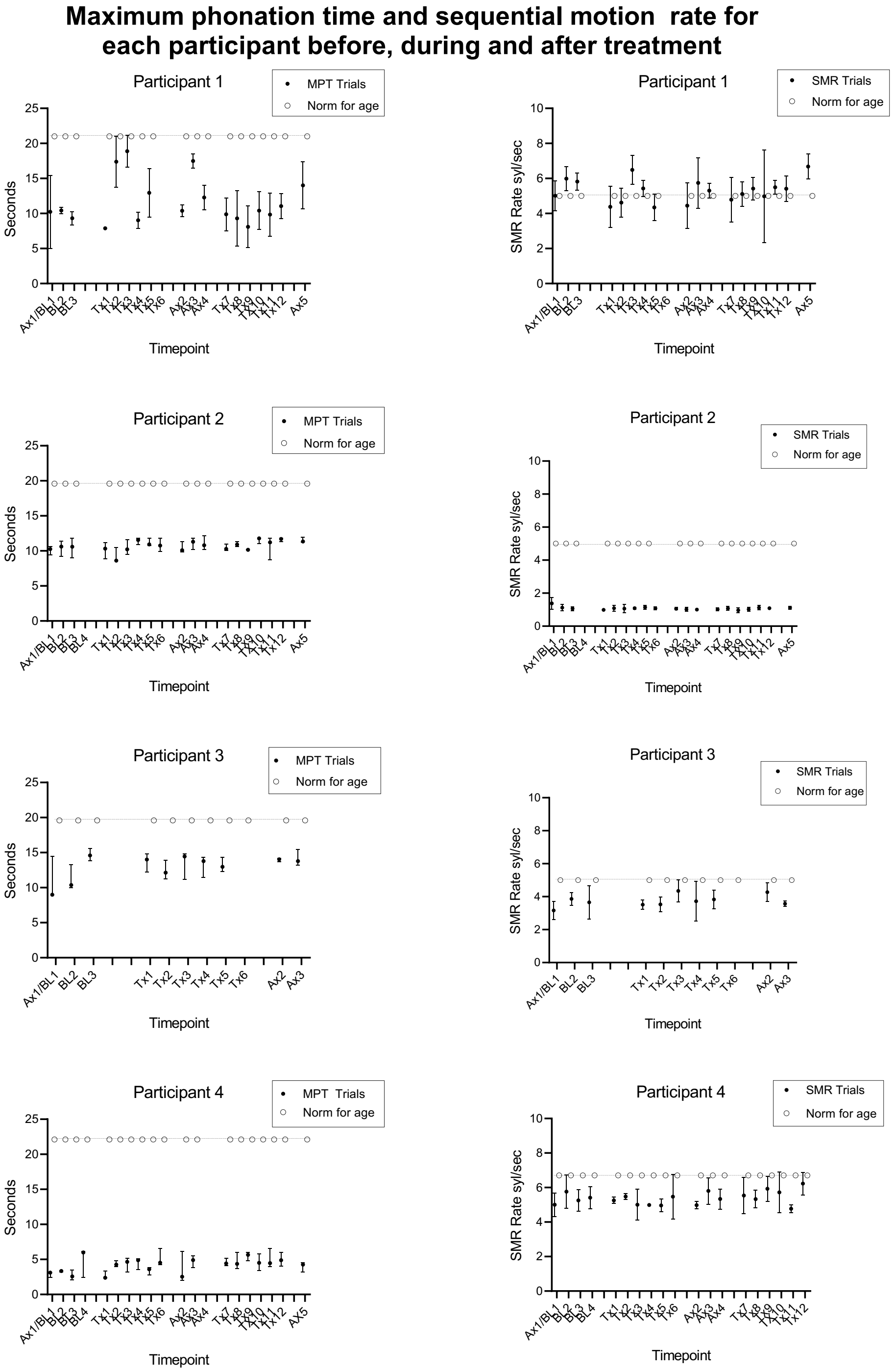


Figure 4. Data for the control measures of voice (i.e., MPT; left panel) and speech (i.e., SMR, right panel) for each participant, across all phases of the study. Data represent median (symbol) and minimum and maximum values (error bars) at each timepoint. The horizontal line shows the age-appropriate normative value.

5.3 DISCUSSION

The current study aimed to test whether four individuals with chronic PEG tube dependence post-stroke could return to some degree of oral intake by engaging in a motor-learning-based intervention program. The dysphagia intervention program was designed according to principles of motor learning, neuroplasticity and strength-based training and provided high intensity practice through the utilisation of swallowing manoeuvres.

Sessions were provided face-to-face, three times a week for one or two 6-week therapy blocks, depending on performance. Hypotheses were supported for all participants in all measures except the modified timed water swallow test. Two participants demonstrated significant improvements in swallowing function, progressing from no oral intake and full reliance on enteral feeding to an unrestricted oral diet with no reliance on supplementary nutrition. Two other participants made meaningful improvements in swallow function by introducing small amounts of restricted oral intake. These changes were maintained at the 4-week final post-treatment assessment point, Further, all participants reported maintaining these gains 6-months post-intervention. Importantly, experimental control was maintained, with the treatment for swallowing triggering no change in voice or speech maximum performance tasks. Below, we discuss the profile of performance across the different outcome measures and potential factors influencing particpants' responsiveness to this therapy approach.

5.3.1 Differences across measures of clinical swallowing ability

Findings for all four participants were relatively consistent across the primary (i.e., modified timed water swallow test) and secondary outcome measures (i.e., MASA, FOIS, and PAS). The water swallow test was effective for assessing progress of swallowing rehabilitation and concurred with the changes observed for the MASA and FOIS rating scales, as well as observation of penetration and aspiration on VFSS. The water swallow test has high clinical feasibility and appears to be a valid and reliable tool for measuring change, with others reporting that actual timing measures for this test also concur with timing measures taken from VFSS (Hägglund et al., 2022; Hughes & Wiles, 1996; Nathadwarawala et al., 1992). Links between outcome measures of the MASA and FOIS have previously been reported (Crary, Carnaby, Groher, & Helseth, 2004; Crary et al., 2005) and our study confirms these findings.

While there was concordance across most measures of swallowing function, they are clearly not completely overlapping and there is likely strong rationale for utilising such a range of measures. Despite just two participants showing a change in swallowing/intake status, all four participants demonstrated improvements on the MASA. The MASA is a broader rating scale, encompassing multiple factors pertaining to neurological status and more items describing various aspects of swallow physiology. The FOIS reports on the method and amount of oral intake. The PAS reports on aspiration-related events. These measures thus offer distinct yet complementary measures of swallow function and together provide a more complete profile to ensure that effects of treatment can be accurately interpreted.

5.3.2 Relationship between swallowing, voice and speech tasks

Here, it was hypothesized that an intervention for swallowing function would be specific to swallowing and not trigger cross-system changes in voice and speech function. Consistent with this, no participant here showed a systematic change in the voice and speech tasks associated with the treatment phases. However, the possibility of swallowing treatment effects transferring to speech and voice measures exists. This could occur as a consequence of peripheral strength improvements secondary to swallow rehabilitation, if the reason for reduced performance on voice and speech measures was muscle weakness. Results of this nature have been reported in the literature (LaGorio, Carnaby-Mann, & Crary, 2008; McFarland & Tremblay, 2006). Here, we did not predict a relationship between the swallowing tasks and the voice and speech tasks for the following reasons. First, our exercise program did not explicitly target force or control of respiratory or phonatory systems. Second, while some manoeuvres may have increased strength in the tongue through the use of effortful and sustained tongue postures and movements, these postures and movements were specific to swallowing and quite different movement trajectories and levels of force are utilised for vocalisation and speaking. It has been argued that specificity of practice is a key principle in motor learning (Schmidt et al., 2018; Zimmerman et al., 2020). It is likely the swallowing manoeuvres practised during treatment were not specific enough to transfer to speech and phonatory function. Furthermore, the maximum performance task of SMR encourages speed and precision rather than strength and so the two tasks are likely not motorically related.

5.3.3 Individual factors

Although this study reports on a small number of individuals, it allows for reflection on various factors which may influence response to treatment in this context that might be explored in future larger scale studies. Here, participants 1 and 3 made the greatest gains in treatment by transitioning from 100% PEG dependent pre-treatment to full oral intake post-treatment. Participants 2 and 4 remained tube-dependent. Participants 1 and 3 were similar in that they were both earlier post-onset (14 and 7 months, respectively, vs. 36 and 18 months for participants 2 and 4). It is possible that being earlier post-onset meant less deconditioning of the swallowing mechanism and so a quicker response to treatment. In future, studies could include instrumental measurement of strength at baseline, manipulate time post-onset, as well as explore effects of longer term strength-based interventions. Other possible factors, such as age, lesion site, or baseline performance on the outcome measures did not appear to pattern with the outcomes. However, it has been argued that subcortical strokes affecting multiple neurological regions may cause symptoms that are too severe to benefit from long term rehabilitation. Here, we have established that this may not be the case with our participants evincing medullary and/or cerebellar infarcts and severe dysphagia but still all being responsive to intervention on at least some measures. Given the psychosocial implications for individuals with dysphagia and their carers, further consideration may be warranted exploring avenues for late stage assessment and rehabilitation of swallow function.

5.3.4 Clinical feasibility

This study intentionally focused on clinically accessible and feasible outcome measures, so that clinicians might rapidly translate the approach into their practice and be already well-trained and prepared to implement sensitive outcome measures. The modified water swallow test, MASA, and FOIS are already in widespread use in clinics here in Australia and overseas. All three are easily administered and scored within a standard clinical assessment session. The PAS is also widely used, in settings with access to videofluoroscopy, and quick to score.

It has been noted, however, that delivering intensive exercise-based interventions in many clinical settings is challenging due to staff shortages and cost. While this has been handled in some fields with allied health assistants, the nature of swallowing therapy with its attendant risks of aspiration and choking, require that the therapy is delivered or supervised closely by a qualified speech-language pathologist. While the results in the current study are promising, just two of the four participants were able to transition away from PEG-dependence. This may challenge investment in such intensive interventions for two reasons. First, we cannot yet predict who will be the patients to achieve the greatest gains. Second, the cost-benefit ratio must be evaluated to determine whether reintroduction of oral intake only for pleasure (i.e., not for sustenance, as in the case of participants 2 and 4) is justifiable given the cost of an intensive intervention. That being said, the economic, health, psychosocial wellbeing, and carer burden benefits of moving a medically stable person from tube-dependence to full or part oral diet are likely profound. This will be explored, in part, in the following chapter.

5.3.5 Limitations and Future Directions

A study of this kind, with limited resources, inevitably has limitations. First and perhaps most importantly, the sample is small and heterogeneous. Larger samples will be needed to more fully explore prognostic indicators, optimal dosage, and refine selection of outcome measures. Second, no objective strength or kinematic measures are presented here to validate or corroborate the results from perceptual rating scales. This could be done in future iterations. Third, guidelines for SCEDs recommend at least three datapoints per phase (Kratochwill et al., 2012). Here, just two data points were available for some phases which challenges the reliability of analysis and conclusions from those datasets.

In terms of new directions, it would first be of value to seek the views of participants as to the tolerability and feasibility of these high intensity exercise regimes for swallowing and enlist participants in co-design to refine and tailor the rehabilitative program. Second, we have only considered one therapy approach. Further research could evaluate other approaches, manipulate dosage, and generally develop a more comprehensive mapping of therapeutic efficacy.

5.4 Conclusions

The current study explored an intensive strength-based treatment, structured using the principles of motor learning approach (Schmidt et al., 2018), to determine whether individuals with chronic PEG tube dependence post-stroke could return to some degree of oral intake. The intervention was provided three times a week over 6 weeks, with three of the four individuals participating in two six-week blocks of treatment. Two participants transitioned from 100% PEG-dependence to full oral intake and removal of the PEG tube, with these results maintained post-treatment. The other two participants were able to reintroduce some oral intake for pleasure but remained

100% PEG-dependent for nutrition. Nonetheless, all participants demonstrated clear gains in swallowing function on at least one of the outcome measures. The only patient factor aligning with outcomes was months post-onset, with the two earlier onset participants showing the greatest gains. It could be hypothesized that such intensive strength-based treatments should be initiated as early as possible to prevent deconditioning of the swallowing mechanism. Future larger-scale studies are warranted to explore prognostic indicators of treatment response, compare competing therapy approaches, manipulate dosage, and evaluate the cost-benefit ratio for this resource-intensive therapy approach.

Chapter 6. Living with Chronic Dysphagia

6.1 Chapter Overview

Stroke sequelae have broad reaching effects on stroke survivors and their caregivers. Dysphagia following stroke has significant psycho-social implications. Measurement of this impact appears to be oriented towards institutional use. This can mean that the perspectives of individuals and their caregivers can be overlooked. Qualitative research offers a valuable tool to explore the individual experience in depth. The following chapter reports data from semi-structured interviews with stroke survivors with chronic dysphagia and their caregivers. Themes from the interviews are developed, including the impact of living with dysphagia, the rehabilitation experience of individuals with dysphagia, and the perspectives of key stakeholders (namely clients and their families) receiving care via stroke pathways in Australia.

6.2 Introduction

The last 25 years has generated a corpus of literature emphasizing patient-centred outcomes (for reviews see Rosewilliam, Roskell, & Pandyan, 2011, and Yun & Choi, 2019) Quality of life (QoL) is now considered a key factor in evaluating outcomes following stroke. Most studies employ questionnaire-based surveys reporting findings from commonly used stroke outcome measures such as the National Institutes of Health Stroke Scale (NIHSS), Barthel Index (BI) and Modified Rankin Scale (mRS), which focus on functional ability. Subjective QoL is also reported from surveys including the Stroke Impact Scale (SIS) and European Quality of Life Scale (EQ-5D); but, again the items within these questionnaires are based on functional ability rather than well-being. These scales are designed to rate various modalities of neurological function across a range of contexts in order to provide a comparable index of neurological status across patients. They are typically easy to administer on a large scale and report useful benchmarking information, positioning them well to guide institutional policy decisions. Nonetheless, in a comparison of stroke scales with WHO guidelines of impairment, disability and handicap, De

Haan and colleagues concluded that "the ability of the stroke scales to explain a patient's psychosocial condition is rather poor" (De Haan, Horn, Limburg, Van Der Meulen, & Bossuyt, 1993, p. 1181).

Research reporting on dysphagia outcomes rarely provides in-depth analysis of perspectives and experiences of individuals following stroke. Several studies have pointed out incongruities between functional outcomes and personal QoL reports. In the Australian context, Sturm and colleagues reported that, despite making functional gains, stroke survivors reported lower health-related QoL outcomes two years following their stroke (Sturm et al., 2004). Other research has also indicated a disparity between functional outcomes and the perception of wellbeing (Clarke & Black, 2005). Following from this, Clarke advocates for the inclusion of qualitative methods in order to fully appreciate psychosocial perspectives of the chronic nature of stroke and its consequences (Clarke, 2009). It is clear that a more nuanced and individualized understanding of psychosocial impacts of chronic stroke related dysphagia is urgently needed.

Existing qualitative research in stroke rehabilitation has provided valuable insight into issues such as the short fallings of healthcare systems in following stroke guideline recommendations (Salisbury, Wilkie, Bulley, & Shiels, 2010) and the impact of carer burden (e.g. Danzl et al., 2013; Gallacher et al., 2013). To date, however, qualitative methods have been absent from investigations of long-term dysphagia in stroke survivors as a unique population. Research showcasing patient and family experiences of participation in dysphagia rehabilitation is also missing from the field. This chapter aims to address this gap.

6.2.1 Understanding the impact of dysphagia

Dysphagia is a common consequence of stroke. The implications of dysphagia are broad reaching and include adverse health implications including poor nutritional status (Perry & McLaren, 2004) and pulmonary complications (Martino et al., 2005). While the adverse health outcomes are serious, another obvious corollary is the psychosocial impact of dysphagia. Research has indicated that dysphagia is strongly associated with depression in elderly community dwelling individuals (Holland et al., 2011). Further, dysphagia has been linked with reduced mealtime enjoyment and social participation (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002) as well as impacting relationships with family, friends and carers (Kaatzke-McDonald, 2003). Despite these known impacts, QoL in dysphagia patients has received little dedicated attention in the literature.

Results from the few qualitative studies on the dysphagia experience are drawn from aetiologies other than stroke. One population that has been explored in-depth is people with developmental disabilities such as cerebral palsy (CP). Dysphagia is common in cerebral palsy (CP), with symptoms gradually worsening with age (Sheppard, 2002, 2006). Using interviews, Balandin and colleagues explored the evolving impact of dysphagia in 32 adults with CP who had self-reported swallowing changes within the previous two years. The interviews document the commonly occurring physical changes to feeding and swallowing abilities but emphasize the psychosocial impact of these changes on mealtimes including reduced social interaction and subsequent flow effect to relationships with family and carers. A key theme for this population was their concerns around further deterioration of swallowing ability and the implications of this for independence in the future. For many people with CP, full feeding assistance or deterioration of swallow function to the point of needing enteral nutrition marks a change in living circumstances requiring institutional placement or fulltime care. This theme of forced lifestyle change is also seen in many acquired dysphagia populations, including those with stroke, traumatic brain injury (TBI), and head and neck cancer (HNC).

A second population frequently encountering dysphagia and its related psychosocial impacts comprises individuals with HNC. It has long been clear to clinicians that individuals undergoing radiotherapy for HNC often present with long-term chronic dysphagia either lasting months to years following treatment, or recurring years following treatment. In an effort to highlight the long term and chronic nature of these swallowing difficulties, Nund and colleagues conducted semi-structured interviews exploring the everyday impact of dysphagia for 24 individuals who had recently received radiotherapy treatment for HNC, and had subsequent self-reported swallowing difficulties (Nund, Scarinci, et al., 2014a, 2014b; Nund, Ward, et al., 2014a, 2014b). Twelve carers were also included in these studies. Interestingly, the themes arising from this series closely echo the themes generated by participants with CP discussed above, and including the physical changes, emotional reactions, and personal and lifestyle impacts evoked by living with dysphagia (Nund, Ward, et al., 2014a, p. 285). These themes relating to change clearly emphasise the wide-ranging impact of dysphagia beyond the realm of eating and drinking.

In hospital settings, dysphagia caseloads span a wide array of ages and aetiologies. Within this setting, Martino and colleagues adopted a multidisciplinary investigation of the dysphagia experience (Martino, Beaton, & Diamant, 2009). In their initial study, they explored the perspectives of patients, carers, and health professionals on dysphagia care. The authors employed a constant comparison method of grounded theory analysis of data collected from six focus groups. Results indicated three consistent themes across groups: nutritional concerns, pulmonary concerns and psychosocial concerns. Although similar domains of importance were identified, individuals with dysphagia nominated psychological factors including feelings of fear, depression, embarrassment, control, frustration, vulnerability and emotional support as the most important factor relating to their dysphagia. They were least concerned about pulmonary consequences. Conversely, carers and clinicians both prioritized pulmonary consequences followed by nutritional concerns as their most salient factors relating to dysphagia. As health systems move towards more inclusive models of care provision, these perspectives are invaluable. In a second study, the authors contrasted perspectives of individuals with chronic dysphagia to those with acute dysphagia (Martino, Beaton, & Diamant, 2010). Data were collected from focus groups and participants presented with dysphagia arising from mixed aetiologies. Themes of vulnerability, depression and frustration were present in both groups. The most prevailing feeling experienced by participants with acute dysphagia was fear; whereas chronic patients felt depression and frustration most strongly. The chronic participants also discussed feelings of worry and embarrassment.

Stroke is another leading cause of acquired dysphagia. Dysphagia following stroke differs from the condition found in CP and HNC in that it has a sudden onset and its severity is typically worst in the most acute phase. Its prognosis from there is unpredictable and varies from complete resolution of all symptoms to chronic persistent dysphagia requiring reliance on enteral feeding. Understanding the unique complexities of the dysphagia experience for stroke patients presents an important key to improved rehabilitation outcomes for this large population. These perspectives have been explored in a number of recent studies (Helldén, Bergström, & Karlsson, 2018; Li et al., 2022; Moloney & Walshe, 2018).

6.2.2 Experiences of enteral nutrition

One common consequence of longstanding severe dysphagia is the necessity of enteral feeding, typically via percutaneous endoscopic gastrostomy (PEG). There is a small dedicated literature exploring the effects of enteral feeding on QoL (Bjuresater, Larsson, Athlin, & Nordstrom, 2015; Brotherton, Abbott, & Aggett, 2006; Brotherton, Abbott, Hurley, & Aggett, 2007; Brotherton & Carter, 2007; Brotherton & Hurley, 2008; Jordan, Philpin, Warring, Cheung, & Williams, 2006). Most participants in this research have acknowledged the necessity of their procedure had been life-saving (Jordan et al., 2006), yet significant impacts on daily life are evident. When considering the impact on QOL, these studies primarily fall into two distinct categories: PEG-related side effects and complications; and everyday management of enteral feeding in the community. The first category reports findings associated with the side effects and complications of having a PEG. Participants have described themes such as: the feeding regime controls daily routine (Jordan et al., 2006); and PEG reliance restricts activities outside of the home (Jordan et al., 2006). The second category primarily focuses on independent management of enteral feeding once back in the community. Here participants report themes such as it is difficult to find a place to feed (Brotherton et al., 2006); and the attitudes of others towards feeding are often negative (Brotherton et al., 2006).

These studies acknowledge the pervasive nature of the impact of having a PEG, and show how the practical difficulties associated with having a PEG cannot be separated from the psychosocial aspects of using this technology. Restrictions on activities such as travel and leisure, eating out, and celebrations have been reported (Jordan et al., 2006). Other researchers also highlight social occasions as being particularly difficult for participants and carers (Brotherton et al., 2006). Interestingly, they reported that few participants discussed missing being able to eat and drink. However, carers reported difficulties coping with this issue and often avoided eating and drinking in front of their family members who were unable to eat and drink orally. In fact, the authors reported a dichotomous theme whereby some of their participants reported feelings of relief associated with reduced pressure to consume an oral diet (Brotherton et al., 2006). In a follow up study, these researchers also found patients receiving enteral nutrition may perceive their quality of life to be higher compared with proxy ratings given by caregivers and health care professionals (Brotherton et al 2007).

There are several limitations to this current body of work. Brotherton et al (2006) noted that the direct QOL impacts of enteral nutrition are often difficult to differentiate from the impacts of causative conditions such as neurogenic disability or cancer. Even where PEG-specific QoL instruments have been used (Brotherton et al., 2006; 2007), data have predominantly been collected in the form of written or phone surveys, and reported as mostly quantitative findings. Finally many of these studies focus on practical issues pertaining to the establishment and management of PEG feeding in the community (Jordan et al 2006, Bjuresater et al 2015), rather than the holistic impacts of having a PEG on personal identity and family life.

The study described in this chapter was conducted to address gaps in the current corpus of literature. It aims to report the experiences of rehabilitation for individuals with dysphagia and their carers, providing vital insights for future rehabilitation planning and delivery. In addition, it reports the holistic impact of living with dysphagia for stroke survivors and their carers, with a focus on under-reported psychosocial consequences (Yun & Choi, 2019).

6.3 Method

Qualitative research design provides scope to explore complex phenomena in rich detail. This study adopts a qualitative, constructivist Grounded Theory Approach (Charmez 2014) to investigate long-term dysphagia experiences for stroke survivors and their families. This method provides a framework for constructing new theories with regard to complex and diverse themes (Charmaz 2014). It also allows for the acknowledgement of the researcher's values and the part they play in interpreting data and developing themes.

6.3.1 Participants

Four stroke survivors and four of their family members (n=8) consented to participate in semi-structured interviews about their experiences with dysphagia and with the rehabilitation that they had received since their stroke. Stroke survivors had sustained strokes 17-47 months earlier and, as a result, had become dependent on enteral tube feeding. They had completed an intensive research intervention with the author CL (see Chapter 5), aiming to improve swallow function and potentially reinstate oral feeding. Table 1 outlines participant characteristics in detail.

Table 1. Details of participants including stroke survivors and their family units, age, months post-onset and current level of functioning of stroke survivors.

Participant	SS age	MPO	Current presentation of SS
Emma (SS)	40	14	Independent in all ADLs; single parent of two school aged children; actively participating in community; mobilising unaided indoors and outdoors; eating and drinking without diet modification following rehabilitation program.
Ava (SS) and Liam (FM)	56	7	Independent in all ADLS; living with husband and two teenaged children; participating in rehabilitation program independently, persisting mild dysarthria and high-level language difficulties; mobilizing with aid outdoors and unaided indoors; eating and drinking without diet modification following rehabilitation program.
Sophia (SS) and Noah (FM)	56	36	Independent with all ADLS; living with husband and son's family; mobilising with aid outdoors and requiring wheelchair for long distances; continuing to work with modified duties post-stroke; severe dysarthria; 100% PEG-tube dependent for nutrition; consuming some oral diet and fluids for taste and pleasure following rehabilitation program.
Oliver (SS), Grace (FM) and William (FM)	67	17	Dependent for some ADLS; living with wife who is primary carer; mobilising with aid; severe global aphasia and apraxia of speech; relying on PEG feeding for 60% of nutrition following rehabilitation program.

Note. All names are pseudonyms. Emma, Ava, and Sophia map to participants 1, 3 and 2, respectively, in Chapter 5; Oliver received the same intervention program but was not eligible as a study participant and so was not reported in Chapter 5. SS = Stroke Survivor; MPO = Months Post-Onset; FM = Family Member; ADLs = Activities of Daily Living; PEG = Percutaneous Endoscopic Gastrostomy.

6.3.2 Data Collection

Participants were interviewed by an independent researcher (a qualified speech-language pathologist) not previously involved with any of the participants. Interviews lasted between 20-

90 minutes and followed a semi-structured interview guide. This guide was employed as a starting point for interview direction, and initially focused on their experiences of the therapy program. Probes were used to explore emerging themes put forward by participants during interviews. Additional topics explored in later interviews were informed by the range of experiences described by earlier participants (Charmaz, 2014). Four interviews were conducted in person, and a further three were completed over the phone to minimize travel, as per participant preference. For interview guidelines see appendix 1.

For participants with adequate speech intelligibility, interviews were digitally audio-recorded and transcribed verbatim by the first author or an external research assistant. One participant with severe speech impairment consented to having their interview video-recorded, and this was transcribed by the author CL to include the participant's non-verbal communication acts such as natural gestures, facial expressions, writing, and use of an alphabet board. None of the participants required any receptive language supports (e.g., pictures or simplified questions) to participate, although some participants with mild word-finding difficulty were prompted by the interviewer where necessary. Any co-constructed or unclear sentences were clarified by the interviewer using a summarizing statement (e.g., Participant: "I know ok because she here. I can try try what I eat what I eat and what I drink because she here and something problem she can help me" Interviewer: "Yes ok ok so you felt safer trying out the eating and drinking while she was here?") before moving on. These modifications to the typical qualitative interview style follow recommendations for interviews with persons with communication difficulties, as outlined by Rose and Luck (2007).

6.3.3 Data Analysis

The transcripts were open-coded by the interviewer and were co-coded by the author (CL). Each interview statement was broken down into meaningful units on a line-by-line basis generating a set of open codes; following this the open codes were examined and any discrepancies discussed until a consensus was reached. From here, focused coding was carried out to determine a number of related categorical sub-themes. Theoretical coding was done to relate main categories to the core category, and lead to an explanatory substantive theory.

Once open coding was complete, overarching themes and subthemes were formulated across the transcripts, based on the identified open-codes. This process involved comparing transcripts to identify similarities and differences within and across the participants' experiences. A card-sort technique was used to facilitate mapping in the focused-coding stage. Finally, descriptive labels were assigned to the final themes; many were developed in-vivo, reflecting participants’ own phrasing around a concept or experience.

Throughout the interviews and open-coding period, the interviewer maintained detailed memos and debriefed with the author CL about her observations. Memoing forms an important part of Constant Comparison, a hallmark analysis process in Grounded Theory research. The memos documented additional details about the interviews that could not be captured in the transcriptions, flagged surprising or conflicting findings for further probing, and were used to compare and contrast preliminary themes across participants. The memos were referred to throughout the analysis process to check and clarify the findings and to contextualise data excerpts. Table 2 illustrates the data analysis process from interview statement through coding and theme development.

Table 2. Example of data analysis

.Interview Statement	Meaning Unit (Open Code)	Sub category (Focused Code)	Category	Theme
SS: Actually the dietician at X Hospital she would a negative spin on it at X Hospital, she said, “You may not be able to eat again.”	Bad news Never eat again Negative interactions with health care professionals	Interactions with healthcare professionals can be supportive or discouraging	Poor prognosis for eating and drinking Providing information regarding potential poor outcomes Hopeful vs discouraging	Food through a tube Uncertainty A certain therapeutic approach
FM: So I said, “What are the chances of him getting his speech or his swallow back?” He said, “I’m not a religious person, I’m a science man,”	Bad news Never eat again Negative interactions with health care professionals	Interactions with healthcare professionals can be supportive or discouraging	Poor prognosis for eating and drinking Providing information regarding potential poor outcomes Hopeful vs discouraging	Food through a tube Uncertainty A certain therapeutic approach

Note. SS = stroke survivor; FM = family member.

By the end of the analysis, two distinct overarching schemas had been identified and tested against the data. The first was a consistent narrative arc that followed the therapeutic journey: starting from the time of the stroke and acute care experiences, tracking through the placement of a PEG and discharge from initial rehabilitation, and ending with the late-term rehabilitation process and reintroduction of oral nutrition.

6.4 Results

This section reports the perspectives of both stroke survivors and their family members with respect to the experience of stroke and its aftermath, especially regarding dysphagia and its implications. It begins with documentation of the experience of the stroke itself, and the uncertainty about the future that this generates. The second section reveals how study participants and their family members feel about the therapeutic experience post-stroke, both in the hospital system and as participants in an intensive community-based rehabilitation program.

Subthemes around the type of intervention, the clients themselves and the therapeutic approach are elucidated.

The majority of participants, although not directly asked, discussed the impact of the stroke on themselves and their loved ones from its onset, through the continuum of care within the hospital setting and their return to the community. This, in part, represents their narrative for discussing their stroke which is naturally described chronologically for them as well as the impact of the sudden change in circumstances in their lives.

At the time of the stroke

Family members recalled their confronting experiences during the early hours and days following their family member's stroke.

"*They took her to Gosford, flew to Royal North Shore. I was met by the team and they said oh she is fit and healthy and she is quite young we think we can do something for and I said well go for it then. She came out she had all these tubes coming she looked bloody terrible well you didn't know that that you did it and they said she had another bleed on the table*". (FM – Noah).

"*In the first three days, we had a meeting and the doctor said, "If by the third day she's not conscious, the chance of her waking up is very rare." It was just a disaster for the whole family*". (FM – Liam).

Given the gravity of the strokes within the sample the stroke survivors have very little recollection of this period.

Over time the stroke had broad reaching effects on the family and household members, Liam comments "*we've got two boys, one in uni one in high school, they were also worried about their mum. Before, when they came back, everything was looked after for them: if they wanted something to eat, food, everything. But after their mother stayed in hospital it was especially hard for everyone, they couldn't concentrate on study. At that time, one child failed two subjects because he couldn't concentrate.*" (FM – Liam).

Uncertainty

For both stroke survivors and their family members, there was a prevailing theme of *Uncertainty* following the stroke which commenced at the onset of the stroke and which continued beyond rehabilitation. For all the participants in this study, initially their survival was uncertain. Emma recalls, "*at that stage I was really – I was just fighting to survive virtually. ...I was too sick to think, very sick.*" (SS – Emma). Family members recollect the gravity of the situation *"he was very, very sick and maybe wouldn't survive, a lot of people came" (FM – William)* and *"The doctor said the recommendation was to turn it (life support) off, that she wouldn't be a contributing member of society" (FM – Noah).*

In addition to the uncertainty around survival, questions were also raised around the need for ongoing residential care. Liam describes the following interaction "*And at the second family meeting the doctor reminded us, "Although she is alive, you must get prepared that in such cases it's lucky if she stands up and walks, but most patients are sent to a nursing home, they just can't do look after themselves and must be taken care of by someone. It was a disaster." (FM – Liam).*

This uncertainty carried on through the course of their post stroke experience. Emma expressed her surprise at the uncertainty of her prognosis "*I thought I'd bounce right back.*" Their experiences of the healthcare system were uncertain "*dad was not able to go to a third party rehab facility, they wouldn't accept him in. But I don't know the full reasoning behind that.*" (FM – William). For some, their rehabilitation outcomes remained uncertain "*Now I don't know whether that will ever improve.*" (FM – Grace). Even those with improvements in swallow function expressed ongoing uncertainty in the resilience of their rehabilitation gains. Emma explains "*it's [the swallow function] never going to be like it was before, … you've always got to think about what you're opening and closing at the right time, you know what I mean*?" (SS – Emma).

A Chance to Progress

Confronted with the prospect of surviving a severe stroke, participants were keen to progress with rehabilitation. For some, this followed a standard clinical pathway; for others, rehabilitation was not freely available. William described the lack of certainty around receiving rehabilitation at all. "*Because he was so sick they didn't think that he would benefit from any further therapy at all. Like he wasn't recommended to have any speech therapy.*" (FM – William).

Sophia and Noah reported a similar challenge in accessing rehabilitation:

Noah "*She was supposed to go to [NAME] Rehab … and the guy, she was at [NAME] Nursing Home, and the bloke came in and he went, he was still at the door like this*"
Sophia "*he opened the door*" (Participant gestures opening door)
Noah "*and he stood there didn't he?*"
Sophia "*He didn't touch me at all*"
Noah "*He didn't ask her anything. And he said 'No, no, no she's not suitable',*"

The rehabilitation experience did not meet the expectations of any of the stroke survivors or their family members. The participants described a range of obstacles hindering their progress including risk aversity, therapist capacity and a lack of resources allocated to dysphagia rehabilitation and more generally long-term stroke rehabilitation.

Therapist Capacity: Time and Expertise

All the participants who received rehabilitation within the hospital system alluded to systemic constraints on the therapists providing services: "…*she* [hospital speech pathologist] *was a bit rushed, she had already had too much on her plate, so to speak. In the public system they're always too busy, they have no time to explain it properly, she only had five minutes with me, whereas a Speech Pathologist needs at least an hour each consult for a new stroke patient to discuss what can be done. … I had just arrived at [the Hospital] and I had no idea who was going to look after me, and five minutes with me and that was it and it was only for two or three visits and then I became an outpatient.…*" (SS – Emma). Ava (SS) was sympathetic to the time-constraints placed on hospital therapists, but felt this stifled their ability to provide adequate services. "*Huge job because now government hospital, because no budget no money for speech pathologists.*

…Whole hospital only one [speech pathologist]: oh my god, it's very busy for her! Yes….Sometimes there she have good idea but you know, too many patients - you can't do it." William (FM) also declared "*There were speech therapists there, but they had limited resources at the time.*" But, he emphasised the importance of taking the time needed: "*…in a hospital environment it's hard for people to give that time, but at the same time it's so important because it's someone's life you're dealing with"*

Moreover, participants had been disappointed by the lack of actual intervention they had received during their rehabilitation course. Emma (SS) expressed dissatisfaction with being given strengthening exercises she wasn't able to do and not having the access to the therapist to adjust her rehabilitation plan: "*the Masako was the hardest exercise, I could manage only five minutes of Masako, and I didn't do the Masako, it was too hard… it's an impossibility.*" She continued *"that's when I said we had to change the Speech Pathologist, because she didn't give me any other strategies, so we had to look around for a private Speech Pathologist."* Ava also pointed out the difference between hospital and home-based therapy: "*Hospital many patients … too many people. … Go home different, like here (at home) …you can half hour, one hour, two hour doesn't matter - in hospital you can't do it that way"* (SS – Ava).

William (FM) suspected that intensive dysphagia rehabilitation was not an "approved" intervention option within the hospital setting because of a lack in available evidence: "*it's hard to get approval for something like that if it's not ever explained… And it must be hard for therapists who in their personal opinion, feel that person would benefit, but they don't have the evidence to back it up.*" Meanwhile, Emma (SS) saw a responsibility for researchers to advocate for intensive dysphagia rehabilitation from within the speech pathology profession itself: "*You have to give them [speech pathologists] encouragement to do what you guys are doing [in the dysphagia rehabilitation research]. … Show it to them so they see it works, with the right tools to do it with.*"

Three of the four families commented on the challenge, yet importance, of finding a speech pathologist with specialist skills in post-stroke dysphagia rehabilitation: "*They have to know exactly what they're dealing with. Now that girl at [hospital], as much as she meant well, I don't think she knew what* *she was dealing with. She had no idea."* (SS – Emma). She went on to say "*If it wasn't for [speech pathologist] I tell you I wouldn't be able to do this right now, … I would be still running around looking for a Speech Therapist that could help me. If I didn't find them I would have been stuffed*". Grace (FM) reported similar concerns: "*I don't think [the hospital] even has someone who specialises in the actual swallowing therapy which is what I felt Oliver needed."*

A risk averse system

William (FM) was further frustrated at the emphasis on 'swallow tests' and the lack of intervention for swallowing as well as communication more broadly: "*there need to be speech therapists, actually communication speech therapists in all public hospitals, not just like focused on swallow tests, because that seems to be the focus.*" Continuing 'failure' of these tests necessitated PEG placement. For some participants, PEG placement felt as though future rehabilitation focused on returning to an oral diet was disregarded. Liam (FM) recalls "*So before she transferred to* [the rehabilitation hospital] *she was tested again and then she went to* [that hospital] *and that all stopped, you couldn't feed her, she wasn't feeding.*" Grace (FM) felt *"Once they've got the PEG they sort of put them on the back burner and almost write them off."* William (FM) pointed out that Oliver's (SS) prognosis seemed to preclude a referral to ongoing rehabilitation. "*we didn't get much* [rehabilitation] *in the public hospital, and then it* (further rehabilitation) *wasn't recommended."*

The interplay of rehabilitating swallowing while mediating the risks of aspiration was a common theme across the participants. A combination of mitigating aspiration risk, focusing on swallowing assessment rather than therapy, and a reduced capacity to provide regular meaningful contact culminated in the perception that therapists within the hospital were 'too conservative' and 'too busy'.

Liam (FM) explains "*I think in [hospital] they were too conservative because they were worried about infection.*" He expressed his concerns about the trade-off between minimizing the aspiration risk and still ensuring enough rehabilitation takes place to make progress: "*always to be very careful. At* *that time you're still too careful, but you have to try. If you're not trying, the function will die. But the speech pathologist there was very strict.*" He went on to point out "*I had the time but I was not allowed to do it. But the speech pathologist was busy with no time and every day - one time she said okay, two times, okay; but sometimes she was busy and didn't come to the hospital and they didn't allow us to do anything.*" And finally, he reflects "*if we still had a conservative speech pathologist from the hospital, perhaps she would never have been able to eat again.*"

These sentiments encapsulate the challenge faced by clinicians managing the dysphagia rehabilitation patients: the right balance of delivering a therapy program that offers the chance to progress, or the knowledge that even with the best intervention progress will be limited; and managing the safety risks within a highly risk averse health system.

Where to from here? Finding the right therapy options

When stroke survivors were released from hospital, they began to look for other rehabilitation options. This often required stroke survivors or their family members to actively research and seek out specialists with little assistance. They did this via a range of pathways, including internet searches, word-of-mouth from other therapists, and connecting with university research projects or clinics.

At the point where further rehabilitation from the hospital was declined, Grace (FM) describes feeling let down at the lack of support to pursue other avenues of rehabilitation. "*it was through William's research that we actually found Freya and the study, or found the study. So it was through his looking and searching. I don't think we got a lot of help from the hospital in that respect.*" William (FM) backed this up saying "*they didn't say we should go and hire a speech therapist, or we should investigate that further…"* Emma (SS) also reported hurdles with this process, only finding someone with the expertise she needed after seeing three separate private therapists. She explained the difficulty: *"In the public system it's really hard to get anywhere and you do get lost in it, whereas the private system – with the private system it's a bit of pot luck, you know what I mean, you've got to know who to go to, who is more qualified, and* *you've got to have a lot more contacts who know who to get results from…My sister found [speech pathologist] she researched her on the internet; you have to do a lot of research to find the right person."*

Accessing services as an out-patient often involved a lot of time and travel. William (FM) commented that *"Even though I was willing to travel and take dad [to the rehabilitation program] every day, it was too hard for him… it would be an hour each way, plus the therapy, and he was already doing – I don't know what else. But I think that would have made it impossible … it would be a shame that people are missing out because they can't travel."*

For others, travelling was part of the support they provided, Sophia (SS) and Noah (FM) travelled over ninety minutes each way to attend therapy sessions.

> *Charlotte (Interviewer): Can you tell me how you found the intensity because they need that you've been coming three days a week? And travelling here to do that. How have you found that?*
>
> *Sophia (SS): Okay …I read in the car and I do puzzles. … It is Noah that has to drive [laughing].*

The four participants had all received the intensive rehabilitation program described in Chapter 5. Two of the participants (Oliver and Ava) received intensive intervention at home and were grateful for this opportunity. For Oliver, the lack of travel was more of a necessity than a convenience due to his fatigue. However, Ava pointed out some secondary benefits of home-based intervention including privacy and confidence: "*At the hospital you worry sometimes about someone laughing at you …but at home doesn't matter. Only she* [therapist] *and me and talking… nobody worry about it, nobody laughing at me*".

A certain type of therapy; patient; approach

One common message shared by all participants was the importance of having ongoing access to structured rehabilitation and the benefit of having a clinician available to support therapy.

Sophia (SS) having never received formal rehabilitation in the period following her stroke; but felt grateful for the guidance she received during the intensive rehabilitation program.

> *Charlotte (interviewer): Has being part of this program changed the way you feel about yourself? Did you know what you could achieve before?*
>
> *Sophia (SS): I knew. But without someone like Freya I didn't know what to do.'*

Emma (SS) also benefited from someone to guide her therapy: "*The first six weeks I was with Freya it was just exercises, so the second block of six weeks we started with food.*" She describes what it was like recommencing oral intake after two hospital admissions for aspiration pneumonia since her stroke, "*In the initial stages, the very first one, when the oesophagus wasn't reacting, opening and closing at the right times, there was a bit of a concern, but I had hope that I would regulate it; it comes with regulation and practise. Freya said to me, "It will come with practise," and it did.*"

William (FM) emphasized, the role of the therapist in maximizing therapy potential, "*Whereas dad might do a certain number of repetitions with me, when he was with Freya, he could do more, and he could do it faster, so you could see he was improving from week to week.*"

As Liam (FM) illustrated, maintaining and adapting home practice could be intimidating: "…*it's lucky we have Freya to help my wife practise at home and to get into a daily routine of how to do it. Because practise is very hard for my wife.*" Liam felt that the face-to-face nature of the current treatment program was particularly valuable. "…*if you do it by yourself and it's not according to the rules, or sometimes you feel lazy and then you stop practising. If someone supervises, it's good for her.*" He also felt that it was important to have clear "practice rules" for patients and their families to follow on their own.

During their hospital admissions, participants had been made aware of the importance of practice but felt practice opportunities were not capitalized on. Liam (FM) highlighted the challenge for patients who are not yet ready to commence independent feeding trials in settings where the therapist has limited availability: *"Because the speech pathologist didn't have time to feed; we had the time to go every day to practice but they were worried about her choking."*

William (FM) also expressed concerns about the reduced amount of practice: "*I think I read that it was really important to do exercises early on."* He commented on the under-utilisation of family members, encouraging SLPs to "*involve the family more, and make them be allies. Like try and include them in the therapy sessions, because especially in the early stages, only so many – like it's hard for a stroke survivor to coordinate all the exercises themselves. So if they can teach the family to do some of the less technically difficult exercises, ones which actually improve their strength in between sessions. From what I've read in the research, trained family members for exercise can be as effective as a therapist. So that's a whole resource – and if you can empower the family it's like it gives them – if they think they're actually doing something really worthwhile, it will improve their – I don't know how to say that. It gives them something to do, and they feel that they're helping as well."*

In contrast, Ava (SS) expressed that there is a limit to how much the family can do, but also pointed out the benefits of achieving rehabilitation goals independently: *"Because they (your family) very very busy you can't ask them help you what to do very hard plus stronger by yourself."* Emma (SS) reported similar sentiments of empowerment and personal growth: *"my children have seen me improve and I think I personally am stronger for it."*

A certain type of patient

Having a chance to re-explore the possibilities of eating and drinking was highly valued by all of the stoke survivors and/or their family members. The participants who completed the intensive rehabilitation program were self-selecting and, therefore, represent a certain type of patient. The majority of these stroke survivors had high motivation and were resolute about achieving their rehabilitation goals. This was reflected in the descriptions of participants themselves and by their family members.

Sophia (SS) stated with determinism: *"I would like my life back and will not be happy until I have."* Emma (SS) expressed a similar attitude toward her progress: *"I'll get there eventually. I'm very determined, aren't I?* Liam (FM) describes Ava's (SS) strong motivation to eat again: "*she's brave but she was eager, she wanted to eat by herself, like her coffee in the morning; she was used to having coffee but couldn't have a coffee."*

Emma (SS) reported that she "*loved the challenge*" of the intervention programme. Similarly, William (FM) described his perspective of his father undertaking rehabilitation: *"I think he really enjoyed it. You could see him, he would occasionally get tired, but he would always do the maximum he could."* Lastly, Noah (FM) put his point of view forward*: "Sophia is one of those girls that loves that… just loves to be pushed. She is a dynamic woman."*

As key stakeholders in the stroke pathway, these perspectives are important for clinicians to hear to promote clinical excellence within this domain. This dedication and determinism can be a powerful predictor of rehabilitation effort. For therapists working within this field, supporting intervention for these clients is essential.

A certain therapeutic approach

As noted above, the participants had completed an intensive rehabilitation program. The program itself aimed to be person-centered and involved working one-on-one with the speech pathologist three times a week for 6 – 12 weeks. As such, a strong therapeutic alliance was established, and these aspects of the program appeared to support participation in therapy.

William (FM) describes this perspective: "Freya had a very good rapport with him, and would get him to do things that I couldn't get him to do, like I tried to. But Freya had a way of making things happen that we hadn't seen before. And getting him to do things encouraged him to do things more… So you could see that, and I think that – So the question was about how did he feel? He enjoyed it. Like he was a sportsman all his life, and I think Freya kind of tapped into that."

Trust and confidence have been identified as positive aspects of the therapeutic relationship that also support participation and promote positive outcomes. Trust seems especially salient in the context of dysphagia rehabilitation where people have had negative experiences and adverse health consequences as the result of eating and drinking since their stroke. All the participants described their trust in the therapeutic relationship and its importance at the point of introducing new food.

Grace (FM) suggested, *"I think he felt more confident with someone with a bit of experience."*

Emma (SS) highlighted the value of trust in the therapeutic relationship for her:

Emma (SS): I trusted her implicitly.

Charlotte (Interviewer): Was that an important thing, to be able to trust her?

Emma: Very important.

Sophia also commented on this therapeutic alliance:

Sophia (SS): Freya is very brave (laughing).

Charlotte (Interviewer): Why is she brave Sophia?

Sophia): She lets me try anything.

Charlotte: How do you feel about that?

Sophia: I like it (participant makes thumbs up sign).

Charlotte: Do you ever worry about trying new things?

Sophia: No never no no.

Ava (SS) and Liam (FM) also commented on the need for trust in the therapeutic relationship:

Charlotte: Do you ever worry about her choking [during therapy?]

Liam (FM): No, because the speech pathologist knows and has experience.

Ava (SS): "I know ok because she here. I can try try what I eat what I eat and what I drink because she here and something problem she can help me."

It appears that the strength-based therapeutic approach instilled hope and optimism, which was valuable to therapeutic engagement and outcomes. William (FM) reflects: *"she gave him a chance when other people were maybe not so positive about the potential for improvement, whereas she actually was quite positive from the start".*

In contrast, participants reacted unfavourably towards healthcare professionals who they perceived as discouraging. Emma (SS) reflected on her experience early in her rehabilitation admission "*Actually the dietitian at [Rehab Hospital] she put a negative spin on it… she said, 'You may not be able to eat again'.*" William (FM) described his frustration with the lack of clarity and explanation in discussing his father's prognosis. "*I said, "What are the chances of him getting his speech or his swallow back?" He* [doctor] *said, "I'm not a religious person, I'm a science man," something like that. … Like he's made his judgement based on whatever the scientific model is, and that's it.*"

Providing clinical information is a challenging aspect of any health professional role; however, it is clear that the language used and manner of delivery when providing information warrants consideration.

Shifting Identities

During data analysis, two overarching schemas were identified. In what follows, the second schema, Shifting Identities is discussed. This schema captures transitions between oral and enteral nutrition and, for some, returning to oral intake again and the associated shift in identity and responsibility.

Food through a tube

Participants in this study all presented with severe dysphagia. Not surprisingly participants discussed the consequent changes to the mode of nutrition. Early tube feeding experiences had been traumatic and intrusive for some. Oliver's (SS) family reported their initial reactions to him requiring non-oral nutrition in the acute phase following his stroke. William (FM) described early attempts at non-oral nutrition: "*They first tried a NGT (nasogastric tube), they didn't place it properly and he was very uncomfortable, so he pulled it out.*" Grace (FM) remembered, "*He* [Oliver] *used to pull it out and all sorts… it must have been dreadful.*"

For the stroke survivors undergoing the intensive rehabilitation program, the insertion of a PEG had been a necessary intervention for sustaining nutrition in the context of their severe dysphagia. In response to requiring long term enteral nutrition, some participants appeared to perceive the PEG as an affliction. Sophia (SS) stated: "*I have a PEG and have [BRAND NAME] as nutrient. I hate the PEG and would dearly like to get rid of it.*" Those who were able to have it removed spoke of being liberated from it and highlighted other aspects of their life that had been impacted by having a PEG. Emma (SS) explains "*I got my PEG out this year in April, so I've got rid of that, so in summertime I can go for a swim.*"

In addition to describing their reactions to the presence of the tube, participants also described their feelings about being unable to eat:

Sophia (SS): *I hate the PEG* (participant pointing to tube in her stomach).

Charlotte (Interviewer): *You hated it?*

Sophia: *I hate it.*

Charlotte: *Why did you hate it? Can you tell me some of the reasons that you really didn't like* *it?*

Sophia: *Because I could not eat.*

Charlotte: *So it was more the fact that you weren't able to eat rather than the fact of necessarily having the PEG?*

Sophia: *Yeah yeah.*

Liam (FM) described Ava's (SS) reaction: "*And her mood was not so good in hospital because when she wakes up, before this, every morning she had a coffee, and she'd say, 'Oh, I want coffee' but she's not allowed to drink. Actually, she couldn't drink, when she drank she began choking. So she felt very sad.*" Liam also described the reaction of the family: "*At that time [insertion of the PEG] we felt very sad that in the future she couldn't eat, for her whole life.*"

Emma (SS) described her family's reaction to the news that she would need long term enteral nutrition and may not return to 'normal' eating and drinking: "*Well my parents heard it and they were not happy to hear it.*" She also commented on her delight at returning to eating or drinking for the first time: *"That was really wonderful, I enjoyed it. …She also gave me tea, I used to drink tea by the bucketful before the stroke, and the first cup of tea was the best …"*

Despite global dislike for PEG feeding amongst the participants and their families, several acknowledged the trade-off between the PEG and its advantages for nutrition and health: "*Because PEG feeding automatically goes down it's 100% nutrition… I try to get her to eat more, but she can't eat more, that's why [she was losing weight without the PEG]*" (FM – Liam).

Providers and Sharers of meals

Not only did the participants react to requiring enteral nutrition but all discussed the consequential impact on mealtimes and social implications. In turn, this altered their roles and identities. In addition to changes around receiving food, dysphagia also altered the identity of the stroke survivors as both providers and sharers of food and drink.

The experience of dysphagia modified participants' views on the psychosocial aspects of eating and drinking. As Sophia (SS) illustrated: "*I no longer have family mealtimes and meals are taken purely to provide substance."* Participants contrasted the sterile experience of enteral nutrition against the human pleasures of eating and drinking: *"…through the PEG there's no taste, nothing; life is uninteresting."* (FM – Liam). The presence of dysphagia also caused dramatic changes to mealtime routines at home and in the community. For example, Liam described an early frustration for his wife Ava (SS): *"Before [the stroke], every morning she had a coffee, and she'd say "oh I want coffee" but she's not allowed to drink. Actually, she couldn't drink; when she drank she began choking."*

Disruptions in mealtime routines had also changed the nature of relationships within the family, particularly concerning the role of food as a means of nurturing or as an expression of love. William (FM) described the impact of his father's dysphagia on his parents' relationship, and their roles within the home: *"It was very hard for [mum] to relate to him and he couldn't eat and enjoy his meal…I think it was such an important part of their relationship because she was the one who always cooked for him I think that was what she really contributed."* Emma (SS) also talked about her family's relationship with food, and its role in the healing process: "*when I returned home the social aspect of eating, say with my family, because I had two young boys, they found it strange I wasn't eating to repair; do you know what I mean?"*. Emma described her parents' relief when she was able to eat her father's ravioli for the first time following her stroke: *"…both my parents are great cooks, and they were so pleased, they were really over the moon"*.

For two families, rebuilding regular mealtime rituals in the absence of eating and drinking had allowed for social connection. William (FM) remembered: *"I know that I used to joke around with him [Dad] and we would go up to the coffee shop together, I would get a milk shake, and I would get him a hot cup, like just the cup with nothing in it, and we would pretend we were having a tea together. And he loved that, like he would joke around … people said, "Don't eat in front of him," you know, that sort of thing. But I actually – I think he liked going up with me to the café and pretending to eat."*

Emma (SS) continued to participate in family meals as well: *"Even though I couldn't eat I used to sit with them [my sons] and they used to eat their meal and I used to eat through the PEG."*

Nonetheless, the mechanics of PEG feeding and the challenges of a restricted diet often imposed restrictions on social mealtimes, especially out in the community. Even though Oliver (SS) had regained some eating ability, his wife Grace (FM) commented on the difficulties of eating out in public: *"… it's rather awkward as well for him to eat. So everything needs to be chopped up and it can be difficult to go to a restaurant. Yes. So you are confined to home with trying to introduce the food."*

During her interview, Sophia (SS) described devastating consequences of the dysphagia for her social life post-stroke: *"I don't have any friends now… because of eating and drinking. … they have flown."* Later she explained via email: "*I no longer have a social life as most events happen around food. I don't even go to local towns as I used to go for a coffee or ice-cream. …Friends no longer invite us round for food of any description and we used to have regular invites for morning teas, BBQ's and dinner."* Sophia commented: *"I no longer respect them".* In contrast when social networks were supportive, a return-to-eating could be a catalyst for renewed social connection. For Ava (SS), cafe trips provided a good opportunity to interact with her friends: "*…usually [when] they go out with me they know what I can do what I can't do*", while Emma (SS) had recently started going out more as well: "*since I've been eating, my sister's been taking me out to cafes to eat as well.*" Looking to the future, Sophia (SS) hoped that her ongoing improvements in eating and drinking would open up new opportunities for dining out with her husband Noah:

Sophia (SS):	*And we can go out.*
Charlotte (Interviewer):	*The two of you together?*
Sophia:	*For coffee and ice cream pParticipant gesturing drinking from a cup].*
Noah:	*You have ice cream now.*

Sophia: *Not out.*

Noah: *Not out.*

Identity shifts

The impact of having a PEG created a shift in identity for many of the stroke survivors. Sophia (SS) viewed the PEG as a threat to her physical identity as a woman. In her interview, she mused: "*I think I can get the PEG out… and then I will feel more like a woman"*. Later by email she elaborated: "*My swallowing problem has impacted on my relationship as I do not see myself as being sexy being fed by the PEG.*" Looking to the future, Ava's husband Liam (FM) felt their young children had also anticipated a return to normalcy with the removal of Ava's PEG. *"… 'Oh, Mum soon will become normal: she can eat and drink and is getting stronger' - and it's good for the family, good for the kids."*

The effects of stroke profoundly affected the relationship a person had with their broader community. William (FM) described the initial concern, and then later discomfort, that people showed in response to his father's disability. "…*when he was very, very sick and maybe wouldn't survive, a lot of people came…There was a mixed reaction, because dad was … a leader in the community. … he was really influential for a lot of people.*"

Returning to health often enabled a welcome reclamation of the survivor's previous roles. As Emma (SS) regained strength and skills, she enjoyed returning to her nurturing role, of which food played an integral part: "*Here* [at home] *I used to cook even while I was not eating. …I didn't mind cooking for anyone else, I used to cook for my two boys."* William (FM) also spoke of his father's gradual return to the role of provider, and the importance this played in restoring their father-son dynamics: "*he took me up … to the café right next to where his office used to be, and then somehow pulled out $50 and bought me and my girlfriend a cup of coffee. … I did cry, because that was a really emotional thing. … after that time, he would actually take me to a restaurant and buy me dinner.*" He also reported how valuable it was for his father to have continuing involvement at community social events: "…*he's* *a life member at the cricket club, and he had a special place where he sat and watched everyone have their afternoon tea.*"

Adjusting to roles and responsibilities as caregivers

The impact of the stroke had significant consequences on caregivers and family members. Liam (FM) stated, *"I couldn't work, I had to just stay home to look after the two kids and go to the hospital to look after my wife."*

William (FM) experienced a similar impact*: "I stopped studying, I just stopped going to one subject, but I just spent a lot of time with him, maybe ten hours a day on average."*

Noah (FM) described the impact the stroke had on Sophia and Noah's family business. "*And when this happened to Sophia, … I said 'I'll have to sell, the business, the house, the cars, everything…I can't run it.*"

All but one of the stroke survivors in this study were independent with their own PEG feeding. None of the participants commented on any inconvenience or complications associated with PEG feeding. On the other hand, returning to an oral diet was not without its challenges. Mealtimes often required more planning and effort to prepare meals with modified textures. Grace (FM) describes a typical daily routine and the difficulties she encounters with meal preparation:

> *"it's still very hard to find food that he can actually eat. Like he's still only having very small amounts. Like tonight, I've cooked a baked leg of lamb… I cut myself off a meal ... So tomorrow at lunchtime, which I find is an easier time for him when he's more alert and I've got the time to sort of sit and be with him while he can eat a small amount. …I find that he gets very tired easily. That's why I choose lunchtime as a good time to sort of try him on the normal meals."*

Grace goes on to discuss the challenge of eating out as a result of being on a texture modified diet: "*I suppose really, still being probably not able, really to go out and have that type of food, I think it's probably difficult. But I think that's also probably affected by him being unable to use his right hand, so he's only got his left to use, so it's rather awkward as well for him to eat. So everything needs to be chopped up and it can be difficult to go to a restaurant. Yes. So you are confined to home with trying to introduce the food. Now I don't know whether that will ever improve.*"

6.5 Discussion

Through semi-structured interviews with stroke survivors and their family members, two schemas emerged encompassing the therapeutic journey and shifting identities. The therapeutic journey is discussed in three sections: (1) uncertainty, a predominant theme throughout the participants' experience from stroke onset to their present circumstances; (2) on the stroke pathway, describing the therapeutic experience within and beyond formal care settings; and (3) A certain type of therapy; patient; approach. Shifting identities is discussed in four sections: (1) food through a tube, (2) providers and sharers of meals, (3) identify shifts and (4) adjusting to roles and responsibilities as caregivers.

6.5.1 Schema 1: The Therapeutic Journey

1 Uncertainty

The theme of "Uncertainty" prevailed throughout the stroke experience. For all of the stroke survivors in this study, initially their survival was uncertain; their prognosis was uncertain; their experiences of the healthcare system were full of uncertainty; and for some their rehabilitation outcomes remain uncertain. The theme of uncertainty, distinguishes this cohort from research exploring other populations with dysphagia. Balandin et al. (2009) reported on chronic swallowing difficulties in people with cerebral palsy. Similarly, the lived experience of dysphagia has been explored in the head and neck cancer population (Nund et al., 2014). In both these conditions, dysphagia tracks along a relatively predictable course. The sudden onset of dysphagia in stroke compared with the gradual progression of dysphagia in cerebral palsy or prophylactic enteral tube placement seen in head and neck cancer differentiates the perspectives between these groups.

While stroke differs in aetiology from other conditions that lead to dysphagia, the results from this study echo many of the same sentiments about the lived dysphagia experience. Nund et al. (2014) reported themes of 'physical changes related to swallowing' and 'altered perceptions and changes in appreciation of food'. Balandin et al. (2009) reported similar themes of 'awareness of changes in mealtime capabilities and experiences' and the impact of these changes including reduced social interactions, loss of independence and other health concerns. In both the studies by Martino and colleagues (2009, 2010) the psychosocial implications of dysphagia were accentuated. Findings from these earlier studies are echoed by more recent studies within the stroke rehabilitation context (Helldén et al., 2018; Li et al., 2022; Moloney & Walshe, 2018). Increasingly, perspectives and insight into the demands of being the partner and carer of a stroke survivor are gaining attention (Robinson, Coxon, McRae, & Calestani, 2022). The theme of uncertainty was pervasive throughout the participants' experience and interplayed significantly with the psychosocial implications that it is further addressed at several points throughout the discussion.

2 On the stroke pathway

All the participants in this study, both stroke survivors and family members, discussed the event of the stroke and their early days of their healthcare experience following it. The theme 'at the time of the stroke' outlines these experiences. This is consistent with other research exploring the experience of stroke (Salisbury, Wilkie, Bulley, & Shiels, 2010) highlighting the saliency of the stroke as a memorable point in time for this population. The rehabilitation experiences for the participants' in this study follow both those on a traditional stroke pathway as well as those who fall through the system as not being eligible for dedicated stroke rehabilitation services. Interestingly, the rehabilitation experience did not meet the expectations of any of the clients, irrespective of whether they were receiving care via a clinical care pathway or not. For those receiving standard care, the rehabilitation process was characterised by systemic challenges including limited therapist time, capacity and expertise; and managing long-term dysphagia in the context of a risk averse system.

Although guidelines exist for the best clinical management of stroke care from initial symptom onset to long term chronic care needs, research has highlighted the difficulties in implementation of these guidelines (McCluskey, Vratsistas-Curto, & Schurr, 2013). Differences between guideline recommendations and the lived experience of having a stroke have been documented (Salisbury et al., 2010). This study reiterates these previous findings and offers further insight into some of the specific challenges faced. This study also highlights a unique perspective of people who are not eligible for standard rehabilitation services but receive no guidance on how to access alternative services should they wish. Typically, these individuals would be excluded from stroke pathway research, so consequently this perspective rarely gets an opportunity to be captured. Despite either being discharged from rehabilitation services or never having received formal rehabilitation, all the participants in this study made rehabilitation gains when later enrolled in an intensive rehabilitation program. This indicates a role for later follow up and review for the possibility of rehabilitation in some cases. This notion has been gaining support in the broader stroke rehabilitation literature for some time (Page, Gater, & Bach-y-Rita, 2004; Teasell et al., 2012). Dworzynski, Ritchie, and Playford (2015), emphasized the importance of accessibility to appropriate skilled rehabilitation at any given point following stroke. Most participants and/or their family members in this study had been searching for alternative therapy options to facilitate ongoing improvements in swallowing. They reported that alternative treatment options were not discussed as part of the hospital discharge planning process.

The timing and context of dysphagia rehabilitation presents an especially challenging clinical scenario. The themes "Therapist capacity: time and expertise' and 'A risk averse system" illustrate some of the issues surrounding this. Stroke survivors and their family members in the current study had a strong perception of hospital clinicians as being "too conservative" and "too busy" in their approach to dysphagia rehabilitation. These sentiments encapsulate the challenges faced by clinicians managing dysphagia rehabilitation patients, the right balance of delivering a therapy program that balances the chance to progress with the need to prioritise patient safety within a risk-averse health system. In the Australian context, stroke patients with severe dysphagia often remain fed enterally throughout the hospital admission and, because they have safe access to nutrition, their dysphagia rehabilitation may get overlooked while competing rehabilitation demands take precedence. Further, clinicians working in hospital settings frequently have large caseloads and limited resources, compromising their capacity to implement intervention. Intervention dosage is especially difficult for clients who are at risk of aspiration with oral intake and are unable to put in place an independent practice routine. Further, anecdotal clinical evidence reports a high degree of fatigue, nausea and complications related to tube feeding affecting the ability to participate in dysphagia rehabilitation.

Despite the complications, the current study showed that some stroke survivors and their families have a strong appetite for rehabilitation in the face of these risks; indeed, their personal identities and relationships may be dependent on it. This study suggested a benefit to having open and honest conversations with stroke survivors and their family members about intervention options, risk profiles, and the logistical and resourcing landscape. To date no research has explored the specific experiences of individuals participating in a dysphagia rehabilitation program. Merlo, Goodman, McClenaghan, and Fritz (2013) explored chronic stroke survivor perspectives of undertaking an intensive task-oriented physiotherapy intervention. Results indicated that participants found this intervention a feasible therapeutic option. In a study exploring perspective in an older age group, Bennett, Luker, English, and Hillier (2016) found participants lacked choice in their therapeutic options but had individual

needs when it came to intensity that was suitable for them. The participants in the current study reported similar experiences. None of them reported therapy intensity as a barrier to undertaking the therapy. Many overcame significant logistical barriers in order to access therapy.
An additional factor no doubt at play is the absence of a precedent for, or evidence supporting, high-risk interventions for those with severely disordered swallow or other medical risk factors. In standard rehabilitation practice clinicians are often reliant on clinical prognostic indicators such as overt signs of aspiration which may be absent in the context of a severe stroke. The stories highlighted in this study emphasise the importance of trialling intervention despite some risk of aspiration. Certainly, the outcomes of individuals returning to oral intake following many months of eating and drinking nothing orally is a valuable therapeutic outcome. Once rehabilitation occurs, a number of secondary complications are resolved – both aspiration risk and complications arising from PEG feeding are resolved.

For individuals with chronic post stroke dysphagia, timing of intervention may warrant reconsideration. There is an abundance of research that indicates that chronic post-stroke dysphagia can be rehabilitated a long time post onset (Bogaardt, Grolman, & Fokkens, 2009; Carnaby-Mann & Crary, 2010; Carnaby, LaGorio, Crary, & Miller, 2012; Huckabee & Cannito, 1999; S (Bath, Lee, & Everton, 2018; Bulow, Speyer, Baijens, Woisard, & Ekberg, 2008; Carnaby-Mann & Crary, 2010; Crary, Carnaby, LaGorio, & Carvajal, 2012). All these studies report successful outcomes for patients undergoing therapy more than a year and in some cases many years post stroke. These factors warrant consideration by rehabilitation specialists, clinicians, healthcare service and policy developers. Guidelines outlining clear lines of accountability and continuity of care would be valuable for individuals managing long term stroke sequalae.

Participants in this study reported an overall lack of actual time spent practising swallowing skills. This occurred for various reasons including therapist availability, actual time spent with the therapist, a lack of options for independent or family supported practice in the context of dysphagia rehabilitation or a lack of therapist expertise in dysphagia rehabilitation. There is research reporting actual time spent undertaking rehabilitation during inpatient stays which typically falls short of recommended guidelines (Clarke et al., 2018). This is concerning considering the amount and nature of practice required (i.e. high volumes of task specific training) required to evoke neuroplastic change. For individuals undertaking dysphagia rehabilitation, clinical support is required for swallowing practice to occur, especially if patients are receiving enteral nutrition. Some therapeutic modalities have independent tasks that can be supervised or monitored by family, other heath care professionals or allied health care assistants or support workers. Swallowing practice in cases where people are at risk of aspiration is not so readily transferable. Typically, full supervision from a speech pathologist is going to provide the optimal practice.

3 A certain type of therapy; patient; approach

The participants in this study, all presented with severe dysphagia and were dependent on enteral nutrition for the majority of their nutrition. Several months post-onset, they had all participated in the intensive rehabilitation program described in the preceding chapter. Participants and their family members consistently reported that having a clinician available to support their therapy facilitated their progress. From a clinical perspective, this provided opportunity to finely calibrate individual targets to ensure intensive practice was achieved at an appropriate level.

The challenge for clinicians working within broader clinical contexts is being able to offer supported sessions for practice without providing inequitable services to other individuals on their caseload. The patients described in this study have been described and represent a specific type of rehabilitation candidate. For clinicians working with this population, the key personality traits of determinism and motivation were commented upon and are important indicators of successful engagement in the rehabilitation program. With advances in technology it may be possible in the future to use both evaluation of swallowing alongside assessment of personality to determine the best candidates for certain types of rehabilitation programs.

Person-centered, and strengths based therapeutic approaches were employed in this study. These approaches facilitate the therapeutic alliance which has in-turn been associated with improving therapeutic outcomes rehabilitation (Hal, Ferreira, & Maher, 2010). Within the dysphagia rehabilitation population, the importance of the therapeutic alliance is paramount in the context of reintroduction of food and fluids following a period of being unable to eat and drink. These findings support previous studies reporting that *how* we engage with clients can influence rehabilitation outcomes.

6.5.2 Schema 2: Shifting identities

Stroke survivors commented upon identify shifts in terms of being a woman, being a parent, being a daughter, being a friend, being a community member and being a professional. The overall impact of having a stroke contributed to these shifts but many expressed that the inability to be able to consume oral nutrition was directly related to changes of these fundamental aspects of identity.

4 Food through a tube

Changes to the mode of nutrition from oral intake to initially nasogastric feeding in the hospital and then subsequently PEG feeding was overwhelming for clients and carers. Initial reactions were confounded with coming to terms with having a stroke. Nevertheless, recalling events associated with the realisation that sustenance was going to be non-oral was powerful for all participants and their family members. Consistent with previous findings there was an interplay between the benefits of having a PEG for nutrition and a global dislike for needing an alternative route for nutrition.

5 Providers and sharers of meals

It is clear that mealtimes encompass more than a means to sustain nutrition. Providing and sharing meals have delineated roles and responsibilities of families and communities for eons. The interplay between oral intake and health and the provision of food and caring were evident in this theme. A variety of shifts occurred relating to the changes in roles associated with this theme. For some, meal provision remained part of their responsibilities despite not being able to share in the mealtime. For others, not being able to provide a meal as an act of caring or needing to provide a specially prepared meal was considered effortful or burdensome. Changes in the mealtime experience were typically considered a loss, and families looked forward to times when their family member could "return to normal" so they could eat and drink. Lost opportunities for social interactions while eating out were highlighted by participants.

6 Adjusting to roles and responsibilities as caregivers

Lastly, family members in the current study spoke of significant adjustments to their roles as carers. Many had to give up time from their careers or studies, in order to support their family member. Research is now emphasising the important role informal caregivers provide in supporting family members who have had stroke on their return to the community (Howells, Cornwell, Ward, & Kuipers, 2019; Robinson et al., 2022). Dysphagia in partners has been linked with depression in their caregivers (Hultman, Everson-Rose, Tracy, Lindquist, & Hadidi, 2019), related to the burden of specialised meal preparation in conjunction with reduced socialisation and shifting purpose of mealtimes. Further, it may add to challenges with carers following mealtime recommendations or restrictions once their loved on is back in the community.

6.5.3 Strengths and Limitations

The current study, interviewed stroke survivors and their family members about their experiences participating in a dysphagia rehabilitation program. All the stroke survivors began the intervention program with severe dysphagia and were completely reliant on PEG feeding to sustain their nutrition. While the sample size is small, the study adds to the growing corpus of literature acknowledging the lived experience of health care conditions as important contributions to improving healthcare outcomes especially those of wellbeing. Further, this study recruited directly from an intervention research program and consequently the sample may present biased viewpoints. Despite this, although variations in perspectives exist, common themes were extrapolated.

6.5.4 Clinical Implications

This study offers a starting point for exploring these themes and guiding clinical practice and research to resolving challenges faced by stroke survivors and their carers with chronic dysphagia. Limitations in accessing long term rehabilitation services and challenges faced by stroke survivors undertaking dysphagia rehabilitation should be considered by professionals as patients transition through the clinical care pathway. Considerations around long-term reviews and access to late stage rehabilitation in this context supports previous findings (Robinson et al., 2022). Novel perspectives on participating in intensive dysphagia rehabilitation, and links between method of nutrition and fundamental identities and sociocultural needs are offered.

6.6 Conclusion

The findings from this study illustrate the complexities of living with long-term dysphagia. Participants discussed the impact of stroke and the rehabilitation journey, the systemic challenges faced by stroke survivors and clinicians in the dysphagia rehabilitation context, and patterns of identify shifts or challenges maintaining identities for both stroke survivors as well as their carers. Participants experienced uncertainty at most points on the care pathway – from initial onset to discharge from formal rehabilitation care. They questioned the extent to which therapists had the knowledge and skills to deliver effective treatment within the dysphagia rehabilitation context or the capacity to be able to provide it. Following discharge from hospital-based services, participants reported a lack of support in seeking further rehabilitation options. The findings from this study indicated that people with dysphagia experienced a lack of support from health care professionals. They felt left on their own and were required to adapt strategies on their own, without support or guidance. Better health care support following discharge from hospital is required to ensure improved health outcomes and patient quality of life.

6.7 Chapter Summary

This section reports the perspectives of both stroke survivors and their family members to the experience of stroke and its aftermath, especially with respect to dysphagia and its implications. It begins with documentation of the experience of the stroke itself, and the uncertainty about the future that this generates. The second, section reveals how study participants and their family members feel about the therapeutic experience post-stroke, both in the hospital system and as a recipient of an intensive rehabilitation program. Finally, reactions which shed light on the psycho-social implications of a severe stroke are reported, alongside existing literature in this area. Clinical implications are discussed.

Chapter 7. Discussion

Dysphagia rehabilitation poses many challenges for clinicians. First, traditional intervention for chronic dysphagia is steeped in a history of compensatory management. Despite at least two decades of research outlining the benefits of rehabilitation, the uptake of the benefits of dysphagia rehabilitation is still underway in many clinical settings. For clinicians working in rehabilitation settings, anecdotal "failure of therapy" to effect change for their clients is not infrequent. While there is a growing body of research exploring therapeutic effectiveness of various techniques, there remain barriers to the selection and implementation of techniques that are appropriate for individual clients. The interplay between mitigating aspiration risk and achieving an appropriate effective behavioural intervention dosage is complex and poorly defined, and in the context of silent aspiration actually impossible in the majority of clinical settings. Systemic health constraint issues further exacerbate these challenges. This setting provides the context for this thesis.

Dysphagia rehabilitation has largely been driven by clinical practice in terms of therapeutic manouvres and intervention dosage. These are well motivated by physiology and are seemingly intuitive and at times generate positive outcomes for individuals with dysphagia. This has created a corpus of evidence which identifies effective therapeutic strategies for some people sometimes. However, crystalising the underlying mechanisms creating these changes remains intangible.

In order to explore the question: ***How can Principles of Motor Learning inform treatment selection and implementation for dysphagia rehabilitation?*** this thesis draws together three elements to deliver a comprehensive examination and application of the principles of motor learning within the dysphagia rehabilitation context. To date no research has considered the theoretical underpinnings of motor control and motor learning and explicitly, prospectively applied it to dysphagia neurorehabilitation.

First, it considers the theoretical perspectives of motor control and motor learning and swallowing as a complex movement involving both volitional and reflexive components. It describes the conceptual synthesis of motor learning in dysphagia rehabilitation and then examines previous research findings in dysphagia rehabilitation through the lens of the motor learning framework. Next, it goes on to portray the clinical dilemma of dysphagia from the point of view of the clinician. Following this it presents an originally developed intervention protocol for applying PML to dysphagia rehabilitation. The application and evaluation of this protocol follows. Finally, perspectives from stroke survivors living with chronic dysphagia as well as their carers are explored.

Together these theoretical considerations, clinician and client perspectives highlight some of the challenges faced by clinicians and healthcare recipients and consequently have has considerable implications for health policy development and reform.

The primary goal of this thesis is to develop and evaluate the outcomes of a prospectively designed treatment program with these theoretical and clinical viewpoints in mind. The research project employs a single case experimental design to assess intervention effectiveness within this context.

7.1 Motor Control and Swallowing

The motor control of swallowing has been explored for decades. Our understanding has been enhanced significantly by advances in neuro imaging and research exploring the neurophysiology of deglutition. The emphasis of historical research ascertaining neural activation pathways for swallowing has focused on subcortical structures and nerves. More recently the focus of attention has shifted to cortical involvement in deglutition (Alvar, Hahn Arkenberg, McGowan, Cheng, & Malandraki, 2021; Daniels, Corey, Fraychinaud, DePolo, & Foundas, 2006; **Martin** et al., **2007;** Martin, Goodyear, Gati, & Menon, 2001; Robbins, 1999; Toogood et al., 2005; Zald & Pardo, 1999). The complete picture of the neurological underpinnings of swallowing continues to evolve. Our understanding of swallowing with respect to motor control also continues to evolve.

One of the complexities of swallowing is that although it is now recognized that there is a volitional component, it transition from volitional to reflexive control throughout the execution of the movement. How this interacts with motor control and learning is also of interest.

7.2 Motor Learning in swallowing

A key concept in motor control is the ability for the nervous system to continue adapting in response to experiences. Goal directed movements take place in the context of inherent variability. An internal feedback loop exists for goal directed movements, which allows for constant prediction and response to sensory feedback. We continue to execute movement goals in environments that need nuanced responsivity, the ability to refine our execution based on predictions of previous executed movements is how motor control develops. This mechanism allows us to refine and improve skills with a lot of practice (motor learning).

There are many instances of this in swallowing, (e.g. biting tongue, swallowing an almost ready to be swallowed bolus, biting into something soft that you expected to be hard or vice versa, reacting to an unexpected pip in a mandarin etc…). As we develop, we are exposed to more and more textures that require more and more sophisticated oro-pharyngeal control, with these increasing exposures (ie interacting with our environment) our motor control for swallowing develops. Neuroplasticity creates the most effective neural pathway or network in order to meet the needs of the goal being executed.

7.3 Motor Learning in Dysphagia Rehabilitation

When the complex neural network governing its motor planning and execution is damaged, neurogenic dysphagia can occur. The mechanism for retraining swallowing pathways is similar to acquiring swallowing pathways. In the context of a stroke, neuroplasticity will occur and our motor learning system will respond to its environment in order to either re-establish old pathways or generate new ones. The challenge following stroke is that without an accurate sensorimotor response to predict and refine movements, creating or re=establishing new pathways is not straightforward. Without effective rehabilitation, it is possible for maladaptive behaviours to develop (Molfenter Sonja & Steele, 2010). In rehabilitation contexts, maladaptive behaviours may require "unlearning" before effective pathways can be developed.

7.4 The Dysphagia Rehabilitation Context

There has over the course of this century been a shift away from compensatory management of dysphagia with rehabilitative efforts aimed at improving swallow physiology. Improved understanding of neural substrates involved in deglutition and the influence of research in neuroplasticity in rehabilitation has produced a resurgence of research dedicated to dysphagia rehabilitation and its underlying mechanisms.

There is now a growing body of evidence indicating the benefits of behavioural intervention for dysphagia rehabilitation. Numerous studies have presented positive treatment outcomes in response to dysphagia therapy (Bath, Lee, & Everton, 2018; Bulow, Speyer, Baijens, Woisard, & Ekberg, 2008; Carnaby-Mann & Crary, 2008, 2010; Carnaby, LaGorio, Silliman, & Crary, 2020; Crary, Carnaby, LaGorio, & Carvajal, 2012; Hägglund, Hägg, Levring Jäghagen, Larsson, & Wester, 2020; Georgia A. Malandraki & Hutcheson, 2018; Georgia A Malandraki et al., 2016; Molfenter Sonja & Steele, 2010; Park, Oh, Hwang, & Lee, 2016). While these studies show promising findings, the underlying mechanism of improving motor control remains elusive.

Several approaches are available to facilitate improved outcomes in the dysphagia rehabilitation context. Both strength and skill based training have yielded promising rehabilitation outcomes (Athukorala, Jones, Sella, & Huckabee, 2014; Clark, 2003; Crary et al., 2012; Huckabee & Lamvik-Gozdzikowska, 2018; Loppnow, Netzebandt, Frank, & Huckabee; Steele, 2012).

The focus of this thesis is explore how PML can be applied to dysphagia rehabilitation in an effort to optimise within session therapeutic intensity. Findings from the current study indicate that PML could offer guidance to facilitate outcomes in rehabilitation. This study provides insight into the scope of providing individuals with chronic dysphagia an opportunity to explore the chance of re-introducing of oral intake for nutrition or taste. The wellbeing of individuals with dysphagia and their carers has been linked with poor wellbeing and is receiving increased attention. Moreover, preventing secondary complications of post stroke sequalae is twofold in the context of dysphagia as individuals are at risk of PEG feeding complications and remain at risk of aspirating saliva.

7.5 Limitations

It had been the intention of this research project to measure motor control using kinematic outcomes from VFSS. In light of the severity of dysphagia in this participant group, their risk of aspiration during VFSS was high and evaluations were often ceased with minimal data. Consequently, PML was measured in the generalised behaviour of swallow function. Linking kinematic measures to generalised behaviours would strengthen the assertion that PML can enhance dysphagia rehabilitation. Moving forward, methods of analysing rehabilitative efforts employing kinematic and timing measures as well as residue ratios would add much value to research projects similar this one in the future. In addition, a larger sample size would add diversity and broaden the applicability of research findings.

7.6 Future Directions

This thesis has sought to explore and evaluate the application of the principles of motor learning to improve swallow physiology people with chronic post-stroke dysphagia. Although this was necessarily shown in a research context, clinical feasibility was paramount in the motivation, development and implementation of the intervention protocol as well as the analysis of results.
Although, this study employed Single Case Experimental Design and therefore necessarily a small -scale study, there is much potential for the further development of this research topic.

In addition, alternative PML-based practice programs should be experimented with and evaluated, so that clinicians have evidence on which to base PML style interventions, specialised to the profile of the client. This could be undertaken as a part of the inter-disciplinary research program outline d above, or it could be developed as a specialist spin-off from that program.

7.7 Future directions for investigating PML in dysphagia rehabilitation.

Research examining amount of practice should be a focus and should consider the impact of other interacting variables including

- The role of direct and indirect therapy
- Baseline performance and progression schedules for therapy
- Translation implications for independent practice in the context of aspiration risk.
- the benefits of relative distribution schedules for various aitiological conditions;
- consider other influencing variables (e.g. age - neuroplasticty)

Some principles lend themselves more easily to clearly delineated research paradigms. Practice principles of amount, distribution over time, variability, pattern of within session practice targets (i.e blocked or random pattern) and target complexity (whole or part) all lend themselves to empirical evaluation. Interaction effects between variables also may warrant specific investigation.

For example, developing treatment dosages with practice principles, strengths based training, and factors enhancing neuroplasticity in mind for specific populations would assist clinicians in developing individually tailored treatment programs.

Other principles require more thoughtful conceptualization of how to evaluate and measure their role in this context. Attentional focus is an example that does not appear to have a clear directive for investigation in this domain.

Lastly, principles of feedback also require more thought in this space. Practice using instrumentally guided feedback that allows for monitoring of pharyngeal clearance and clinically feasible monitoring of real-time aspiration would allow for augmented feedback to be offered in a reliable manner for individuals with disrupted sensorineural pathways that interfere with adaptive processes enhancing post stroke neural regeneration.

To comprehensively investigate the role of PML in dysphagia rehabilitation would require the collaboration of specialists from a range of disciplines beyond speech language pathology including neuroscientists, radiologists, neurologists, physiotherapists and others. If such a research program were to be undertaken, its translation to clinical practice would be essential.

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Appendix 1

Interview Guide – Stroke Survivors

After the stroke:

- What changes did you notice in your eating and drinking in the period after you had your stroke?
    - How did you react to this at first?
    - Have these feeling changed over time?
- Have you done anything different since the stroke to fulfill the enjoyment you used to experience from eating and drinking? (if relevant)

Before you started the rehabilitation program:

- Did you find that your swallowing difficulty affected your general health?
- Did you notice any changes in your family mealtimes or home routines as a result of your swallowing condition?
- Did you notice any changes in your social life and out-of-home routines as a result of your swallowing condition?
- Did the changes in your eating and drinking affect your relationships with family members, colleagues or friends?
- What were your experiences of swallowing rehabilitation before joining this program?

About the training program:

- Have you noticed any changes in your eating or drinking since the training program?
- Have you noticed any changes in other aspects of your life (probe if necessary).
- How did you find the experience of being in this training program?...
    - What was good about it
    - What was challenging about it
- Are there any changes you would recommend for future use of this program with other stroke survivors?

Is there anything else you wanted to share with us today?

Interview Guide – Family Members

After the stroke:

- What changes did you notice in XX's eating and drinking in the period after they had their stroke?
- How did they react to this at first? How did you feel about these changes?
- Have these feelings changed over time?
- What have these changes been like for you as XX's partner/son/daughter/family member?

Before starting the rehabilitation program:

- Do you think that XX's swallowing difficulties have affected his/her general health?
- Did you notice any changes in your family mealtimes or home routines as a result of XX's swallowing condition?
- Did you notice any changes in XX's social life and out-of-home routines as a result of his/her swallowing condition?
- Do you think the changes in XX's eating and drinking have affected XX's relationships with family members, colleagues or friends?
- Can you tell me about XX's experiences of swallowing rehabilitation before joining this program?

About the training program:

- Have you noticed any changes in XX's eating or drinking since the training program?
- Have you noticed any changes in other aspects of their life (probe if necessary).
- What do you think has been good about this training program?
- Have there been any challenges?
- Are there any changes you would recommend for future use of this program with other stroke survivors?

Is there anything else you wanted to share with us today?