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Speech Language Pathologists (SLPs) Enactment of Dysphagia Education and Counselling in TBI Inpatient Rehabilitation.

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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Abstract

Background

Traumatic brain injury (TBI) incidence rates are rising significantly across all age groups, often requiring complex and expensive medical care. Common causes of TBI include motor-vehicle accidents, violence, sport injuries and falls. For some individuals, inpatient rehabilitation (IPR) is used as a care pathway to provide intervention(s) for the physiological, psychological, neurobehavioural and cognitive-communication sequelae of a TBI. Many patients with a TBI will also experience dysphagia, an impairment or disorder of deglutition (swallowing). Dysphagia affects hydration, nutritional intake, respiration and can significantly impact an individual's quality of life. It has been identified as a contributing factor in the mortality and morbidity of patients in many hospital care settings.

In the Province of Ontario, patients with dysphagia concomitant with a TBI often receive inpatient rehabilitative care by a Speech-Language Pathologist (SLP). Successful outcomes for dysphagia are best achieved when the patient, independently whenever possible, and the family when it is not possible, have been educated and counselled to know which foods they can and cannot safely consume and why this is important. This requires that the SLP enact education and counselling with the patient who has a cognitive-communication disorder related to the TBI and their family in an effective way to provide critical and understandable information about the assessment results and the risks and benefits of the various management choices under consideration. It is also considered part of the SLP's scope of practice to ensure that all members of the interdisciplinary IPR team are aware and understand the assessment results, management recommendations and know how to recognize and respond to signs and symptoms that reflect a risk of harm.

As a Speech-Language Pathologist (SLP) working in an IPR setting for over 20 years with patients who have a TBI and dysphagia, I have recognized that there is a lack of accessible, evidence-based, comprehensive methods that are patient and family-focused for SLPs to use to enact education and counselling within this practice context.

Therefore the objectives of this thesis were to: (1) conduct a scoping review of the literature to better understand how SLPs enact education and counselling with patients who have dysphagia and a TBI, especially within the context of inpatient rehabilitation settings; and (2) use qualitative hermeneutic inquiry to understand how SLPs enact dysphagia education and counselling with patients who have a TBI and are in inpatient rehabilitation settings in Ontario.

Method

This research started with a scoping review of the literature followed by a qualitative study using a philosophical hermeneutical perspective and semi-structured interviews with twelve SLPs working in IPR settings with individuals who have dysphagia and a TBI. Participants also provided for consideration the materials they used when enacting education and counselling with their patients.

Results

The scoping literature review helped to reveal important parts of the enactment of education and counselling, especially as it relates to the numerous people and groups of people within the inpatient practice context who must be part of the education and counselling conversations. The results of the hermeneutic inquiry revealed important information about the complexities and constraints of practice and provided evidence of how SLPs continually try to mitigate the risks within this environment to keep their patients safe. These important conversations also revealed that SLPs generated practice-based knowledge and used innovation(s) around education and counselling primarily due to the lack of guidance around education and counselling currently available within guideline documents.

Conclusion

This thesis project provided a useful framework for examining the individual accounts of the SLPs and bringing these together in a thematic manner to generate important information for SLPs, educators, policy makers, and health care administrators. It advanced our understanding of how SLPs enact dysphagia education and counselling for patients with a TBI within IPR settings in Ontario.

Keywords

Speech Language Pathology, Traumatic Brain Injury, Dysphagia, Swallowing, Inpatient Rehabilitation, Education, Practice Based Research, Hermeneutics.

Summary for Lay Audience

Traumatic brain injuries (TBI) often occur after motor-vehicle accidents, violence, sport injuries and falls. Some individuals will receive inpatient rehabilitation (IPR) to provide intervention(s) for the physical psychological, behavioural and cognitive-communication consequences of a TBI. Many patients with a TBI will also experience a swallowing disorder (dysphagia) which may affect hydration, nutritional intake, respiration and quality of life. If a patient does not follow the intervention instructions provided by their care providers, their dysphagia may result in continued hospital admissions/readmissions or, in some cases, death. In the Province of Ontario, patients with dysphagia and a TBI often receive inpatient care by a Speech-Language Pathologist (SLP). As part of provision of care, the SLP must educate and counsel the patient whenever possible, and the family when it is not possible, to know which foods they can and cannot safely eat and why this is important. This requires that the SLP enact education and counselling with the patient who may have difficulties with attention, memory, listening, social interactions, speaking, reading, and writing related to the TBI, and their family, in an effective way to provide critical and understandable information about the assessment results and the risks and benefits of the various management choices being considered. It is also considered part of the SLP's responsibilities to ensure that all members of the in-hospital care team are aware and understand the assessment results, management recommendations and know how to recognize and respond to signs and symptoms that reflect a risk of harm.

The results of this thesis work helped to reveal important parts of the enactment of education and counselling, especially as it relates to the numerous people and groups of people within the inpatient practice setting who SLPs must ensure are part of the education and counselling conversations. The SLPs interviewed helped us to better understand the complexities and constraints of practice and provided a better understanding of how SLPs enact dysphagia education and counselling for patients with a TBI within IPR settings in Ontario. Results provided important information for SLPs, educators, policy makers, and health care administrators.

Dedication

This work is dedicated to my daughter, Sophie Lise Muir Derbyshire.

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Completing a thesis and working during the time of a global pandemic will be a story that is told for years to come. I am grateful to the community of teachers, colleagues, family and friends who took the time to support me on this journey.

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Abbreviations

Note: For the purposes of this study individuals with dysphagia and a traumatic brain injury are within a medical model and will be referred to as "patients".

APC: annual percent change

ASHA: American speech-language hearing association

CASLPO: College of Audiologists and Speech-Language Pathologists of Ontario

CCI: Cognitive and communication impairments

CDMQ: Caregiver Dysphagia Mealtime Questionnaire

CIHI: Canadian Institute for Health Information

CNA: Certified Nursing Assistants

CPGs: clinical practice guidelines

CVA: cerebrovascular accident

dysphagic patient: dysphagic traumatically brain injured patient

IDT: Interdisciplinary team

IPR: Inpatient rehabilitation

HCPs: health care professionals

KT: knowledge translation

LPNs: licensed Practical Nurses

MBS: modified barium swallow

MDQ: Mealtime and Dysphagia Questionnaire

NINDS: National Institute of Neurological Disorders and Stroke

NHP: non-health professionals

NPO: Nil per os (nothing by mouth)

OT: Occupational Therapist

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analysis

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-analysis
Extension for Scoping Review

PSW: personal support workers

PT: Physiotherapist

RCSLT: Royal College of Speech and Language Therapists

RD: Registered Dietician

RN: Registered Nurse

RT: Respiratory Therapist

SLPs: Speech Language Pathologists

SPA: Speech Pathology Australia

TBI: traumatic brain injury

VFSS: videofluoroscopic swallow study

Chapter 1: Introduction to the thesis

1 Research question

This research explored how speech-language pathologists (SLPs) working in inpatient rehabilitation (IPR) settings in Ontario, Canada, enact dysphagia education and counselling with patients who have a traumatic brain injury.

1.1 Background and significance

Traumatic brain injury (TBI) is a form of acquired brain injury which occurs when sudden, external physical trauma injures the brain (National Institute of Neurological Disorders and Stroke [NINDS], 2015). TBI results in the hospitalization of more than 16,000 Canadians each year (Canadian Institute for Health Information [CIHI], 2006), with many of the affected being healthy, young males (Baguley et al., 2012; Rao, McFaull, Thompson and Jayaraman, 2017). Each TBI is unique, and symptoms can be mild, moderate, or severe, depending on the extent of the damage to the brain (NINDS, 2015). Adult TBI is a heterogenous category because of the different causes of injury (motor vehicle, blunt force trauma, assault, fall or gunshot wound) and the broad age range of individuals affected (i.e., 16 to 85+ yrs.).

Dysphagia is the term used to refer to an impairment or disorder of deglutition (swallowing); it can affect any or all of three phases of swallowing: the oral, pharyngeal and/or esophageal phase(s). The occurrence of dysphagia in individuals with a TBI is reportedly as high as 25% to 40% (Mackay, Morgan and Bernstein, 1999a/b). Dysphagia after a TBI may be caused by or related to physical injury to the head and neck regions, oropharyngeal neuromuscular and sensory deficits, cognitive-communication and behavioural impairments, other simultaneous injuries, medications, prolonged endotracheal ventilation and tracheostomies (Cherney and Halper, 1989; Halper, Cherney, Cichowski & Zhang, 1999; Howle, Baguley & Brown, 2014; Logemann, Pepe & Mackay, 1994; Mackay et al., 1999a/b; Morgan & Mackay, 1999; Perel, Yanagawa, Bunn, Roberts, Wentz & Pierro, 2008). Dysphagia affects hydration, nutritional intake, respiration and can significantly impact an individual's quality of life (Logemann et al.,

1994). Dysphagia has been identified as a contributing factor in the mortality and morbidity of patients in acute hospital care settings (Morgan & Mackay, 1999).

The patient with a TBI is also at considerable risk, with reported incidences rates of 75% of the time, of experiencing difficulties in listening, speaking, reading, writing, as well as impairments in attention, memory, organization, information processing, and other cognitive abilities (MacDonald, 2017). This can compromise capacities to adhere to the recommendations of healthcare providers, affect meaningful engagement, and increase reliance on others for decision-making (Douglas, Knox, De Maio & Bridge, 2014; Knox, Douglas & Bigby, 2015; MacDonald, 2017).

Patients with TBI tend to have complex medical problems and needs. Patients who experience significant functional or psychological problems early in the post-injury stages, frequently participate in inpatient rehabilitation in dedicated care settings in an attempt to achieve the best possible outcomes (Zarshenas, Horn, Colantonio, Jaglal & Cullen, 2019). Eligibility for inpatient rehabilitation (IPR) may be warranted if the TBI prevents a return to home and family care. IPR is designed to help improve function after a moderate to severe traumatic brain injury (TBI) and is usually provided by a team that includes physicians, nurses and other specialized therapists and medical professionals. The patient's medical condition must be stable enough to allow participation in the rehabilitative therapy designed to meet their needs. Most patients receiving TBI rehabilitation participate in individual and/or group-based physical therapy, occupational therapy and speech-language therapy.

In the Province of Ontario, patients with dysphagia concomitant with a TBI and a cognitive-communication disorder often receive inpatient rehabilitative care by a SLP who is a regulated member of the College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO). It is within the scope of practice for SLPs to assess, develop and implement interventions for dysphagia. SLPs are also uniquely qualified to deliver services for patients with cognitive-communication impairments associated with a TBI. As a regulated healthcare professional, SLPs have the required competencies, knowledge and skills to provide dysphagia services; these are described in detail in the

Practice Standards and Guidelines for Dysphagia Intervention by Speech-Language Pathologists (CASLPO, 2014).

Consistent with most clinical practice guidelines (CPGs), the *Practice Standards and Guidelines for Dysphagia Intervention by Speech-Language Pathologists* (CASLPO, 2014) document provides guidance specifically on dysphagia, focusing on identifying and describing the recommended specifics for dysphagia screening, assessment and intervention. This ‘single-condition’ approach is due in part to the difficulty of synthesizing good-quality evidence for every combination of complex conditions (Guthrie, Payne, Alderson, McMurdo & Mercer, 2012). SLPs like other healthcare professionals have been trained to use their critical thinking, clinical judgement and experience to adapt the CPGs when working with more complex patients. However, research has shown that this type of extrapolation of evidence may increase clinical uncertainty in the application of the evidence into practice (Uhlig et al., 2014).

Successful outcomes for dysphagia are best achieved when a person-centred approach to care is provided. Person-centered care (PCC) is a holistic approach to care that is responsive and respectful considering a person’s whole well-being including context, individual expression, preferences and beliefs (Santana, Manalili, Jolley, Zelinsky, Quan, & Lu, 2018; Tomaselli, Buttigieg, Rosano, Cassar, & Grima, 2020). It incorporates an ethical and health promotion foundation, and views each person as unique with capabilities, resources, strengths and limitations (Tomaselli et al., 2020). PCC also highlights the importance of relationships, family and others (Santana et al., 2018). It contributes to patients’ empowerment by respecting their values and involving them, significant others, or both in decision-making processes throughout the rehabilitation pathway (Dwamena et al., 2012; Légaré, 2011). The CASLPO Professional Practice Standards document (CASLPO, 2021) states that “Audiologists and speech-language pathologists ensure that their patients are treated with respect and are provided with sufficient information and opportunities to make informed decisions regarding intervention. In making clinical decisions, the patient’s interests should be primary” (p. 2).

Person-centred care would ensure that the patient, independently whenever possible, and the family when it is not possible, have been educated and counselled to know which foods they can and cannot safely consume and why this is important (Rosenbek, 2017). DiLollo and Neimeyer (2021) define counselling as “those components of the clinician-client relationship that facilitate personal growth and empowerment for clients (and their families), with the goal of helping individuals and/or families manage, adjust to, and cope with communication and swallowing disorders and the treatments for those disorders” (p. 5). However, guidance documents may be vague, perhaps necessarily so given the heterogeneity of the patients, on efficient and effective ways to successfully educate and counsel the dysphagic patient who has a TBI and the associated cognitive-communication impairments (CASLPO, 2014).

Given the importance of education and counselling to positive outcomes in care for patients with dysphagia and a TBI, it may be important to consider the following:

“although it is not possible to have good-quality evidence for every combination of chronic conditions, it would be helpful to bring together relevant recommendations for different chronic conditions, highlighting synergies, cautions and contraindications” (Nelson, Grundniewicz & Albadry, 2016, p. 42).

As a Speech-Language Pathologist with more than 20 years of experience in this practice context, I have been motivated to address this practice-based topic because of a self-perceived lack of guidance for education and counselling with these patients necessitating repetition, revision and re-education for patients, family-members and interprofessional colleagues. It is important that I am transparent about my ‘insider’ status and to reflect and be reflexive at various points in the thesis about the implications and potential influences that this status may have on the research outcomes (Ross, 2017). ‘Insider’ status, which describes a member of the community of practice as well as its observer in research, may have the advantages of rapport building, possession of knowledge of the norms and values of the practice community, and enabling interpretation of collected data because of contextual, historical and practice knowledge (Chavez, 2008; Finefter-

Rosenbluh, 2017; Ross, 2017). However, one important challenge associated with being an ‘insider’ that should be noted is that power differential issues may arise because I am part of the practice community due to my role as a peer assessor with the regulatory College in which participants are required to be members (Ross, 2017). The challenges of these power differential issues are addressed later in the thesis.

1.2 Aim of the thesis

To achieve the outcome of “optimizing the individual’s ability to swallow and thus improve their quality of life” (CASLPO, 2014, p. 3), SLPs should engage with the patient who has a TBI and their family in a person-centred way and provide critical and understandable education and counselling about the assessment results and the risks and benefits of the various management choices under consideration (DiLollo and Neimeyer, 2021; Tomaselli, Buttigieg, Rosano, Cassar, & Grima, 2020). This important dialogue and co-construction of treatment plan(s) requires the SLP to engage in education and counselling. Although these dialogue conversations require important exchanges between the person, their family and the SLP, the ways in which education and counselling is enacted by the SLP is the focus of this research. The objectives of this thesis were to: (1) conduct a scoping review of the literature to better understand how SLPs enact education and counselling with patients who have dysphagia and a TBI, especially within the context of inpatient rehabilitation settings; and (2) use qualitative hermeneutic inquiry to understand how SLPs enact dysphagia education and counselling with patients who have a TBI and are in inpatient rehabilitation settings in Ontario.

1.3 Thesis outline

With these objectives in mind, the chapters in this dissertation are organized as follows.

Chapter 1: An introduction to the thesis

Chapter 2: How do Speech-Language Pathologists working in inpatient rehabilitation settings enact education and counselling for patients with dysphagia and a traumatic brain injury?: A scoping review

Chapter 3: Methodology: A description of the hermeneutic inquiry used in this thesis study

Chapter 4: Study method

Chapter 5: Study results

Chapter 6: Discussion

Chapter 7: Conclusion, study limitations and future directions

Chapter 2: How do Speech-Language Pathologists working within inpatient rehabilitation settings enact education and counselling for patients with dysphagia and a traumatic brain injury?: A scoping literature review

2 Introduction

Traumatic brain injury (TBI) is increasingly being recognized as a global health priority. Incidence rates are rising significantly across all age groups; often requiring complex and expensive medical care. Common causes of TBI include motor-vehicle accidents, violence, sport injuries and falls (Faltynek and Teasell, 2019; Zarshenas, Horn, Colantonio, Jaglal & Cullen, 2019). For some individuals, inpatient rehabilitation (IPR) is used as a care pathway to provide intervention(s) for the physiological, psychological, neurobehavioural and cognitive-communication sequelae of a TBI.

An interdisciplinary healthcare team is formed in the IPR context to support the diverse/complex medical and rehabilitative needs of patients with a TBI. These teams are often comprised of a wide-network of collaborative professionals including speech-language pathologists (SLPs), physiotherapists (PTs), occupational therapists (OTs), physicians, nurses, dietitians, social workers and other hospital staff that interact with the patient and their family in the 24 hour/7day-per-week IPR setting.

A TBI affects all family members, albeit to differing degrees, with some families describing the effects as overwhelming and life-changing (Savage & Egan, 2018). Pielmaier et al., (2011) report substantial levels of post-traumatic stress disorder (PTSD) in family members of patients with severe TBI in the period up to one month after their family member sustained the injury. Even after the initial shock has resolved challenges and changes remain for families including financial strain, insufficient time for themselves, lack of resources, health literacy levels, and stress (Barclay, 2013; Rivera, Elliott, Berry & Grant, 2008; Savage & Egan, 2018). However, despite these challenges, family members feel compelled to become “the patient’s voice”, especially in the early

stages of IPR, becoming an important member of the IPR rehabilitation team (Savage and Egan, 2018).

When an individual has a TBI, they have a 25-40% risk of having dysphagia and are at risk more than 75% of the time of also experiencing cognitive-communication impairments (Blake, Frymark & Venedictov, 2013; MacDonald, 2017; Mackay et al., 1999 a/b). SLPs have the knowledge, skills and, in Canada, the scope of practice to address the swallowing and motor-speech deficits in the simultaneous presence of cognitive-communication impairments (and possible additional impairments) for the individual with TBI.

2.1 Dysphagia assessment and management by SLPs

In Canada, as Regulated Healthcare Professionals, SLPs are expected to implement best practice guidelines for dysphagia assessment and management which generally follow a series of important stages (Regulated Health Care Professions Act, 1991; CASLPO, 2014):

1. Assessment includes a review of medical history, medical status and readiness for dysphagia assessment, followed by a non-instrumental assessment, and when appropriate an instrumental assessment to further delineate the nature of the individual's dysphagia;
2. Dysphagia management which includes education to the patient and/or caregivers regarding the assessment findings and any risks of harm that are judged to exist. The management plan may include instruction in the performance of compensatory techniques and/or courses of treatment in which rehabilitative techniques are used with the intention of remediating disordered swallowing physiology. The management plan must be regularly monitored and evaluated, to determine whether refinement and or discharge are appropriate; and
3. Discharge from dysphagia service delivery occurs when the individual is judged to have completed or declined an agreed-upon management plan.

Internationally, Speech-Language Pathology regulatory bodies in Australia, the United States, the United Kingdom and Canada have created and implemented similar general guidelines and standards of dysphagia assessment and management service delivery with the desired outcome of improving the individual's ability to swallow (American Speech Hearing Association (ASHA), 2001; 2004; The College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO), 2014, 2018; The Royal College of Speech and Language Therapists (RCSLT), 2013; Speech Pathology Australia (2012); & Speech-Language Pathology & Audiology Canada (SAC), 2007).

2.2 Enacting education and counselling with patients who have dysphagia, a TBI, and cognitive-communication impairment(s)

To achieve the outcome of “optimizing the individual's ability to swallow and thus improve their quality of life” (CASLPO, 2014, p. 3), SLPs should engage with the patient who has a TBI and their family in an effective way to provide critical and understandable education and counselling about the assessment results and the risks and benefits of the various management choices under consideration (DiLollo & Neimeyer, 2021). This important dialogue must ensure that patients/families are invited to actively engage in goal setting and decision-making. It is also imperative that SLPs not only educate and counsel the patient and family, they are responsible for ensuring that all members of the interdisciplinary IPR team are aware and understand the assessment results, management recommendations and know how to recognize and respond to signs and symptoms that reflect a risk of harm, (CASLPO, 2014).

The enactment of education and counselling after dysphagia assessment generally occurs through dialogue supported by handouts or other written materials to reinforce the verbal education between the SLP, the patient and frequently the family (Morrow, Hereford, Covington & Duff, 2020). This education and counselling, which lays the groundwork for the patient/family's understanding of the care pathway, can be challenging because of the myriad of issues related to cognitive-communication disorders often co-occurring with a TBI.

Cognitive-communication disorders are “difficulties in communicative competence (listening, speaking, reading, writing, conversation and social interaction) that result from the underlying cognitive impairments (attention, memory, organization, information processing, problem solving and executive functions)” (MacDonald, 2017, p. 1763). Cognitive-communication impairments can affect meaningful engagement and increase reliance on others for decision-making (Douglas, Knox, De Maio & Bridge, 2014; Knox, Douglas & Bigby, 2015; MacDonald, 2017).

Recently, Morrow et al., (2020) highlighted the need for SLPs working with TBI patients to have a consistent and efficient means for assessing and describing their patients cognitive-communication competency for patients, families, and interdisciplinary team members. This model or framework should promote a greater and shared understanding of the complex, multifaceted variables that must be considered by everyone during the care pathway for patients with a TBI (Hinckley, 2014; Norman, 2005; Turkstra, Politis & Forsyth 2015). It should also provide important shared terminology which could lead to more efficient communication along the continuum of care (Morrow et al., 2020).

One model that aims to integrate the components for consideration in cognitive-communication competence has been developed by MacDonald (2017) and is provided as Figure 1. This model was created based on a review of previous models of communication, relevant systematic reviews, meta-analyses, peer- and non-peer reviewed literature, and in consultation with experts from the Academy of Neurological Communication Disorders (ANCDS; MacDonald, 2017). The model brings attention to the intersection of the areas of cognitive-communication competence that are important to consider when providing services to an individual with a brain injury. The seven domains of the model of cognitive-communication competence are: (1) individual; (2) contextual or environmental; (3) cognitive; (4) communication; (5) physical/sensory; (6) emotional/psychosocial; and (7) self-regulatory/control. Each of the domains are summarized and examined in relation to their importance for education and counselling of the patient who has a TBI and dysphagia in Appendix A. One of the advantages that SLPs may find in adopting an integrated model of cognitive-communication competence is that it may provide impetus and direction to broader relevant clinical practice

guidelines that might offer helpful strategies when counselling/educating patients who have a TBI and dysphagia or when sharing information within an interdisciplinary team (Faltynek, Marshall, Bayley, Ferri, Welch-West & Teasell, 2019; MacDonald, 2017).

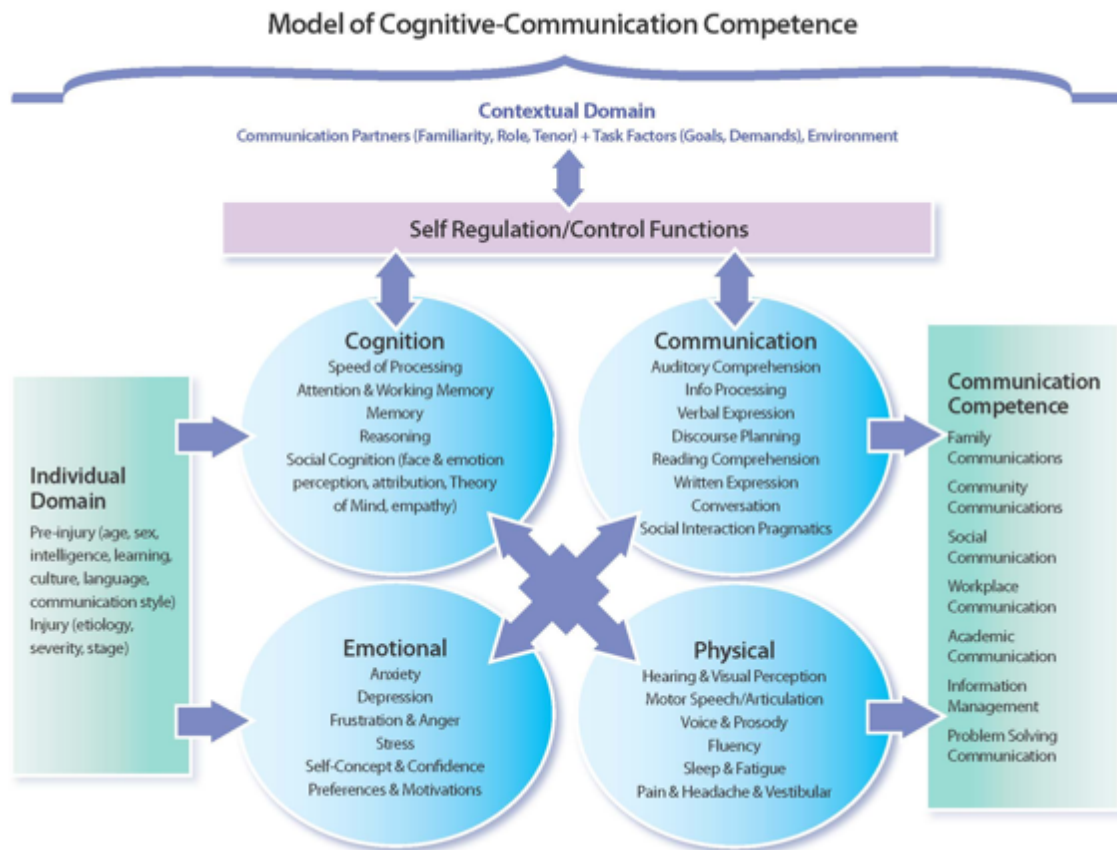


Figure 1: A model of cognitive-communication competence (MacDonald, 2017).

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The model could support and enhance SLPs’ dysphagia education and counselling interactions with TBI patients/families and potentially reduce communication breakdowns which can result in potential misunderstandings and non-adherence to

recommendations (CRICO, 2015; Krekeler, Broadfoot, Johnson, Connor & Rogus-Pulia, 2018).

Dysphagia diet nonadherence is problematic and costly. The impact of nonadherence with a dysphagia diet may include pneumonia, readmission to acute care, choking, and malnutrition (Finegold, 1991; Hammond et al., 2015; Hansen, Larsen & Engberg, 2008; Howle, Nott & Baguley, 2011; Langmore et al., 1998; MacKay et al., 1999a/b; Morgan, 1999; Murphy, 2012; Terré & Mearin, 2009; Vitaz, Jenks, Raque & Shields, 2003; Wang et al., 2013). The economic impact of treating pneumonia, a potential outcome of dysphagia diet noncompliance, has been estimated at \$1,000 per day of hospitalization (CASLPO, 2014). This nonadherence interrupts and prolongs the rehabilitation process.

Communication difficulties/misunderstandings are not exclusive to patient/family-SLP relationships; they frequently occur on interdisciplinary teams (CRICO, 2015).

Regardless of the mode and/or system by which case-based information is shared, assessment results and management plan information often is unrecorded, misdirected, never retrieved or ignored presenting a significant risk of harm in the presence of dysphagia (CRICO, 2015). Perhaps the use of a model that integrates the components for consideration in cognitive-communication competence in a visual way and which also integrates important considerations based on interdisciplinary fields of practice might facilitate collaborative conversations reducing communication breakdowns within the interdisciplinary teams (MacDonald, 2017).

The SLP in an IPR setting has a primary and critical role in the assessment and management of patients who have dysphagia, a TBI and cognitive-communication impairments. Optimal outcomes will be facilitated not only through an accurate assessment of the complex needs of the patient, but also through the efficient and effective communication of the results and the recommended and ongoing management plan(s) to patients, families, and the interdisciplinary team. This requires that SLPs use clear, easy-to-understand, efficient methods of communication including shared terminology during education and counselling with patients/families and their interdisciplinary team partners.

2.3 Aim of the scoping review

The aim of this scoping review was to summarize, disseminate and add to our understanding of what is currently provided in guidelines, peer-reviewed and grey literature about how SLPs enact dysphagia education and counselling with patients who have a TBI, especially within the context of IPR settings.

A scoping review, defined as “a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research” (Colquhoun et al., 2014, p.1292), was used for this work. The review was focused on mapping, reporting and discussing the enactment of education and counselling and, as such, made a scoping review more appropriate than a systematic review (Munn, Peters, Stern, Tufanaru, McArthur & Aromataris, 2018).

Since the 1990’s there has been an increased understanding of the importance of ‘systematic’ literature reviews to guide practice and policy. This does not mean however that all reviews of the literature should be ‘systematic reviews’ (Booth et al., 2016). It means that all reviews should follow well-defined, systematic, thoroughly documented approaches to knowledge synthesis that facilitate replication (Booth et al., 2016; Sutton et al., 2019). The types of literature reviews have continued to grow exponentially with Sutton et al., (2019) identifying 48 distinct review types. Two quite common types of reviews found in peer-reviewed journals are systematic reviews and scoping reviews.

Systematic reviews are usually undertaken to address more specific questions concerning the impact of interventions (i.e. population, intervention, comparison, outcome) (Tricco et al., 2016). They also are often undertaken “to confirm or refute whether or not current practice is based on relevant evidence, to establish the quality of that evidence, and to address any uncertainty or variation in practice that may be occurring” (Munn et al., 2018, p.2). Systematic reviews frequently analyze and synthesize the findings of studies which use experimental controlled designs such as randomized control trials so that the information can be used to develop clinical practice guidelines and to impact policy (Steinberg, Greenfield, Mancher Wolman & Graham, 2012). They often address questions

related to effectiveness/effects of interventions; accuracy of diagnostic tools; and intervention cost-benefits.

Scoping reviews provide researchers with a method for “knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research” (Colquhoun et al., 2014, p. 1292). They can be useful for presenting a broad overview of the evidence, irrespective of study quality (Tricco et al., 2016). They are also useful for identifying gaps in knowledge that can be useful for setting research priorities and agendas (Tricco et al., 2016). Scoping reviews use standardized and replicable procedures (Davis, Drey & Gould, 2009; Grant & Booth, 2009). One important limitation with the scoping review process is that findings are not scrutinized using a formal appraisal process and as such they may not provide support of the effectiveness of interventions.

For my thesis work, a decision was made a priori to conduct a scoping review of the literature because my aim was to obtain an assessment of potential size and scope of available research literature and to provide an overview of the evidence, irrespective of study quality, so that I could understand the enactment of education and counselling by SLPs with patients who have dysphagia and a TBI in the context of inpatient rehabilitation (Grant & Booth, 2009; Tricco et al., 2016).

Other review types may also have been appropriate, such as a narrative review (a ‘conventional’ review of the literature) or a realist review (what works for whom under what circumstances and contexts?) (Sutton et al., 2019). At the time of my dissertation work, methods for conducting a realist review were less detailed and available in published literature than methods for conducting a scoping review and methods for conducting a scoping review seemed a more thorough approach than a ‘conventional’ literature review. It may also have been possible that if the scoping review results provided significant literature which focused on measuring the effectiveness of education and counselling strategies, a follow-up systematic review could have been considered to address the effectiveness question. It was hypothesized after a preliminary literature

search that there were likely to be limited experimental control design studies published in peer-reviewed journals to conduct a systematic review at this time.

Arksey and O'Malley (2005) developed a six-stage methodological framework for conducting scoping reviews. This framework was clarified and enhanced by Levac et al., (2010), who identified the six stages as (1) identification of the research questions; (2) identification of relevant studies; (3) study selection; (4) charting of the data; (5) collation, summary, and reporting of the results; and (6) consultation. This scoping review used the first five stages proposed by Levac et al., (2010) and was also guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018).

2.3.1 Identifying the research question

This scoping review addressed the following question: How do SLPs enact education and counselling with patients who are experiencing dysphagia as the result of a TBI, especially within the context of inpatient rehabilitation settings?

The context of interest for this scoping review was inpatient rehabilitation because it is a fundamental part of the care pathway for many individuals with traumatic brain injury and is the context in which I work. The individual within the IPR context is more conscious, able to receive critical assessments, participate in intervention, and is becoming more aware of their impairments. I was not only interested in examining the IPR context as a physical location or pathway of care, but was also interested in understanding what the literature might offer about the experiences of SLPs providing education and counselling in this particular location and discovering information about the broader cultural influences that occur with interactions within this location (Bates & Ellaway, 2016). This might add to our understanding of the “high, hard ground where practitioners can make effective use of research based theory and technique, and a swampy lowland where situations are confusing “messes” incapable of technical resolution” (Schön, p.42, 1983).

2.3.2 Identifying the relevant studies

The following electronic databases were searched by an experienced medical librarian (L. Leff) in May 2016: CINAHL (1982- 5/2016), Cochrane Database of Systematic Reviews (1991 – 5/2016), EMBASE (1947 – 5/2016), MEDLINE (1946 – 5/2016), PyscINFO (1806 – 5/2016). A combination of subject headings and keywords were used to represent the main concepts of dysphagia, swallowing, brain injury and education (see Table 1). Automatic monthly search updates were monitored up to the end of May 2019. The medical librarian also conducted a search of the Evidence-based Review of Acquired Brain Injury (ERABI; erabi.ca) database. Citation tracking from relevant articles and a search of the grey literature was also conducted to identify additional sources of evidence.

Evidence-based clinical practice guidelines (CPGs) and practice statements from countries with practices similar to Ontario, Canada have been included as background documents in this review as SLPs dysphagia assessment and management practice behaviour is guided by the evidence contained within these CPGs/practice statements. The guidelines reviewed were produced by: The American Speech Hearing Association (ASHA, 2001; 2004), The College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO, 2014; 2018), The Royal College of Speech and Language Therapists (RCSLT, 2013), Speech Pathology Australia (2012), and Speech-Language Pathology and Audiology Canada (SAC, 2007).

Any type of study design (e.g., qualitative or quantitative methods) as well as essay, commentary articles were included. Literature search results were screened at the level of titles/abstracts and a content screen for initial eligibility criteria by the primary investigator (SMD). Relevant articles meeting the eligibility criteria were printed and the full articles independently reviewed by two authors (SMD and SM).

Peer-reviewed studies and grey literature met the inclusion criteria if: (a) they contained or discussed dysphagia assessment; (b) referenced traumatic brain injury; (c) subjects were adults 18 years or older; and (d) full articles were written in English. Studies were excluded if they focused on pharmacological interventions, biological research, pediatrics

or cerebrovascular accidents. There were no date restrictions/parameters placed as the documented study of dysphagia has occurred within the last 40 years.

Table 1: Subject headings and keywords used in literature search.

CATEGORY	TERM
DYSPHAGIA	Swallowing Problem Eating Malnutrition Dehydration
TUBE	Enteral Nothing By Mouth (NPO) Gastro-Jejunostomy (G-J) Nasogastric (N-G)
ASSESSMENT	Modified Barium Swallow (MBS) Fiberoptic Endoscopic Evaluation (FEES) Bedside Swallow Assessment
BRAIN INJURY	Acquired Brain Injury (ABI) Traumatic Brain Injury (TBI)
HEALTH CARE PROFESSIONAL	Speech-Language Pathologist (SLP) Registered Dietitian (RD) Occupational Therapist (OT) Medical Doctor (MD) Physician Nurse
COUNSELLING – WHO	Family Caregiver Substitute Decision Maker
COUNSELLING - HOW	Education Tool Timeline Instruction Guideline Print Material: Brochure Or Pamphlet E-learn/Online/Internet/Email/Telephone

Following Greenhalgh, A'Court and Shaw (2017), the final selection of included articles was based on an overarching question: Is this paper likely to add to our understanding of how SLPs enact dysphagia education and counselling with patients experiencing dysphagia and a TBI, especially within the context of IPR settings.

Data extraction was done independently by the primary investigator and research supervisor (SMD and SM) using an a priori agreed-upon process. The publication title, author(s), year of publication, and journal the publication appeared in was charted in an Excel spreadsheet. Each paper was carefully read in order to document and visually organize the results to highlight relevant concepts that added to our understanding of how SLPs enact dysphagia education and counselling with patients who also have a TBI. The data extraction sheet is included as Appendix B.

Neither a critical appraisal nor a risk of bias assessment was conducted, consistent with procedural requirements for conducting scoping reviews (Levac et al, 2010; Munn et al., 2018; Tricco et al., 2016).

2.4 Results

2.4.1 Literature Search

As shown in Figure 2, the database search identified 252 peer reviewed articles. An examination of reference citations identified 53 additional peer reviewed articles for consideration. Duplicates (n=13) were removed. After a review of titles and abstracts, an additional 191 articles were removed because they did not meet the eligibility criteria. One author (SMD) reviewed 101 articles to determine if they met the defined eligibility criteria. When unsure if an article met the criteria, the article was brought forward to the next stage where a second reviewer (SM) joined the process. After a full-text review of the articles, 84 were excluded with reasons. The 17 remaining articles were independently reviewed by SMD and SM. The two reviewers reached consensus that 10 articles either did not meet the eligibility criteria or did not contain content that would add to our understanding of how SLP's enact dysphagia education counselling in TBI population in an IPR setting. The final 7 articles were read independently by two authors (SMD and SM).

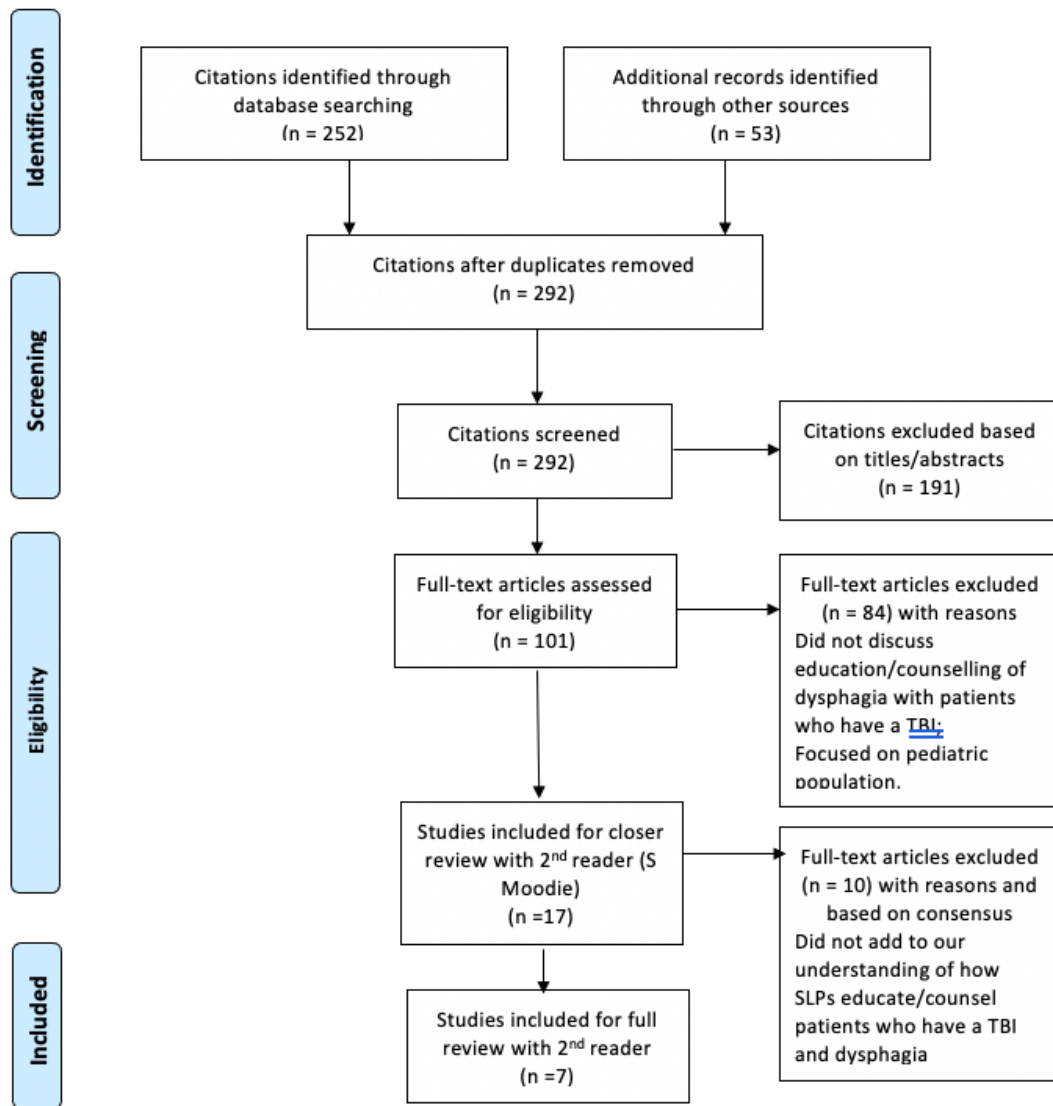


Figure 2: Results of the literature search.

2.4.2 Characteristics of the included studies and other documents

The articles and guidelines included in the review were published between 2001 and 2018. The countries represented through the publications were: Australia, New Zealand and United States. The types of studies and guideline-related documents included were: qualitative research studies (n=6), mixed methods studies (n=1).

2.4.3 Components present and important during SLP enactment of education and counselling in the area of dysphagia assessment and management for patients with a traumatic brain injury

As illustrated in Figure 3 below, the results of this scoping review identified six related components that are present and important during the enactment of education and counselling in the area of dysphagia assessment and management with patients who have a TBI. These factors are:

1. The SLP;
2. The patient;
3. The family members;
4. Other health care professionals (HCP) working in IPR settings;
5. Education and counselling materials;
6. Knowledge Translation (KT) components.

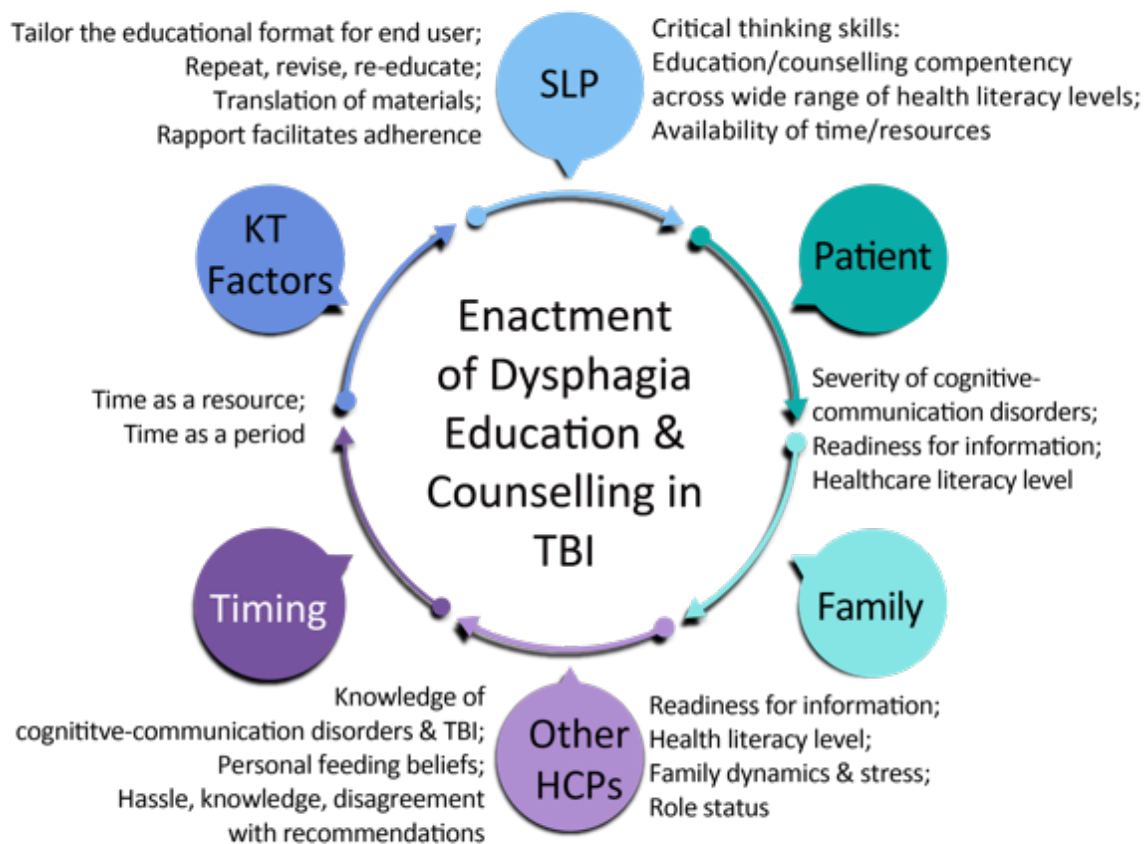


Figure 3: Six components that are present and important during the SLP enactment of education and counselling in the area of dysphagia assessment and management for patients with a TBI.

2.4.3.1 Component 1: The SLP

The adverse consequences that could occur due to improper assessment of dysphagia and communication of oral intake recommendations make it incumbent upon the SLP to effectively and efficiently communicate with the patient, the family, and other interdisciplinary team members throughout the time the patient is present in the IPR setting (CASLPO, 2014; Colodny, 2001; 2008; Foster et al., 2012; Howle et al., 2014; Pegg, Auerbach, Seel, Buenaver, Kiesler & Plybon, 2012; Pelletier, 2005; Short,

McCormack & Copley, 2014). The literature review revealed that SLPs working in IPR settings with patients who have dysphagia and a TBI must have, among other strengths, the following skills, knowledge and competencies: assessment/management of cognitive-communication disorders; assessment/management of dysphagia; ability to coalesce this knowledge into an assessment/management plan for the complex patient who has dysphagia and a TBI; development of individualized care plans for complex patients; working on multidisciplinary teams; and educating and counselling at differing health literacy levels across patient, family and multidisciplinary team members so that optimal swallowing outcomes are achieved.

In some patients with a TBI, the cognitive-communication disorder may determine the dysphagia assessment and management plan (Howle et al., 2014). Therefore, SLPs must be knowledgeable, skilled and competent in the assessment and management of cognitive-communication disorders as well as knowledgeable, skilled and competent in the assessment and management of dysphagia (Howle et al., 2014). They must merge this knowledge in applied practice in the IPR setting when working with patients who have dysphagia and a TBI (and possibly other impairments).

Research has also shown that some patients who have sustained a moderate to severe TBI and who are in an IPR setting can benefit from individualized cognitive interventions designed to enhance their sense of control and personal involvement in their care (Pegg et al., 2012). This requires knowledge, skills and competency on the part of the SLP to develop individualized dysphagia management plans with a patient who has a cognitive-communication disorder.

Developing individualized care/feeding plans can be time consuming and complex (Colodny, 2001) and SLPs must possess an appropriate degree of competency in plan development and educating and counselling this plan to differing audiences with varying capacities to process and understand the education information provided. This includes providing the education and counselling information at appropriate health literacy levels to the patient, family and interdisciplinary team members in order to positively affect

dysphagia management plan adherence (Colodny, 2001; Foster et al., 2012; Howle et al., 2014).

SLPs working in an IPR setting should possess effective listening and communication skills to be able to educate and counsel not only the patient, but also the family and all members of the interdisciplinary team. Poor communication of individualized care plans could put patients at greater risks for dysphagia-related complications such as bronchitis, pneumonia, dehydration, malnutrition, choking and even death (Colodny, 2001).

This scoping review underscores the importance of graduate-level education and system-level/organization-level continuing education opportunities for SLPs who wish to work in the area of dysphagia assessment and management. Results show that SLPs must be able to rely on their critical thinking skills and abilities to coalesce important information across various clinical practice guidelines and cognitive-communication disorder models. While clinical practice guidelines are critical documents for practice, similar to the CASLPO (2018) *Practice Standards and Guidelines for Dysphagia Intervention by SLPs*, they most frequently focus on providing guidance for a ‘single-condition’. This “single-condition” approach (p.1) is due in part to the difficulty of synthesizing good-quality evidence for every combination of complex conditions (Guthrie et al., 2012). This scoping review did not find clinical practice guidelines or other materials that had been systematically developed to assist SLPs working in IPR settings with patients that combined dysphagia and TBI assessment/management, education and counselling information. This is consistent with the findings in other areas of healthcare (Toman, Harrison & Logan, 2001).

2.4.3.2 Component 2: The patient

The review of the literature confirmed that SLPs working with people with dysphagia and TBI need to enact education and counselling within the seven domains of functioning that are affected by a TBI as reported by MacDonald (2017). This presents numerous complexities and challenges. The cognition, communication, emotional and physical impairments of the patient with a TBI often limit their ability to participate in the co-development of an intervention plan as well as in receiving education and counselling

about their dysphagia assessment results and management plan from the SLP (Colodny, 2008; Foster et al., 2012; Lazarus, 1987; Macdonald, 2017; Pegg et al., 2005; Short et al., 2014). The patient may not be able to access the social interaction skills necessary to appropriately give voice to their emotions and feelings about the proposed diet. Auditory comprehension, working memory and reasoning impairments may impact the patient's ability to engage in education and counselling with the SLP and raise the possibility for decreased adherence to recommendations and therefore increased risk of pneumonia, readmission to acute care, choking, and malnutrition. Short et al., (2014) and Pegg et al., (2014) recommended that SLPs assess each patient's readiness for information and healthcare literacy because lack of readiness for information or delivery of information at an inappropriate literacy level can lead to poorer outcomes. Short et al. (2014) reminds us that both readiness for information, and timing, are important considerations. Information provided to clients must be presented at an appropriate level and at a time in their rehabilitation when they are able to engage with and process information. One suggestion provided in the literature in terms of provision of quality information in this complex-care environment is to provide it "regularly in small amounts, using less complex language, multiple modes, repetition, employing visual aids such as pictures and diagrams" (Short et al., 2014, p. 225). Pegg and colleagues (2014) found that patients with TBI exerted greater effort and achieved more positive outcomes when the presentation of information to them was detailed and individualized.

2.4.3.3 Component 3: The family/caregivers

Family can be considered some of the most important members of the rehabilitation team; they provide information and take part in decision making along with (or on behalf of) the client, and they are emotionally invested in the client's care and outcomes (Foster et al., 2012). It is important to note that some patients may not have family available to assist them. When family is not available, the TBI patient is often placed in the position of performing the operations to comprehend, manipulate and retain the information presented regarding the proposed diet. SLPs should be aware that there is a two-way process of education occurring when working with family members; the SLP and other professionals are experts on TBI, and the family members are experts in the history and

life roles of the patient (Foster et al., 2012). It behooves SLPs to ensure that patient caregivers are adequately educated because post-hospitalized care may rely on them to ensure adherence to dysphagia management in order to obtain optimal outcomes (Foster et al., 2012; Howle et al., 2014). SLPs should have support staff available (i.e., social workers) and be prepared to discuss and manage the emotion and family dynamics that could arise when discussing the possible, and probable, change in the patient's role in the family and potential dependency on carers following the TBI (Howle et al., 2014). Family members who are better able to cope with the stress and possess the health literacy to comprehend the assessment and management strategies presented are more capable of facilitating knowledge-sharing with the patient who has dysphagia and TBI (Short et al., 2014). Therefore, it is incumbent upon SLPs to possess the knowledge, competency, receptiveness, flexibility and creativity necessary to manage family dynamics and to provide support and support-resources for the family (Colodny, 2008; Foster et al., 2012; Howle et al., 2014; Short et al., 2014). The family's readiness for information and health literacy are also components found within this scoping review that help SLPs understand what makes families more or less likely to be able to receive information from the SLP, and to be able to perform the necessary role of carer, supporter and advocate for the patient with dysphagia and a TBI (Colodny, 2008; Foster et al., 2012; Howle et al., 2014; Pegg et al., 2005; Short et al., 2014). Families may not be able to engage with and process information if they have had insufficient time to adjust to their loved one's injury (Short et al., 2014). Carers of adults with TBI have expressed concerns about the resources available for carers/families, and also expressed difficulty in obtaining information about the long-term consequences of TBI (Short et al., 2014). SLPs should ensure the dysphagia information that they provide family members contains specifics. This helps manage fears and concerns and decreases feelings of uncertainty (Foster et al., 2012; Howle et al., 2014). SLPs should also ensure that they provide appropriate time for questions and provision of answers (Short et al., 2014). Receiving health information in an understandable format and at a level that is appropriate for a person's health literacy level has been shown to lead to more positive outcomes (Colodny, 2008; Howle et al., 2014; Short et al., 2014). Howle et al. (2014) recommend that guidance for the family include the use of short verbal and/or simply written

instructions without including abstract language. They also suggest family education and training programs in feeding techniques, understanding the implications of nonadherence, and provision of individualized management strategies that work for the patient with dysphagia, as well as the family.

An interesting finding from the literature review was a discussion around role status between the SLP and patient/family members who are more affluent non-health professionals (NHPs). Colodny (2008) found in a study that used the Caregiver Dysphagia Mealtime Questionnaire (CMDQ) that, the higher their income, the more the NHP disregarded the recommendations and care advice of the SLP, generally because the affluent NHP felt that they were more informed about the patient's needs than the SLP. This may be related to the fact that the NHP may have a work-related higher role status because of their expertise and knowledge in their career-related area and they may perceive a higher role status than the SLP. This led to a recommendation that, when collaborating with family carers who are more affluent NHPs, SLPs should stress their medical-related background, expertise and knowledge base in the areas of TBI and dysphagia and ensure that the family understands that they are familiar with the needs of, and care required by, the patient with a TBI and dysphagia (Colodny, 2008).

Family carers who visit the patient less frequently may feel guilty and/or forget the management strategies in place for the patient with dysphagia and TBI (Colodny, 2008). Feelings of guilt and/or forgetfulness may result in less adherence to the management plan, and more feeding of restricted foods than carers who visit more frequently. Therefore, it is suggested that NHP caregivers who visit infrequently should be provided with counselling and repetitious dysphagia management instruction (Colodny, 2008).

2.4.3.4 Component 4: Other HCP working in IPR settings

Nonadherence by HCP to SLP recommendations for thickening liquids and other dysphagia and feeding interventions can put patients at greater risks for complications such as bronchitis, pneumonia, dehydration, malnutrition, choking and even death (Colodny, 2001). Colodny (2001) has created a 21-item survey instrument called the Mealtime and Dysphagia Questionnaire (MDQ). The MDQ can be used in healthcare

settings to provide reliable and valid indicators of nonadherence to SLP dysphagia management recommendations. It was used by Colodny (2001) to examine the adherence rates between registered nurses (RNs), Licensed Practical Nurses (LPNs), and Certified Nursing Assistants (CNAs) with SLP dysphagia management recommendations. The MDQ measures three components: hassle, knowledge of feeding techniques, and disagreement with recommendations of the SLP. Results of the initial study using the MDQ indicated that, for dependent feeders, nursing staff were routinely nonadherent with SLP recommendations for dysphagia management plans, with RNs having greater nonadherence than the CNAs. It should be noted that this study was conducted in one relatively large nursing-home setting located in a large metropolitan area in the United States leading the author to recommend additional research be conducted. Interestingly, it was hypothesized by Colodny (2001; 2008) that perhaps RNs might view the dysphagia-related feeding tasks outside of their purview and their perception of the status of the RN in the hierarchy of care, increasing their hassle, knowledge and disagreement components and adherence to SLP recommendations. In another study healthcare providers were observed to follow nothing-by-mouth (NBM) recommendations 100% of the time (Rosenvinge & Starke, 2005).

Colodny (2001) recommended that, because of the negative impact of nonadherence to the patient and burden on the health system, on-going educational initiatives with appropriate monitoring should be required to improve adherence by HCPs to SLP recommendations for thickening liquids and other dysphagia and feeding interventions. Rosenvinge and Starke (2005) found that the creation and delivery of individualized training programs (e.g., The Dysphagia/Nutrition Link Nurse program), targeting various HCPs who had contact with patients, educated and empowered them, resulting in increased adherence to SLP dysphagia-management recommendations. Pelletier (2005) also provided evidence that individualized training programs may be effective in changing practice behaviour. Her findings indicated that CNAs feed residents based on their personal feeding beliefs (social feeding versus technical feeding) and not only on their knowledge; further, their practice behaviour may be modified when presented with knowledge and information that acknowledged and helped them incorporate their beliefs into practice.

2.4.3.5 Component 5: Time as a resource and time as a period

This review revealed that time as a resource (the SLP's time) and time as a period (time since TBI) are both important components that add to our understanding of how SLPs enact education and counselling in the area of dysphagia management with patients who have a TBI.

The need for, and importance of, relevant and individualized education and counselling materials for patients, for family and for other HCPs was cited frequently in our review of the literature (Colodny, 2001; 2008; Foster et al., 2012; Howle et al., 2014; Pegg et al., 2012; Pelletier, 2005; Short et al., 2014). This means that SLPs should possess competency in developing such materials, and knowledge of ways in which to produce and disseminate this information to the appropriate audience (i.e., infographics). They also should be able to develop materials that facilitate understanding and recall (Short et al., 2014). The creation of these important materials occurs in organizations and healthcare systems that are experiencing caseload pressure and staffing levels such that there is a reduction in time, or non-existent workplace time available for SLPs to do these important tasks (Short et al., 2014).

Cognitive-communication impairments (CCIs) are some of the most debilitating and complex consequences of a TBI with a reported incidence greater than 75% (Blake et al., 2013; MacDonald, 2017; Short et al., 2014). CCIs increase the likelihood that an individual will experience difficulty with emotional adjustment, insight, readiness for information and health information understanding (Foster et al., 2012; Howle et al., 2014; Pegg et al., 2012; Short et al., 2014). Time to come to terms with, and adjust to, the complex set of impairments that may exist helps develop readiness for information for the patient and for their caregivers (Foster et al., 2012; Short et al., 2014). Patients and caregivers must be provided with the time and opportunity to ask questions (Short et al., 2014) and to discuss their own feelings and develop realistic expectations during their loved one's recovery (Foster et al., 2012). Over time, the needs of the patient and family will change as they respond to rehabilitative efforts and or adapt to living with a TBI (Foster et al., 2012). It is also important that the SLP, caregivers and other HCPs repeat,

revise and re-educate as necessary (Foster et al., Howle et al., 2014; Pelletier, 2005; Short et al., 2014).

2.4.3.6 Component 6: Knowledge translation (KT) Components

Six other components related to education and counselling were located and noted in the scoping review of the literature:

1. It is imperative that all end-users (other HCPs, patients, caregivers) are provided with written and verbal instructions, and that these instructions are tailored using visual cues, simplified language, and step-by-step instructions as needed (Howle et al., 2014; Short et al., 2014). Information appropriately formatted and received by the end-user leads to empowerment (Short et al., 2014) and to understanding (Pelletier, 2005). Patients who received tailored, individualized information were more satisfied with their communication with HCPs and other aspects of their care (Pegg et al., 2012).
2. It may also be useful for patients to use perform-and-recall methods (such as teach back/ talk back) as a way to ensure information is being provided at an appropriate health literacy level and to assist patients in learning a new sequence of actions (related to swallowing; Howle et al., 2014).
3. Concrete plans for next steps, with the patient and family should occur (Foster et al., 2012).
4. All materials should be translated into languages as necessary (Foster et al., 2012).
5. Rapport helps SLPs know when information is required and builds trust in information received by patients and families (Short et al., 2014).
6. Finally, SLPs should have the competency and knowledge to appropriately document what steps they took (ex. caregiver education and counselling) when readiness for information was not achieved by the patient with TBI (Short et al., 2014).

2.5 Discussion

The objective of this review was to develop an understanding of how SLPs enact education and counselling with patients who are experiencing dysphagia and also have a TBI, especially within the context of inpatient rehabilitation settings.

Results of this scoping review of the literature revealed that education and counselling of the patient, family, and interprofessional healthcare providers is multi-dimensional, iterative, complex and that strategies for effective and efficient education and counselling are not readily available.

The scoping review suggested that SLPs working in IPR settings with patients who have dysphagia and a TBI must have, among other strengths, the following skills, knowledge and competencies: assessment/management of cognitive-communication disorders; assessment/management of dysphagia; ability to coalesce this knowledge into an assessment/management plan for the complex patient who has dysphagia and a TBI; development of individualized care plans and associated materials for complex patients; working on multidisciplinary teams; and educating and counselling at differing health literacy levels across patient, family and multidisciplinary team members so that optimal swallowing outcomes are achieved. These skills, knowledge and competencies may be emerging for new SLP practice registrants and it would be helpful for them to learn, prior to entering this practice context, how they come together in the counselling and education of this patient population and their families. Howle, Baguley & Brown (2014) present the importance of short verbal instructions and avoidance of abstract language. This seems especially important when considering MacDonald's (2017) cognitive-communication disorder model. Interpreting medical terminology and concepts that are important to dysphagia education and counselling into lay language is an important skill that may improve with practice experience.

The enactment of education and counselling should be individualized for the patient and the family (Colodny, 2001; 2008; Foster et al., 2012; Howle et al., 2014; Pegg et al., 2012; Pelletier, 2005; Short et al., 2014). Education and counselling information should be individualized, detailed, presented regularly and repeatedly, in small doses, revised over time, using less complex language, and multiple modalities. Perform and recall methods of education and counselling may prove beneficial especially in contexts where assessment of health literacy levels is not possible (Howle et al., 2014). SLPs should have the competency and knowledge to appropriately document what steps they took (ex.

caregiver education and counselling) when readiness for information is not achieved by the patient with TBI (Short et al., 2014).

Families are an integral part of the care team. Family involvement in education and counselling is crucial for compliance with therapy within IPR and at discharge (Howle, Baguley & Brown, 2014). Education and counselling for families should include the use of short verbal and/or simply written instructions without including abstract language. Optimal outcomes might be better achieved through family education and training programs in feeding techniques, understanding the implications of nonadherence, and provision of individualized management strategies that work for the dysphagic patient as well as the family. All education and counselling materials should be provided at appropriate health literacy levels and translated into other languages as necessary. An unanticipated finding in the literature was the significance of family relationships and power. The review results recommended the inclusion and involvement of families post TBI and described the stress the family members endure and which should be attended to by the SLP (Foster et al., 2012). The TBI population, and their families, may require more “receptiveness, flexibility and creativity than in more medical models of rehabilitation” (Foster et al., 2012, p. 1860). Dependency needs arising from the TBI and dysphagia may change roles within a family (Howle, Baguley & Brown, 2014). The academic and professional preparedness on the part of the SLP must be present for education and counselling to be conducted amidst such family dynamics. A practice wisdom, awareness of professional scope of practice and an awareness of facility resources may be required by the SLP to navigate these scenarios.

The concept of interpersonal dynamics was highlighted by Colodny (2008) who found that more affluent non-health professionals, who are family members of a patients with dysphagia and TBI, may challenge and disagree with SLP’s education and counselling recommendations. Colodny offers that the SLP in this scenario would require a high degree of professional wisdom and confidence to address this power imbalance. Power was also a factor in Foster et al. (2012) who stressed the importance of addressing the “perceived power imbalance between rehabilitation professionals and family members”. What we did not learn in this review was how SLPs address these power imbalance

situations when education and counselling in those situations where it exists. The SLP would require the resource of time, access to other HCPs and access to documentation to navigate this terrain and to learn about the documented family dynamics, if in fact these dynamics have been documented. The power differentials do not exist only within family-SLP relationships; Colodny (2001) discusses the power differentials on healthcare teams and how they may impact care. Unless there is leadership support for continued HCP education and ongoing inter-disciplinary team communication, the SLP may be unaware of these disagreements with recommendations.

SLPs should also participate in, and advocate for, education (and continuing education) of the interprofessional healthcare providers on their team. The creation of individualized training programs (e.g., The Dysphagia/Nutrition Link Nurse program), targeting various HCPs who had contact with patients, educated and empowered them, resulting in increased adherence to SLP dysphagia-management recommendations (Rosenvinge & Starke, 2005). In addition, a model such as the one described by MacDonald (2017) may provide SLPs working in IPR settings with TBI patients with a consistent and efficient means for assessing and describing their patients cognitive-communication competency for interprofessional team members (Hinckley, 2014; Norman et al., 2013; Turkstra et al., 2015).

To achieve the outcome of “optimizing the individual’s ability to swallow and thus improve their quality of life” (CASLPO, 2014, p. 3), the SLP working in IPR settings should have access to appropriate assessment/education and counselling materials that can be used across a wide range of health literacy levels (the patient, the family, other HCPs) and be trained on how to use them. This could be facilitated by having access to a resource ‘library’ of materials that have been proven to be effective/efficient for SLPs educating and counselling patients and their families within IPR settings. There is evidence available regarding effective methods for developing education material and programs for education that take these important considerations into account (Toman et al., 2001). A resource library where education materials have already been translated into other languages than English might also help offset the cost of translating materials for individual healthcare organizations. A resource library of optimal education and

counselling materials might also assist SLPs who are often working in organizations and healthcare systems that are experiencing caseload pressure and staffing levels such that there is a reduction in time, or non-existent workplace time available for SLPs to develop appropriate and individualized education and counselling materials for the patient, the family and the interprofessional team.

Several gaps exist in the current literature leading to the following six questions: (1) What strategies for counselling and education have SLPs found effective and efficient with patients who have dysphagia and a TBI?; (2) How might optimal outcomes of education and counselling be measured?; (3) How are SLPs measuring health literacy in patients with TBI?; (4) How are they measuring health literacy for family members and HCP teams?; and (5) How might power differences be addressed within this practice context?, and (6) How are the tenets of patient-centered care and shared decision-making implemented within this complex patient-SLP partnership?

2.6 Study Limitations

There are several limitations with this research. The articles reflect the search terms and keywords used. The literature search was facilitated by a research librarian using best practices, but all relevant articles may not have been found. Although I tried to examine numerous appropriate databases, may not have included all relevant peer reviewed or grey literature in this review. Articles available in English were the only articles included in this review. There was only one article that addressed the combination of dysphagia and TBI (Howle et al., 2014). The other articles discussed dysphagia and TBI in lesser detail and were used in combination with the MacDonald (2017) model to add to our understanding. Quality appraisals and risk of bias of the evidence was not conducted. Given this, the implications for clinical practice and/or for policy-making are limited (Munn et al., 2018).

2.7 Conclusion

This scoping review provides information on six important components that need to be considered during the enactment of education and counselling in the IPR setting for patients with dysphagia and a TBI. These include the SLP, the patient, family members, other interprofessional team members, educational materials and methods for translating knowledge. There is a paucity of accessible, evidence-based, comprehensive methods that are patient and family-focused for enacting education and counselling with patients who have dysphagia and a TBI. This lack of information may create clinical uncertainty in practice (Uhlig et al., 2014). Single-condition CPGs, while helpful, reportedly lack the specificity in recommendations some clinicians are looking for in complex clinical practice (Nelson et al., 2016). Therefore, there appears to be a need for the collaborative development of a patient/family/interprofessional team education program that could be used in an IPR setting to educate and counsel patients who have dysphagia and a TBI, their families and the interdisciplinary team working with them. Results of this review reinforce Leslie (2016) and Rosenbek's (2017) recommendations for a re-examination of current clinical dysphagia practices in the areas of education and counselling.

Several areas for future research were identified including (1) understanding how SLPs in IPR settings enact dysphagia education and counselling for patients who have dysphagia and traumatic brain injury; (2) understanding how a model such as the cognitive-communication model of communication competence might be utilized by interprofessional teams working with patients and families who have dysphagia and TBI; (3) measuring the health literacy levels of patients, family members and interprofessional team members; (4) measuring the health literacy levels of materials used during education and counselling; and (5) identifying effective strategies for measuring readiness for dysphagia assessment and management information for patients with cognitive-communication disorders.

Chapter 3 Methodology: Hermeneutic Inquiry

3 Hermeneutics and practice-based research.

Qualitative research uses a wide range of approaches to enable access to people's subjective worlds and meanings, and to marginalized and often invisible groups (Braun & Clarke, 2013). It uses techniques that “describe, decode, translate, and somehow come to terms with the meaning, rather than the measurement or frequency of phenomena in the social world” (Rowlands, 2005, p.81). In preparing to undertake this thesis work, I considered a variety of potential approaches to conducting the research through coursework and independent study. Two methods were initially considered: case study research (Yin, 2014) and constructivist grounded theory (Charmaz, 2014). A multiple case-study research approach would have been appropriate for this work because it “investigates a contemporary phenomenon (the “case”) in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident” (Yin, 2014, p. 16). A decision to not pursue this method was made to ensure anonymity of participants from the relatively small practice context in which the study took place. Aspects of case study research may still be apparent in the work. I spent one summer researching and being mentored by a peer who had used constructivist grounded theory as a method for his thesis work. My aim was not to develop a theory of counselling and education but to develop an understanding of how SLPs enact education and counselling in the specific context of IPR settings with patients who have dysphagia and a TBI. Hermeneutic inquiry was chosen as the qualitative approach for this work because it enables the opportunity to acknowledge and explore SLPs understanding and interpretations of how they are enacting education and counselling in dysphagia management with TBI individuals, within the real-life settings and contexts of inpatient rehabilitation settings in the province of Ontario. This chapter offers a brief history of hermeneutic inquiry to assist readers to better understand the methodology employed in this research, as well as the assumptions informing this work.

Hermeneutics is humble, acknowledges the situatedness of researchers and participants, and respects practice-based knowledge. Moules et al. (2015) note that practices can go “unnoticed and unexamined, lost to discourse, assumption and involvement; often they

remain in a state of being taken for granted” (p.75). Hermeneutic inquiry provides an approach to better understand clinical practice. It has been used to study professional practice in multiple disciplines (Karlsen, Moe, Haraldstad & Thygesen, 2018; Laing, 2014a/b; McAffrey, Raffin-Bouchal & Moules, 2012; Moules, 2009a/b; Moules, McAffrey, Morck & Jardine, 2006). Gadamerian hermeneutic inquiry is useful for practice-based SLP research for a variety of reasons. Firstly, it allows practitioners perspectives to be included and centred in-the research process and allows for clinically important topics to lead the direction of the research. A priori knowledge of the topic is recognized in Gadamerian hermeneutic inquiry, allowing the clinician-researcher to explicitly situate themselves with respect to the topic, to deepen their understanding of the topic, and to balance their own understandings with what might be learned (Moules et al., 2015; Thirsk & Clark, 2017). Secondly, this applied approach to hermeneutic inquiry seeks to advance understanding of the phenomenon through interpretation. Interpretation is about understanding what participants have to say about the topic that points to a new or different understanding of the topic and allows a path for contradictory findings to be reconciled (Crist, 2018; Moules et al., 2015; Thirsk & Clark, 2017). Finally, participant perspectives are not the only way that a topic can be understood. Other materials, such as literature or theory are recognized as potentially assist with understanding what is going on in hermeneutic inquiry (Jardine, 2000; Moules et al., 2015; Thirsk & Clark, 2017). This is important because often clinical questions are best described through language, text, visualization(s) and other clinically relevant information.

3.1 Historical underpinnings of hermeneutics

In this chapter I present a detailed account of the hermeneutic approach to inquiry adopted for the study. I begin with an overview of historical trajectories and philosophical underpinnings of hermeneutics to show the evolution of the approach, and to situate my methodology in a Gadamerian informed, applied approach developed by Moules, McCaffrey, Field & Lang (2015).

Hermeneutics is often defined as the art of interpretation (Kinsella, 2006). It originated in attempts to understand texts, particularly theological texts, and has over time been applied to theorize interpretive acts more broadly speaking (Gadamer, 1960/2013). The

word hermeneutics has commonalities with the Greek verb “*hermeneutica*” which is to explain or to interpret (Schmidt, 2006). Perspectives on hermeneutics have evolved and shifted over time based on distinct historical and philosophical discussions. Given that hermeneutic inquiry is a relatively new approach to scholarship in the health professions, a brief overview of the historical development of hermeneutics is offered to assist readers in understanding important aspects of the philosophy of hermeneutics underpinning this study (Moules et al., 2015). Philosophers such as Schleiermacher (1768-1834), Dilthey (1833-1911), Husserl (1859-1938), Heidegger (1889-1976) and Gadamer (1900-2002) have defined, discussed and expanded our understanding of hermeneutics (Schmidt, 2006).

3.2 A Brief History of Hermeneutics

3.2.1 Friedrich Schleiermacher (1768-1834)

Schleiermacher is often referred to as the father of modern hermeneutics. Prior to this, classical hermeneutics had focused on the written word only, Schleiermacher brought focus to language, dialogue and the spoken word (Moules et al., 2015; Schmidt, 2006). Schleiermacher contrasts hermeneutics as the art of understanding with the art of speaking (Schmidt, 2006). Schleiermacher presented a goal of hermeneutic practice as understanding the intentions or that which has been expressed by another, to gain or grow in understanding of the other (Schmidt, 2006). Schleiermacher’s view of hermeneutics suggested that both the psychological and technical applications must be attended to. Psychological in that it is an attempt to understand the thinking and meanings of the author. Technical in that one attempts to understand how the author’s thoughts are expressed in their writing. Schleiermacher described that as one cannot have a thought without words, he preferences the technical (grammatical, written expression) before a psychological (thoughts of the author) interpretation (Schmidt, 2006). Gadamer’s views aligned with Schleiermacher in recognizing the importance of language, however he did not agree with the concept of psychological interpretation, arguing that the author’s original ideas could never be reconstructed (Moules et al., 2015).

3.2.2 Wilhelm Dilthey (1833-1911)

Dilthey offered a different vision for hermeneutics than Schleiermacher, one with a focus on history and methods (Moules et al., 2015). Dilthey was writing at a time when the natural (explaining) sciences were favoured for research. Dilthey thought this method an inconsistent model for interpreting the human (understanding) sciences. Dilthey proposed hermeneutics to provide a unification of these sciences (Moules et al., 2015, Schmidt, 2006). He discussed that theories in the human sciences require their own methodology, which he termed understanding (*Verstehen*) as opposed to explanation (*Erklären*).

Dilthey's hermeneutics proposes a theory, oriented toward rules for interpreting written work, he theorized that language is the form of communication most able to express inner life and the lived experience (Moules, 2002; Schmidt, 2006). Dilthey and Schleiermacher both focused on hermeneutics as rules for interpreting and understanding written documents or texts. Dilthey had hoped for prescriptive rules for hermeneutics that did not materialize (Moules et al., 2015). Gadamer did not accept the concepts (human science methods versus natural sciences methods) proposed by Dilthey for his vision of a hermeneutic approach. He argued instead for the universality of the hermeneutic method (Kinsella, 2006).

3.2.3 Edmund Husserl (1859-1938)

Husserl is viewed as a founder of phenomenology. He shared a view with Dilthey that natural sciences were superior to the human sciences (Gadamer, 1960/2013). He highlighted the importance of bracketing assumptions and presuppositions about that which we know, something known as the phenomenological reduction. Husserl believed that this type of reduction could allow for an examination of the phenomenon's core. He believed that through a careful method of peeling back the layers of appearances one could get to the true nature of things, established as permanent characteristics or structures (Schmidt, 2006). Husserl discussed two different types of attitudes. One is a natural attitude towards the world around us that is an awareness where we do not question but accept phenomenon as they are. This is *Lebenswelt* or "lifeworld". The second is a phenomenological perspective where the phenomena are not just accepted as is, but complicated and questioned (Moules et al., 2015). This type of phenomenology

attempts to bracket out pre-understandings to get to the essence of the phenomenon, interpretation is bracketed as one suspends all preconceptions and bias (Moules et al., 2015). Others following Husserl have questions if this pure reduction of the phenomenon is possible. Gadamerian hermeneutic inquiry for instance, encourages interpreters to recognize that preconceptions shape interpretations and can never be fully put aside in the quest for understanding.

3.2.4 Martin Heidegger (1899-1976)

Heidegger was a student of Husserl; however, he did not agree with the approach of Husserl towards bracketing one's assumptions. He discussed this to be implausible due to our presence in the world. He pointed out that we are in the world and have developed our understandings from being in the world, and these experiences cannot be separated from us (Moules et al., 2015). A Heideggerian approach to hermeneutics acknowledges the historicity and positionality of the author (Schmidt, 2006). Heidegger, drawing from Aristotle, was concerned with the truth of what is said "aletheuein" or the "unconcealing" of what is concealed or hidden (Schmidt, 2006). A central concept, in Heidegger's work is "Dasein" which means to be there/ being in the world/being human. The "how" of our being is our manner of living; the active living of life. He proposed that interpretation should include the parts and the whole of an experience. This builds on the foundation that was posited by earlier philosophers such as Schleiermacher, and towards the hermeneutic circle (Moules et al., 2015). Truth for Heidegger was different than from that of his teacher, Husserl. Heidegger's truth was the lived experience *interpreted*; not bracketed and decontextualized (Moules et. al, 2015).

3.2.5 Hans George Gadamer (1900-2002)

This study is based on a Gadamerian philosophy of hermeneutics. Gadamer was a student of Husserl and Heidegger and furthered their work. He believed among other things that meaning and understanding is universally facilitated through language, but this meaning and understanding is finite. For Gadamer, understanding is achieved through identification of historicity and by pre-fronting of prejudices (i.e., making assumptions and preconceptions explicit). For Gadamer, understanding of a topic is not arrived

through a method, but through the listener being prepared for dialogue and conversation and “keeping oneself open” to other points of view about the topic. As such, he conceptualizes important understanding(s) as occurring through ever widening circles; by moving from whole to part and from part to whole (Gadamer, 1975/2013; Schmidt, 2006., Moules et al., 2015).

In the next section, some of the key elements of Gadamerian hermeneutic inquiry incorporated by Moules et al. (2015) in their approach to conducting hermeneutic research are described to introduce readers to the terms that informed the design and conduct of the study and which are used throughout the thesis.

3.2.5.1 Universality and Finitude

Two important concepts for applied hermeneutic inquiry are universality and finitude. To live in world of meaning, a universal world, is to live in a world that is understood and interpreted through language (Moules et al., 2015). Understanding often emerges through participation with another in dialogue. However, and because “language is endlessly proliferative, any given word, statement, text or interpretation is finite within the world of meaning” (Moules et al., 2015, p. 36). In other words, the research has to start somewhere and finish somewhere, while the topic of inquiry continues on – beyond the interpretation (Moules et al., 2015).

3.2.5.2 Historically-Effectuated Consciousness

“The openness of a question is not a total openness” (Gibson, 2017, p. 46). Our historicity informs the initial position from which we start to experience and interpret a topic. Our history, context, and culture are embedded in us and this historically-effectuated consciousness is said to be present in our thoughts and conversations (Moules et al., 2015). In applied hermeneutic inquiry, our historically-effectuated consciousness is acknowledged as important. When we become aware of and acknowledge our history and the context in which we are already a part, then we can begin to critically think about and evaluate that history and be open about where to go next (Moules et al., 2015). Recognizing our historically-effectuated consciousness means that we do not come to our research topic as blank slates and we must respect and be aware of this historicity in our

work (Moules et al., 2015). This is why it is important that I consider how my historicity shapes this work and my interpretations, and why my experience as a SLP with over 20 years of experience working with patients who have a TBI and dysphagia, and as a peer assessor for the regulatory College of SLPs in Ontario, are essential to acknowledge.

Hermeneutic inquiry also requires that researchers be aware and responsible for understanding the topic of interest and its history. There is a temporal element to hermeneutic inquiry and the topic of interest collects more of a history as each day passes. Moules et al. (2015) state that “We can consciously do our best to clarify our understanding from within the flux, but what we cannot do is step out of history” (p. 38).

3.2.5.3 Prejudices/Preunderstandings

Consciousness is influenced not only by our history but also by what Gadamer refers to as ‘prejudices’ (Moules et al., 2015; Schmidt, 2006). Prejudices, in Gadamerian hermeneutic inquiry, are the prior and existing understandings that we bring to a topic (Crotty, 1998; Moules et al., 2015). This prejudice is the context in which we will accommodate new understandings of the topic of interest. For Gadamer, these prejudices are integral to our interpretations because they are the reality of our being and the basis for our being able to understand history at all (Moules et al., 2015). In applied hermeneutic research interpretation occurs in dialogue and it is our prior and existing understanding of a topic that gives us something to say in dialogue with a new experience (Moules et al., 2015). Thus, we do not hold our historically-effected consciousness or preunderstandings back, rather we think with them, acknowledge them and situate them in our understandings (Moules et al., 2015). Given that prejudices are always present in hermeneutic inquiry and understanding, what is critical for the process is that the researcher engage in initial and ongoing reflexive examinations of their prejudices (i.e., assumptions and pre-understandings), ensuring that one remains open to the meaning of the other person’s language or text, thereby being open to possibilities of surprise regarding one’s own prejudices (Crist, 2018; Moules et al., 2015).

3.2.5.4 Fusion of Horizons

“To acquire a horizon means that one learns to look back beyond what was lost at hand- not in order to look away from it but to see better, within a larger whole and in truer proportion” (Gadamer, 1960/2013, p. 316).

Interpretive understanding occurs through an active coming together in conversation/dialogue, which includes our history and prejudices about a topic being examined, and an openness to the meaningful possibilities of the other person or text, thereby allowing a formation of a new understanding, and what Gadamer refers to as a fusion of horizons, to occur (Gadamer, 1960/2013, Moules et al., 2015). As stated earlier, from a hermeneutic perspective this understanding is not finite, nor is it the only correct meaning. Time, our situatedness, and tradition inform the limits of our interpretation (Moules et al., 2015; Trede, Higgs & Rothwell, 2009). Our understanding is constantly evolving over time as we add knowledge to our interpretations and begin anew each time we engage with the topic (Moules et al., 2015). The fusion of horizons between people involves the coming together of their history, prejudices, language and by extension conversation (Moules et al., 2015). It is important to note that the

“term neither implies that one side surrenders understanding to the other, nor that the fusion involves complete sublimation of both ... there are many possibilities of combining and blending our prior understandings or holding onto differences – but in a new constellation in relation to each other” (Moules et al., 2015, p. 49).

3.2.5.5 Alethia: Unconcealment/Understanding

Through conversation, text and other supporting materials, openness to the potential of possibilities in the process of understanding is referred to in hermeneutic inquiry as alethia (Moules et al., 2015). Alethia is a Greek word meaning “the event of concealment and unconcealment” (Caputo, 1987, p. 115). Alethia occurs where new or unconcealed understandings are revealed. The understanding could be new, or it could be an “enlivening and remembering of something that was forgotten, lost, or left” (Moules, 2012, p. 3). Moules (2015) suggests that this process of understanding encourages us to

remember why it is that certain things matter and to bring these things alive in the present.

3.2.5.6 Hermeneutic Circle

A discussion of hermeneutic inquiry is incomplete without discussing the metaphor of the hermeneutic circle. Gadamer's hermeneutic philosophy further developed the concept of the hermeneutic circle proposed by Schleiermacher emphasizing that it is best understood as an exercise in moving understanding in ever widening circles by moving from whole to part and from part to whole. The hermeneutic circle begins with what intrigues us and what fuels our interest. Once we enter the hermeneutic circle our position is forever altered (McCaffrey, Raffin-Bouchal & Moules, 2012). Being in the circle involves a dynamic, iterative process of reading, writing, discussing, reflecting on understanding through the language, text, visuals and/or other materials important to the topic (Moules et al., 2015).

In her doctoral thesis, Catherine Laing (2013) describes what occurs throughout the hermeneutic circle in an understandable way. "Occasionally, the complexity and beauty of a piece of art is best appreciated by looking at its parts, then stepping back and looking at the whole, then looking at another part and stepping back to once again look at the whole" (p. 38).

The metaphor of the hermeneutic circle can be applied in various ways in this thesis work. First, on an individual interview basis a hermeneutic interpretation of the text of the interview and the supporting materials of each clinician is undertaken by reading the whole of the text/materials, stepping back to gain understanding looking at the individual parts, then looking back again with reference to the whole interview. Interviews are read, re-read and interpreted, through an iterative process of circling, memoing and diagramming, and coming back to develop an understanding of the topic. Next, moving from individual data, there is an examination of the collective interview data in a similar hermeneutic circle method. A dynamic, iterative approach is used once again to develop an understanding of the topic based on the multiplicity of perspectives offered by the SLPs, looking across all the various parts and then again looking back to reference the

whole topic in an effort to develop an ever-widening understanding, often uncovering things which may not have been initially visible (Moules et al., 2015). Finally, across this doctoral research project, I have engaged in a hermeneutic circle through recognition of my own history and prejudices as an interpreter (Asselin, 2003; Finefter-Rosenbluh, 2017), a growing appreciation of the complexity of the patients we see, moving forward to a review of the literature, then to interviews, then to a representation of the findings, all the while engaging in dialogue with my doctoral research committee. In my discussion chapter I have aimed to bring the parts together into a representative whole and to consider the relevance to SLP practice, while recognizing this as a finite interpretation of the topic.

Figure 4 provides a visualization that may assist in understanding the Gadamerian hermeneutic inquiry used in this thesis from my personal experience. I began my doctoral research with a practice history (more than 20 years) immersed as a SLP in the topics of TBI, dysphagia and with a desire to better understand the enactment of education and counselling of dysphagic patients within the IPR setting. The hourglass at the centre of the figure depicts that consistent with hermeneutic inquiry our understanding is constantly evolving over time. We bring our practice history, insidership, prejudices and pre-understandings with us. But as we engage in the dynamic and iterative act of literature review and combining this information with conversations about practice constantly interpreting and being open to interpretation to develop new understandings or reinterpretation of previous understandings of the topic we are changed. Like an hourglass used to measure the passage of time, Alethia/understanding occurs as a moment in time. These new understandings are then a starting point for a re-examination of the topic – time starts anew – we start anew with our revised history and acquired practice wisdom. Surrounding the hourglass is the hermeneutic circle of the study starting with practice history, my prejudices and historically-effected consciousness. The literature review and the interviews done over time and analyzed individually and collectively provided new/revised understandings, resulting in evolved practice and a revised history. There is this juncture where conversations between my participants and I coalesced and expanded understanding occurred. This (re)new(ed) understanding has been added to my history and impacts my interpretation(s) moving forward.

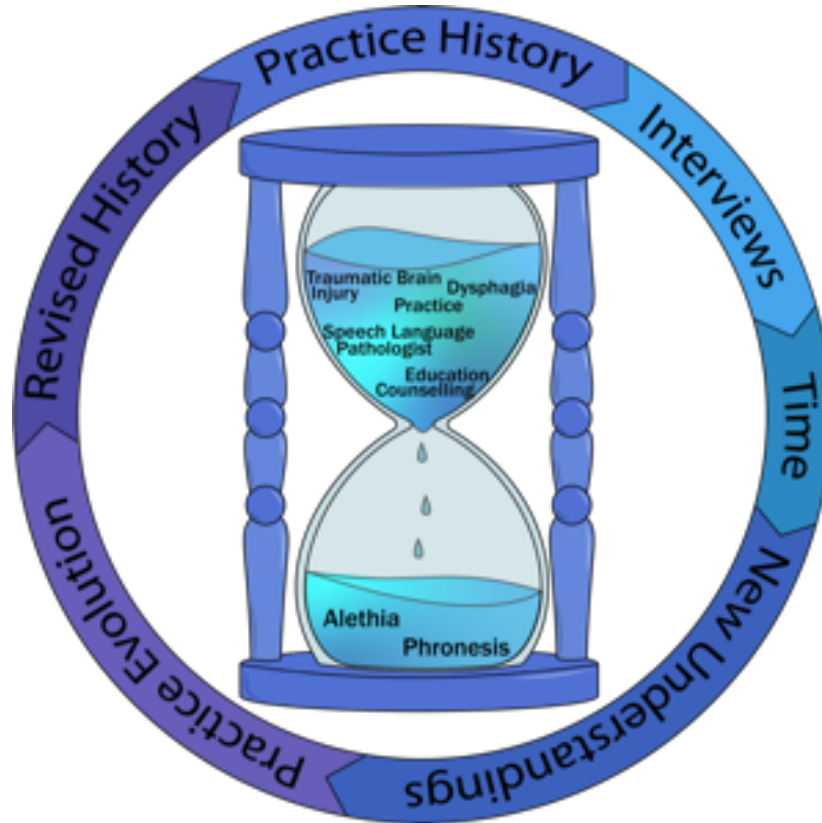


Figure 4: An illustration of the concepts of Gadamerian hermeneutic inquiry as it relates to the thesis.

Chapter 4 : Method

4 Method

Denzin and Lincoln define qualitative research as “involving the studied use and collection of a variety of empirical materials...that describe routine and problematic moments and meanings in individuals’ lives” (2017, p. 8). In practice-based research, qualitative studies contribute to, and advance, our knowledge of practice by providing methodology and methods for describing experiences, environments, and relationships often as they occur in natural rather than experimental situations (O’Brien, Harris, Beckman, Reed & Cook, 2014).

Hermeneutic inquiry was chosen as the qualitative approach for this work because it enables the opportunity to acknowledge and explore SLPs’ understanding and interpretations of how they are enacting education and counselling in the area of dysphagia management with TBI individuals, within the real-life settings and contexts of inpatient rehabilitation settings in the province of Ontario. Hermeneutic inquiry is situated in the interpretive paradigm and seeks to study everyday experiences to understand a phenomenon (Moules et al., 2015; Thorne, 2016; van Manen, 1992). The interpretivist paradigm also acknowledges the interpretive role of the researcher in the research context. As an ‘insider’ researcher, I can cautiously use my “insight into the matter at hand and the people involved” (Locke, 2019, p. 175) being mindful of the critical role reflexivity will have in the research process (Finefer-Rosenbluh, 2017). One significant advantage I have come to realize through this process of hermeneutic inquiry is that, by engaging in this research in the manner that I have, my professional knowledge has been expanded “revealing what otherwise may have remained taken for granted by myself and possibly unchallenged in my workplace” (Locke, 2019, p. 175).

4.1 Design

Qualitative data were gathered through semi-structured interviews, and collection of educational materials informing SLP practice in this area. One aim of the interviews was to engage in dialogue and reflection with SLPs on this complex aspect of practice.

4.2 Sampling strategy and recruitment

A purposive sampling strategy was used to recruit speech-language pathologists working in IPR settings in Ontario with patients who had dysphagia and traumatic brain injury. Potential participants were identified through an examination of the public CASLPO registry where practice settings are identified. A letter of information and consent (Appendix C) was mailed to 53 SLPs who upon examination of the CASLPO registry appeared to meet the study inclusion criteria. Interested participants were invited to contact the primary researcher (SMD) to enroll. Ten envelopes were returned because individuals no longer worked at the IPR setting or without reason (return to sender). As a follow-up to the email invitation and to recruit additional participants, potential participants were contacted by phone using the contact information available on the public CASLPO registry.

Twelve SLPs who met the inclusion criteria agreed to participate in the study. They represented IPR practice contexts extending from Southwestern Ontario to Northern Ontario.

As shown in Table 2 the majority of participants had greater than ten years of experience in the profession of SLP, with years of experience ranging from 10-30 years. All the participants were women.

Table 2: Participant number and years of experience as a Speech-Language Pathologist.

PARTICIPANT NUMBER	CAREER YEARS
1	20
2	10 to <15
3	30
4	>20
5	27
6	20
7	>25
8	10
9	25
10	14
11	26
12	18

4.3 Interview guide

A semi-structured interview guide was created with several purposes in mind: (1) to explore and gather information and experiences from the SLPs around enactment of education and counselling; (2) to develop a more conversational relationship in order to hear about and understand enactment from each participant's perspective; (3) to help participants explore the topic and to probe for further thoughts and reflections; and (4) to keep the questions open but also to keep the researcher and the participant focused on the topic of interest (Moules et al., 2015; van Manen, 1992).

The interview guide was informed by the results of the scoping review. The themes were: the actions of the SLP, enacting education to the patient, the family and other HCPS, timing and the knowledge translation requirements. Open-ended questions were formulated to encourage reflection and rich descriptions of ideas and experiences. Probes were developed in an attempt to assist the participant with the question being asked.

Participants were invited to elaborate on their answers using examples and experiences. They were encouraged to expand on statements to generate dialogue to facilitate an understanding of the when, the where, the how, what was used, what was successful, what had been unsuccessful, barriers to education and counselling, materials used, and evolution of their practice. This approach is consistent with Gadamer's concept of dialogue where open questions and answers allow for the emergence of new understanding (Gadamer, 1975; von Zweck, Paterson & Pentland, 2008).

Braun and Clarke (2013) note that the key to successful interviews is to ensure that you are well prepared. Preparation requires more than writing questions to be included in an interview guide. In hermeneutics it is imperative that the researcher uses reflexivity to continually assess their own relation to the collection and analysis of data and to evaluate their own responses to the issues raised within that process (Gagnon, 2019; Moules et al., 2015). "The researcher's own fore-structure, pre-understandings, experiences, and theoretical positions are considered an integral part of the development of the guide, the collection of data, data analysis and interpretation and understandings generated within the hermeneutic circle" (Agrey, 2014, p. 399). I was aware that my pre-understandings, historicity and insiderness might influence my study and I chose to adopt a stance that Gagnon (2019) recommends. He suggests that the researcher should keep open the range of understandings that can emerge during the interview dialogue because there are transformative opportunities that could happen.

My reading of the text *Conducting Hermeneutic Research: From Philosophy to Practice* (Moules et al., 2015) also helped prepare me early in the research process. Important learnings included that: (1) the researcher has a responsibility to respect the individual they are interviewing, following their lead during the interview, remaining open to the possibilities that emerge and are co-constructed in dialogue; (2) it is important to be aware of and respect perspectives – your own and the participants. The process of taking each other's knowledge and background into account is a complex process and "can frequently break down" so one must be prepared to work within this and create opportunities and a conducive environment for sharing (Boland, 1995, p.358); (3) each voice brings their history and their experiences and this manifests itself in a lived

experience, bounded by a shared horizon, that we can learn from; and (4) each interview influences and may alter your pre-understanding for subsequent interviews. Another crucial point that I learned in the preliminary stages of my work is that the researcher should be prepared and understand that they are receiving a 'gift' from their participants, and they should enter the interview ready to receive from a place of gratitude, humility, and mutuality (Bridges, 2001).

Hermeneutic inquiry invites us into conversation. The conversation challenges that which we believed we knew. Gadamer asserts that "to be in conversation means to be beyond oneself, to think with the other and to come back to oneself as if to another" (Gadamer as cited in Michelfelder & Palmer, (1989), p.1). Gadamer in conversation with Carsten Dutt (2001) said, "The fact that conversations lead us to better insights, that indeed they have a transformative power is certainly something each of us has already experienced personally ... what happens to one in conversation is really without an end" (p.60).

The reading of the article *Incorporating Perspective Taking in Reflexivity: A Method to Enhance Insider Qualitative Research Process* (Finefter-Rosenbluh, 2017) also had me pause and reflect. This article encourages the insider researcher to spend time reflecting on the concepts of positionality and transparency because she brings an added depth to the research due to an embodied knowledge of the material and the situatedness of the research question. As an insider I possess a shared language (swallowing, tube feed, education, behaviours), shared community of practice (SLP, dysphagia and traumatic brain injury), and tacit knowledge (my 24 years in clinical practice). My shared language proved useful in the writing of interview questions and probes. Transparency would be crucial as the participants were aware that I am an SLP in a similar practice context, some were aware of my role as a peer assessor within the regulatory college. They were coming to know me now as a novice researcher.

My reading, reflexivity and conversations with my advisory committee assisted me as I started the process to create the interview guide with a revised understanding and appreciation for the hermeneutic interview process. Like others, I acknowledge that it is very difficult to approach a text, experience, or topic as a completely blank slate because

we generally have some knowledge or understanding that must be accommodated (Gagnon, 2019; Moules et al., 2015). However, following the principles of hermeneutics means ensuring that you remain open to what the other has to say. It also means that you must not ignore information that does not fit with what you already think you know (Gagnon, 2019; Moules et al., 2015). I was authentically curious and did not believe that I had “the answers.”

The questions were written in an open-ended way to illicit conversation so that co-emergence of meaning might occur (Agrey, 2014; Gagnon, 2019; Kinsella, 2012). I was careful that the questions did not reflect any assumptions, so as not to lead the SLP into any result. For example, I did not ask the SLP participant: “Tell me what efficient/effective methods you use for counselling and educating patients.” I instead asked the question in the following more open-ended exploratory way: “Describe your specific dysphagia practice particularly related to swallowing assessment and education and counselling with TBI patients as if I know nothing about what you do. If you brought materials with you today, please feel free to refer to them, demonstrate how you use them, or discuss their importance to the overall process of enacting education and counselling.” This question related back to the component “the SLP” from the scoping review. It may result in the SLP discussing topics such as critical thinking skills, education and counselling competency across a wide range of health literacy levels and availability of time and resources. I did not directly ask what happens when a plan goes awry; nonadherence has been documented in the literature (Colodny, 2005). Instead, the interview guide question was worded as “In the event the proposed dysphagia swallowing plan does not go as discussed /planned how are you informed of this?” This question could reflect many of the scoping review findings, the patient, the family, the other HCPS and knowledge translation. The results of the scoping review often discussed ‘timing’ and time. I was curious to hear about the SLPs experience of the phenomenon of time so the question was worded as: “When you counsel/educate your patients where and when does it tend to occur?”. The full interview guide is available as Appendix E and I have provided a cross-reference for each question and the results of the scoping review there.

My doctoral advisory committee, including one member with many years of experience conducting and teaching qualitative research, worked collaboratively with me to develop the final guide. The interview guide went through several important iterations. The interview guide, technique and recording processes were tested in a pilot interview with an SLP working in IPR with patients with TBI and dysphagia who was not eligible to participate in the study (a colleague of the PhD Candidate) (Tracy, 2010). The feedback from the pilot interview was satisfactory in terms of timing, opportunity for information exchange and provided confirmation that the interview guide met the purposes described above.

4.4 Education and counselling documents and materials

A request was made at the time of recruitment for SLPs to provide supporting education and counselling documents and materials in the form of policies, protocols, guidelines, print materials, or models and to bring these to the interview to enhance the discussion of how they enacted education and counselling in the IPR context with their patients. The use of practice-based materials during the interview was hypothesized to develop shared interest and to facilitate relationship building and conversation during the meeting (Agrey, 2014; Muganga, 2015). Asking SLPs to gather the education and counselling materials also reinforced the topic of interest for them and provided additional information in which to better understand the context in which each of the SLPs practiced.

The combination of multiple data sources helped provide a more comprehensive description and presentation of the SLPs enactment of education and counselling within an IPR context. It was also meant to facilitate a greater depth and breadth to the researcher's understanding and to enrich the thick descriptions provided within the thesis (Agrey, 2014; Curtin and Jaramazovic 2004).

All participants submitted education and counselling materials. There were various methods by which these materials were collected and submitted including: mail/email/and through photographs. One participant described the 'tool' they used

during the interview, the researcher made a visualization of the tool and sent it back to the participant for accuracy confirmation (see Appendix H, p. 154).

4.5 Ethics and consent

Approval for this study was granted by The Office of Human Research Ethics at the University of Western Ontario. Each SLP consented to participate in the study by signing and returning the consent form.

4.6 Data collection: Methods, documentation, and process

Hermeneutic research calls for a genuine curiosity to exist about what the other might have to say (Moules et al., 2015). Interviewing is an active process where the interviewer and interviewee through their iterative and interactive dialogue and relationship produce knowledge (Moules et al., 2015). During the interview, the interviewer is focused on listening for new understanding and remaining vigilant about the tendency to listen for agreement with their prejudices. Prior to the start of each interview, I prepared mindfully for the conversation by reflecting on my intention to remain curious, openminded and humble, and to remain vigilant regarding my preconceived understandings, my historicity and my insiderness. I entered each interview authentically curious, recognizing I did not know the ‘whole’ story of how SLPs enact dysphagia education and counselling with TBI patients within the context of their practice settings (Agrey, 2014). The aim was for the dialogue not to be “simply a special kind of space or place (platform or ‘plaza’) in which views are exchanged and new information is obtained, but an event in which one experienced growth in self-understanding” (Schwandt, 2001, p. 236).

Gadamer reminds us to focus on conversation because:

“As to the art of asking questions dialectic proves its value because only the person who knows how to ask questions is able to persist in her questioning, which involves being able to preserve her orientation towards openness. The art of questioning is the art of questioning even further, that is, the art of thinking. It is called the dialectic because it is the art of conducting a real dialogue” (Gadamer, 1960/2004, p. 360).

All participants opted for semi-structured interviews by phone, despite in-person interviews being offered as an alternative choice. Interviews occurred most frequently while the SLP was at the workplace, but on their own time (i.e., after work, on breaks). The interviews lasted, on average, 50 minutes and ranged between 45-70 minutes. The interviews were audio-recorded using a Zoom H4n Pro 4-Track Audio Recorder (<https://zoomcorp.com/en/ca/handheld-recorders/handheld-recorders/h4n-pro/>).

As an experienced interviewer (I have been a peer interviewer for the CASLPO for many years), I brought important skills that I have developed over many years to the interviews including being able to listen intently, drawing attention to meaningful statements, avoiding invitations to counsel or teach, following leads, and being authentic (Moules et al., 2015). Despite my role as a peer assessor and as an SLP in the same practice context, I entered each interview as a curious learner (Asselin, 2003; Finefter-Rosenbluh, 2017; Kvale and Brinkmann, 2009). My aim was that my experience, preparation and interview guide would help uncover what was important to understanding the enactment of education and counselling. This would be achieved through the process of engagement in the interview (Thorne, 2016).

At the completion of each interview, I summarized the dialogue as a form of member-checking and participants were invited to verify, clarify, or elaborate on my interpretations. This was done to confirm my understanding, correct errors, reassess the information provided, to provide additional time for elaboration(s), or to provide new information not provided earlier. At the end of the session the participant and I came to a consensus that the summary (and therefore the related and recorded interview) accurately captured their enactment of education and counselling at this moment in time.

After each interview, the audio recording was transferred directly to the password protected computer/server within The National Centre for Audiology at Western University and was deleted from the recording device.

4.6.1 Field notes

During the phone interviews, handwritten ‘jottings’ and short memo writing was possible. These were done on the printed interview guide and the raw data was saved in the participant’s file and in electronic format in the participants’ database. These ‘jottings’ would be used to cross-reference data and were referred to during data analysis and interpretation (Phillippi & Lauderdale, 2018; van Manen, 1992).

4.6.2 Reflexivity

Reflexivity is an essential component of qualitative inquiry. Being reflexive in research practice means that the researcher explicitly pays attention to and analyzes the research process itself, attending to how their perspectives, assumptions, and actions are interacting with the research process and the emerging findings (Baker et al., 2016; Ng, Wright and Kuper, 2019). Prior to study initiation, I completed a reflexive exercise documenting my experiences as an SLP in an IPR setting working with patients who have dysphagia and a TBI (Moules et al., 2015). This reflexive exercise was done to be transparent about my relationship to the topic and to acknowledge the prejudice and historicity that I bring to the study (Moules et al., 2015). I examined my “taken -for-granted” assumptions of education and counselling and the context of IPR. Perhaps there was a uniform, tailored approach to TBI, IPR and dysphagia education and counselling of which I was unaware. As I reflected on the research question, I thought about what had called me to this topic. There were thousands of TBI patients with dysphagia, in IPR, whom I had educated and counselled. Over this period of time my “script” and the materials I have used has evolved. Consistent with Leigh (2014) and Finefter-Rosenbluh (2017) I tried to minimize the extent to which my insiderness would affect my research. I was critically aware because the practice area in which I work is so small, as an insider, this closeness could make the researcher “resistant to an unsympathetic critique of the field, or if they brave an unsympathetic critique, they may be at risk of damaging or losing their closeness to the field and/or someone within it” (Taylor, 2011, p. 14).

Keeping a reflective journal throughout the course of the study is a strategy that is used in hermeneutic research to help the researcher acknowledge their history and the context in

which they may already be a part of thereby allowing for critical thinking, evaluation and transparency (Moules et al., 2015). Ongoing reflexive writing also helps to make the researcher's prior and existing understanding of a topic clear, identified and acknowledged. This helps to ensure that the researcher remains open during each interview to the meaning of the participant's language, text and anecdotal materials during data analysis; thereby also being open to possibilities of surprise and new or revised understandings of the topic of interest (Crist, 2018; Moules et al., 2015).

In addition to the initial reflexive journaling exercise, after each interview I wrote in a reflective journal to record thoughts, feelings, worries, ideas and questions. A review of this writing reveals a journey of growth, self-efficacy, and changed understanding of my role as a researcher, interviewer, and interpreter of data.

Reflexive contemplation after each interview had me returning to my practice context with an expanded appreciation and a deepened understanding of the realities related to how SLPs enact education and counselling with patients who have dysphagia and a TBI (Van Manen, 1992). The questions that I asked myself, and answers I recorded after each interview comprised the following: Did my pre-understandings impact what I heard? Was I surprised by things said? Tools used? If so, why? Did new understandings occur? How does the new knowledge impact my thoughts about wisdom and practice? Were there things I should have asked but didn't? Were there changes need to the interview? These notes were reviewed prior to the start of each new interview.

The interviews were conducted over a 60-day period. All recorded transcripts were transcribed verbatim by two laboratory research assistants. The researcher listened to the audio-recordings while reading the transcripts for the first time to ensure transcription accuracy. Written transcriptions allowed for a careful analysis and interpretation of each participant's account of practice, not only regarding their pedagogical practice but also their beliefs, hopes, goals, frustrations, and attitudes as they relate to the topic of enacting education and counselling within the context of their practice setting (Agrey, 2014).

4.6.3 Power relations

There exists a tension for insiders, like me, who have multiple roles (Locke, 2019). I reflected on this tension as it relates to my role as an insider, a peer assessor with the regulatory college (CASLPO), and a researcher. There was the potential because of the multiple roles I hold for participants to feel apprehensive about being open and honest. I proactively prepared how I might manage any power differentials. Despite my concerns and what I had heard about the negativity associated with power relations, I came to realize that there may be some advantages in terms of my role as an 'insider' (Coar & Sims, 2006). The shared knowledge I have about the topic as a SLP in the same practice context may facilitate the conversation I have with participants because I understand the topic and share a professional culture and shared terminology (Coar & Sim, 2006; Gagnon, 2019). The shared understanding of the topic and the context might in some cases increase my credibility with my participants (Andersson, Troein, & Lindberg, 2001) and encourage disclosure (Aira, Kauhanen, Larivaara, & Rautio, 2003). This reinforced for me the need for confidentiality and the need to ensure that in data reporting I was careful to protect, as much as possible, their anonymity.

Jackson (1989) argues that, as researchers, our understandings of others can only proceed from within our own experience, and this experience involves our personalities and histories as much as our field research (p.17). This is acknowledged as preunderstandings (Gadamer 1960/2004) that I bring to this research question. As an insider researcher I was tasked with reflecting on my capacity for new understandings of this research question, perhaps different from that of my own. I had been called to this topic by my recognition that there appeared to be a lack of available and appropriate resources for this specific population, and that re-education, and repetition of the education and counselling messaging was perhaps the result. Kanuha (2000) posits that insider-researchers may find it difficult to detach their personal experiences from those of the participants. Reflexivity and reflection will be required to mediate this and to offer a distinct point of view (Chawla-Duggan, 2007; Gagnon, 2019). Specifically, reflexivity turns the researcher's lens back onto themselves to recognize and take responsibility for their own situatedness within the research and for

the effect that it may have on the setting, participants, questions asked, data collected, and data interpretations (Berger, 2015). I will address this through reflexive writing after each interview and through conversations with my supervisor(s). I will attend to facilitating rapport with the participants by engaging them in conversation prior to turning on the audio recorder. I will create a space for the SLPs to question me, to ask me to repeat a question at any time and to remind them that they may stop the interview at any time. I will also be attentive to the perceived power dynamic. When interviewing one's peers they may feel that the interview is a test of knowledge or competence, despite assurances to the contrary (Coar & Sim 2006). Participants will be encouraged to record our time together as a continuing education experience in their CASLPO learning portfolio. Coar & Sim (2006) caution that some of the participants may ask for feedback on their performance, perhaps anxious to know if there are any glaring gaps in their clinical knowledge, or if their clinical practice differs significantly from others. Verbal reassurance(s) will be provided. Prior to the interview ending I will make a point to summarize what I had heard the participants share about their education and counselling practice, ensuring that I ask if there was any misinterpretation or if I had omitted anything they felt important.

During development of the interview guide an experienced qualitative researcher on the advisory committee reviewed the questions to ensure they did not reflect my own clinical bias. All participants were informed that all study materials were approved by the institutional research ethics review board and that they could contact this department if they had any concerns about the conduct of the study. I reinforced for each participant that as an insider I was doing this research because I was genuinely interested in and curious about how SLPs were enacting education and counselling. I was looking to learn and grow through this process, and I emphasized my privilege of being able to connect with them as experts to learn more. It is not possible to erase the power differential (real or perceived) due to my role as a peer assessor in the quality assurance program at CASLPO, but attempts were made to address them using self-reflection and reflexive journaling and being transparent with participants about that role during interviews. It was reinforced that the role of peer assessment has changed over the years. CASLPO has committed significant efforts to educating registrants and employers that:

“Peer Assessors are experienced practicing clinicians and come to the process with a strong sense of what is practical and reasonable. All peer assessors have been peer assessed themselves and appreciate what is involved in the preparation. Peer assessment is one way to recognize a registrant’s strengths as well as identify areas that may benefit from improvement. The goal of Peer Assessment is to be a positive learning process, with a focus on remediation as needed.” (CASLPO, 2021 p. 1, 2).

In summary, like Gagnon (2019) I did not see my interviews and study as a “timeless verity” but rather as opportunities to hear about someone else’s “lived understanding” (p. 8). This was made clear at the start of each interview. I used creativity and my skills in interviewing that I bring from my years of experience as a peer assessor to make people feel comfortable and supported in their narrative telling. I was prepared to explain that I believe my role as a peer assessor is to look at people’s strengths and ways in which they can be supported, not as an examiner. Most of all, I was transparent about my research objectives and the ethical obligations that I am accountable for and believe in. Finally, I shared with them my passion to hear their story and to learn from them.

4.7 Data analysis

Data analysis in hermeneutic research is a process of iterative, insightful, divergent, discovery that “seeks to see meaning and deepen understanding of a topic in such a way that it can be seen differently and, ultimately, can be practiced differently” (Moules et al., p. 119). Analysis involves careful reading, re-reading, reflecting, and writing around significant interpretations that arise from the data (Kinsella, 2006; Moules et al., 2015; van Manen, 1992).

Hermeneutic cycling involves a reading, re-reading and reflecting on the transcript using a process of questioning the texts (and other materials) and responding with more questions to interpret the data. Through the hermeneutic circle an emerging, interpretive conceptualization of the phenomenon begins to emerge through an iterative examination of the parts of the text and through relating those parts back to the ‘whole’ data set and research question (Kinsella, 2006; Moules et al., 2015).

The process for data analysis of individual transcripts, anecdotal materials along with field notes and reflexive writing began by writing the research question in the centre of a large piece of blank paper: *How do SLPs working in IPR with patients who have dysphagia and a traumatic brain injury enact education and counselling?* After reading the full transcript and referring to the other materials offered, careful, multiple, re-readings of the transcripts occurred while asking myself “how does this help me to understand”, “what is meaningful here”, “what is here to learn”, “what is this example”, “what are their experiences and how can I best capture them”, “why is this important to them”, “what statements/ sentences/phrases/ are essential or revealing about how education and counselling is enacted” (van Manen, 1992). This questioning dialogue between the text, educational materials, and myself, were noted and mapped onto the large sheet of paper to help me visualize the data and to gain knowledge and deepen my understanding of how SLPs enact education and counselling in IPR with patients who have dysphagia and a TBI (Moules et al., 2015). This same, iterative, mind-mapping process occurred for each of the 12 transcripts. Common topics/themes/understandings began to emerge, and these were highlighted, and their re-occurrence was noted across the transcripts. The co-coder performed a similar exercise. An example of this mindmap exercise may be found as Appendix F.

According to Gadamer (1975), researchers bring their history, context, culture (historically-effected consciousness), and existing pre-understandings (“prejudices”) to a topic. These are integral to the data analysis process because they are an important pathway to understanding and the basis for our ability to understand at all (Moules et al., 2015). What is critical for the process and what this researcher did was to engage in initial and ongoing reflexive examinations of my pre-understandings trying to ensure that I remained open to the meaning of the other SLPs’ language or texts, thereby being open to possibilities of surprise (Crist, 2018; Moules et al., 2015 ;Thorne, 2016).

Interpretive understanding of how SLPs working in IPR with patients who have dysphagia and a traumatic brain injury enact education and counselling occurred through a merging together of my knowledge of the topic and through a process of iterative, open data analysis across all transcripts to the meaningful possibilities from the other SLPs.

The result was the formation of new knowledge and understanding(s), and what Gadamer refers to as a fusion of horizons to occur (Gadamer, 1960/2013, Moules et al., 2015; von Zweck, Paterson and Pentland, 2008).

4.8 Co-coding

An independent analysis of the transcripts and the provided educational materials was undertaken by a second researcher co-coder (thesis co-supervisor, SM) who was also knowledgeable about the hermeneutic inquiry process. Results were compared and consolidated through regular discussions and meetings.

Overall results of the data analysis were presented and discussed with an experienced qualitative researcher (thesis advisory committee member, EAK) and the thesis co-supervisor (REM) who has expertise in dysphagia.

Chapter 5 : Results

5 General Introduction to the Findings

Six overarching themes were identified through the hermeneutic interpretive data analysis process across the twelve interviews of SLPs. The themes represent the SLPs accounts of enacting education and counselling in IPR contexts with dysphagic traumatically brain-injured patients. In contextualizing the findings, it is worth noting that many (8/12) of the SLPs interviewed had over 20 years of experience as SLPs. The overarching themes include: (1) enactment of education and counselling, (2) complexity of education and counselling, (3) constraints relating to education and counselling, (4) collaboration with respect to education and counselling, (5) mitigating risk and education and counselling, and (6) practice evolution in relation to education and counselling. Within these themes, emergent insights are highlighted, which guide the presentation of the results and summarize the main points to facilitate readers' understanding. The themes and emergent insights are provided in Table 3. It is also important to note, that many of the quotes and findings overlap across themes, emphasizing the complex nature of education and counselling, and the numerous stakeholders who are important to the enactment of this work.

Table 3: Education and counselling with dysphagic traumatically brain-injured patients: Themes and emergent insights.

THEMES	EMERGENT INSIGHTS
Enactment of Education /Counselling (primarily focused on the dysphagic patient)	Materials used in education and counselling
	Materials used across groups
	Methods of education and counselling
	Mitigating risk through education and counselling
	Leveraging technology
Complexities of Enacting Education / Counselling	Cognitive-communication abilities of the dysphagic patient
	Number of people to be educated besides the patient
	Required repetitions of the education
	Complexity of practice environment
	Moral dilemmas for the SLPs
Constraints on Education / Counselling	System
	Environment
	Time
Collaboration and Education / Counselling (including education and counselling of the family and other healthcare providers)	Tools used to mitigate risk
	Education and collaboration
Mitigating Risk through Education / Counselling	Mitigating risk for the patient
	Mitigating risk for the context
	Decision-making: MD / SLP
	Innovations created to mitigate risk
Practice Evolution and Education / Counselling	Entry to practice considerations
	Moral dilemmas
	Evolving practice wisdom

5.1 Enactment of Education and counselling

All the SLPs interviewed discussed the importance of education and counselling with their patients. “Education is the biggest tool in my toolbox” (Participant 6). The SLPs discussed how they adapted their education and counselling to the communicative capabilities and cognitive abilities of the patient. One way in which this was done, as discussed by the majority of the participants, was through the use of ‘talk back’ or ‘teach back’ methods to reinforce the transfer of educational messages. Participant 1 shared that, when she sees “that awareness” in patients, and their ability “to repeat back what some of our strategies have been”, that is when she knows that the education and counselling have “really gotten through.” Another participant discussed the ways she asked the dysphagic patients to ‘talk back’ to her to confirm their understanding:

“Can you tell me what you got from this conversation?” For many of our clients I have to give more probes, and from there I will ask... “What happens if you were to drink a big sip of water?” Listening for their answer, and “What can that lead to?” “Those are the questions I typically ask if it doesn’t come out in the first structured re-tell.” (Participant 8)

Some SLPs shared their approach of using cognitive and communication assessment results to inform their educational/counselling approaches with patients with cognitive impairments:

“You have an assessment and understanding of what their communication abilities are. I guess, I adjust my knowledge of what it is they understand and how much information they can take in. I gear my explanation towards that patient’s level. At the end of the day if they’re following recommendations, I guess that’s understanding.” (Participant 10)

Another means of addressing the potential for attention, memory, organization, information processing, problem-solving and executive functions issues was to use the ‘teach back/talkback method’, where the patient teaches the therapist what they have learned in the session. One therapist talked about how she brought a “diagram that ...

made the trachea and windpipe stand out more from the esophagus” as an approach to educate the patient about swallowing and the used “teach-back at the end.” (Participant 8) as a means to check on the patient’s comprehension.

The majority of the SLPs educated and counselled patients about the risks of dysphagia by leaving safe swallowing educational materials with the dysphagic patient and their family: “I leave them the safe swallowing guidelines and list of foods that may be difficult. Having something to look at helps a great deal.” (Participant 7). Some tailored the materials for the individual: “I have paper and visuals that I can give to them and then I’ll frequently type out information specifically for them.” (Participant 11).

It was important to the SLPs in this study to educate and counsel family members of the dysphagic patient. In part, they reported taking this action because families will provide and reinforce information to the patient and take part in decision making along with (or on behalf of) the client.

A number of SLPs indicated that they tailored education provided to families in different ways than HCPs or dysphagic patients. The information was described as more in-depth and descriptive with families as compared to patients: “I use concrete language with the patient and larger words with the family” (Participant 6) and “I will definitely have a long conversation with the family member if this person is obviously not capable of understanding consequences” (Participant 2).

The SLPs also talked about using less technical jargon with families as compared to HCPs trying to ensure education and counselling occurred in an understandable format:

“So, I use very layman terms, and I don’t really like to use the word consistency, I like to use texture [when referring to food]. It’s a little simpler. We like to get fancy, I find here they’re very fancy. Well, people don’t get fancy. People get toilet. Okay? And plumbing. And laymen’s terms. ... We have a lot of more workers than highly educated people and let’s be honest this (dysphagia), is a totally different area, and not well known anyway.” (Participant 9)

At least one SLP questioned this practice of offering different information to the family versus the dysphagic patient and wondered if it was consistent with the provision of ethical practice (Participant 8).

The majority of SLPs reported value in bringing the families on board in the education and counselling of dysphagic patients, and many further noted it was not without challenges, recognizing that families are emotionally affected after their loved one has experienced a TBI. Some described how family members' good intentions could be misguided:

“It’s the education of the family members that is also difficult because they obviously see their loved ones, and they’re like: well they’re alive, so if they want a muffin I’m going to give them a muffin.” (Participant 10)

The twelve SLPs talked about the various materials they used with patients and their families to facilitate and ensure understanding of the education and counselling recommendations. My favourite tool is actually a tracheostomy model. It is a side view of the head, and it shows all the structures. It is one of my favourite tools because it is very visual.” (Participant 13). The materials ranged from pen and paper drawings, formal apps and videos).

Examples of education and counselling materials used in practice were provided by all the SLPs and can be found in Appendices F through K. The SLPs referred to these materials during the interviews with many giving specific examples of how they use them to address education and counselling needs.

The SLPs discussed that, while printed education and counselling materials were effective with some patient populations, they could be less effective with the dysphagic patients. Participant 7 explained “we do give the written information, but how much are they going to retain if you have someone who has trouble with reading and comprehension? That is not going to do much.”

Instead, most of the SLPs discussed how visual tools and pictures were used in their practice. Participant 1 said “Our patients definitely need the visuals to assist with

understanding” and Participant 8 indicating that she thought that “having a visual, something very clear” can help to make the educational messages “more concrete.” Another participant talked about using “pictures to explain the swallowing mechanism” (Participant 10). Participant 5 reinforced these ideas commenting that “the diagrams help support anything I am saying” but that their effectiveness sometimes depends “on where the patients are in their recovery.” Participant 7 reiterated this, stating that not everyone will benefit from visual cues, “We try to rely on a visual cue but not everyone will pay attention to that”. Participant 13 talked about using an educational book, “Follow the Swallow” (Puntil-Sheltman, 1997), to help patients visualize the messages in her education and counselling sessions.

Some SLPs have moved to using technology to assist with visually-based education and counselling: “I use my iPad to show modified barium swallow studies and let them know what we are doing. I show them a video of what a normal swallow looks like, what aspiration, penetration looks like. Then I show it again afterwards” (Participant 7); and “I have a beautiful little app - it shows the whole process of the swallow” (Participant 9). TIMS^{TM1} was also used by multiple participants (Participants 1,3, and 4).

Some SLPs discussed sketching their own visuals to accompany as part of the education / counselling they provide: “I draw, and I talk, and I go back and draw that picture again and I talk about it as many ways as I possibly can” (Participant 6). Similarly, Participant 10 stated: “I use pictures to explain the swallowing mechanism, where things go, and where things may not be working. One is medical, formal ENT model, and the other is hand-drawn.”

¹TIMS DICOM System: May be used in conjunction with Videofluoroscopic study (VFSS) recording. It is a system that allows for capture and edits in the VFSS study and these can be used in education and counselling to provide an individualized tool to explain to the patient/family what is happening during the swallow.

Some SLPs discussed learning that some commercially available strategies did not always work, and how they created better strategies over time. Participant 9 discussed the following:

“Placemats don’t work because you put the food on the placemat, okay? And if you can’t read the strategies on the placemat it won’t work. So, we did a menu card on a photo frame with an alligator clip. I laminate the feeding guides for the individual. They’re customized to fit that individual.”

Dysphagia education and counselling is important because patients are at risk of pneumonia, readmission to acute care, choking, and malnutrition. In order to mitigate the risks of these negative outcomes SLPs considered the cognitive-communication profiles of their patients. SLPs were aware of the patients reading skills and they reported this as a factor and consideration for the types of educational materials created. The SLPs in this study indicated that different educational materials may be provided for families than patients. The SLPs discussed ‘teach back’ methods, use of repetition, visual aids, and technological approaches as important approaches.

5.2 Complexities of Enacting Education and Counselling

The cognitive-communication issues associated with dysphagic patients who have experienced a TBI, including impairments with insight, memory and ability for new learning, were frequently described as contributing to the complexity of enacting dysphagia education and counselling. SLPs described cognitive-communication issues such as diminished insight, awareness and compromised working memory as shaping patients’ capacities to adhere to education and dietary recommendations. For example, Participant 2 said: “it’s recalling these strategies that is the biggest problem with our TBI population. And actually, buying into it; so full insight is the biggest issue in TBI”... “some patients have enough insight to realize this is not a normal diet texture and this is not normally what they would be eating.” The SLPs recognized that non-compliance with recommendations was not intentional but often related to cognitive issues related to TBI:

“The awareness, and the ability to follow instructions or the compliance with recommendations is much more difficult, I find, in the brain injury population. Not because they are not wanting to be compliant, but because the memory piece or the awareness piece is lacking.” (Participant 3)

A number of SLPS discussed challenges related to compromised memory in the TBI population. Memory impairments may reduce an individual’s ability to recall and appreciate, at mealtime, the education and counselling they had previously received. Participant 1 stated that:

“It is a challenging population. We are working with people who, you know, while they are on a dysphagia modified diet are also experiencing post traumatic amnesia. So, they are not retaining what we are educating them on. So that is difficult.”

Regardless of the presenting patient complexities, the SLPs discussed some of the ways they managed this complexity during educating and counselling. Participant 3 spoke about how she tries to be inclusive stating, “even the ones who I know who do not get it cognitively, I try to include them in the education.” Some SLPs described entering into an education and counselling session with an appreciation that it will be important to assess the patient’s understanding even during the course of a single session. Participant 7 described, “what you have to keep in mind with the brain injury is, how much they are going to understand, and are they going to be able to pay attention to the information I am giving them.” Participant 8 noted how abstract information was particularly difficult for patients in this context, saying that “a lot of patients will have trouble with the abstract information, hanging onto those concepts, talking about them for a whole conversation. It can be tough to keep everything in the mind at once.” Participant 13, who has worked in other SLP practice areas, indicated that with dysphagic patients, “you have to do a lot more coaching, a lot more education” and, Participant 4 reflected on the complexities associated with education and counselling by saying, “at times the patient may not be at the point where they can look, in terms of handouts, and understand the information.”

She expanded, “not only could you be dealing with the physical in terms of brain injury... But when it is the cognitive, I am looking for a level of alertness.”

Another layer of complexity discussed was how to best determine whether the education had been successful. Participant 6 shared that, given the cognitive issues with dysphagic patients, “I really make sure they are able to employ the right strategies, at the right time.” This emphasis on re-education and trying to discern when patients have acquired enough knowledge was also discussed by Participant 8 who stated “most often we’re helping to re-educate (the clients who have more severe impairments) ... It’s hard to find the point where I go ‘Okay, I trust them to remember this and do it.’”

The importance of consistent team and family communication, in light of patient-related cognitive-communication impairments, was also emphasized. Participant 7 stated, “[his] memory was very poor... So, he needed constant cueing and we had to work as a team to help him out.” Participant 3 discussed how she works with the nursing team to prepare for reiteration of educational material, reminding them to be prepared for “the same questions over again as to why they (a dysphagic patient) can’t have the regular (dietary) things.”

5.3 Constraints on Education and Counselling

The findings of this study revealed constraints on education and counselling related to the systems in which patients received care, the healthcare environment and time.

Many SLPs voiced challenges related to the lack of availability of more standardized education and counselling materials. Participant 1 highlighted the availability of evidence to support technological aspects of practice (VFSS² for example), however commented that the same level of evidence and resources to support education and counselling were

² A VFSS is a videotaped or digitized dynamic fluoroscopic image that focuses on the oral, pharyngeal, laryngeal and upper esophageal swallow physiology and incorporates compensatory treatment strategies such as various textures, patient positioning, swallowing maneuvers, etc. (CASLPO, 2014, p.18-9).

lacking: “I think for bodies of evidence around the VFSS all the instrumental stuff is there. As for treatment or counselling I don’t think we are aware of any research out there.” And Participant 12 discussed:

“It’s funny because when you to try to find resources on the internet you would think there’s lots, but there’s not, which is mind-boggling to me. Like if people are making this educational material for dysphagic patients why aren’t they sharing them?”

A number of SLPs discussed how, although the use of interprofessional collaboration to achieve positive outcomes is desirable, it can be difficult to achieve effective communication across the various professional disciplines within the IPR context. Many talked about frustration associated with the necessity for replication and duplication of their dysphagia diet recommendations and associated instructions in multiple locations for the IDT and for the family. Participant 10 provided the following list of multiple locations where they provided information:

“So, there’s information at the bed side, there’s documentation in the chart, there’s a separate swallowing alert sheet in the nurse’s Kardex. So, the whole team knows what the diet recommendations are, and what changes are made. And then there’s a weekly rounding where the team is made aware of that information if they had not read it in the chart already.”

Interestingly, almost all of the SLPs interviewed described that they did not have a single, clearly defined location for the charting or recommendations and presentation of education and counselling materials. Most discussed having many locations. Participant 2 stated, “we have about seven different ways of passing on that message.” SLPs placed materials in multiple locations for a variety of reasons. Participant 7 recounted: “Because others forget or may be in multiple places; I write it in the patient’s chart, I write it as an order, I write it on the sheet.” Participant 11 stated that she was “required to document in multiple places: day planner, sheet above bed, medical chart, Kardex system.” Participant 13 reported that she was required to document in “the medical chart, progress notes, RN

communication vehicle, progress sheet in another location and another separate update sheet.”

The majority of SLPs discussed that, while they personally prioritized education and counselling because of the known impact on patient outcomes, their ability to perform what they felt to be optimal education and counselling was obstructed by clinical time constraints. Participant 4 explained, “my caseload always exceeds in terms of time allowed.” This was expanded upon by Participant 8 who noted how important diet changes could be delayed due to time constraints despite good intentions: “if you keep delaying the conversation, waiting for a really good time, then the diet change gets delayed, you want to get there but the constraints can be tough.” Finding the time to address the unique education and counselling needs of individual dysphagic patients and family members was another challenge identified. One participant shared the following:

“And then the time to educate...Some people need more time they have question’s, and they need to hear things more than once maybe. Some people we need to give them unpleasant news and sometimes they get upset, and I really hate the time constraint with that.” (Participant 7)

Some SLPs also shared that clinical time constraints were amplified in light of the level of impairment of dysphagic patients in current IPR settings:

“Patients are coming to us much more acutely, with shorter length of stays, they are adjusting to their injury, we have to hit the ground running and discuss that we don’t want you to go home on a feeding tube. The patient response is: what do you mean go home, how can we be talking about me going home already?” (Participant 6)

Constraints on SLPs’ practice in the context of TBI dysphagia within the IPR context was not limited to time and materials; equipment was another factor. SLPs identified constraints in and on their practice related to access to (VFSS) and physical space. The value of access to, and capability to review VFSS images with the dysphagic patient and their family members, was discussed as an important way to offer education about

swallowing and to show the potential hazards of aspiration. Access to VFSS was regularly described by the SLPs as following best practice guidelines, as optimal care, as useful for helping patients and family members visualize and understand what is occurring during swallowing, and for aiding in the education and counselling process:

“And that’s where something like having access to VFSS, and especially if the patient and a family member are right there, they’re looking at that feedback, they can visually see what’s happening, they’re having to right now, (just) listen to my expertise.” (Participant 11)

Many SLPs discussed the challenges inherent in their systems of care due to a lack of timely access to VFSS. This lack of access was noted to compromise the SLP’s ability to be aware of how their patients swallow is currently functioning, and to provide effective rehabilitation and education and counselling in a timely manner to patients and their families. As Participant 11 stated:

“A challenge is our lack of access to VFSS, and we need to see what’s going on and there are long delays before we can access that information and often they are discharged from our care before we can get that. So that’s a real missing part of our ability to provide service.”

The challenges of patients being discharged without access to VFSS, institutional regulations that precluded access, and long wait lists, were frequently highlighted. In Participant 8’s words: “unfortunately we (IPR) are not able to send them back for any kind of instrumental imaging (VFSS) and the outpatient center here, the waiting list is 8 months, so that is a challenge at times.” Others discussed the challenge of not having onsite access to VFSS and the logistical challenges. Participant 5 stated: “if you need to go to instrumental (VFSS) then you need to send them out and this is a bit more complex because there is logistics to sending people out.” In addition to not having access to VFSS onsite, SLPs also explained that limited time frames and offsite access restricted their ability to use VFSS. Participant 6 noted “we have to travel (offsite) for VFSS – and I may only do so on a certain day- that’s just the way resources are allocated to us.”

The SLPs discussed how access to a quiet, private space was a crucial factor in optimizing rehabilitation and engagement with education and counselling for dysphagic patients and their families. Unfortunately, many noted that quiet private spaces were infrequently available ('at a premium') and not always readily available. A SLP commented:

“We know with TBI, they often in terms of them getting overstimulated that it leads to a whole bunch of issues...I always advocate as much as possible for them to have a private room. But this does not always necessarily work, but if I can get them in, I find that would make things go much easier and often have more success with them.” (Participant 4)

Participant 1 offered:

“In our hospital there is a premium on space. So, getting rooms for patient education is not optimal because everywhere is so booked and there is only so long you can hang out in the radiology suite after the VFSS. Most of our patients are in semi-private rooms so there is the issue of confidentiality.” (Participant 1)

Space was also an issue in terms of what could be accessed throughout the physical environment of the IPR context (the cafeteria), particularly for patients whose cognitive impairments compromised judgement. Participant 9 pointed out that despite education and counselling “there’s nothing to say they [patients] won’t go to the cafeteria and order whatever they want”, which could pose dangers related to aspiration if they chose items not within their current dietary plan. This challenge was elaborated on by Participant 11:

“We have younger patients come here on a very modified texture and they are sitting in the dining room where people are eating at times it’s very difficult for them to stay on their texture no matter what I’m saying or showing them.”

The role of the physical dining space in relation to SLP staffing constraints was voiced by Participant 9: “and we have the patient agree to eat in the dining room where they have more eyes on him, supervision if you will, some of our rooms are isolated from the nursing station. I can’t watch the whole unit.”

All of these complexities and constraints of practice reinforce the need for the dysphagic patient to have external assistance and supervision across and within the healthcare team. A number of SLPs described practice constraints related to limitations in availability or in the knowledge base of the staffing unit within the IPR setting. The lack of knowledge regarding dysphagia or TBI of casual or new staff was also noted as a challenge in terms of implementation and supervision of SLPs' recommendations. As Participant 7 described: "Staff don't realize, staff that don't work with patients (TBI) with swallowing issues, how simple some things, like posture, how important it is, and that they might be able to eat regular food, if they are sitting upright."

The awareness of the role of staff and constraints on the enactment of education and recommendations, was discussed by Participant 3 who voiced "I find so much of it (assistance) to depend on who the staff is that day." An example was shared of how constraints related to staffing impacted the enactment of education and counselling recommendations in the form of the actual diet:

"And I worry, we rely on nursing staff, because we can't observe everyone at mealtimes. We have a dining room, and we can't have too many people in the dining room program. For some reason, that causes a great deal of problems. Like the dietary staff bringing in the trays to the dining room instead of the patient's room it's a big rigmarole, I don't understand why. We rely on other people if we can to help the patient." (Participant 7)

Many of the SLPs elaborated on how collaborative conversations with various team members helped to uncover topics for practice improvements in the areas of snack selections, tray verification and conversations involving kitchen/dietary aids. Participant 5 gave the following example of a nurse raising a system issue on the ward that could prove dangerous for a dysphagia patient: "I get a call from nursing that the evening snack tray will go around, and people will grab whatever they like instead of adhering to their diet level." In this scenario, dysphagic patients were in a context where the snack tray was being passed around to all patients leading them to an easy path to non-adherence and potential risk of choking or aspiration.

Another constraint of practice, related to time, was the inability of SLPs to oversee HCPs. A problem with dietary adherence was frequently described when HCPs interacting with the dysphagic patients did not verify the recommended diet. The vast majority of SLPs indicated that they address this challenge by documenting results, strategies and recommendations in multiple locations. A reason for needing to post information in multiple locations was shared:

“We have people that do not bother checking. We have it written on the board, it’s in the patient room and you can forget when you have them in the physiotherapy room. So, most people will ask me, or some go check the board.”

(Participant 7)

5.4 Collaboration

Collaboration between the SLPs, the patients, family, and HCPs was another theme identified in the education and counselling of dysphagic patients. Collaboration is essential to maximize safety and nutritional intake for patients with dysphagia. The SLPs described dysphagia practice as inherently collaborative. Participants talked about who they collaborated with, the importance of, and challenges associated with, family as collaborative partners; the need for creativity and innovation in collaboration, and the duplication of patient recommendations for their collaborative partners.

There was an awareness and appreciation that the education and counselling of dysphagic patients cannot happen in isolation. The SLPs spoke about the ways that they engaged in dysphagia education and counselling with a variety of team members including dysphagic patients, their families and numerous HCPs. The HCPs included Registered Dietitians, Registered Nurses, Respiratory Therapists, Occupational Therapists, Physical Therapists, Personal Support Workers, Physicians and the kitchen staff.

The majority of the SLPs discussed how they partner with a Registered Dietitian (RD) to ensure that individuals receive adequate and appropriate nutrition:

“With your ABI’s [patient’s with acquired brain injury] sitting tolerance, and attention is quite often an issue. Right? So, we’ve got 15 minutes to get enough nutrition into this person. And they’re really going to take a good 40 minutes if they’re going to follow all their strategies. But we get 15 minutes, so what can we do? Can we put some protein powder in [their meals]?” (Participant 9)

SLPs also talked about the need for collaboration and direct communication at times with the kitchen and kitchen staff. They frequently talked about kitchen staff members’ desire to assist with dietary adherence. Participant 2 indicated that this communication was vital and could be time consuming “I spent half an hour with the kitchen passing on preferences.”

Some of the SLPs recounted how at times “micro teams” developed within the health care team. Participant 6 talked about how she worked closely with Occupational Therapists (OTs), Respiratory Therapists (RTs) and Registered Dietitians (RDs) forming collaborative relationships almost like their “own little department.” She described working closely with the OT:

“You know, around working on self-feeding, what can I give them...working on pincer grasp”, and with the (RT), and a (RD). She noted “a lot of times I will email...can you keep an eye on or check in on [particular patients].”

The majority of SLPs described how they collaborate with various allied health care disciplines to assist in the implementation of the dysphagia education recommendations. Some of the SLPs discussed how they have learned from collaborations within the Interdisciplinary Team (IDT). Participant 9 talked about working with physiotherapy (PT) to assist with positioning, “quite often for positioning our folks. So, they can only sit up for 10-15 minutes without being in excruciating pain, how do I get them through a meal?” She also discussed her conversations with PT collaborating on how practice approaches specific to PT could perhaps be applied to assist with a dysphagic patient.

The goal was to apply strategies to assist with the dysphagic patients with a slower rate of eating, as she was concerned it was a safety issue. This participant spoke with her PT colleague to point to a similarity in practice: “They’re on a walker at 100 miles an hour too, and that’s not safe, so, how are you guys getting them to slow down? Maybe I can apply that to getting them to slow down eating.”

When it came to education and counselling of dysphagic patients, many of the SLPs spoke of their preference for communicating their patients’ dietary needs with experienced versus more novice RNs. Participant 1 relayed that she had observed that experienced RNs had a quicker and innate comprehension of the issues, and abilities to adopt the consistent communication needed regarding dietary adherence: “I like to speak to the more seasoned RN who really understand dysphagia. After all these years, they are more successful in incorporating strategies.”

Many SLPs described experienced RNs as collaborative partners in reiterating the education messaging. Participant 3 stated: “And sometimes you get the nurses, or the patient, that is complaining about the slightly thick [fluids] and they (RN) help with retelling the reason why.” Some described educational collaboration with nursing as follows:

“All the nurses are pretty good on the unit...once they see something [education material] posted at bedside that kind of alerts them that ‘I have got to watch this’. They are also good at complying with recommendations – they’ll leave us voicemails during nightshift so we’re aware [of issues] when we get to work in the morning.” (Participant 5)

Overall, most of the SLPs spoke positively of their collaborations with various members of the interdisciplinary team. On one team the SLP particularly praised the physicians: “The physicians are excellent at using the SLP skill-set, they value the input, and they do sort of acquiesce to an SLPs expertise in dysphagia.” (Participant 6)

The SLPs in this study regularly spoke of the family as an integral part of the collaborative team. The crucial role families play and the importance of education of

family members was described as follows: “Rehabilitation is too short. Family are taking them home, family have to deal with them at the end of the day, not me.” (Participant 7)

Many SLPs described their rationale for including family in the collaborative team and as part of the education process. Participant 4 highlighted the importance of family “buy in”, “I find that family have to have an understanding or else they will not buy in or follow or remind the patient.” Participant 9 shared observations about the influence family can exert as a result of education and counselling:

“I try and educate with a family or a friend, and I make them part of our team. I do not believe that we are a separate entity, because when they go home, they’re not taking the nurses with them right? So, this is where I really designate, or I should say delegate to a family member.”

The SLPs had mixed responses when discussing the type of education provided to families compared with that provided to their dysphagic patients. Many reported that they were more honest with families, whilst being more encouraging to a dysphagic patient. The vast majority of SLPs reported that their honesty was a response to scenarios they witnessed in practice. Participant 5 shared: “It can be kind of depressing for some family members you know - full puree - oh man, that is old man’s food.”

A few participants described incidents of tension within collaborative practice that required education with their IDT members. Participant 10 described a situation where their proposed professional assessments were inconsistent for a shared dysphagic patient who could not take food by mouth:

“I had a patient that was NPO and they (IDT members) wanted to take him into the kitchen for an assessment of his cognition. But still, it was a big contradiction to his actual eating status. It was sending the wrong message to send him to the kitchen when he was not allowed to eat.”

Participant 12 noted that some of her team members complain about restrictions related to dysphagia recommendations:

“Many complain the patient may be dehydrated or hooked up to an IV or feeding tube and so they may see it is limiting...so they make comments but it’s not like I chose to put them on these things.”

One SLP articulated that being aware of the education (diet textures) and counselling (strategies) for a dysphagic patient was the responsibility of each HCP. They mentioned that if the HCP is part of the collaborative team, they should be held accountable for that responsibility. She stated, “We all have responsibility – you’re responsible for your responsibilities – I’m responsible for mine” (Participant 9).

At other times some of the SLPs described the relationship with the RNs as complicated. Participant 2 noted how sometimes nurses changed patients’ dietary orders, which could have serious implications for dysphagic patients: “the kitchen has found that nurses sometimes accidentally have made changes and the kitchen wants confirmation that the change was done by the SLP and was intended to be done.”

Several of the SLPs reported that they perceived inconsistent dysphagia knowledge from the RNs they encountered. For instance, given the importance of body positioning for safe eating practices, Participant 3 highlighted the need for ongoing education:

“Positioning - that is a big one for the nurses, and it is not done very well, and also setting up the patients to eat by the nurses.”

The majority of the SLPs discussed the strategy of revisiting education with team members in challenging scenarios, for example, when patients aspirate. An example, one participant stated the following:

“... in terms of nursing staff, well to be honest, there have been nurses that say, ‘oh I think they will be fine’, and you know they [the patient] aspirated and I had to explain that they may seem fine and (re)explain the concept.” (Participant 4)

5.5 Mitigating Risk

All of the SLPs stressed the need for education and counselling of dysphagic patients related to dietary plans, given the risks and dangers of aspiration and even the potential for fatality associated with non-adherence to dietary recommendations.

The SLPs in this study all supported patient choice. These choices could at times involve risk. They described supporting these choices by providing a form of scaffolding; offering some protection to the patient and to the organization. In order to mitigate risk, the SLPs also discussed how they used the hospital environment to reinforce education and counselling recommendations. All of the SLPs spoke about posting information – such as dietary textures and consistency, positioning information, food tray set-up instructions - in strategic locations such as above the bed, or on a communication board, or in the chart. Most of the SLPs reported that they place the education and counselling recommendations in many locations. Participant 13 articulated her rationale for this as protective: “I just wanted to protect him.”

Some described posting colour-coded forms to convey dietary information:

“We have a spot above the bed. They are pink forms and they have check boxes for the different textures and liquid consistencies. Under that we’ve got strategies, so we can check what they need. So that’s at everybody’s bedside.” (Participant 8)

Participant 1 noted, “I have a sign that goes above the bed with recommendations including remembering to sit up for 30-45 minutes after eating.” Many SLPs described the use of communication white boards at the bedside or as means of communication: “The diet texture and any strategies get written on a white board beside their bed” (Participant 2); “Every patient has a white board with their information and scheduling on it and a spot for diet, so we write in the texture and the fluids. It is a very busy board” (Participant 5).

Some described the use of a communication board at the nursing station to convey information to various HCPs:

“We have a white board in our nursing station for our patients that require supervision. We have a supervision whiteboard basically. And so, we can reflect diet changes there. Also, we have to document our suggested orders, and we also write it in the nurse’s progress notes. Document, document, document.”

(Participant 13)

An approach to communication which has the advantage of physically moving with the patient was discussed by Participant 2: “The procedure for informing other HCPs is that the patient gets an orange wristband to warn of dysphagia”. One SLP described how she attempts to control the physical environment to mitigate risk of aspiration by placing orders for physical positioning: “Sometimes especially at breakfast, they get up, especially in bed, they would be slouching so, I write it in the patient’s chart, I write it (positioning) as an order” (Participant 7). There was one SLP who took a different approach to the documentation process described by most therapists. Participant 9 articulated “I don’t duplicate. You want to know what the diet is? That is your patient. The information is all there, it’s in the orders.”

Given the cognitive challenges of dysphagic patients, the need to provide education to not only the patients but also to the dysphagic patient’s family, the interprofessional team, dietary staff, and a myriad of HCPs was frequently emphasized. All of the SLPs spoke about the range of stakeholders who needed to be aware of, enact, and reinforce the diet choice, and the various strategies they used were to keep the dysphagic patient “safe.”

On another level, the findings of this study indicated that the SLPs acted in ways that mitigated risk related to the potential consequences for professionals or institutions when dysphagic patients failed to adhere to recommendations. The role of documentation in mitigating risk related to non-adherence was discussed by all SLPs in the study. Some documented the dysphagic patient’s choice: “I document that the patient is refusing the least restrictive and safest diet by choice” (Participant 9). Some shared how they address risk through education practices:

“We write in our reports that we discuss not only the risks of aspiration but of the fatal sequelae that could follow. So that they have a strong understanding that you know if they were to aspirate it possibly could be fatal.” (Participant 13)

Others shared how documentation served as a contract and was imbued with facility mandates:

“Documentation-yes. They actually have a form that says the education has been provided, that they’ve understood the risks and they’re willing to accept that risk. They have to sign it, it’s almost like a contract and it goes into the patient chart.” (Participant 10)

Mitigating risks related to legal implications of non-adherence was discussed. The notion of defensive medicine, legal implications, and waivers for non-adherence were topics of concern:

“We used to have people sign something saying that they have heard that I have explained to them the consequences of things like aspiration and can result in aspiration, pneumonia and possibly death and have them sign a waiver. We were told it would not hold up anyway, so now we just document in the chart that we have educated this patient, what we have said, what the patient response was and that’s supposedly good enough. As long as we document very well what we do, what we said.” (Participant 7)

SLPs acknowledged that they are informed through a variety of sources when dysphagic patients (or family) have consented to a diet but engage in nonadherent choices:

“It turns into a discussion of just educating and documenting, and making sure they understand the risk, and then just connecting the dots with the doctor, the rest of the team. Like (explaining) how risky it is for them to go off-roading with recommendations.” (Participant 8)

A number of SLPs talked about the ethical implications of their work-related decisions. SLPs discussed when nonadherence is the choice that dysphagic patients have made. Some SLPs discussed a level of comfort, if this is a decision that dysphagic patients have made from an informed choice perspective:

“If someone does make that choice (non-adherence) then I do a lot of education around it. I involve all the stakeholders, all the team. It happens a lot, more than not. And that’s fine, I’m comfortable with that. As long as I have the discussion and then document it.” (Participant 11)

Some SLPs talked about their frustration, but also acceptance, that despite completing and repeating and revisiting education, and doing all they could to mitigate risks, sometimes non-adherence was beyond their control:

“I’d like to say it is controlled but I can honestly say that I find there are some families who take your word and wouldn’t bring in anything extra, they check with everything and then there are those families that have jujubes for individuals on puree.” (Participant 3)

Repeating and revisiting education as a means to mitigate risk was frequently discussed as a matter-of-fact part of what SLPs were required to do:

“When families just do not want to follow the recommendation even though we explained it to them - that they can’t, it’s not safe for them to be on this particular texture. And they will bring in grapes or beef jerky and stuff like that. So, it becomes a matter of, okay let’s try this (education) again.” (Participant 5)

The SLPs in this study have practiced within the medical setting for the majority of their careers. They were aware of and spoke to the fact that in their medical professional hierarchy, the physician is considered the final decision maker on many rehabilitation teams. Some SLPs discussed trying various strategies, like contracts, and then having the issue move up to a higher level on the medical hierarchy when these failed: “I tried to negotiate a contract with him, and that didn’t go anywhere. He kept becoming acutely ill, and the decision came out of my hands and went to the physician.” (Participant 6)

Methods in which the SLPs used collaborative innovations in dysphagia education were provided by the SLPs in this study. Participant 2 stated that “We have a band system so everyone can verify [patient] dysphagia.” The wristband system is a communication system that is commonplace and an integral part of overall hospital-based collaborative practice. Wristbands can communicate various forms of information such as: patient name, date of birth, medications, medication allergies, or falls risks. In this instance, the wristband also allows all involved staff to be aware that the patient is experiencing dysphagia without having to access their medical chart. Another SLP discussed communicating dysphagia alerts via electronic communication orders. This system was being trialed to alert RNs to methods of delivering medication when dysphagia is present. Participant 1 reported that, in her organization “dysphagia alerts in this manner has been positive.” Participant 4 talked about a collaborative interdisciplinary approach to education and counselling using football terms: “The ‘huddle’ facilitates collaborative education and counselling . The ‘huddles’ occurrence ranged from daily to weekly, with the aim to communicate timely information.” Another SLP described the ‘huddles’ as a chance to convey the education to the IDT all at once. “On-site collaboration occurs via a ‘huddle’” (Participant 7).

5.6 Practice Evolution

SLPs discussed this evolution as relative to their entry into practice. Many shared stories of their initial distress, and rigidity. Over time they spoke to being able to place context of dysphagia in the patient’s life. Participants discussed various forms of distress in their early career years. Distress was linked to the potentially fatal consequences of errors in dysphagia management, and the cognitive issues that create challenges for education with this population. Beyond the risk of death, participants noted other outcomes for patients when errors occurred. The dysphagic patient may become unwell, they may have to return to the acute care setting, and rehabilitation progress may be interrupted and or set back. The majority of SLP participants discussed their early year worries regarding consequences similarly to Participant 11: “I used to worry... pneumonia, aspiration, choking.”

The majority of SLPs spoke emotionally about feeling ill-prepared for the realities of dysphagic practice. Participant 7 gave the example of being ever fearful that a patient would aspirate “I used to be terrified any time that someone coughed.” Several spoke about a lack of confidence in the early years around translating assessment findings into education and ultimately into dietary recommendations. The majority of participants recounted cases of nonadherence that triggered distress. Participant 8 shared “I struggled mostly with the confidence of the decision-making at first, and oh man it’s on me now.” Participant 6 discussed that, despite the education, “he kept becoming acutely ill.”

Some SLPs discussed forms of distress in light of a dysphagic patient’s cognitive, communication and emotional limitations and family members distress during conversations about unsafe diets:

“These conversations [around unsafe diet choices] are still a very uncomfortable feeling I think for a lot of people. I was worried about the patient getting pneumonia aspirating or choking. To the point where it was very difficult to have tough conversations with the patient and family members about unsafe diets.”
(Participant 11)

SLPs discussed that it was not always easy to witness non-adherence to dietary recommendations “there have been clients that just do not comply...it is hard”, but that over time she had learned that “you have to respect” patient’s choices (Participant 3).

The SLPs described their practices in the early stages of their careers as more prescribed, rule-driven in nature, and rigid. Participant 6 noted: “Early in practice I was quick to [recommend] purée and thick liquids.”- This type of rigidity was also described “When I started I recommended everyone be NPO” (Participant 10). Over time, the therapists described shifts in their knowledge and capabilities whereby they considered contextual elements and practiced in ways that incorporated a bigger picture view. Participant 8 stated “over the years [my] practice has evolved to look at the bigger picture to take in all the factors - safety, efficiency and quality of life. And I incorporate those three things better now, compared to when I first started.” Similarly, Participant 10 highlighted how they became more comfortable with some degree of patient risk: “Over the years I’ve

tried to be less rigid and more open and accepting to the fact that a dysphagic patient can take risks and also have a quality of life.”

Participant 7 described becoming more open to experimenting with the unknown: “And now I am a little bit more easy-going; I now know we can try things with people, see what they can do.” Participant 9 talked about becoming more flexible over the years: “My practice has evolved tremendously. I have gotten in my years, very flexible on swallowing.” Participant 3 highlighted how her current approach to education and counselling was more flexible; whereas in the past she was more rigid and directive in her communication: “I used to be: this is what I found, and this is what you have to do.”

Some SLPs discussed how over time their education and counselling practice evolved toward greater compassion and shared decision-making with patients. These discussions centered around negotiating with a dysphagic patient their ability to make choices and to consent to the diet of their choice. Participant 2 discussed: “I am able to educate them on the risks of aspiration and let them take their chances because it is their anatomy and life to love, so ultimately it is their decision.” Participant 5 spoke about her comfort level increasing with years in practice “As a seasoned clinician I am more comfortable,” I “allow the patients...” “informed choice”, “poor choice is ok.” Increased flexibility with a dysphagic patient choice was described by Participant 2 as, “I would rather the patient make an informed decision and have them happily cough away”, and Participant 9 stated, “I have gotten very flexible on swallowing and I will definitely respect the patients and the family.” Some therapists spoke about changes in their practices wherein, over time, they developed respect for a dysphagic patient’s choices and decisions about nonadherence. “I respect patients’ wishes in terms of wanting to eat things that may not be “allowed”, eating is one of the joys of life, if you are taking that away from someone you should be conscious and not restrictive” (Participant 10). Participant 2 discussed being able to openly listen even when decisions were not in alignment with recommendations: “I am better able to listen to patients and what they want as opposed to being afraid they might aspirate.” Participant 12 stated “I evolved to recognize more quality of life over straight safety.”

Many SLPs also described an evolution in recognizing the importance of education and counselling as a crucial complement to assessment and intervention. Several SLPs acknowledged this was touched on in their formal preparatory education yet indicated they had not considered this in relation to service delivery. Participant 8 described how this shaped her practice “I incorporate safety, efficiency and quality of life compared to when I first started, the amount of time I spend talking about the results has increased, they [patients] understand there’s a risk involved but my job is to help them understand and place it in the context of their life.” Similarly, some participants spoke about how the ability to develop innovative solutions is learned “on the job”: “There is no doubt that after years of dealing with these families ...you come up with more innovative solutions...as a new grad, you do not have that experience” (Participant 1).

A perspective voiced was that practice experience allowed for greater creativity in practice in the area of TBI and dysphagia. The majority of the SLPs described their evolution as moving towards being more realistic and aware of the challenges the TBI individual encounters adhering to a dysphagia diet and that they (the SLP) experience in the complex IPR context. Participants spoke about recognizing the implications of the cognitive challenges inherent in TBI: “I don’t think it’s done in the negative, like they are not trying to comply they just don’t have the memory skills, reasoning and whatever to comply because of the brain injury.” (Participant 3). The context of the nonadherence was elaborated by Participant 10: “They are not wanting to be noncompliant but because the memory piece or the awareness piece is lacking, it happens.”

All of the clinicians acknowledged change as a constant within healthcare. In reflecting on her evolution in practice, Participant 2 noted, “I feel different than when I started (practice) and this is a good thing.” Some of the SLPS offered advice to SLPs still receiving their graduate-level dysphagia education: “I would say to somebody coming to work on this floor, if I was mentoring, dysphagia education is more than the

Tactus™³ app and the Nestle™⁴ products. Just sort of look at the whole patient - that might be my message” (Participant 11).

³ Tactus™ refers to Tactus Dysphagia Therapy for Swallowing App - a for purchase application that provides evidence-based therapy approaches that match your patients’ needs.

⁴ Nestle™ products in the context of this conversation refers to the Thicken-Up product for adapting thin liquids.

Chapter 6 Discussion

6 General Introduction to the Discussion

This study examined how SLPs enact education and counselling with patients who have dysphagia and a traumatic brain injury within inpatient hospital settings. This inquiry into SLPs' experiential knowledge revealed deep layers of complexity within practice in this context.

In the first section, various complexities in the enactment of education and counselling are discussed with a focus on communication, working with the dysphagic patient with a TBI, and the IPR practice context. In the second section, the ongoing need for SLPs to work toward the mitigation of risks and harm to their patients, and the consequent potential for moral distress, are considered. In the third section, the ways in which SLPs professional practices seem to evolve over time in adaptive ways are highlighted.

6.1 Complexities and the enactment of education and counselling

SLPs play a leading role in meeting dysphagia-related healthcare needs within Canadian settings, with many SLPs reporting that their primary job involves dysphagia service delivery to patients in hospital or rehabilitation centers (Steele et al., 2007). The findings of the current study revealed SLPs perceptions of the complexity of patients, families, and the healthcare system(s). These complexities were revealed in three main areas of practice: communication, the patient, and the IPR contexts.

6.1.1 Complexities of communication

Upon completion of a swallowing assessment, best practice guidelines indicate that it is the SLP's responsibility to educate and counsel the patient and/or caregiver regarding the results of the swallowing assessment and the recommended management plan in terms that are easily understood (CASLPO, 2014). Communication is meant to ensure that patients and their caregivers are educated and counselled so that they fully understand that patients are at risk of pneumonia, readmission to acute care, choking, and malnutrition if the recommendations are not followed (CASLPO, 2014; Speech

Language Pathology and Audiology, 2007). Patients and families are also to be counselled that these complications can interrupt and prolong the rehabilitation process (Hammond et al, 2015).

The dysphagic patient with a TBI is more complicated to communicate with than the typical patient, in that they will often experience a cognitive-communication disorder which may result in difficulties with comprehension, memory, recall, motivation, learning new tasks, and self-regulation (MacDonald, 2017). These types of challenges directly affect the two-way communication processes that SLPs typically engage in during education and counselling sessions with patients and their families (MacDonald, 2017; Pegg et al, 2005).

Consistent with recommendations for health care services, all of the SLPs in this study expressed their commitments to patient-centred care (PCC; Hughes, Bamford May 2008), and discussed the ways they considered the patient's rights to receive information and to participate in shared decision-making (Trede and Flowers, 2014). SLPs efforts to educate and counsel patients frequently aimed to engage the individual, provide them with information, and determine what the patient understood and where gaps in knowledge were still present. SLPs described the ways they listened and negotiated with patients to try to enact effective education and counselling, their descriptions of trying to respect patient autonomy in challenging circumstances were consistent with calls for informed choice as a hallmark of patient-centred care (Hughes et al., 2008; Trede and Flowers, 2014).

SLPs discussed adjusting and tailoring their education and counselling to try to facilitate patient understanding in ways that considered the patient's health literacy levels. For example, SLPs relied heavily on tailored visual materials, simplified language, and used step-by-step instructions as needed. These approaches were consistent with strategies identified in the literature as leading to improved patient understanding (Howle et al., 2014), empowerment (Pelletier, 2005) and satisfaction with care (Pegg et al., 2012). Similar to the approaches identified in the scoping review of the literature (Chapter 2 of

this thesis), the SLPs also provided written and verbal instructions, often customized and individualized.

The participants in this study embody the deliberate professional defined by Higgs (2016). They described what it is to *be* a professional practitioner not just what it means to *do* their practice. Participant 4 exemplified this by identifying that “we are so used to it (*dysphagia*), because that is what we live and breathe, because of where we work and so it just becomes second nature for us.” There is an awareness by the SLPs that this “being used to it” is not the case for the patient and or their families. Participant 6 shared, “I work around the position they (*the patient*) are coming from, and what they consider a victory, and there is nothing wrong with small victories.” Higgs explains that, to be a deliberate professional, one understands and owns the decisions made in “shaping the path and impact and nature of one’s practice and model of practice” (Higgs, 2016, p.191). Participant 10 demonstrated this position when she shared, “I’d rather give them options that are less safe, at least they have the option to decline rather than me saying no you can’t eat this it’s not safe for you; that’s old school paternalistic view of medical care that we are trying to get away from.” However it should be noted that, in combination with this view of ‘optional’ care, SLPs talked about ensuring safety measures were put in place to mitigate risks presented when patients declined to follow recommendations.

The SLPs in the current study discussed the importance of communication with the family members. Families were frequently viewed as an integral part and valued member of the collaborative team. Families bring another layer of complexity to the enactment of education and counselling because they are affected when their loved one experiences a TBI, and they are frequently the ones helping patients to carry out therapeutic recommendations. The literature review supported this finding indicating that it is incumbent upon SLPs to possess the knowledge, competency, receptiveness, flexibility and creativity necessary to manage family dynamics, help allay their fears and concerns, and to provide the needed support and support-resources for them (Colodny, 2008; Foster et al., 2012; Howle et al., 2014; Short et al., 2014). While this seems like a straightforward dimension of practice, the SLPs discussed frequent challenges with enacting education and counselling not only with the patients but with family members.

For example, numerous repetitions of the material were regularly required. Many of the SLPs shared that they were bewildered when they completed what they considered successful education and counselling sessions with families, for instance informing them about the risk of aspiration with inappropriate food choices, yet there seemed to be a failure of communication with family members. SLPs described how family members who appeared to have good health literacy (i.e. comprehension of anatomy, asked probing questions, could recount information provided), would return a few days later and question the recommendations, for example to inquire whether the dysphagic individual could participate in “a normal Christmas dinner.” Comprehension of the intended message seemed incomplete; perhaps due to emotions surrounding food, family, and celebratory events (Leslie & Crawford, 2017). While the scoping review results seemed to focus on ways to facilitate adherence to management recommendations, many of the SLPs interviewed in this study discussed the importance of a holistic approach to the patient. They recognized the importance of the individual participating in the lives of their family and important family dining events, even as they had to recommend that they not do so. Rosenbek (2017) presents that the biomedical model, which currently underpins the dysphagia education and counselling process, may suppress, ignore or minimize the important participatory components and lived experience of the patient. Perhaps some of the challenges that are being experienced in counselling and education would be lessened if a biopsychosocial approach (Borrell-Carrió, Suchman & Epstein, 2004) to dysphagia assessment and management were taken with more of a focus on the importance of participation with food, meals and the enjoyment that is being missed for these patients and their families. Consistent with the experiences of SLPs in this study, various scholars have discussed how the family’s readiness to receive information, and health literacy levels, are important to be aware of because they shape capabilities to receive information, and to be able to carry out the role of carer, supporter and advocate for the patient with dysphagia and a TBI (Colodny, 2008; Foster et al., 2012; Howle et al., 2014; Pegg et al., 2005; Short et al., 2014).

Consistent with recommendations in the literature (ERABI, 2018; CASLPO, 2014), the SLPs in this study provided specific and more in-depth education and counselling for family members while trying to ensure the non-use of technical ‘jargon’. The scoping

review suggested that family education should include training programs in feeding techniques (Foster et al, 2012), understanding the implications of nonadherence (Horner, Modayil, Chapman & Dinh, 2016) and provision of individualized management strategies that work for the patient and family might be a beneficial education and counselling pathway (MacDonald, 2017). While SLPs in the study endeavoured to carry out these types of activities with families, none of the SLPs mentioned availability of these types of education and counselling programs in their IPR context or community.

The CASLPO guideline calls for interventions that optimize “an individual’s ability to swallow, thus improving their quality of life” (CASLPO, 2014, p. 3). SLPs in this study highlighted how following this mandate required significant collaboration across the professional healthcare team in today’s IPR context. There are decisions enacted in acute care to refer patients to IPR (Cuthbert et al., 2011; Rogers, Richards, Davidson, Weinstein & Trickey, 2015). It was the opinion of several participants that patients are coming to the IPR setting in more acute stages, with shorter length of stays, such that SLPs had to “hit the ground running.” SLPs needed to rely on collaboration with others as they “can’t observe everyone at mealtimes.”

Colodny (2001) suggests that it is incumbent upon SLPs to ensure that people throughout the entire facility (from administration to those who feed patients) are prepared to support efforts toward proper patient feeding and to follow the SLP prescribed recommendations. It is incumbent upon SLPs to ensure that everyone is aware of the potential consequences for the patient if instructions are not followed. This creates a heavy burden of responsibility on the SLP, requiring a high degree of comfort and competency in developing and delivering targeted information to various audiences with differing health literacy levels, and in shaping behaviours at a systems or organizational level. It is not clear in the literature ‘who’ should be monitoring the entire facility to ensure that everyone is enacting the recommendations of the SLP.

Team collaboration in the IPR context is made complex because of the numerous HCPs involved in patient care. The SLPs in this study listed 8 different professions that they regularly collaborated with (Registered Dietitians, Registered Nurses, Respiratory

Therapists, Occupational Therapists, Physical Therapists, Personal Support Workers, Physicians and the Kitchen Staff). A number of SLPs described practice constraints related to limitations in the availability of team members, and/or in the knowledge base of the staffing unit regarding dysphagia or TBI (especially with casual or new staff) within the IPR setting.

Colodny (2001) recommended that, because of the negative impact of nonadherence to the patient and burden on the health system, on-going educational initiatives with appropriate monitoring should be required to improve adherence by HCPs to SLP recommendations, for instance for thickening liquids and other dysphagia and feeding interventions. Rosenvinge & Starke (2005) found that the creation of individualized training programs (e.g., The Dysphagia/Nutrition Link Nurse program), targeting various HCPs who had contact with patients, educated and empowered them, resulting in increased adherence to SLP dysphagia-management recommendations. Pelletier (2005) also provided evidence that individualized training programs incorporating HCPs personal feeding beliefs (social feeding versus technical feeding) may be effective in improving adherence to SLP dysphagia-management recommendations. The opportunity to create or introduce such initiatives or access to ongoing collaborative team education initiatives was not discussed by any of the SLPs in this study.

Many of the participants in this study reported that their practice environments are busy and leave little time for anything other than direct patient care. Most participants completed the interviews on their own time (after work or during lunch break) because they thought the work was interesting and important and they did not have the time during the workday to participate. As I reflect on the practice scenarios described by participants, I wonder what increased staffing levels would mean for the constraints described in this work. How is an increased SLP presence in the IPR context to be achieved? It is unlikely that clinical release of time to participate in anything other than direct patient care will be provided based on the current practice landscapes they described. How do SLPs create a time for reflection, planning and critical review of their practices in this current environment? How do they access and implement continuing education and best practices? How does one stay an engaged and curious learner and

bring this into practice when the perception is that all paid time is related to, or directly, patient-contact. Many participants indicated that funding for continuing education was arduous to obtain, They also shared that continuing education was often completed on the SLP's own time. Liaising with leadership and outlining the benefits of continuing education benefits for the facility, patient care and staff may prove useful. In reflecting on my own practice experience, I found that engaging organizational leadership positively affected the trajectory of projects that had languished for quite some time. It was a mindset shift on my part to create a business plan approach within a clinical, healthcare environment and to then advocate for the implementation of said plan. The novice SLP in this practice environment may not feel confident or may feel their employment status at risk if they took this approach with leadership. It would be interesting to learn more about how the IPR context has changed over time for SLPs working in dysphagia with TBI patients and how this has impacted delivery of care, opportunities for time to prepare and learn and willingness to advocate to leadership. It may be of interest in future studies to explore how larger healthcare settings engage and encourage practice-based feedback, what mechanisms are available and how this translates into changes for patient care.

6.1.2 Complexities of the dysphagic patient with a TBI

Clinical practice guidelines (CPGs) provide evidential direction for the assessment and management of specific diseases, disorders or clinical problems. In Ontario, CPGs written for dysphagia assessment and intervention (CASLPO, 2014) aim to provide a way to ensure quality patient care and reduce practice variation to achieve optimal outcomes while promoting efficient use of health resources (CASLPO, 2014; Kryworuchko, Stacey, Bai, and Graham, 2009). Dysphagia CPGs recommend that SLPs must engage with patients and provide critical information about the assessment results and the risks and benefits of the intervention choices under consideration (CASLPO, 2014). The guidelines and practice standard statements emphasize requirements and 'musts' associated with SLPs' skill development and the necessity for continual learning associated with dysphagia service delivery. Guidelines also recommend that the management plan must be regularly monitored and evaluated, to determine whether refinement and or discharge are appropriate. Two important complexities of practice

become apparent when the guidelines are considered in light of the results of this study. First, because CPGs are developed from an evidentiary perspective, they generally exclude patients with multiple healthcare conditions. This is due in part to the difficulty of synthesizing good-quality evidence for every combination of complex conditions (Guthrie et al., 2012). However, this “single-condition” approach to guidance has, as a consequence, unclear recommendations for healthcare providers about treatment recommendations, education and counselling when more than one condition is present, and particularly when such conditions often involve cognitive impairment, as is the case when a patient has dysphagia and a TBI (Boyd et al., 2005). Second, similar to other CPGs, the dysphagia CPG does not include guidance on specific education and counselling interventions, despite the evidence that patient and family education, counselling and support are considered critical to effective treatment and self-management (Toman et al., 2001). A concern of evidence-based practice is that it may place practitioners at times in the role of technicians whose skills lie in the application of knowledge created elsewhere, rather than in considering its relevance and utility in specific practice situations. This is not to discount that evidence-based knowledge does assist with clinical decision-making (Taylor and White, 2001). It instead points to the need to ensure that clinicians are educated about the fact that evidence-based practice is meant to pair the evidence with a clinician’s expertise, practice context and the needs, values and preferences of the patient (and family). Many of the participants were aware of the dysphagia CPG, but they also felt that there were significant limitations with implementing it within the dysphagia/TBI/IPR practice context. For example, the CASLPO Practice Standards and Guidelines for Dysphagia Intervention by SLPs states that “SLPs must have the required competencies to provide dysphagia services” (CASLPO, 2018, p. 12), and must “demonstrate skill in developing clear and effective methods for educating patients/clients and their caregivers regarding selected swallowing management techniques” (CASLPO, 2018, p. 12). However, the document does not provide guidance on the most effective methods for “communication regarding the nature of the swallowing problems”, (CASLPO, 2018, p. 28), or how to best educate patients/clients and their caregivers about “how to recognize and respond to signs and symptoms that reflect a risk of harm” (CASLPO, 2014, p. 28). Similarly, none of the

peer-reviewed or grey literature reviewed provided succinct information on how SLPs enact education and counselling in the area of dysphagia service delivery with patients who are experiencing dysphagia and also have a traumatic brain injury, especially within the context of inpatient rehabilitation. As regulated HCPs, the SLPs in this study were aware of their roles and responsibilities and the availability of current dysphagia practice guidelines. The SLPs lamented the lack of guidelines for TBI compared to those for cerebrovascular accidents, and collectively they spoke of the lack of a “cognitive-communication dysphagia” category.

6.1.3 Complexity within the IPR practice context

The results of this study suggest that SLPs are needing to adapt to system pressures which include limited access to important equipment, time, spaces, and effective materials to facilitate education and counselling across the diverse partners in practice.

As an example, the VFSS is regarded as the ‘gold standard’ for dysphagia investigation and is considered an important tool that can assist in the education of the patient and those influencing their care (Boaden, Nightingale, Bradbury, Hives & Georgiou, 2020). Access to VFSS images was recognized by SLPs in this study as an optimal way to know in real-time what is happening with their patient in terms of swallowing function. They also reported that it provides an ideal and effective way to educate about swallowing and to provide critical information to the patient and their family regarding the assessment results, the benefits of intervention choices, and the potential hazards of aspiration. However, across the rehabilitation settings there were a number of SLPs who had no access to VFSS, some who were limited by institutional regulations that precluded access to it, others where the wait lists created barriers, and still others whose patients were required to go off-site to access VFSS. The challenges of patients being discharged without access to VFSS, institutional regulations that precluded access, and long waiting lists, were frequently highlighted as challenges. This need to adapt their practice to system-level pressures and complexities constrained the SLPs ability to provide education and counselling in a manner that would typically be regarded as best-practice.

Further, the current IPR setting for the dysphagic patient was shown to not always be conducive to delivering assessment results and managing intervention(s) in a way that upholds the practice tenets of privacy and confidentiality. Some SLPs in this study had to adapt their practice to the system-level pressures of space and time. Space and time (both time for education and counselling and time associated with caseload demands) are at a 'premium' in the IPR context. SLPs discussed ways that they work to maintain confidentiality 'as best they can' and to deliver ethical care regardless of their caseload size. Some SLPs shared that clinical time constraints, were amplified in current settings where patients are coming into the IPR context in a more acute state and with shorter lengths of stays.

A noted complexity of collaboration in the IPR was the extent of the circle of care. To verbally collaborate with colleagues, to document and chart the education and counselling recommendations in multiple locations requires extra time beyond the one-to-one patient/family education and counselling. The system may appear as though it provides opportunities for collaboration (huddles, rounds and charts), however when the SLP is required to communicate within all these collaborative opportunities, the time and methods to do so become extraordinarily complex. Organizational leadership and IPR facilities may feel that they are providing adequate and multiple pathways for staff communication. These options become cumbersome when you are unsure which one of the many options the HCP teams will choose to access. Participants expressed significant frustration and discussed the challenges with documentation, rework, and communication. Many IPR facilities in Ontario have moved towards, or there are efforts underway, for electronic charting and "one source of truth". Participants in this study shared that, despite institutional efforts with electronic charting, hybrid models of documentation continue to persist. The lack of a single and accessible source for documentation creates practice uncertainty and attempts to mitigate risk persist. I am curious to know what would happen if the SLP education and counselling message was documented in a place that HCPs did not read.

Upon reflection, I had believed that, throughout my doctoral work, I was compartmentalizing my studies and my clinical practice, but this was not the case. The

conviction that one participant shared regarding collaborative practice and charting caused an unconscious shift in my own practice. This SLP participant felt strongly that each HCP on the team had roles and responsibilities especially around informing and being informed. This translated into each person knowing where to go to obtain information documented about each patient. Being firm about having interprofessional team members read the chart notes for information rather than continually engaging in question/conversation with her to obtain the needed information was time-saving and important for her. I found that this conversation transformed my own practice behaviour and I implemented some of her suggestions. I found myself asking team members “have you read the chart note?”, and reiterating this over time when the response was “it’s faster to just speak with you.” Colleagues have commented on this change in my practice. The extent to which SLPs talked about designing, developing and revising educational materials was astounding, and did not appear to be recognized or accounted for in institutional mandates. There appears to be an obvious and unmet need for educational materials that respond to the complex needs of the dysphagic patient, their families, and the collaborative team. Integral to the design and development of the materials is the uncovered information that the education needs are different for each stakeholder group and they must be easily alterable for the complex cognitive-communication needs of the dysphagic patient. The MacDonald (2017) model illustrates the critical role of communication as a determinant of full life participation; the ultimate goal of communication being competence in real-world functioning. MacDonald (2017) informs us that the cognitive-communication interventions are particularly complex and require analysis of multiple domains of functioning and multiple influences on performance, in multiple communication contexts.

Interestingly, almost all of the SLPs interviewed described that they did not have a single, clearly defined location for the charting of recommendations and presentation of education and counselling materials. Most discussed having many locations. They provided the intervention recommendations in these multiple locations and repetitively for patient, family members, HCPs, other individuals within the circle of care because they worried about the potential for adverse swallowing complications if they did not.

6.2 Moral distress and mitigating risk

Norman (2005) argues that when practitioners are faced with these system-level complexities and adaptations to their practice it impacts their ability to optimally provide education and counselling. The adaptations to practice required because of the complexities associated with the patient, family, and healthcare context were seen at times to create moral distress for the SLPs. A well-established definition of moral distress is that it “occurs when one knows the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action” (Raines, 2000, p. 30). Distress is a natural response to a situation in which you are between “a rock and a hard place.” Moral distress has been described among healthcare providers who have encountered barriers to ethical action in their practice context (Austin, Kelecevic, Goble & Mekechuk, 2009; Carnevale, 2013; Ulrich & Grady, 2018). There is some evidence that moral distress may be linked to burnout in the health professions (Kalvemark, Hoglund, Hansson, Westerholm & Ametz, 2004).

Root causes of moral distress, and those mentioned by the SLPs in this study, included clinical interactions or working conditions. Clinical interactions included lack of continuity of care or conflicting duties. Working conditions included inadequate communication amongst team members, and inadequate staffing hierarchies within the health care system. Addressing moral distress also crucially requires attention to the environments and systems in which health care workers care for patients (Ulrich and Grady, 2018). Often these institutional constraints are facts of practice; present and non-negotiable.

The ethical tenets of non-maleficence (avoiding harm to people who have put their trust in us), beneficence (act for people’s benefit), and professionalism could be seen as components of the SLPs everyday practice that helped them navigate the moral distress (Chabon et al., 2011; Kenny, Lincoln & Balandin, 2010). I came to understand that SLPs used “repeat, revise, re-educate” strategies, posting their recommendations in multiple locations and in multiple ways, as well as collaboration, clinical innovations, and ethical deliberation to facilitate the mitigation of patient risk within this complex practice environment. All of the SLPs discussed the challenges of facilitating difficult (emotional)

conversations, decisions and plans regarding eating and drinking with individuals with cognitive-communication disorders, and about the range of stakeholders who needed to be aware of, enact, and reinforce the diet choice, and the various strategies they used to keep the dysphagic patient “safe.” The literature discusses that there are occasions when a person finds it mildly distressing that they are constrained from doing what they think morally best. Episodes of mild distress when they occur on a regular basis can have an adverse cumulative effect on those who experience them (Ulrich & Grady, 2018, p.63). Ulrich and Grady (2018) note that HCPs experiencing moral distress may experience burn out, perhaps even leave their profession or employer. While participants described scenarios of moral distress, they did not talk about leaving the profession. Most talked about needing and wanting support available through mechanisms like a community of practice. This raises an important question of how a community of practice of SLPs in this IPR context setting might work together to facilitate practice change. It appeared to me that, although the SLPs appeared to be experiencing moral distress in their work, they talked about how their work in dysphagia and TBI created a mostly positive impact on the patients and family in their care. Future work may wish to explore what mechanisms did they enact to cope with their distress.

Results of this study showed that the desire to practice in a way that is patient-centred, combined with the complexities of the individual’s cognitive-communication disorder, necessitated numerous repetitions and diverse presentations of assessment results and management plan recommendations. This was frequently conveyed as a time-intensive, frustration-inducing part of daily practice. The SLPs repetitive education and counselling initiatives with the patients (as well as families and multiple healthcare providers) could be interpreted as attempts not to be seen as what one participant called the “swallowing police”, but rather as efforts to work tirelessly to mitigate risks and adverse events in a patient-centred, time- and resource-constrained practice context.

Mitigating risk through education and counselling strategies was facilitated in an abundance of ways by the SLPs. As shown in Appendix G,H, I, J, K and L. SLPs used drawing and/or produced visual images/diagrams, coaching, swallowing Apps, tracheostomy models, books (“Follow the Swallow”) with their patients, families and

sometimes HCPs. They tailored strategies whenever possible for the cognitive-communication complexities of the patient, and the health literacy levels of families and the collaborative team. They participated in daily-to-weekly team “huddles, provided dietary recommendations at the bedside in colour-coded notes, and in whiteboards at the bedside and/or at nursing stations, used Kardexes in the nursing care binders.

Three novel methods for education and counselling are noteworthy. First, some SLPs created a system-level innovation in which they propose orders (Chalmers, Girma., Barker, Liu & Heck, 2016) that are written by the medical team as a medical directive. The Federation of Health Regulatory Colleges of Ontario (2007) indicates regulated health professionals, including SLPs, can receive a medical directive to order diet texture changes (such as initiating a diet texture, modifying the texture, or discontinuing oral nutrition), when patients meet the criteria defined by the medical directive. They define a medical directive as a process where a regulated health professional can receive advance authorization from a physician or physician delegate to perform the ordered procedure under specific conditions without a direct assessment by the physician or physician delegate at the time. SLPs in this study provided examples of medical directives such as patient positioning, method of medication administration, and dietary and fluid textures. As illustrated in Appendix H, one SLP created a customized/tailored and laminated dysphagia compensatory strategies ‘tool’ and fixed it on a photo frame with an alligator clip. Finally, an innovative but context-familiar dysphagia alert band was used by one SLP. The wristband system is a communication system that is commonplace and an integral part of overall hospital-based collaborative practice. In this instance, the wristband would allow all healthcare providers to be aware that the patient is experiencing dysphagia without needing access to their medical chart. An advantage of this method is that it ‘travels’ throughout the hospital context with the patient (for example, to physiotherapy and/or to the cafeteria).

Consistent with the literature on non-adherence, some SLPs talked about their frustration, but also acceptance, that despite completing and repeating and revisiting education, and doing all they could to mitigate risks sometimes non-adherence was beyond their control (Coy, 1989; Dunbar, Burke & Pucznksi, 1995; Low; 2001; Hermer, Larsen & Engberg,

2010). Many SLPs spoke about how years of practice experience has shaped their views and enabled them to respect the individual patient's choices, however they also spoke of how they worked to educate patients, and to mitigate the risk of these personal choices as much as possible. My clinical experience with the adult TBI population suggests a general theme of nonadherence with dysphagia diet recommendations that was also mirrored in the accounts of the SLPs in this study. Rationale for nonadherence includes texture, taste and feeder non-cooperation (Colodny, 2005). Although family members may be expected to ensure adherence with dysphagia diet recommendations, this is a complicated issue. It has been my clinical observation, supported by the literature, that through the trauma associated with TBI, families have difficulty enforcing required dietary adherence (Colodny, 2001; Colodny, 2005; Foster et al., 2012; Pegg, 2003; Pelletier, 2004).

Davis and Aroskar (1978) discuss the competing loyalties of HCPs - such as nurses - to hospital, physician and patient, but also to the hierarchical structures of authority and communication. This dynamic of balancing competing interests in response to complexities of practice was present in the findings whereby SLPs discussed being involved in balancing risk to patient and risk to facility. Whilst Davis and Aroskar (1978) were discussing the role of the nurse and physician there are parallels to what the SLPs in this study reported. Individuals who refuse or challenge recommendations are unfortunately described as noncompliant or non-adherent; such terms may be construed as pejorative or at least paternalistic when used to describe patients whose views and preferences may differ from theirs (Horner et al., 2016). Patients sometimes "bear the brunt" of defensive medicine practices because the systems are designed to escape liability rather than to benefit patients (Raper, 2013). When patients choose not to adhere with dietary regimens, some SLPs or the institutions in which they work may ask patients to sign waivers. These waivers are documents that limit or release practitioners from liability. The SLPs in this study indicated that in their practice, waivers were another form of documentation that informed conversations regarding risks and outcomes of nonadherence. When waivers were not used the SLPs were careful to include in their documentation that the risks of aspiration and potential for fatal sequelae were discussed with the patient and family. Some SLPs discussed trying various strategies, like contracts,

and then having the issue move on to a higher level (the physician) on the medical hierarchy when these failed.

It is challenging to counsel patients about risk(s) because the evidence in peer-reviewed literature is often contradictory and constantly evolving. The counselling of the dysphagic patient may raise reasonable questions from patient and or family, and may involve discussions regarding risk (airway obstruction, chest infection) and the potential for their dysphagia to resolve. A facet of standard of care is to fully disclose the nature of the treatment, the risks of and alternatives to the proposed treatment, and the risks associated with the refusal of a proposed treatment (Horner et al., 2016; Sharp & Bryant, 2003). Scientific evidence about risk factors for pneumonia after stroke exists (Hibberd, Fraser, Chapman, McQueen & Wilson, 2013; Paintal & Kushner, 2007), however, comparable research in the TBI population has not occurred. This does not allow for individualized risk assessment (Macciocchi & Stringer, 2001). Given the lack of evidence, the SLP would be unable to provide a confident assessment of the likelihood that a patient would acquire complications such as pneumonia (Langmore et al., 1998; Martino et al., 2005; Bray, Smith et al., 2015). The SLPs in this study discussed that they were able to educate their patients using evidence-based information. The complexity and limitations were that the evidence-based information available for them to educate their patients and their family was not specific to this patient population (TBI) and did not address the myriad of complexities this diagnosis adds to adherence (i.e. cognitive impairments such as attention, concentration, memory). The SLPs identified that they are hampered by the reality that until the TBI specific research knowledge base regarding effective rehabilitation interventions is established for dysphagia, aspiration, oral care, and malnutrition, therapeutic management will continue to be guided by extrapolation from the cerebral vascular accident (stroke) literature (ERABI, 2015). A SLP may be able to explain relative (statistical) risks, but not absolute (individualized) risks (Horner et al., 2016). Related issues involve iatrogenic harm, meaning harm caused by the treatment itself. Statistics show that dehydration and malnutrition are serious comorbidities of stroke and other neurologic conditions. These problems can be exacerbated when thickened liquids are used (Cichero et al., 2013; Garcia et al., 2005; Robins et al., 2008;

Studdert et al., 2011). Some literature indicates that a risk will be present despite a clinician's best efforts to minimize it. Neuberger (2005) comments:

“it is as if we are trying to create a risk-free society, in which we know that in our heads and hearts is impossible. The result is that we restrict and regulate, hoping to make terrible things impossible, whilst knowing we cannot, and in the process, deterring the willing and the kind. Risk aversion creates an environment where it will be difficult to do what is inherently natural and kind, in case there are accusations of behaving improperly or riskily” (cited in Higgs et al., 2008, p.24).

6.3 Practice evolution in a complex environment

In this section, I make the case that the practitioners with whom I spoke demonstrate the evolution of practice in a direction toward phronesis. Phronesis is wise practice, which is embodied within the social, situated context of professional life. It is enacted through ethical deliberation, guided by virtuous and compassionate care, practical judgment, and is informed by processes of reflection (Kinsella & Pitman, 2012; Sinclair et al., 2018). ‘Phronesis-applied’ practice can be seen to include competency, explicit use of acquired practice-based knowledge, clinical reasoning, and an awareness of patient needs.

The SLPs in this study, when asked to describe and recall the evolution of their dysphagia practice, reported that, upon entry-to-practice, they felt that they were initially unprepared or ill-prepared for dysphagia practice. Practice decision trees or CPGs are prompts for decision making, not recipes in a cookbook. “Cookbooks cannot deal with the unknown or the uncertain but clinical decision making frequently encounters them” (Yoder & Kent, 1988,p.xi). The resulting emotions described by SLPs in their early practice years were notable; “fear”, “terror” and “worry”. The SLPs in this study reflected on how as entry-to-practice clinicians they ran into problems that were not amenable to straightforward solutions. These kinds of problems reflect the limits of what Schön (1983) refers to as the “high hard ground.” Higgs (2016) describes that many clinicians experience “practice shock” upon entry-to-practice. Higher workloads, more challenging practice tasks, increased complexity of practice situations and overall increased responsibilities are experienced without the guidance and oversight of

preceptor supervisors that were available to student clinicians. SLPs described that their distress, tension and rigidity in response to the challenges arising in the early years of practice. Their expectation and application of theoretical dysphagia practice (assessment, treatment and counselling) did not fit the practice settings they encountered (complexity re: patient cognition, lack of resources, lack of time and space, caseload demands, organizational communication challenges, inability to complete counselling due to length of stay restrictions). Practical knowledge contrasts with knowing material in a textbook or theoretical knowledge learned in a classroom (Eraut, 1994; Ryle 1949). It is this practical knowledge that was absent. It is important to note that their reflections should be paired with the historical context of when they entered practice, many of the SLPs in this study have been in practice spanning 10-30 years. As dysphagia caseloads have risen over the years, there has been an evolution of education and training of SLPs in this important aspect of practice. Nonetheless, the current literature (ERABI, 2018, CASLPO, 2014) and the interviews with the SLPs provide evidence that there continues to be a gap in practice and lack of guidance within current dysphagia practice standards around education and counselling in general, and no specific written guidance provided for education and counselling when the person has dysphagia and a cognitive-communication disorder after a TBI.

The interviews helped us learn that over the course of their careers these SLPs developed competency in providing safe care in a manner that incorporates an awareness of patient values with an ability to accurately assess and critically think and reason through the best options for care using evidence-based practice **and** practice-acquired evidence (Higgs et al., 2008; Meehan, 2016). When the CPGs did not provide evidence on what to do, SLPs generated practice-based evidence based on their years of working with their patients. They tailored their education and counselling approaches and products for individuals, for families and for their IPR context. The SLPs discussed how the acquisition of practice-based added to their ability and confidence in self-evaluation and clinical reasoning. The SLPs in this study discussed how their practices had evolved. Changes include increased awareness of emotions, cultural connectivity, ‘invisibles of practice’ tied to eating, and expanded views of patients’ autonomy. Leslie and Crawford (2017) advocate for a view of patients equally as socially connected humans and not just

bodies that need fuel; a view that held resonance with the reflections of a number of the SLPs in this study.

Consistent with the wise practice developed through phronesis, the findings suggest that as the SLPs developed experience their practices evolved so that they were better able to work in complex patient and systems environments and adapt their education and counselling to meaningfully collaborate with the patient, their family and other healthcare providers. This accumulated knowledge enabled SLPs to work in an ethical manner and allow for patient choice while mitigating the risks of dysphagia when non-adherence to recommendations occurred. Understandably, navigating these tensions is difficult for novice clinicians.

The SLPs advocated for a sharing of knowledge between clinicians across similar IPR practice contexts in order to:

- 1) provide assistance to educators and students so that they are provided with education to be prepared for the challenges associated with provision of dysphagia services, especially to patients with cognitive-communication disorders;
- 2) develop a central bank of education and counselling materials that could be effective for the large variety of patients that might be served within an IPR context;
- 3) develop a peer-to-peer network to support and guide service delivery for patients, families and HCP teams; and
- 4) develop a practice-based research network for future studies.

Most of the SLPs in this study talked about a desire to work together to change practice. For instance, the 12 participants could constitute a knowledgeable community-of-practice who could work together with researchers to co-construct and tailor the relevant knowledge, educational design, curricular materials, and pedagogical approaches to best inform higher professional education, as well as the development of best practices in this area of clinical practice.

This distillation of the ‘essential elements for education and counselling’ of the dysphagic patient into a document could have a profound effect on professional education and

positively impact the education and counselling that future patients receive.

Unfortunately, although there was an expressed desire to contribute, the SLPs were articulate in noting that this community-of-practice-type-work may not be achievable in light of current contextual demands. Many SLPs perceived that they would not receive permission to use workplace time to contribute to knowledge generation, or professional education, beyond direct patient care.

One objective of this study is that the results will potentially enrich SLP practice, first by explaining how practices are shaped in complex environments by contextual dimensions, and second by exploring how practitioners speak and reflect upon practices, thereby reaching a new and revised understanding of what a “good” practice is (Geiger, 2009).

The SLPs in this study advocated for change on many levels. They advocated for their patients and their care. They access practice wisdom – phronesis - in the care of patients with dysphagia and TBI because they do not fit the available evidence. They advocated for change in clinical education programs especially around the development of clinical reasoning skills in the midst of complexity. They advocated for their practice and for reduced constraints on practice in order to provide better care. They advocated to reduce the moral distress they experience and to increase their ability to provide best-practice and ethical care to patients and their families.

Chapter 7 Conclusion

7 Conclusion

This concluding chapter will begin with a reflection on how the parts of the dissertation have come together to advance understanding of the topic. Limitations of the work will be discussed. Based on the novel contributions of this dissertation, six recommendations for leadership, practice, practice settings, clinical guidelines, and education will be offered. Finally, recommendations for future research will be provided.

7.1 Final Reflections: Contributions to a revised/new understanding

There is a paucity of research focused on examining how SLPs enact education and counselling with patients who have dysphagia and a traumatic brain injury. This dissertation addressed this knowledge gap and advanced understanding through a hermeneutic interpretive study that utilized in-depth qualitative interviews with 12 SLPs who worked in the context of IPR settings in Ontario. Figure 5 provides an illustration of the practice-based research hermeneutic journey.

There are multiple ways to represent the hermeneutic inquiry; some people posit a spiral, some a circle. The hermeneutic circle aims to allow us to understand our research question, moving from part to whole and back again. Kinsella (2006) informs us that the hermeneutic circle is constantly augmented by new information. The concept of the evolution of the hermeneutic circle occurs “because information only comes to us serially...it must be incorporated piecemeal into the synthetic vision which illuminates the meaning of the object of comprehension” (Bontekoe, 1966, p.3.) To step out of the circle for further clarification is not impossible as one is continually expanding the horizon of the research by interacting with participants, texts or materials (Kinsella, 2006).

Kinsella (2006) comments on the evolving nature of understanding, citing Rich (2001) who explores how earlier levels can seem unthinkable in light of one’s current insight: “it’s hard to look back to the limits of my understanding, a year, five years ago- how did I

look without seeing, hear without listening? It can be difficult to be generous to earlier selves” (Rich, 2001, p.75). This statement is accurate as I reflect on my journey through the hermeneutic circle as evidenced in Figures 1, 3, 4 and 5 included in the thesis. The finitude of the research question has been achieved, in my sense for this work. Figure 5 is the culmination of the circle represented in earlier diagrams with the earlier Figures being a “part” that contributes in the end to the “whole”. They are unique to each part of this journey. The parts for this researcher, my pre-understandings, culture, language, historicity and insiderness create a unique, contribution to the whole hermeneutic circle of understanding.

Like many students who have used a Gadamerian hermeneutic approach to their dissertation work, I experienced a ‘calling’ to this topic which created a desire; a need to act (Moules, Field, McCaffrey & Laing, 2014). The hermeneutic process of questioning the whole and examining the parts of the phenomenon under study has served the aim of the research well and expanded knowledge. The SLPs individual and collective voices were an integral part of this process, helping develop a greater understanding of how they enact education and counselling regarding dysphagia with the TBI patients within IPR environment. Additionally, they helped us to understand and gain information about the important contextual factors that influence the ‘how’. One of the key tenants of hermeneutic inquiry is for researchers to continuously revisit their data. This was a part of my reflexive process and I believe that this has allowed the voices of my participants to have an impact on me long after the actual interviews. As I reflected on this doctoral journey, I note that my practice has changed. My awareness of patient and family dynamics and relationships has a deeper resonance. My advocacy efforts, not only for myself but for my profession, have evolved. I am more likely to engage meaningfully and with acquired knowledge with organizational and professional leadership to speak about what I have learned and about the context in which dysphagia and TBI practice is taking place.

A further evolution of my practice has been twofold. My recent clinical supervision with SLP students during my doctoral research took on a different tone. Practice is justified with theories, guidelines and professional training. The ideology behind these theories

and training may be hidden. To bring assumptions out of hiding and question our way of reasoning enhances practice awareness and provides choices to practice optimally in each clinical context (Higgs, Jones, Loftus & Christensen, 2008). This thesis work made clear to me many aspects of practice associated with counselling and education and made explicit important links, including the tacit distress around uncomfortable swallowing decisions and discussions with family members. Through the supervisory opportunity, I was able to discuss this distress openly with the SLP student and to make them aware of it. Higgs et al, (2008) reminds us that:

The myth in training in the health professions is the idea that skills are generic and once learned in one place can be unproblematically applied (will “transfer”) to all others. But good practice is context specific, and skills need to be adapted every time they are used (Higgs et al., 2008, p. 29).

The manner in which I interact with the HCPs and place the accountabilities with them for their own practice behaviour is also evolving. I am always willing to help and expand learning but am also becoming increasingly comfortable directing the HCPs to the information I have created and provided. This increases the awareness of the HCPs about dysphagia education and counselling and from a longer-term perspective may relieve some of the time constraints experienced from having to conduct HCPs re-education.

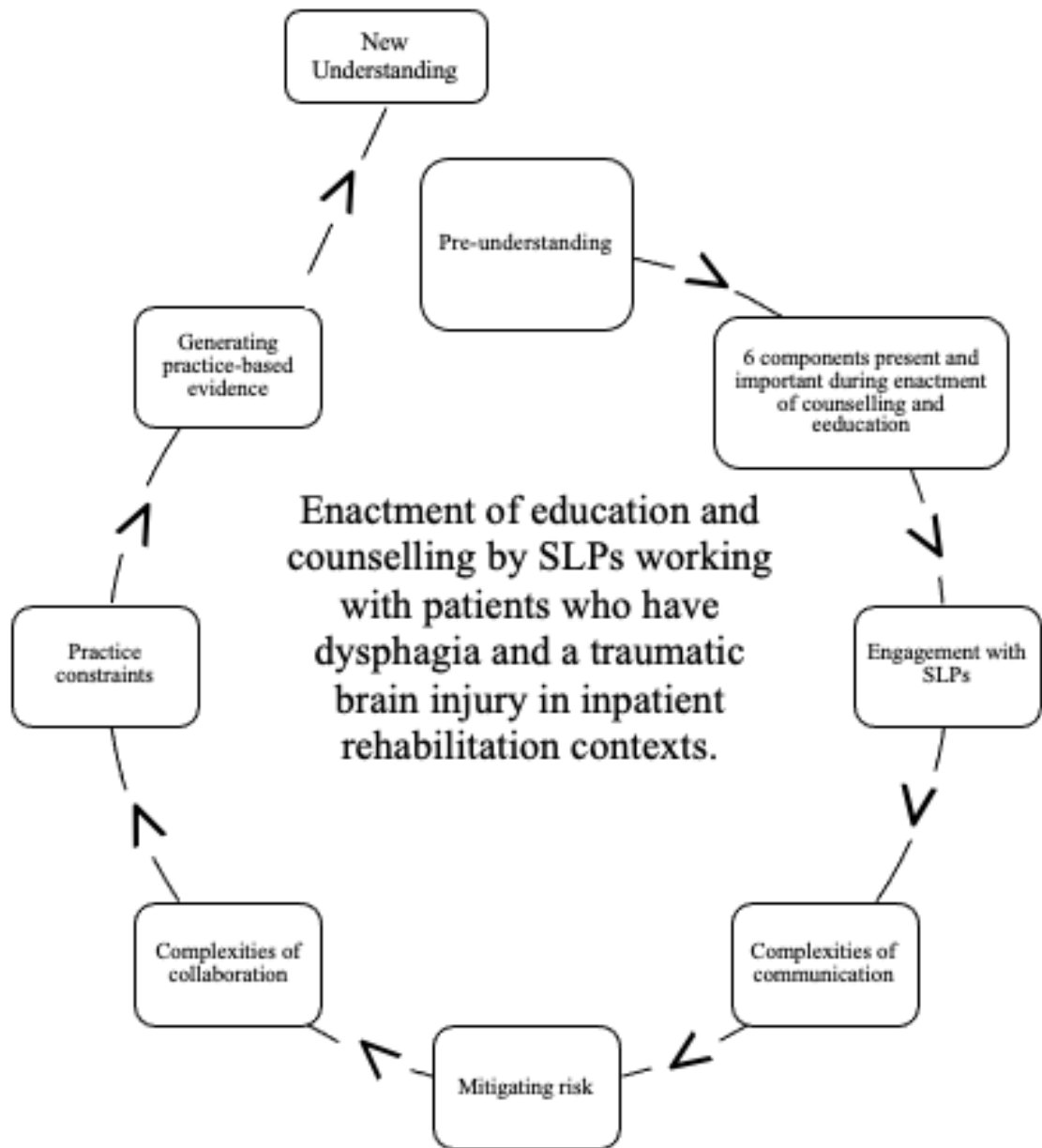


Figure 5: The hermeneutic process, practice-based research and SLP dysphagia education and counselling.

As discussed in earlier sections of this dissertation and illustrated in the Figure above, I came to this work with a pre-understanding affected by my 'insiderness' as an SLP working in education and counselling of dysphagic patients within the IPR setting. As a researcher, I tried to continually pay attention and attend to my 'insider-ness' as an SLP working in this practice context. I reflexively questioned if the 'uncovering' of understandings revealed to me would be as poignant to other readers as they were to me.

Conversations with my supervisors and advisory committee members over time have revealed that the results also resonated with them and contributed to revised and new understandings for them about this important topic. There were regularly scheduled meetings that were attended by various members of the thesis advisory committee. This researcher kept emails and journals from all meetings. The adherence to this biweekly schedule was maintained and the varied professional and research lens of the committee proved invaluable as they kept the research focused on the primary research question.

The scoping literature review helped to reveal important parts of the enactment of education and counselling, especially as it relates to the numerous people and groups of people within the inpatient practice context who must be part of the education and counselling conversations. The review of the literature added to our current understanding of the factors that are present and important during the enactment of education and counselling by SLPs in this context. The literature supported that the patient, family, HCPs and non-HCPs adherence to SLP recommendations for dysphagia management is important. Adherence to recommendations is made more complex when the patient has a TBI and is in an inpatient rehabilitation setting. By examining the MacDonald (2017) cognitive-communication model with the literature associated with dysphagia intervention adherence and literature associated with dysphagia and TBI, we identified six factors that are present and important to consider during the enactment of education and counselling for patients with dysphagia and a TBI. The scoping review results provided a rationale and confirmed the aim of our study which was to understand how SLPs are enacting dysphagia education and counselling in this context.

The interviews contributed novel and important information about the complexities and constraints of practice and provided evidence of how SLPs continually try to mitigate the risks within this environment to keep their patients safe. These important conversations also revealed that SLPs generated practice-based knowledge around education and counselling because they lacked guidance from guideline documents.

This thesis also makes an original contribution in the use of hermeneutic inquiry as a methodological approach to elucidate the practice-based knowledge of SLPs.

Hermeneutic inquiry allowed for an in-depth investigation of SLPs' reports of what they 'do' in the practice context, and the meaning they make of the contextual dimensions they weigh in such contexts. Hermeneutic inquiry provided a useful framework for examining the individual accounts, bringing these together in a thematic manner, and generating insights and practical knowledge that is of relevance to SLPs, educators, policy makers, and health care administrators. This approach to research may be useful for other researchers interested in investigating practice knowledge in contexts of uncertainty and ambiguity.

7.2 Study Limitations

As we heard from the SLPs who participated in this study, time for anything unrelated to direct patient care is difficult to come by. So perhaps it is not surprising that the time needed to conduct the interviews was a barrier for SLPs who expressed interest in the study but were unable to commit 90 minutes for an interview. This impacted recruitment. The results of this study may not be reflective of all IPR contexts in Ontario, nor the practice patterns of all SLPs working in the area of dysphagia with patients who have a TBI. The process of recruiting potential participants via regular mail delivery was cumbersome and is not reflective of common, current communication modalities (electronic). Return-to-sender recruitment letters meant that some potential SLP participants may not have been contacted. The participants in this study were experienced clinicians with a range of experience between 10 and 30 years. SLPs with less than 10 years' experience did not participate. Newer-to- practice SLPs may have a different understanding and contextual practice lens. One hypothesis on why they may have chosen not to participate is that for some they may have felt that they were under

professional scrutiny because of my years of experience or their knowledge that I was a peer assessor for the College (Coar & Sim, 2006). They may also have feared that the interview was a test of their factual knowledge (Coar & Sim, 2006). This feeling is not surprising to me since almost all participants and myself felt that we lacked factual knowledge in the area of dysphagia and TBI in our early years of practice.

The SLPs in this study were all from Ontario, English speaking and female. The selection of the Province of Ontario was purposeful because it is the context in which I have acquired the knowledge that I have about the complexities of this practice context. Other provinces may have brought other results since healthcare funding and service provision could differ. The specificity of the IPR context resonated with this researcher from a hermeneutic perspective, however IPR occurs at a very select time-line in the traumatic brain injury rehabilitation spectrum. The results of this research may not be indicative of what occurs at a different point along the patient's rehabilitation journey. My role as an insider and a peer assessor for the CASLPO may have impacted study recruitment and shared conversation with participants. My personal reflection based on results of my interviews and the off-record discussions we engaged in is that the peer assessor role did not impact the conversations in ways that might have been imagined a priori. Perhaps the SLPs who participated believe that the goal of peer assessment is for it to be a "positive learning process conducted by peers with a strong sense of what is practical and reasonable"(CASLPO, 2021, p.1). Having stated this I do recognize that some SLPs, perhaps those with fewer years of experience, may have chosen not to participate because of my role with CASLPO.

7.3 Recommendations

The collective coming-together of the 12 SLP voices provided important contributions to new knowledge. Based on these contributions, this section presents six recommendations that emerge from the data analysis and the researcher's interpretation of the findings.

7.3.1 Leadership within organizations need to become or be more aware of the complexities of practice and practice constraints experienced by SLPs in this practice context.

The burden on SLPs to “revisit, revise and re-educate” when working with dysphagic patients who have experienced a TBI is significant. Through conversations, data analysis, discussions with my advisory committee and the writing of this document, it has been made clear that workflow is impacted by the cognitive-communication status of the patients. The current documentation systems described by the participants in this study were varied (medical charts, Kardex, over the patient bed, huddles and RN communication boards). The workplace cultures around roles and responsibilities of the HCPs in the IPR context were described both in the literature and by participants as varied. This variability caused documentation repetition and rework practice realities for the SLPs in this study. It is conceivable that leadership and organizational systems are unaware of the practice inefficiencies created by these (communication of and re-documentation) requirements. It may be helpful and increase efficiencies in practice and in the education and counselling outcomes for patients if leadership were aware and developed a better understanding of complexities and constraints. However, as Cartmill, Comans, Clark, Ash and Sheppard (2012) reported, conversations around practice issues for allied health practitioners (SLPs) such as those raised in this study may be limited due to the possibility that the staffing levels may not exist for practitioners to be afforded the space and time for leadership/practitioner engagement. The first recommendation is that organizational leadership in IPR contexts should afford the space and time for SLPs to raise awareness of the complexities of practice and practice constraints experienced and the ability to provide suggestions for improvements that may affect optimal patient and family outcomes.

7.3.2 Continuing education of interprofessional teams within the IPR context needs to occur so that patients and their families are well-supported during intervention.

In the IPR context, the patient is served by a multidisciplinary team. This team of HCPs do not necessarily share the same clinical ‘language’ and knowledge of dysphagia and TBI. The results of this research study indicate that further HCP training in the IPR

context may be beneficial in order for patient and family education and counselling to be optimized. MacDonald (2017) has developed a cognitive-communication model that was described in this thesis. This model may serve as a guide and provide a common language that could be used by multidisciplinary teams when considering the cognitive competency domains of a patient who has dysphagia and is receiving dietary intervention. The model may help to achieve more widespread awareness of the individual, the contextual or environmental, cognitive, communication, physical/sensory, emotional/psychosocial and self-regulatory/control factors that may impact adherence to these recommendations. In addition, a cognitive-communication model such as this may provide an internal checklist for SLPs as they prepare their education and counselling script, materials and consider the environment in which they will be working.

This recommendation was supported by peer-reviewed literature. Rosenvinge and Starke (2005) created an individualized training and continuing education program for team members who had contact with patients (The Dysphagia/Nutrition Link Nurse program) and found that it expanded their knowledge and empowered them resulting in increased adherence to SLP dysphagia-management recommendations. It should be noted that, if this system-wide education and awareness training is to be undertaken by SLPs, it would require access and opportunity to engage with organization(s) and leadership so that requirements such as SLP clinical release time for the development of the training program, and funding and support for HCPs to attend training, are established in order to achieve the desired outcomes of such a program.

7.3.3 SLPs need to have access to equipment, space and time to enact education and counselling.

The VFSS is regarded as the ‘gold standard’ for dysphagia investigation and is considered an important tool that can assist in the education of the patient and those influencing their care (Boaden, Nightingale, Bradbury, Hives & Georgiou, 2020). Access to VFSS images for education and counselling was recognized by SLPs in this study as best practice. They explained that this tool provides an ideal and effective way to educate about swallowing and to provide critical information to the patient and their family regarding the assessment results, the benefits of intervention choices, and the potential

hazards of aspiration. In this study, there were a number of SLPs who had no access to VFSS, some who were limited by institutional regulations that precluded access to it, others where the wait lists created barriers, and still others whose patients were required to go off-site to access VFSS.

Significant cognitive-communication task demands are present for the patient with a TBI receiving dysphagia education and counselling. The environment plays a key role in the presentation of education and counselling. The SLPs in this study reported that equipment, space for confidential conversations and time to work with this complex population were constraints in and on their practice. SLPs and other HCPs providing services in an IPR context will need to be aware of the fact that the environment, interruptions, load on the individual's working memory, response requirements and predictability of messaging are all factors that need to be considered during the education and counselling process (MacDonald, 2017). It would be opportune if SLPs could present to their organizations and make known to the wider systems of care their needs around space for confidential education and counselling, the advantages of access to VFSS equipment and the workflow constraints experienced in the IPR context. This type of partnership and engagement could move forward important questions and conversations such as:

- What are the associated constraints (budgetary, time, etc.) for access to VFSS at some sites and could these be overcome?
- Does access to VFSS facilitate education and counselling, for whom, and what are the outcomes for intervention adherence?
- Would a continuing education program and introduction of the MacDonald (2017) model facilitate collaborative education and counselling within the IPR context and lead to improved patient outcomes and less time spent on revisit, revise and reeducate needs?

7.3.4 SLPs would benefit from a repository/library of materials known to be effective for a wide variety of dysphagic patients, including those who have a TBI.

The scoping review and the SLPs in this study have reinforced the need for end-users (other HCPs, patients, caregivers) to be provided with written and verbal instructions that are tailored using visual cues, simplified language, and step-by-step instructions as needed (Howle et al., 2014; Short et al., 2014). Literature further supports that information appropriately formatted and received by the end-user leads to empowerment (Short et al., 2014) and to understanding (Pelletier, 2005). Patients who received tailored, individualized information were more satisfied with their communication with HCPs and other aspects of their care (Pegg et al., 2012). It may also be useful for patients to use perform and recall methods as a way to assist them in learning a new sequence of actions (Howle et al., 2014). These practices were enacted by the SLPs in this study. However, repeated messaging to patient and staff, revisiting education with patients and family members, and repetitious HCP education messages verbally and in multiple-place documentation greatly impacted and increased SLP workload. The invisibility of this aspect of the SLP workload may not be apparent to leadership and organization systems.

Participants discussed that it would be helpful if the education and counselling materials collected in this study (and other materials/resources) could be made available to them in an electronically-available resource. As a community working in similar practice settings, they appreciated that access to this type of repository/library of materials might save them time and provide them with alternative ways to educate and counsel patients, families and other HCPs.

7.3.5 SLP student preparation for working with dysphagic patients with TBI in the IPR context could be facilitated by partnerships between SLPs and clinical educators in graduate training programs.

The importance of the clinical placement was discussed by the SLPs in this study as formative to student practice development. The majority of participants discussed the emotions they experienced when, as new-to-practice clinicians, they realized that the

responsibility of patient care rested solely with them. These entry-to-practice experiences are similar to those described by many other clinicians (Higgs, 2018). An opportunity exists for graduate training programs to collaborate with clinical field educators to examine the situatedness of advocacy and ethical practice and to make these practice components more explicit for their shared SLP students. Clinical placements are positioned to provide real-time exposure to advocacy for patient and the professional in the “messy” context of practice. These clinical placements have the ability to place the student clinician into the context of staff, professional practice and other interprofessional meetings that could be the basis for reflective practice scenarios/exercises. An interesting question that arises from these considerations is how we might educate student clinicians to advocate for themselves in these complex practice environments especially as it relates to practice constraints and their ability to interact with leadership.

The SLPs in this study expressed the distress and burden their dysphagia practice created. Walton (2018) shared that moral distress may be better mitigated if professionals are able to define concerns within an ethics framework. There is an opportunity for the role of ethics to take a more prevalent space in formal education, and for a lexicon to be provided to students to facilitate a description of moral distress in their placement and ultimately work-related settings. Perhaps there is an opportunity here for partnership between clinical education programs and experienced SLP clinicians to facilitate a clinically-relevant awareness of ethical care, advocacy and the opportunity to develop and refine these skills.

7.3.6 Guidelines need to be written for complex patients and include guidance on education and counselling within them.

While it is recognized that high-quality clinical practice guidelines (CPGs) are difficult to create for every combination of complex conditions, SLPs in this study wished for additional guidance and specificity on recommendations within the current dysphagia practice guideline in the Province. Despite receiving graduate-level training to use their critical thinking, clinical judgement and experience to adapt the CPGs when working with more complex patients, they, like many other HCPS, felt that extrapolation of evidence into their “real-life daily practice” sometimes increased clinical uncertainty

(Nelson, Grudniewicz & Albadry, 2016; Uhlig et al., 2014). As noted by Nelson et al., (2016), “although it is not possible to have good-quality evidence for every combination of chronic conditions, it would be helpful to bring together relevant recommendations for different chronic conditions, highlighting synergies, cautions and contraindications” (p. 42). Education and counselling of the patient with dysphagia and a TBI in the inpatient rehabilitation context of Ontario is one clinical area where this synergistic strategizing might be achieved because it is a relatively specific practice context with a focus on a specific area of practice (education and counselling).

If provided with appropriate clinical release time, there exists a space for SLPs who work with these complex patients to consider the creation of communities of practice where guideline writing and/or amendments to current practice guidelines or accompanying clinical protocol documents could be co-created.

7.4 Recommendations for research

Based on the study results, several areas have been identified for future research.

Several novel practice innovations were offered by SLPs who participated in this study including writing of orders and a dysphagia wristband alert. Future research might aim to address questions around implementation and uptake of these strategies and their overall effectiveness/impact on adherence to dietary recommendations by patients and the multidisciplinary team.

Should a databank of materials and strategies be developed, future research could use realist investigation methods to investigate which strategies work, how, why, for whom and under what circumstances. Similarly, an important research study might investigate the effectiveness of VFSS imaging for education and counselling and compare it to environments where it is not used.

Given the recommendation for implementation of an organizational model of cognitive-communication competence an important research question might be: does interprofessional education and training on a cognitive-communication disorder model

improve dialogue among team members and promote adherence to SLP dietary intervention recommendations?

The moral distress vocalized by the participants and their years of practice seems to be in contradiction to published literature. I would be curious to know why and how SLPs working in dysphagia and TBI remain in this area of practice. What strategies have they developed to manage the everyday stresses that they have spoken about in the context of this study? Finally, further research into staffing and workload requirements in this area of practice could help organizations to better meet patient needs. Would an increase in SLP advocacy allow leadership to recognize the workload implications of the iterative nature of the communication required in these instances?

7.5 Concluding statement

This study sought to gain a better understanding of how SLPs enact education and counselling of patients with dysphagia and a TBI in IPR contexts. Through hermeneutic inquiry using in-depth interviews with 12 SLPs, this research added to our understanding by revealing that education and counselling is complex and time-consuming and that there exist practice constraints on the SLP that further complicate this process. It is my hope that the results from this study will help SLPs, organizational leadership and educational institutions to engage in helpful conversation. I believe that the findings of this work can assist us in understanding what might be enhanced in the area of education and counselling to facilitate optimal outcomes for patients with dysphagia and traumatic brain injury and their families.

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Appendices

Appendix A: A summary of the seven domains of the cognitive-communication model (MacDonald, 2017) and their importance for education and counselling of the patient who has dysphagia and a TBI.

The seven domains of the model of cognitive-communication competence are: (1) individual; (2) contextual or environmental; (3) cognitive; (4) communication; (5) physical/sensory; (6) emotional/psychosocial; and (7) self-regulatory/control. Each of these domains as they are presented by MacDonald (2017) will be briefly discussed below as they relate to the topic of education and counselling of the patient who has a TBI and dysphagia. The interested reader is encouraged to read MacDonald (2017) to have a more detailed understanding of the domains summarized here.

A1. Individual domain

Patient engagement in the education and counselling process during dysphagia service delivery with an individual who has a TBI is influenced by a complex interaction of the etiology, severity, location and extent of the neurological impairment, and time since the injury occurred. Communication outcomes may also be affected by the age, education level, presence of pre-existing learning disabilities, brain injury, substance abuse, and the individual's mental health. Clinicians need to also consider that patients with a TBI may vary greatly in their resilience, motivation and/or adjustment to the trauma.

A2. Contextual or environmental domain

There could be significant communication task demands of the patient with TBI receiving dysphagia education and counselling. SLPs providing services in an IPR context will need to be aware of the fact that this environment, interruptions, load on the individual's working memory, response requirements and predictability of messaging will be factors that need to be considered during the education and counselling process. SLPs will also need to ensure that the many communication partners that a dysphagic patient encounter in the IPR context (for example, Registered Nurses, dietary aids, Personal Support

Workers (PSWs), Physicians) are also educated about the effect of task demands on communication competence. All professionals working within an IPR setting with patients who have a TBI need to also be aware that their communication skills, authority differential, and relationship with the patient will be influential factors on communication and communication outcomes. Historical communication partners such as family and friends can facilitate communication competence and therefore are considered important partners in the education and counselling process.

A3. Cognitive domain

The MacDonald cognitive-communication competence model discusses multiple cognitive processes (in addition to control/self-regulation discussed earlier) that are impaired after a brain injury and which influence communication competence including: speed of information processing, attention and working memory, and problem solving.

A3.1 Control Functions/Self-regulation

Cognitive processes that regulate thinking, behaviour and communication competence are frequently impaired after a TBI. This causes challenges for the SLP as they work to educate and counsel patients with dysphagia who may have little behavioural and emotional self-regulation, executive functions and meta-cognitive abilities. It is important to point out that these impaired control and self-regulation functions have an overarching effect on all of the other domains of cognitive-communication competence.

A3.2 Speed of information processing

After a brain injury speed of information processing is frequently impaired affecting reading comprehension, written, spoken and social communication.

A3.3 Attention and working memory

The dysphagic patient and who is receiving dysphagia assessment, education and counselling may have difficulties with directing, sustaining, shifting, and regulating attention as well as suppressing distractions affecting outcomes. In addition, they may

also experience significant difficulties in mindfully storing and manipulating information in their working memory for immediate and future use.

A3.4 Memory

Memory impairments of episodic, explicit and/or prospective nature occur frequently after a brain injury. Therefore, SLPs need to thoughtfully consider this in all aspects of their dysphagia service provision process.

A3.5 Social cognition

Communicating about assessment results, receiving information, participating in shared decision-making, and communicating informed choice occurs within a dynamic, engaging clinician-patient partnership. Disruption(s) in social cognition may make it difficult for the patient with a brain injury to participate in this relationship or to understand and/or describe their emotions during the counselling / education process.

A3.6 Reasoning and problem-solving

Reasoning is an important component of decision-making. Impairment of reasoning after a brain injury can affect their ability to extract important information from conversations or from written material, with the facts, generate alternatives and predict consequences of behaviours or decisions, or problem-solve. Problem-solving impairments affect the patient's ability to identify a problem or potential problem and consider / implement potential solutions. These impairments also affect a patient's ability to monitor, evaluate, refine, or revise information received or their behaviours related to it. According to MacDonald (2017, p. 1768) "Clinically those with ABI [acquired brain injury] may present with difficulty following discussions, understanding team meetings, expressing a choice, or interpreting education or counselling sessions."

A4. Communication domain

Important to considerations of dysphagia education and counselling when a patient has a brain injury is the knowledge that the brain injury can "impair any modality of

communication (e.g. listening, speaking, reading, written expression, non-verbal expression), any aspect of the language system within that modality (e.g. phonology, semantics, syntax, pragmatics), or any aspect of non-verbal communication (i.e. facial expression, tone of voice)” (MacDonald, 2017, p. 1768).

A4.1 Auditory comprehension

Counselling of assessment results and education regarding intervention(s) are often conducted in IPR hospital settings using the auditory pathway (audition). In addition to the auditory comprehension difficulties associated with resultant hearing loss or concussion secondary to a TBI, patients may experience difficulties processing the auditory information, may misunderstand inferences, and may not follow instructions properly when they are provided aurally.

A4.2 Verbal expression and discourse

Difficulties in verbal expression for the patient with a TBI include errors and delays in retrieving words and lack of verbal fluency. Discourse is often disorganized, incomplete, lacking information and/or accurate information and tangential. Patients may also experience difficulty in explaining, planning or providing rationale(s). They may provide too much, too little, or inappropriate information during patient consultation(s).

A4.3 Pragmatics and social interaction

In a compassionate model of care multidisciplinary team members and the patient come together in a relational space where they communicate to seek to understand and attend to the patient’s needs (Sinclair et al., 2018). Patients with a brain injury also experiencing difficulties in pragmatics and social interactions can unintentionally cause relational breakdowns as they struggle with their ability to manage conversational turns or self-regulation of non-verbal behaviours such as facial expressions. It might also be negatively affected by their non-utilization of appropriate levels of politeness, their lack of perspective taking, and their reduced ability to ignore distractions in the environment.

A4.4 Reading comprehension

Reading difficulties that need to be considered in education and counselling include problems in oral reading, problems with comprehension recalling details, or difficulty understanding the main point in text-based materials.

A4.5 Written expression

Cognitive deficits expressed by a patient with TBI can cause written expression difficulties because of problems with motor control, word retrieval, sentence formulation and/or sentence generation.

A5. Physical/sensory domain

Comorbid and co-occurring physical factors after a TBI are common and must be considered in all aspects by the clinical team because they influence cognitive-communication competence. Hearing loss, vestibular disorders, dysarthria, apraxia, prosody, fluency and/or voice disorders, fatigue and visual perceptual impairments are just some of the physical domain factors that need to be considered by the multidisciplinary team counselling/educating patients with a brain injury.

A6. Emotional/psychosocial domain

Participation in dysphagia assessment and intervention can be impacted by the presence of anxiety, depression, post-traumatic stress disorder (PTSD), emotional regulation, aggression, quick temper, emotional reductions in arousal, motivation, increased levels of stress, difficulties with decision-making, autonomy, and reduced self-confidence.

A7. Communication competence domain

The model of cognitive-communication competence facilitates an understanding of the importance of all the domains above and their impact on communication competence as it relates to the enactment of education and counselling with the patient who has dysphagia and a TBI. Cognitive-communication impairments can affect family communication and

functioning and can produce barriers to communication with rehabilitation specialists and support personnel in the IPR setting. The individual with a cognitive-communication impairment may have difficulty with their ability to problem-solve, organize, recall and convey information. Interventions to assist with education and counselling of the patient with dysphagia and a TBI may be necessary in situations where communication competence is impaired.

Appendix B: Data extraction sheet for the scoping review.

	Author(s) / Paper Title / Publication Journal	Year	Type of Study/Methods	Country	Summary: Enactment of education and counselling in dysphagia with patients who have a TBI
1	<p>Colodny</p> <p>Construction and validation of the mealtime and dysphagia questionnaire: An instrument designed to assess Nursing staff reasons for Noncompliance with SLP Dysphagia and Feeding Recommendations.</p> <p>Dysphagia 16:263-271. (2001)</p>	2001	Mixed	United States	<p>Discusses the importance of a collaborative approach to education among all healthcare providers and other staff.</p> <p>Discusses power dynamics and role status on healthcare teams and how they might impact care. Higher status healthcare workers were less compliant in implementing SLP recommendations than lower status healthcare workers. It could be because of role status perceptions where higher-status workers regard certain tasks as outside their purview, more appropriately performed by a person of lower role status.</p> <p>Registered Nurses (RNs) are likely to be noncompliant with SLP recommendations because of a lack of knowledge, suggesting a need for additional and more frequent learning opportunities.</p> <p>Certified Nursing Assistants (CNAs) in this study indicated disagreement with the SLP recommendations. They may lack an awareness about the deleterious consequences of their actions.</p>

	Author(s) / Paper Title / Publication Journal	Year	Type of Study/Methods	Country	Summary: Enactment of education and counselling in dysphagia with patients who have a TBI
2	Colodny Validation of the caregiver mealtime and dysphagia questionnaire. <i>Dysphagia 23:47-58 (2008)</i>	2008	Quantitative	United States	Discusses the importance of power, role status and SLP comfort with counselling and their practice wisdom. SLPs must emphasize their well-developed expertise in dysphagia, their medical knowledge of TBI and dysphagia and use their practice wisdom when dealing with more affluent non-health professionals who are family members of a patient with dysphagia and TBI.

	Author(s) / Paper Title / Publication Journal	Year	Type of Study/Methods	Country	Summary: Enactment of education and counselling in dysphagia with patients who have a TBI
3	<p>Foster, Armstrong, Buckley, Sherry, Young, Foliaki, James-Hohaia, Theadom & McPherson</p> <p>Encouraging family engagement in the rehabilitation process: a rehabilitation provider's development of support strategies for family members of people with traumatic brain injury</p> <p><i>Disability and Rehabilitation</i> 2012:34(22):1855-1862</p>	2012	Qualitative	New Zealand	<p>Discusses education of patient and family.</p> <p>Families experience many and various stressors arising from new practical demands, from worry, from grief and are in a fragile emotional state. Knowledge on how to manage family dynamics is important.</p> <p>Aside from the patient, family can be considered the most important members of the rehabilitation team; they provide information and take part in decision making along with (or on behalf of) the client, and they are emotionally invested in the client's care and outcomes.</p> <p>Providing support to family and patient requires higher levels of receptiveness, flexibility, and creativity than may be delivered in more medical models of rehabilitation.</p> <p>Education is seen as a two-way process because the rehabilitation professionals are experts in brain injury recovery and the family members are experts in the history and life roles of the client.</p> <p>It is important to address the perceived power imbalance (role status) between rehabilitation professionals and family members.</p> <p>Information and training are provided to families in formal and informal ways.</p>

	Author(s) / Paper Title / Publication Journal	Year	Type of Study/Methods	Country	Summary: Enactment of education and counselling in dysphagia with patients who have a TBI
4	<p>Howle, Baguley and Brown</p> <p>Management of Dysphagia Following Traumatic Brain Injury</p> <p><i>Curr Phys Med Rehabil Rep</i> (2014) 2:219-230</p>	2014	Qualitative	Australia	<p>Discusses the role of educating patient and family, and that cognitive communication domains be attended to. Involvement of the patient, family and caregivers is also critical to functional settings, such as the home. This is particularly the case post TBI as attentional and memory impairments may affect their ability to recall and implement strategies. Guidance for the family and caregivers regarding adequate communication is important, for example, use of short verbal instructions and simple, written instructions, repetition and avoidance of abstract language can be discussed and modeled.</p> <p>Family education programs must explain dysphagia and provide training in feeding techniques and management strategies where appropriate, as increasing the family's awareness of these potential issues may assist with compliance with therapy and strategies in the home environment.</p> <p>Discussions must also address psychosocial issues such as the probable change in the patient's role in the family and dependency issues following the TBI. p.226</p>

	Author(s) / Paper Title / Publication Journal	Year	Type of Study/Methods	Country	Summary: Enactment of education and counselling in dysphagia with patients who have a TBI
5	<p>Pegg, Auerbach, Seel, Buenever, Kiesler, & Plybon</p> <p>The Impact of patient centered information on patient's treatment satisfaction and outcomes in TBI rehabilitation.</p> <p><i>Rehabilitation Psychology</i>, 50(4), 366-374.</p>	2006	Quantitative	USA	<p>Discusses the role of educating both the family and the patient, and family as surrogate decision makers.</p> <p>Hospital personnel often give patients minimal treatment relevant information on the assumption that it will not be comprehended, and that it will be of little value to them.</p> <p>This study is the first to demonstrate that the use of detailed, personalized medical information to patients with clear cognitive deficits can have a strong positive impact on patient outcomes. Significant positive effects were observed in patient effort exerted in therapy, cognitive functioning, and self-reported satisfaction with rehabilitation treatment.</p>
6	<p>Pelletier</p> <p>What do Certified Nursing Assistants actually know about dysphagia and feeding nursing home residents</p> <p><i>American Journal of Speech Language Pathology</i> May 2004;1(2): 99-113</p>	2004	Qualitative	United States	<p>Discusses importance of educating team members and staff. Provides strategies to promote compliance of CNA feeding practices. Raises the importance of understanding that there are 2 types of feeders, those that believe that feeding is a social activity and those that believe that feeding should focus on ensuring adequate food has been eaten (technical feeders).</p>

	Author(s) / Paper Title / Publication Journal	Year	Type of Study/Methods	Country	Summary: Enactment of education and counselling in dysphagia with patients who have a TBI
7	Short, McCormack and Copley The current practices of Speech Language Pathologists in providing information to clients with Traumatic Brain Injury. <i>International Journey of Speech-Language Pathology</i> 16:3,219-23	2014	Qualitative	Australia	<p>Discusses barriers of enacting education: health literacy of patient and family, and their readiness for information</p> <p>Discusses barriers to information provision including: clinical considerations, family functioning and support, level of impairment, personal characteristics and time.</p> <p>Health literacy is impacted for patients with cognitive-communication disorders because they have impaired comprehension, vague tangential or disorganized discourse, deficits in social communication, and difficulties using language or communication to assist memory and new learning.</p> <p>SLPs need to have knowledge about readiness and timing when providing information.</p>

Appendix C: Letter of Information and Consent

Western



Project Title: An interpretive hermeneutic exploration of how Speech Language Pathologists (SLPs) working within IPR settings in Ontario, with TBI individuals, enact education and counselling in the area of dysphagia management.

Document Title: LOI and consent for participants: REB XXXXXX

Principal Investigator: Sheila Moodie, PhD, Health & Rehabilitation Science, School of Communication Sciences & Disorders and The National Centre for Audiology, Western University, London, ON Phone

Co-Investigators: Stephanie Muir-Derbyshire, PhD Candidate, Health & Rehabilitation Science Western University, London, ON

Ruth Martin, PhD, Health & Rehabilitation Science, School of Communication Sciences & Disorders and School of Graduate and Postdoctoral Studies, Western University, London, ON Phone:

Elizabeth Anne Kinsella, PhD, School of Occupational Therapy, Western University, London, ON Phone:

Julie Theurer, PhD, Health & Rehabilitation Science, School of Communication Sciences & Disorders, Western University, London, ON Phone

Dear Study Participants

Researchers in the Health & Rehabilitation Sciences program at Western University invite you to participate in a study that aims to explore how Speech Language Pathologists (SLPs) working within IPR settings in Ontario, with TBI individuals, enact education and counselling in the area of dysphagia management. The purpose of this letter is to tell you about the study so that you can decide if you would like to participate. We want you to understand the research project, and its risks and potential benefits. We would like you to make an informed decision about participating in this investigation. This consent form may contain words that you do not understand. Please ask the study investigators to explain any words or information that you do not clearly understand. You may take the time you need to consider whether or not you would like to participate in the study. You will be given a copy of this consent document once it has been signed.

Purpose: This study will include up to twenty (20) participants. The questions that will frame this study are: (1) how do Speech Language Pathologists (SLPs) working within

IPR settings in Ontario, with TBI individuals, enact education and counselling in the area of dysphagia management? (2) What protocols, tools, documents and other materials, if any, are used to assist them in education and counselling of TBI patients in the area of dysphagia management?

Time Commitment: If you agree to participate, we will require approximately 60 – 75 minutes of your time for a one-session interview. The interview may take place in person at Western University or an agreed-upon location convenient for you. It may also be done via remote audio/video interface if travel distance is significant. It will require you to do some pre-interview activities, namely collecting the materials that you use to ensure that during our interview you are able to refer to them during our conversation. During the interview you can have rest breaks when needed.

Risks and Benefits: There are no known or anticipated risks to participating in this study. You may experience inconvenience because you may have to spend non-work-related time for the interview. The interview will be audio recorded and transcribed for data analysis purposes. The recordings will not be attributed to an identified person and will be deleted from the recording device after they have been uploaded to the secure University network drive. We will be collecting personal identifying information, you should be aware that there is always the risk of breach of privacy. Although there may not be any direct benefit to you, the results of this research will be used to provide us with an understanding of how SLPs working within IPR settings in Ontario, with TBI individuals in the area of dysphagia management enact education and counselling. Results can also be used to inform specific recommendations for practice in Ontario.

Compensation: You will not receive any direct compensation for participating in this project. If you prefer to participate at Western University, you will receive a parking pass so that you will not have to pay for parking. You will also be compensated for the distance you have travelled, from your workplace or from your home, to Western University, Elborn College at a rate of \$0.57/km.

Confidentiality: The researchers at Western University will use the information from this study for scientific purposes. Data collected may be included in scientific reports. Your

name will not appear in any publication. We protect your confidentiality by assigning you an identification number. All data retained corresponds to that identification number only. Any data shared with the study sponsor will include that identification number only. All data obtained in this study will be stored in a network drive specific to Dr. Sheila Moodie's research laboratory. This network drive can be only be accessed by authorized personnel.

We will be collecting your name and signature on the form attached to this letter. This form will be kept separate from any data collected. Hard copy records will be stored in a locked cabinet in a secure office. While we will do our best to protect your information there is no guarantee that we will be able to do so. We retain the de-identified collected research data indefinitely. The signed letter of consent will be shredded after seven (7) years or at any time at your request.

Please note that email communication is not a secure method of communication.

Representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

Voluntary Participant and Withdrawal: Participation in this study is voluntary. You can refuse to participate. You can withdraw from the study at any time. You can choose to participate in other research studies at Western University even if you choose not to be in this study. If you withdraw from the study before you complete the interview, your de-identified information will not be used in the data analysis. If you withdraw after the completion of the interview your data will not be able to be withdrawn.

Questions: If you wish to obtain additional information regarding this project, please contact the principal investigator Sheila Moodie at XXX.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, 1-844-720-9816, email: ethics@uwo.ca. The REB is a group of people who oversee the ethical conduct of research studies. The HSREB is not part of the study team. Everything that

you discuss will be kept confidential. Representatives of the University of Western Ontario Health Sciences Research Ethics board may contact you or require access to your study-related records to monitor the conduct of the research.

This letter is for you to keep.

Sincerely,

Sheila Moodie, PhD

Principal Investigator

Ruth Martin, PhD

Co-Investigator

Stephanie Muir-Derbyshire

PhD Candidate

Co-Investigator

Consent Form

Project Title: An interpretive hermeneutic exploration of how Speech Language Pathologists (SLPs) working within IPR settings in Ontario, with TBI individuals, enact education and counselling in the area of dysphagia management.

Principal Investigator: Sheila Moodie, Ph.D*

PhD Candidate and Co-investigator: Stephanie Muir-Derbyshire

***Health & Rehabilitation Sciences, School of Communication Sciences & Disorders and The National Centre for Audiology**

****Health & Rehabilitation Sciences**

I have read the information in this Letter of Information and Consent form. I have had an opportunity to discuss the purpose, methods, risks, potential benefits, and available alternatives of this research. I have been able to ask questions regarding my participation in this research. I have had my questions answered to my satisfaction.

I understand that I may have a copy of this signed and dated consent form.

My participation in this research is voluntary. I agree to participate in this research study.

By signing this consent form, I have not given up any of my legal rights.

Name (participant):

Name (person obtaining consent)

Signature

Signature

Date

Date

Appendix D: Telephone recruitment script

Hello, may I please speak with [**insert the name of the SLP here**].

If the potential participant is not at the number provided, ask if there is a better time to call. Do not leave a message as it may be a confidential matter you are calling about that may not be apparent to you

If they are at the number called, continue with the conversation

Hi, [**insert the name of the SLP here**] this is Stephanie Muir-Derbyshire calling from the University of Western Ontario, Health & Rehabilitation Sciences Program. I am calling today to ask if you are interested in a research study we are conducting. The study is being conducted by Dr. Sheila Moodie, myself, Dr. Ruth Martin, Dr. Anne Kinsella and Dr. Julie Theurer and will aim to explore how Speech Language Pathologists (SLPs) working within IPR settings in Ontario, with TBI individuals, enact education and counselling in the area of dysphagia management. Are you currently an SLP working within an IPR setting in Ontario with TBI individuals who have dysphagia?

If no, explain that they are not eligible for the study, thank them for their time and say good-bye

If yes, continue to explain study details to them based on the letter of information

Participants in this study will be asked to attend one interview session either in a one-to-one person format or remotely through audio and/or video links. The session will last between 60 and 75 minutes. Would you be interested in hearing more about this study?

If no, thank them for their time and say good-bye

If yes, continue to explain study details to them based on the letter of information

I am now going to read you the letter of information over the phone [**Clearly read the letter of information to the participant over the phone**]

Do you have any questions?

[Answer any questions they may have]

Do you agree to participate in this study?

**If yes, continue with questions below*

**If no, thank them for their time and say good-bye*

The pre-interview activities will require you to gather materials that you use in your education and counselling with patients who have TBI and dysphagia. It will require us to continue our interactions via phone, regular mail, or email. Knowing that email is not a secure form of communication, would you like for me to follow up with you via phone, regular mail or email communication.

**If regular mail, ensure you have their preferred address noted*

**If phone, ensure you have preferred phone number noted*

**If by email, ensure you have preferred email noted*

Do you have any questions?

[Answer any questions they may have]

Thank them for their time and indicate that you will be following up with them shortly to send them the study information and to schedule an interview time.

Appendix E: Interview guide

A hermeneutic exploration of how Speech Language Pathologists (SLPs) working within IPR settings in Ontario, with TBI individuals, enact education and counselling in the area of dysphagia management.

Interview Guide

I am interested in understanding more about how SLPs who work in Ontario, in IPR with TBI patients counsel/educate after a VFSS/MBS. There is very little known about how this transpires. I hope that what I hear from practitioners will inform practice and contribute to our understanding in this area. So, if there is anything that you would like to share with respect to this topic in the interview today, I'd love to hear from you about it.

I have some interview questions to help guide the interview however they are simply guiding questions, so please feel free to share any other information that you think will be important for my understanding about how you counsel/educate and develop swallowing plans after your swallowing assessment process.

Demographics

Age group: 25-34 35-44 45-54 55-64 65+

Years in practice: 0-5. 5-10. 10-15. 15-20. 20+

Interview questions and probes

This question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of "SLP" in the scoping review.

1. Please describe your current position as an SLP.

The next question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of "SLP" in the scoping review.

2. Describe your specific dysphagia practice particularly related to swallowing assessment and education and counselling with TBI patients as if I know nothing about what you do. If you brought materials with you today please feel free to refer to them, demonstrate how you use them, or discuss their importance to the overall process of enacting education and counselling.

The next question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP “in the scoping review.

3. In your practice as an SLP working in the area of swallowing assessment and education and counselling have you encountered any particularly memorable successes or challenges in this area of practice?

PROBE: Please tell me about your most memorable successes

Please tell me about your most memorable challenges

PROBE: How did these experiences shape your clinical dysphagia practice?

-Specific examples of practice change?

The next question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP, Family, Other HCPS “in the scoping review.

4. How has your dysphagia practice in the area of swallowing assessment, education and counselling evolved?

PROBE: is your practice the same as when you entered practice with this patient population?

The following question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP” in the scoping review.

5. What have you learned over time from your experience in this area of practice?

The next question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP, Patient, Family, Other HCPs and KT” in the scoping review.

6. What do you use to support your dysphagia patient education or counselling post VFSS? MBS?

PROBE: Have you developed, or do you use any standardized educational materials? If so, may I see the material?

PROBE: Did you create the materials?

PROBE: How did you discover these materials?

This question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP, Patient, Family, Other HCPs and Timing” in the scoping review.

7. When you counsel/educate your patients/stakeholders/family members /other care providers what is the focus of your intervention?

PROBE: dysphagia status information exchange?

PROBE: dietary status information exchange?

The following question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP and Timing” in the scoping review.

8. When you counsel/educate your patients where and when does it tend to occur?

PROBE: Is this ever a constraint of practice?

PROBE: Do you build this into the time allotted for the actual intervention?

The next question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP, Patient, Family, Other HCP’s” in the scoping review

9. In the event the proposed dysphagia swallowing plan does not go as discussed /planned how are you informed of this?

PROBE: Are you informed? By who? What do you do? Are there opportunities for you to intervene?

The next question presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP, Patient, Family, Other HCP’s” in the scoping review

10. In the event the proposed dysphagia swallowing plan post VFSS/MBS does not go as discussed is the plan re-evaluated?

PROBE: What is the process for re-evaluation? What do you do? Are there opportunities for you to intervene?

The question below presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP, Patient, Family, Other HCPs and KT” in the scoping review

11. How if at all, are other stakeholders (family members, other care providers, colleagues etc.) involved in education and counselling regarding swallowing plans?

PROBE: What are the opportunities to involve others in the plan?

PROBE: What does that look like? Can you give me examples of when others were successfully involved, and when others were involved but it was not an optimal situation?

The question below presents the opportunity to describe the enactment of education and counselling. It links back to the finding of “SLP” in the scoping review.

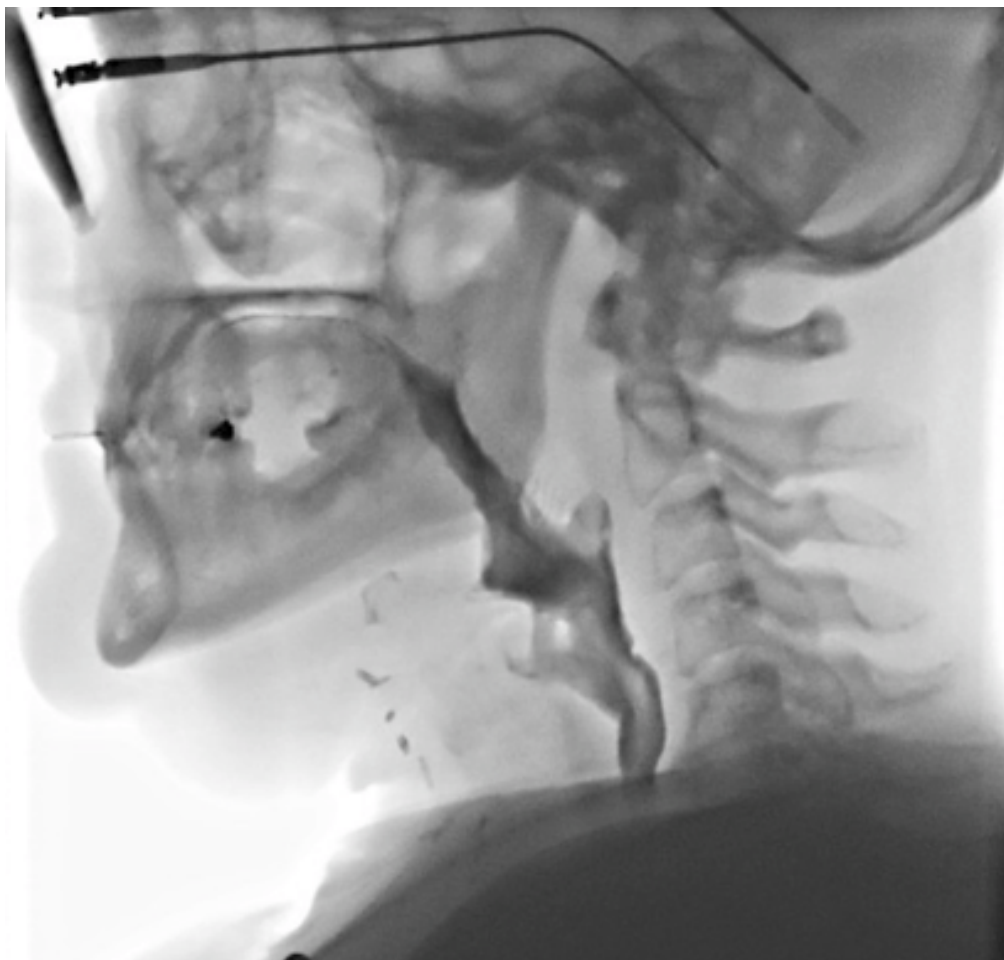
12. Is there anything else you’d like to tell me to help give me a full picture of what it is like to work in this area of practice?

PROBE: Institutional support? Available evidence? Communities of practice?
Professional supports?

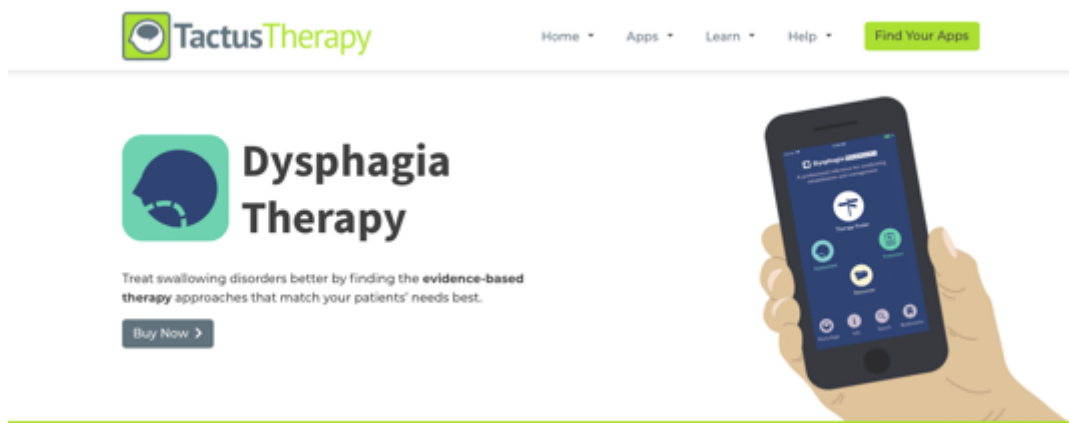
This comment is an opportunity to perform “member checking” and address perceived power imbalance.

In summary today I have heard you say.....

Appendix G: SLP Materials - Technology

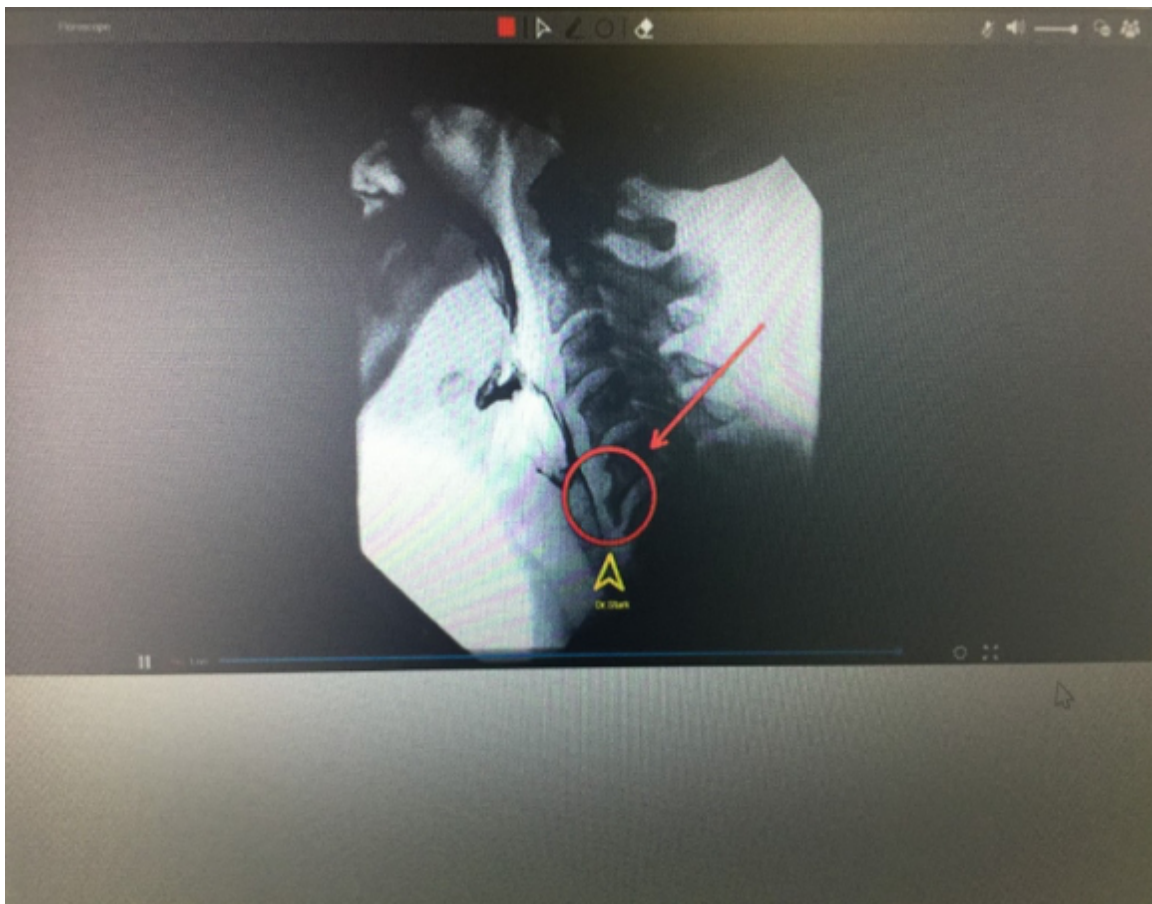


SLP Materials – Technology (continued)



The image shows a screenshot of the TactusTherapy website. At the top left is the TactusTherapy logo, which consists of a green square with a white circle and a green dot inside, followed by the text "TactusTherapy". To the right of the logo is a navigation menu with links for "Home", "Apps", "Learn", and "Help". A green button labeled "Find Your Apps" is positioned to the right of the navigation menu. Below the navigation menu is a horizontal line. The main content area features a large advertisement for the "Dysphagia Therapy" app. On the left side of the ad is a green square icon with a white silhouette of a head and a blue arc representing the mouth. To the right of the icon, the text "Dysphagia Therapy" is displayed in a large, bold, black font. Below this text is a smaller line of text: "Treat swallowing disorders better by finding the **evidence-based therapy** approaches that match your patients' needs best." At the bottom left of the ad is a dark blue button with the text "Buy Now" and a right-pointing arrow. On the right side of the ad is an illustration of a hand holding a smartphone. The smartphone screen displays the app's interface, which includes a blue header with the text "Dysphagia Therapy" and a white circular icon with a blue 'T' inside. Below the header are several circular icons representing different therapy options, and at the bottom of the screen is a navigation bar with several icons.

SLP Materials – Technology (continued)



SLP Materials – Technology (continued)



Appendix H: SLP Materials - Innovation

Photo clip with custom innovation



Laminated card with individualized instructions dysphagia management strategies from SLP would be inserted into the clip. These are updated as patient progresses. They are taken home by the patient if needed.

SLP Materials – Innovation (continued)
Communication Order Dysphagia Alert

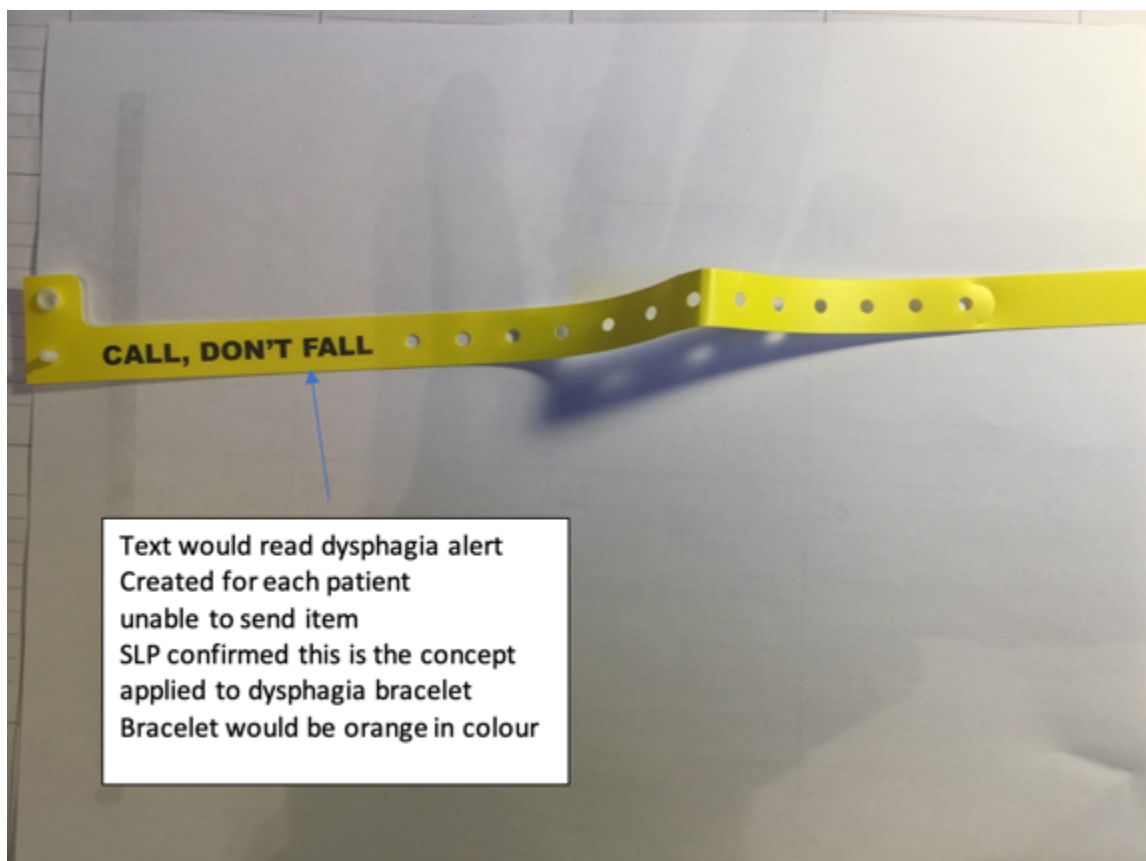
Dysphagia Communication Order

Details Additional Info History Comments Ingredients Pharmacy Plan History Co

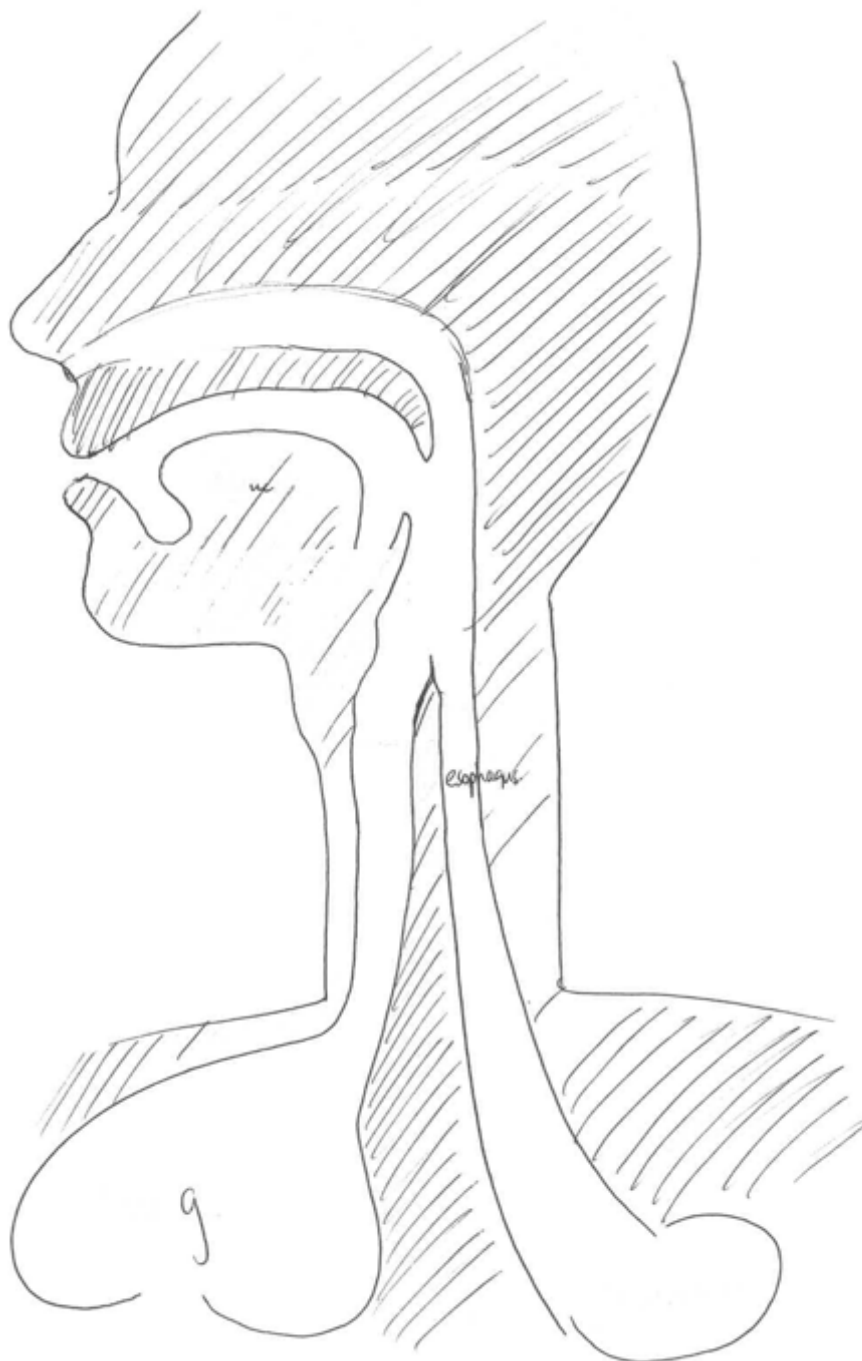
Details

Requested Start Date/Time	2020/04/07 14:56 EDT
Enter verbatim order	meds to be crushed(pudding/applesauce)
Stop Date/Time	2020/04/07 14:56 EDT
Frequency	ONCE
Constant Indicator	No
Stop Type	No renewal notification

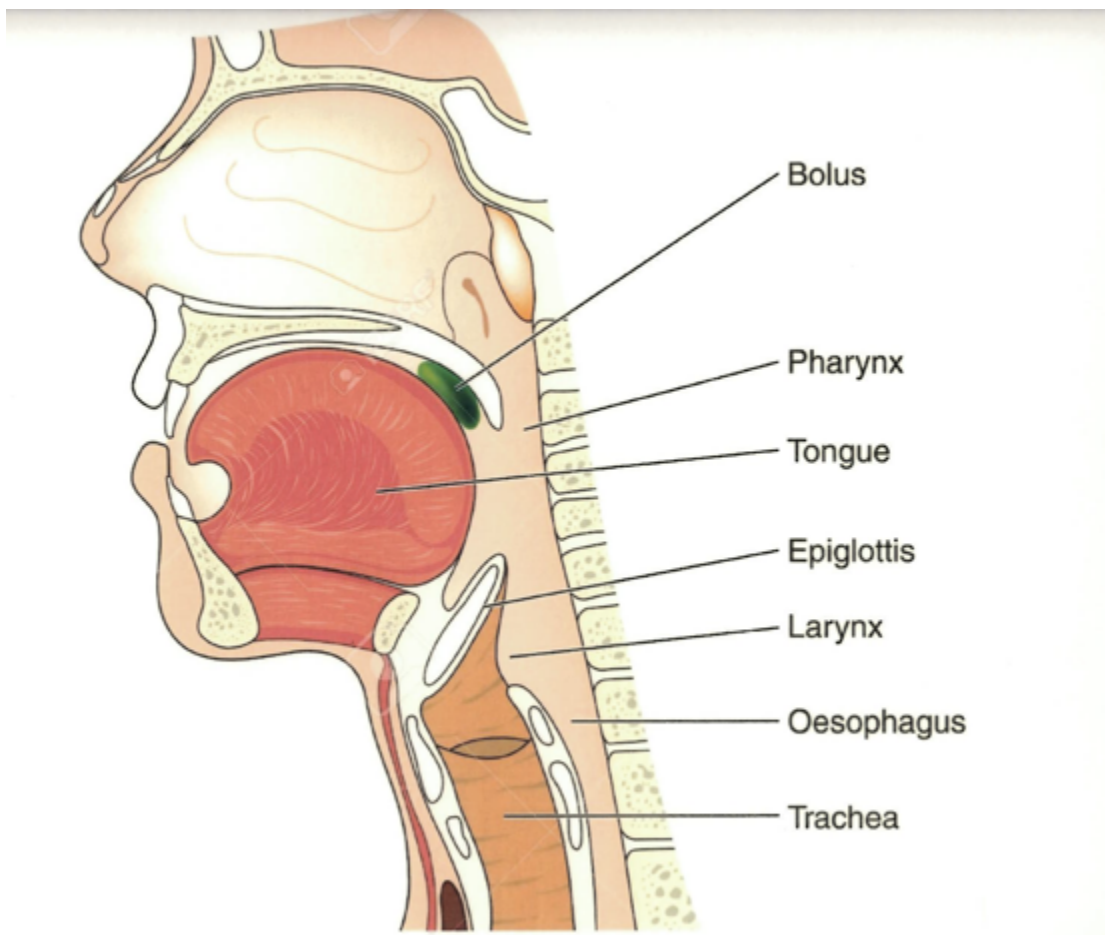
SLP Materials – Innovation (continued)
Dysphagia Alert Bracelet



Appendix I: SLP Materials – Diagrams
Hand-drawing Diagram

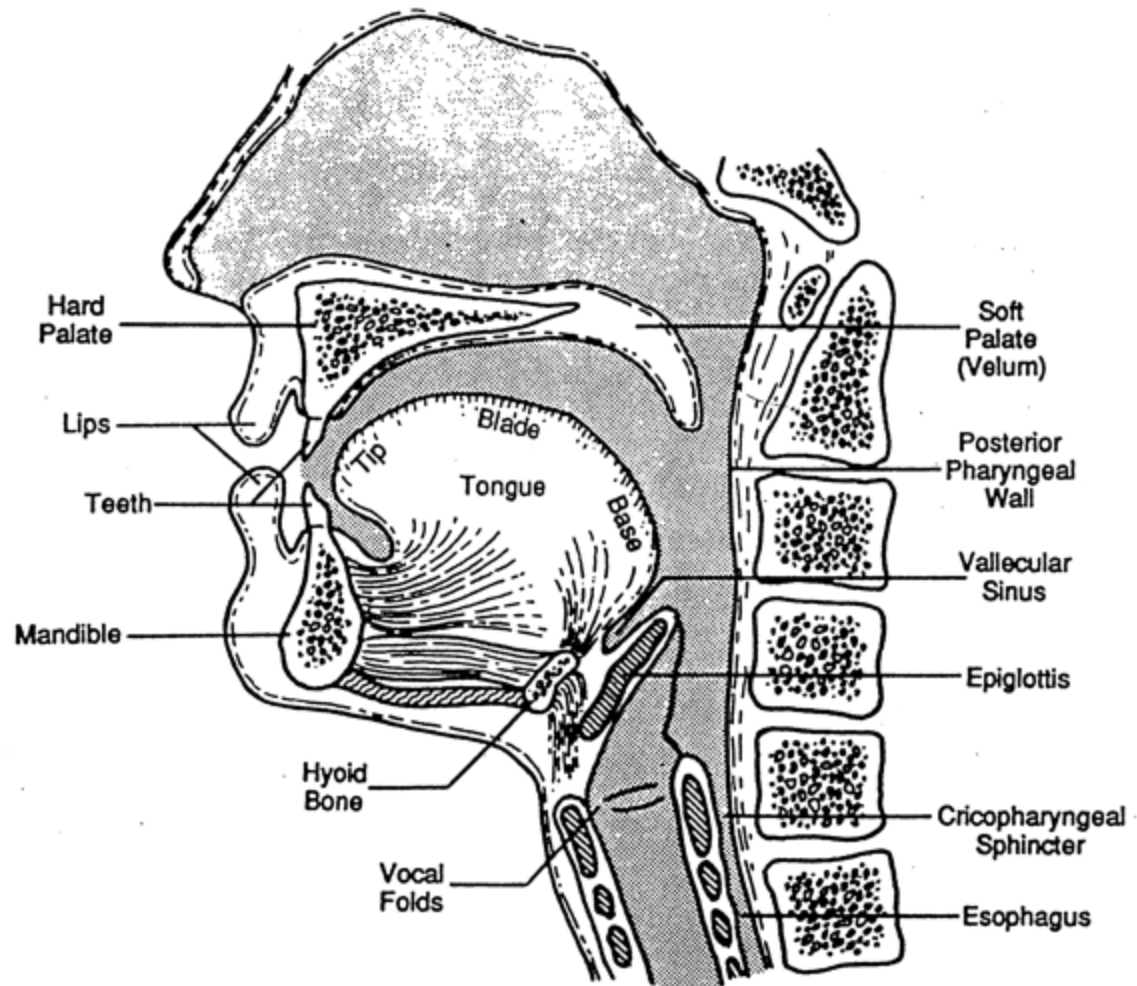


SLP Materials – Diagrams (continued)
Formal Medical Diagram



SLP Materials – Diagrams (continued)
Formal Medical Diagram

Swallowing Mechanism at Rest



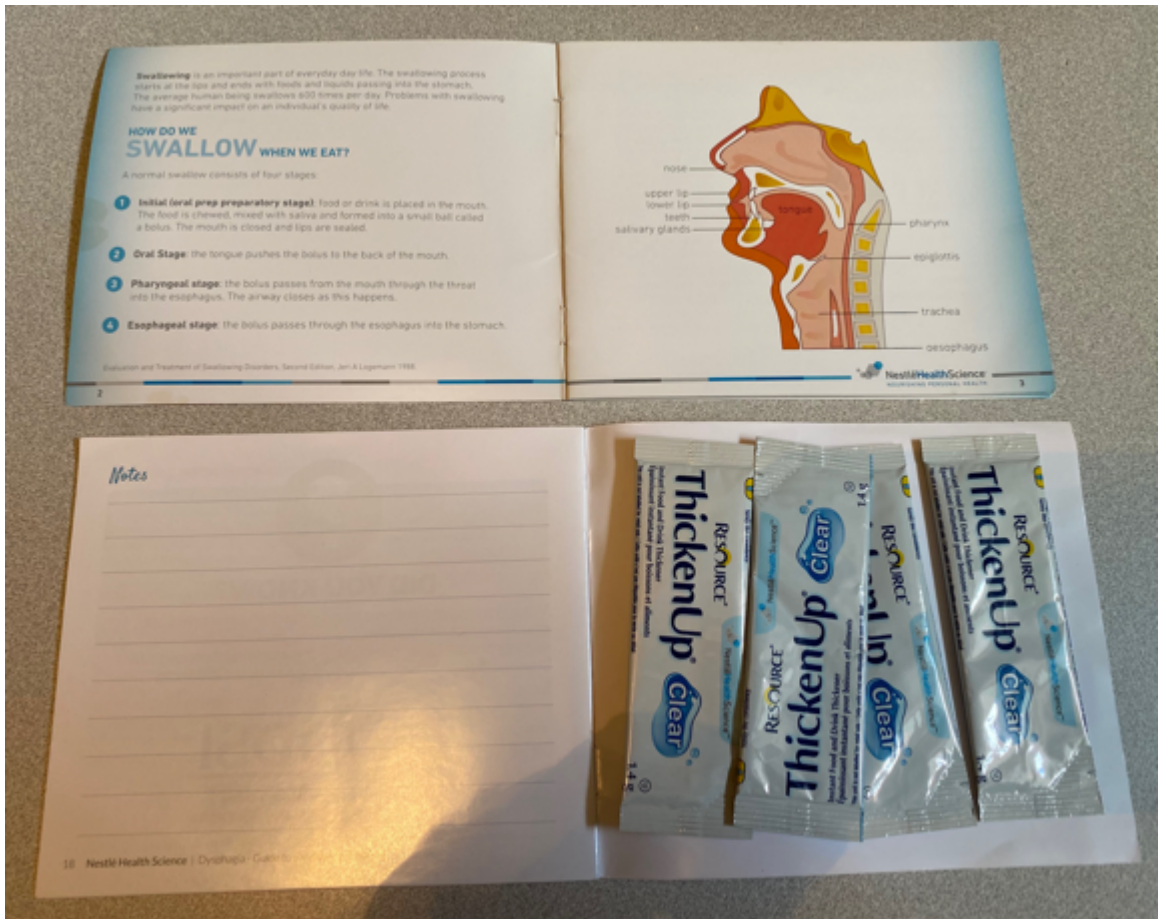
Appendix J: SLP Materials – Models
Medical Model Tracheostomy T.O.M



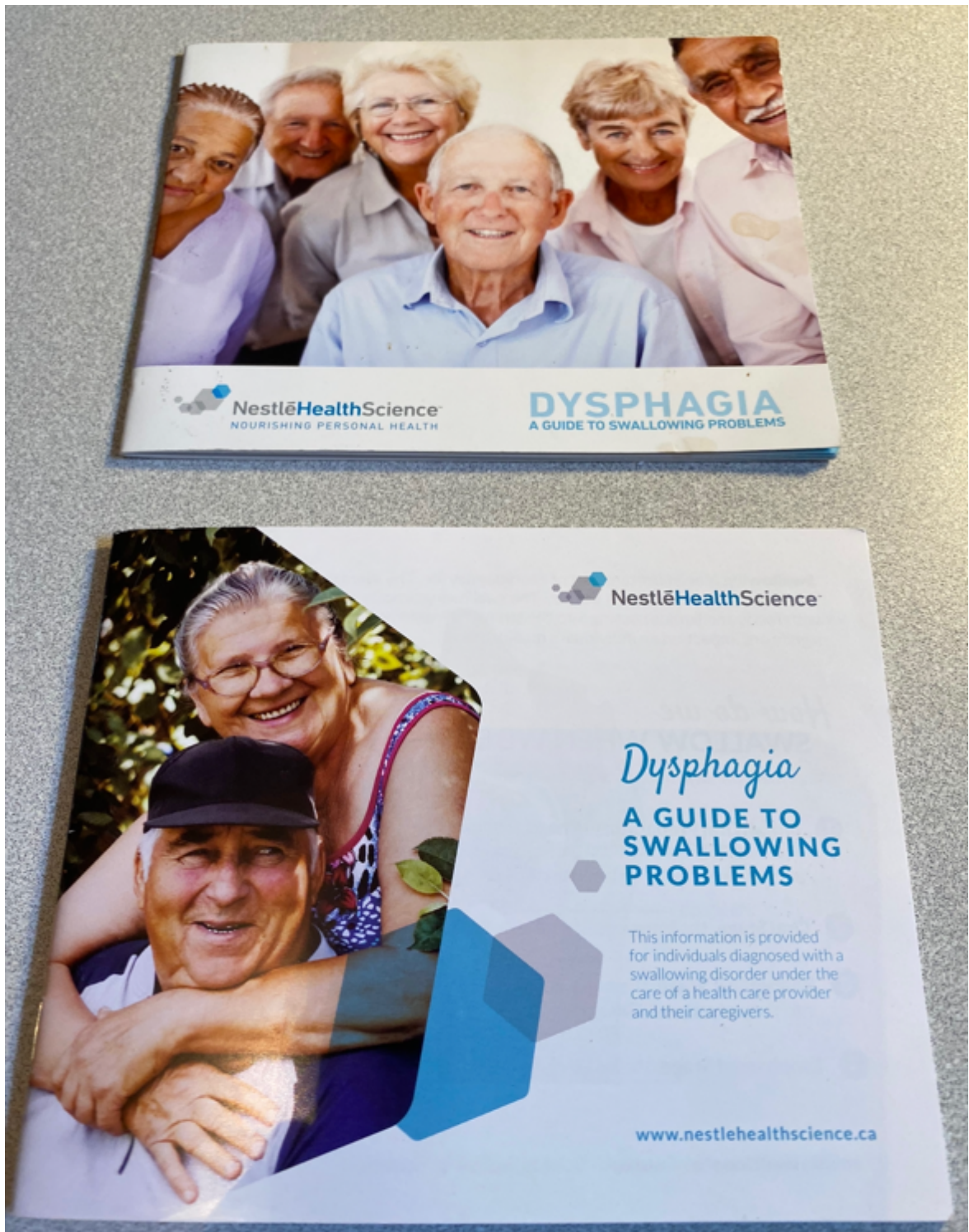
SLP Materials – Models
Medical Model #2



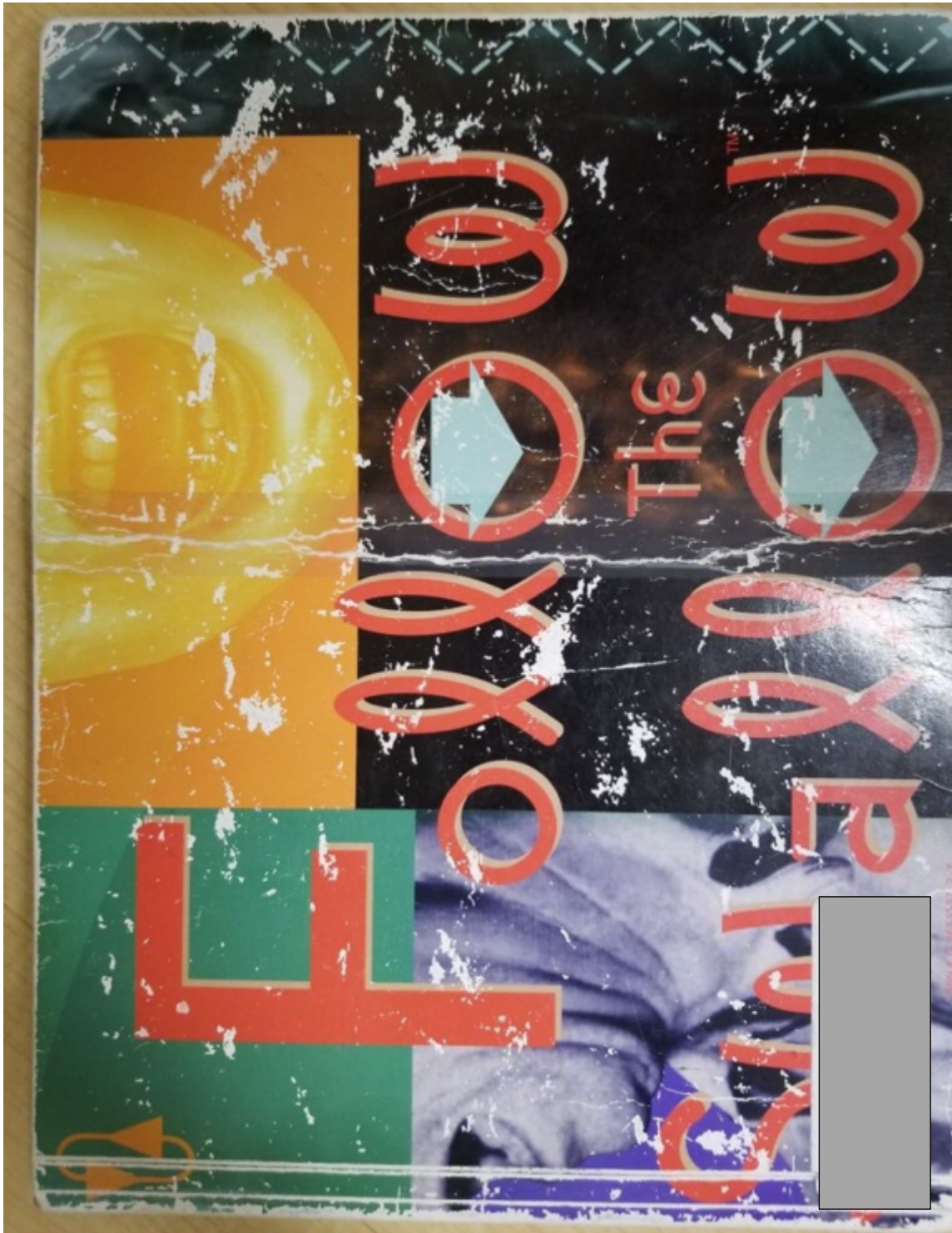
Appendix K: SLP Materials - Commercially available Materials



SLP Materials – Commercially-available Materials (continued)



Appendix L: SLP Materials – Written Materials



SLP Materials – Written Materials (continued)**Written Materials: Patient Education Sheets****Pureed Diet (Thin liquids allowed)**

Name: _____ Date: _____

Dietitian: _____ Contact Info: _____

Speech Language Pathologist: _____ Contact Info: _____

- Pureed foods do not require chewing.
- Pureed foods should be the texture of a thick pudding or whipped cream.
- Pureed foods should not contain any lumps.
- Ensure medications are crumbled in a pureed mixture or come in a liquid form.

Suggested Foods:

Any food that you can puree to an even consistency.

Most foods can be thickened or thinned to desired consistency with tips below.

Food Group	Suggested Foods	Foods to Avoid
Grain Products	Cream of wheat / oatmeal Pureed bread products Pureed pasta and rice	All others
Vegetables and Fruit	Pureed fruit or vegetables without seeds or skins <ul style="list-style-type: none"> • applesauce or other fruit sauces • mashed / pureed ripe bananas • mashed potatoes with extra milk or gravy • pureed cooked carrots, squash or turnip Fruit and vegetable juices (may use a juicer)	Corn Cabbage Peas Fruits and vegetables with seeds, skin, or tough membranes such as celery, green pepper, grapes, etc.
Milk and milk products	White or chocolate milk Strained cream soups Smooth yogurt (without fruit pieces) Smooth custard, pudding Blenderized cottage cheese Cheese sauces	Cooked or stringy cheese
Meat and Alternatives	Pureed meats, poultry and fish Pureed scrambled eggs Pureed legumes (chickpeas, lima beans and black beans, etc.) Pureed Tofu	All other meats Peanuts, nuts and seeds
Others	Pureed stews, soups and casseroles Butter, gravy, sugar, spices and flavourings that do not alter consistency too much	

Sample Menu

Breakfast Choices

- Hot cereal (cream of wheat or oatmeal)
- Eggs (scrambled or soft poached)
- Smooth yogurt or custard
- Juice or milk
- Coffee or Tea

AM Snack

- Applesauce

Lunch Choices

- Strained cream or broth soup (e.g. chicken, celery, mushroom or pea)

- Pureed moist casseroles (tuna noodle, macaroni and cheese)
OR
- Pureed cottage cheese with (canned) fruit puree
- Milk

PM Snack

- Smooth yogurt (without fruit pieces)/ Pudding/ Ice Cream
- Juice or supplement *

Supper Choices

- Pureed beef, pork, poultry or fish
- Mashed potatoes
- Pureed or mashed soft cooked vegetables (carrots, turnip, cauliflower)
- Moist cheesecake/ Jello/ pureed fruit
- Milk

Night Snack

Pudding or supplement*

***Supplements if not eating well**

Discuss with your dietitian which supplements are best for you.

How do I puree?

1. Place small amount of cooked / soft foods in a blender or food processor.
2. Add liquid (soup, gravy, broth, sauce, milk or juice) to attain desired consistency (see ideas below).
3. Blend until smooth adding more liquid if needed.
4. No lumps should be present.
5. Stir and reheat if needed.

Easy Meal Ideas

- Canned stews, soups (Chunky Soups) casseroles blend up easily in the blender.
- Baby foods are very nutritious but require extra seasoning as they are made without salt, sugar or seasoning.
- Canned ham, tuna, salmon, chicken blend up well with canned soup/mayonnaise or white/cheese sauce added.
- Canned fruit or ripe fresh fruit with added cottage cheese.
- Frozen pureed meals are available for purchase*.

Cut up food into small pieces and place in the blender	Add small amounts of fluid and blend until smooth	To add more flavor, try the suggestions below
Beef stew Meatloaf Roasted meats Corned beef	Gravy Broth Mushroom soup Stewed tomatoes Tomato or V8 juice	Garlic Basil Oregano Ketchup Worcestershire sauce
Baked Fish Tuna or salmon Ham	Mayonnaise thinned with milk or cream White or cheese sauce	Tartar sauce Lemon juice Pickle juice
Macaroni and cheese Cabbage rolls Canned chunky soups (no extra liquid is needed) Chicken a la King	Chicken or vegetable soup Milk or cream Broth or gravy	
Cooked vegetables Canned vegetables	Milk or cream Cooking liquid Cheese sauce	Parmesan cheese Onion powder
Canned fruit Ripe fresh fruit (no skins or seeds unless a juicer is used)	Juice or syrup from the can Yogurt or pudding	

Minced Diet with Bread no Crust (Thick liquids only)**Name:** _____ **Date:** _____**Dietitian:** _____ **Contact Info:** _____**Speech Language Pathologist:** _____ **Contact Info:** _____

- Foods may be minced, mashed, soft or finely grated.
- Meats and poultry may be minced with a meat grinder, blender or food processor.
- All foods should be moist. Add thickened soup, gravy, sauce, butter or margarine to enhance the flavour and nutrition of the minced foods. This will also increase the portion size.
- Soft casseroles are allowed. Breads and bread products should be soft and crustless.
- Thicken all liquids to _____ consistency.
- See instruction sheet.

Food Group	Suggested Foods	Foods to Avoid
Grain Products	<p>Smooth cream of wheat or oatmeal</p> <p>White or whole wheat pasta (small pieces)</p> <p>White, rye, or whole wheat bread or buns</p> <p>Well-cooked rice moistened with sauce</p> <p>Plain crackers and cookies</p> <p>Muffins, moist cakes or donuts</p> <p>Pancakes or waffles</p>	<p>Granola cereals</p> <p>Doughy bread/bagels</p> <p>Potato and tortilla chips, pretzels</p> <p>Crackers, cookies, muffins, cakes, or donuts containing nuts, seeds or dried fruit.</p>
Vegetables and Fruit	<p>Cooked/canned vegetables cut in small pieces</p> <p>Tips of asparagus</p> <p>Chopped cooked spinach or swiss chard</p> <p>Mashed turnip or squash</p> <p>Mashed or creamed potatoes</p> <p>Tomato paste or puree</p> <p>Canned fruit pieces (drained), banana</p> <p>Grapefruit/orange segments with membrane removed, cut into small pieces</p> <p>Baked apple with the skin removed</p> <p>Thickened applesauce or fruit purees</p>	<p>Raw, fried or stringy vegetables</p> <p>Dried fruit (raisins, dates, prunes, figs, etc.)</p> <p>Potato skins</p> <p>Skins and seeds</p> <p>Fruits with pits, seeds, membranes or coarse skin e.g. cherries</p> <p>Canned pineapple</p>

Food Group	Suggested Foods	Foods to Avoid
Milk and milk products	Thickened white or chocolate milk Thickened cream soup Yogurt, custard, pudding, thick milkshakes Cottage cheese, grated cheese and other soft cheeses, thick cheese sauce	Yogurt with chunks of fruit or seeds
Meat and Alternatives	Minced or ground meat, fish, and poultry Soft poached (mashed) or scrambled eggs Mashed cooked/canned legumes (chickpeas, lima beans, black beans, etc.), tofu	Meat with coarse skin e.g. sausage Peanuts, all nuts
Others	Soft stews and casseroles with gravy or broth (thickened), butter, gravy, sugar, spices and flavourings, ketchup, mustard, relish, Honey, syrups and fruit jellies Thickened nutritional supplements	Thin fluids such as water, or that melt to a thin fluid such as ice cubes, jello, popsicles, sherbet, etc.

Sample Menu

Breakfast Choices

- Hot cereal (cream of wheat or oatmeal)
- Eggs (scrambled or mashed)
- Yogurt or custard
- Thickened juice

Morning Snack

- Thickened juice or fruit puree (applesauce)
- Lunch Choices
- Strained thickened cream or broth soup
- Sandwich with crustless bread with a soft or minced filling (such as chicken/tuna/salmon/ham/egg salad, etc.)
- or Soft casserole
- or Cottage cheese with allowed fruits
- Thickened juice

Afternoon Snack

- Custard, pudding or yogurt
- Thickened juice or supplement*
- Supper Choices
- Minced beef, pork, chicken or fish with gravy or sauce
- Mashed potatoes with butter or margarine or gravy
- Piece of soft bread without the crust (with butter or margarine)
- Finely grated raw vegetables such as coleslaw or shredded lettuce mixed with salad dressing or mayonnaise
- Minced or mashed soft cooked vegetables (carrots, turnip, cauliflower, etc.)
- Moist cheesecake (without crust) or moist cake
- Thickened milk or juice

Night Snack

Pudding or supplement*

***Supplements if not eating well**

Discuss with your dietitian which supplements are best for you.

****Your SLP or dietitian will talk to you about peanut butter – it is quite a sticky food and may or may not be appropriate for your swallowing needs.**

Instructions for Using “Thicken Up Clear”

This product can be used to thicken all thin fluids to the appropriate Consistency as recommended by the Speech Language Pathologist.

The consistency that is safest for you is to thicken all thin fluids to a _____ consistency.

How to Thicken:

1. For each 3/4 cup serving or 175ml portion you will need to measure out _____ mL of Thicken Up. *
2. Slowly add Thicken Up to liquid while stirring briskly.
3. Stir for 20-30 seconds.
4. This will thicken within 1 to 5 minutes with exception of nutritional supplements which need to be left for 15-20 minutes before serving.

***For more accurate measurements refer to “Preparation Guide for Resource Thicken Up Clear”**

Note: Thickened beverages may be covered and refrigerated up to 12 hours. Make sure to stir well before serving.

How to buy Thickener

Thickener is available to purchase from the kitchen office at XXXXXXXXXXXX Hospital which is located in basement. Please call ahead if possible to place order (519-XXXXXX ext.). You can order this product from your drug store, but you will need to give them advance notice as this product is not routinely stocked on pharmacy shelves.

Price of Thicken Up Clear Food Thickener at (note that prices are subject to change)

125g	\$12.50
1 case (12 x 125g)	\$125.00

SWALLOWING RECOMMENDATIONS

- Make sure to be sitting (i.e. not laying down) when eating and drinking, even when taking pills or having a snack
- Tuck your head slightly forward, not backward, as you swallow
- Eat/drink slowly
- Try not to talk or laugh when you are trying to swallow.
- Take small bites of food, chew well and do not take another bite until everything from the first bite has been swallowed
- Take small sips of fluids. Hold drink in your mouth for a few seconds in order to make sure your swallow is ready
- It may be recommended for you not to use straws when drinking
- If it feels like food or fluids did not go down completely with the first swallow, swallow again.
- Take 1-2 pills at a time as this makes it easier to control when swallowing
- Try not to lie down for at least a half hour after eating or drinking
- Make sure to do mouth care before/after eating or drinking. Use of an anti-bacterial mouthwash may be suggested.

SLP Materials – Written Materials (continued)

List of Foods on a Soft Diet

Food should be easy to chew and should “mush” together well for swallowing. Avoid foods that are dry, hard, or crumbly!

Breads, Cereals, Grains



Safe soft foods in the grains group include cooked cereals such as oatmeal, cream of wheat or easily softened cold cereals such as Rice Krispies and Corn Flakes. Also acceptable are soft breads and muffins, pancakes, french toast with the crusts cut off and pasta.

Eggs and Dairy



All eggs are acceptable except for raw and fried, with scrambled and soft-boiled considered the best. All dairy products, including chocolate milk, ice cream and yogurt, are included.

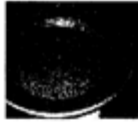
Fruits and Vegetables



Fruit and vegetable juices, fruits and vegetables that are cooked and/or canned. Avocados and tomatoes and potatoes without the skins, bananas, ripe berries and ripe melon.

SLP Written Materials – Written Materials (continued)

Soups, Sauces and Condiments



Creamed soups and broths are good soft diet foods, as is any other pureed or blended soup. For sauces, choose those that are pureed or well-blended, avoiding chunky pieces. For spices and condiments, use salt, pepper, all finely chopped or ground leaf herbs and mild spices and ketchup. For sweeteners, use sugar, honey, jelly, smooth preserves, syrup and jellied cranberry sauce.

Meats and Entrees



Meats like chicken, turkey, beef, veal, lamb and liver must be cooked so that they are tender. They can be baked, broiled, creamed, roasted or stewed. Pork must be stewed. Chicken and turkey must not be fried. Cooked, fresh or frozen fish without bones such as tuna, salmon or white fishes are included, as is canned tuna. Other good protein sources include tofu and well-cooked legumes with soft skins, such as baked beans or lentils.

Desserts



Desserts can include ice cream, icees, sherbet and sorbet; pudding or custard; soft candy, butter cookies, plain chocolate. Avoid deserts that have nuts, seeds or hard pieces.

SLP Materials – Written Materials (continued)

A Sample Soft-Food Diet Daily Menu

- Breakfast: scrambled eggs with grated melted cheese, ripe cantaloupe

Lunch: tuna salad made with tuna, mayonnaise and some spices, applesauce

Supper: poached salmon, mashed or baked skinless sweet potato

Dessert: pudding with whipped cream

SLP Materials – Written Materials (continued)

Products to Thicken Liquids

How to find thickener:

1. Ask your local pharmacy for "Thickening Powder." They may be able to order for you.
2. Hospital pharmacies often sell thickening powder. Sick Kids Specialty Food Shop will deliver.
3. Order online (Well.ca, Amazon.ca etc.)

Older Brands:

Thicken Up

Consist Rite

Quick Thick

Ultra Thick

Measurements are listed on the package. Measure powder, add to the liquid, and stir 1-5 minutes. You can adjust by adding more thickener or liquid. In general,

Nectar thick "Mildly thick": approx. 2 tsbp thickener per 1 cup of liquid (250mL)

Honey thick "Moderately thick": approx. 3 tsbp thickener per 1 cup of liquid (250mL)

Pudding thick "Extremely thick": approx. 4 tsbp thickener per 1 cup of liquid (250mL)

Newer brand:

Thicken Up Clear

Thicken up CLEAR is more expensive per can, but you use less. It comes with a small plastic scoop inside each can. Measure liquid, add powder, stir 2 minutes. This thickener "sets": once it has reached its full thickness, it will maintain its thickness for 24 hours but you cannot add more: it will clump.

Measurements:

Nectar thick "Mildly thick": 1 scoop thickener per ½ cup of liquid (125mL)

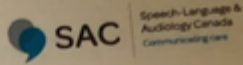
Honey thick "Moderately thick": 2 scoops thickener per ½ cup liquid (125 mL)

Pudding thick "Extremely thick": 3 scoops thickener per ½ cup liquid (125 mL)

Other thickening agents: Mashed potato flakes, infant rice cereals, pureed vegetables or fruits, gelatin, cornstarch or arrowroot powder (mix with water first, then add to food/soups and cook it).

SLP Materials – Written Materials (continued)

Helping Your Loved One Eat Comfortably at the End of Life



During the dying process, it is normal for people to lack the desire to eat. As their disease progresses, they may also be at higher risk for choking or having food or liquid "go down the wrong way". Many people stop eating and drinking at the end of life due to:

- Loss of appetite or thirst
- Pain, discomfort or fatigue
- Difficulty swallowing
- Nausea
- Dry mouth
- Low level of consciousness
- Inability to sit upright
- Shortness of breath

It can be distressing when your loved one doesn't eat or drink well or stops eating altogether. However, artificial nutrition or hydration (e.g. tube feeding, IV fluids) can actually increase discomfort and present new risks without improving someone's quality of life or prolonging their life.

Comfort feeding plans can help people at the end of their life enjoy eating and drinking as safely as possible. If your loved one wishes to continue eating and drinking, a **speech-language pathologist** can develop a comfort feeding plan tailored to suit their needs.

Comfort Feeding Strategies:

- Minimize distractions while eating and drinking.
- Make sure the person is alert enough to eat or drink.
- Help them into an upright position, as tolerated.
- Offer preferred food and fluids that are easy to swallow (e.g., soft, moist foods).
- Where possible, encourage the person to feed themselves.
- Sit at eye level and slowly offer small amounts of food and fluid.
- Watch the person's throat for a complete swallow before offering the next sip or bite.
- If they cannot swallow or begin coughing or choking, remove any remaining food or drink from the mouth, then provide oral care.
- If you notice the person has difficulties drinking from a straw, try small sips from a cup or spoon.

Tips for Oral Care at End of Life

Mouth care is an important way to maintain dignity at the end of life. It can also help to alleviate symptoms like thirst and improve the experience of eating and drinking. **Here are some tips to help you provide oral care:**

- Ideally, use a soft toothbrush and a small amount of toothpaste to clean teeth and gums. Remove secretions or foam from the mouth with a suction toothbrush or a suction wand.
- For those who cannot sit upright or who are not alert, use a soft damp face cloth to gently clean the teeth, gums, inside of the cheeks and tongue.
- Apply lip balm to dry lips.
- Use a humidifier to add moisture to the air.
- Ask the health-care team to recommend alcohol-free oral hygiene products and saliva substitutes.

Communication Health & End-of-Life Care

Speech-language pathologists are an important part of the end-of-life care communication

SLP Materials – Written Materials (continued)

**Minced foods
for people with dysphagia**

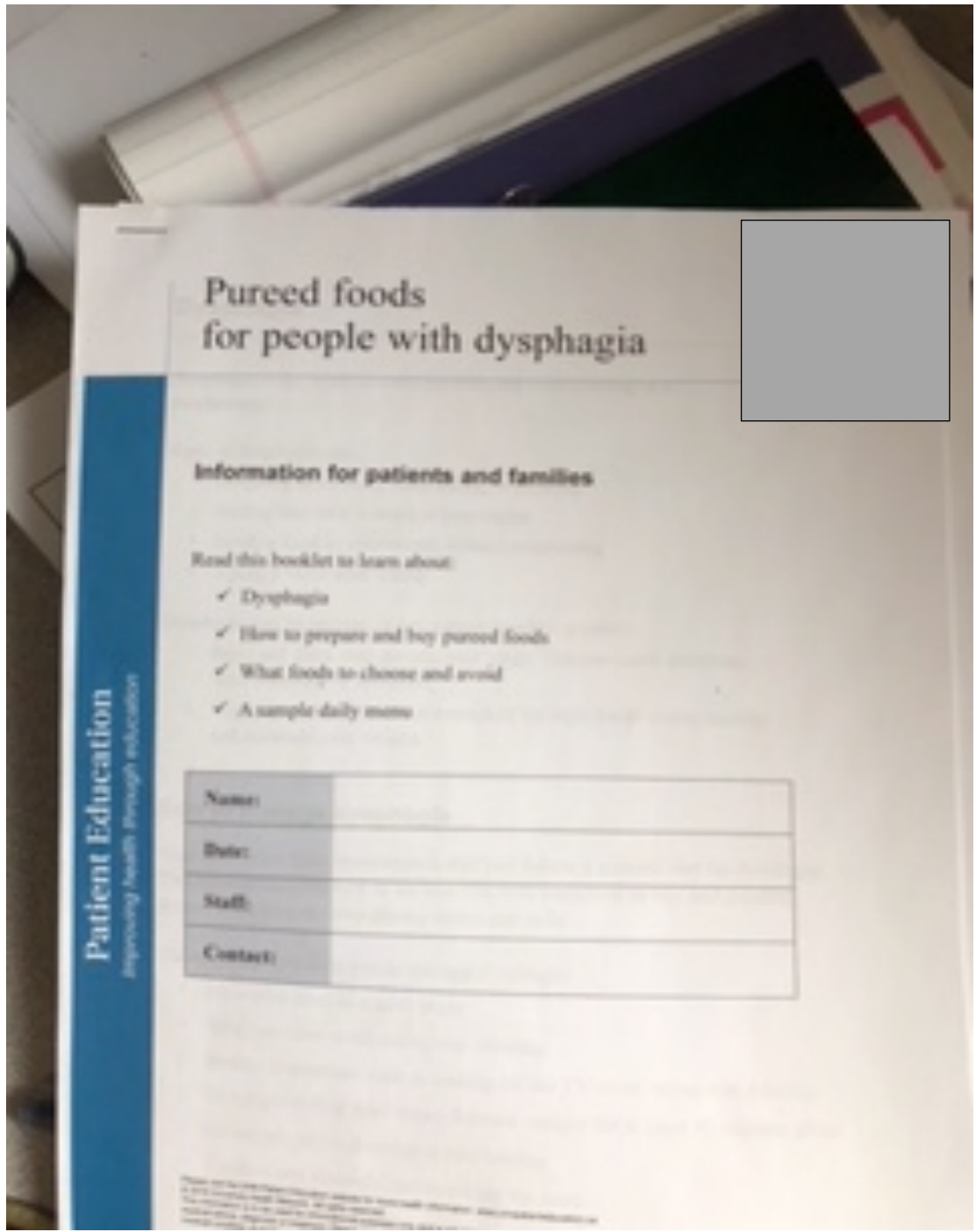
Information for patients and families

Read this booklet to learn about:

- ✓ Dysphagia
- ✓ How to prepare minced foods
- ✓ What foods to choose and avoid
- ✓ A sample daily menu

Name:	
Date:	
Staff:	
Contact:	

SLP Materials – Written Materials (continued)



Appendix M: Curriculum Vitae

Curriculum Vitae

Name: Stephanie Muir-Derbyshire

Post-Secondary Education and Degrees: **Carleton University**
Ottawa, Canada
- 1991, Bachelor of Arts in Applied Linguistics (Honours)
Boston University
Boston, USA
- 1993, Master of Science-Speech Language Pathology
The University of Western Ontario
London, Canada
- 2020, PhD-TDO, Health and Rehabilitation Sciences-Health Professional Education

Related Work Experience: Lecturer
The University of Western Ontario
2004 - 2013
Peer Assessor-College of Speech Language Pathologists and Audiologists of Ontario
Corresponding Member CASLPO Preferred Practice Guideline for Cognitive Communication Disorders
2001 - Present
Speech Language Pathologist
St. Joseph's Health Care, Parkwood Hospital & Grosvenor Site, London, Canada
1994 - Present
Speech-Language Pathologist, Clinical Fellow Position
Massachusetts General Hospital
Boston, U.S.A.
1993 - 1994

Adult Neurogenic/Dysphagia Training
Assessment and treatment of adult population with varying disorders (apraxia, aphasia and dysphagia)