

**PATIENT PERSPECTIVES OF DYSPHAGIA FOLLOWING CRITICAL ILLNESS AND
ARTIFICIAL AIRWAY USE**

by

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Abstract

Patients requiring artificial airways and prolonged mechanical ventilation while in critical care frequently suffer from various iatrogenic complications during and after hospitalization. One of these is dysphagia, or disordered swallowing, which can affect over 90% of this population. Patients unable to swallow safely are often at risk of other adverse sequelae, including serious pulmonary complications. Intervention may necessitate tube feeding and/or modified food and/or liquid; as a result, the treatments necessary to sustain life during critical illness may affect psychosocial well-being and quality of life. To date, no study has examined the perspectives of patients with dysphagia following critical illness and artificial airway use.

Using a prospective study design, we recruited a convenience sample of patients who had swallowing impairment following artificial airway use from three healthcare facilities in a single health care region. Four patients were recruited to this study from January to April 2021. Using a semi-structured interview format, one interviewer explored their experiences. Following interview transcription, results were analyzed thematically by two reviewers. We identified several common themes reflecting participants' beliefs and values around eating and drinking, in the context of: 1) connectedness with family, 2) recovery and overall health, and 3) personal autonomy and dignity. We further identified latent patient perceptions of swallowing and instrumental assessment – in particular that swallowing was a volitional action, and that assessments were a test of ability with a binary outcome.

This study is the first to investigate the perspectives of a sample of this population. As communication specialists, S-LPs have a vital role to play in fostering effective multi-directional communication between all members of the care team, including the patient and their family.

Understanding this role within the context of these patients' perspectives will enable clinicians to deliver enhanced patient-centered care.

Lay Summary

Swallowing difficulty frequently occurs when people are very ill and require machines to help them breathe. As a result, people sometimes require changes to their foods and/or liquids, or need tubes to feed them. Since eating and drinking are essential to physical, emotional, and social well-being, not being able to eat or drink normally can decrease ones' quality of life. This study investigated what people think about eating and drinking after having been very sick, and their experiences following their illness.

We interviewed four people after they recovered from hospital and needing breathing machines. Common “themes” from these interviews highlighted the participants’ perceptions of eating and drinking, illness and recovery, and the treatment they received. Our findings will help clinicians, especially speech-language pathologists, better understand the patients’ point of view. Understanding patients’ perspectives regarding their care and involving them in determining research priorities will improve outcomes.

Preface

This thesis is the original work of G. Fullerton, written under the supervision of Dr. S. A. Skoretz. Reviews of the thesis were conducted by the supervisory committee members, Drs. C. Backman and L. Li.

The study design was developed by G. Fullerton and S. A. Skoretz with contributions from V. Letawsky and R. Deng. The study was conducted in Vancouver, British Columbia, at two Vancouver Coastal Health sites and one participant's home. Recruiting, enrolment and consenting were performed by T. Findley, D. Hendy, C. Marcoux, G. Modha, G. O'Toole, K. Roodenburg, and E. Sullivan. Participant interviews were conducted by G. Fullerton. Transcription of interview data was performed by G. Fullerton. Transcription verification was performed by A. Wu. Analysis of interview data was conducted by G. Fullerton and S. A. Skoretz.

The study process was approved by the Behavioural Research Ethics Board through the University of British Columbia on November 13, 2020 (Certificate number H20-00167).

Table of Contents

Abstract	iii
Lay Summary.....	v
Preface	vi
Table of Contents.....	vii
List of Tables.....	xi
List of Figures	xii
List of Abbreviations	xiii
Acknowledgements	xv
Dedication.....	xvii
Chapter 1: Introduction.....	1
1.1 Swallow Physiology	1
1.2 Disordered Swallowing	4
1.2.1 Physiological Impacts.....	4
1.2.2 Psychosocial Impacts.....	6
1.2.3 Populations at Risk.....	8
1.3 Critical Illness and Artificial Airway Use	8
1.3.1 Mechanical Ventilation.....	8
1.3.2 Dysphagia following Artificial Airway Use.....	9
1.4 Patient-centered Care.....	10
1.5 Epistemology and Methodology.....	11
1.6 Patient Perspectives of Dysphagia: State of the Science.....	12

1.7	Rationale and Objectives.....	12
Chapter 2: Methods.....		14
2.1	Study Process.....	14
2.2	Participants	14
2.3	Participant Recruitment	14
2.4	Consent and Enrollment	15
2.5	Data Collection	15
2.5.1	Demographics.....	15
2.5.2	Semi-structured Interview	16
2.6	Data Analysis.....	16
2.6.1	Transcription.....	16
2.6.2	Theme Identification and Analysis.....	16
2.6.3	Peer Debriefing.....	17
2.6.4	Reflexivity.....	17
Chapter 3: Results		18
3.1	Participants and Interviews.....	18
3.2	Theme Identification	19
3.3	Psychology is a Big Part of It	19
3.3.1	Mealtime: Enjoyment, Connection and Structure.....	21
3.3.2	Loss	22
3.3.3	Under Pressure	25
3.3.3.1	Assessment as Performance Exam	26
3.3.3.2	I Eat Therefore I Am	28

3.3.4	Acceptance	31
3.3.5	Empowerment	37
3.4	Recovery is a Team Effort.....	40
3.4.1	Communication	40
3.4.2	Active Involvement.....	45
3.4.3	Connectedness.....	45
Chapter 4: Discussion.....		47
4.1	Perspectives of Eating and Autonomy	47
4.2	Perspectives of Swallowing Assessment.....	49
4.3	Perspectives of Eating, Health, and Recovery.....	51
4.4	Acceptance, Empowerment, and the Power of Positivity	52
4.5	Patient Involvement in Care	53
4.6	Family Support	54
4.7	Communication: The Key Ingredient.....	55
4.7.1	Importance of Patient-Clinician Communication	55
4.7.2	Barriers and Bi-Directionality.....	55
4.7.4	Communication: Implications for Clinical Practice	57
4.8	Limitations and Lessons Learned	58
4.9	Role of the Researcher.....	59
4.10	Future Directions	59
Chapter 5: Conclusion		61
References		63
Appendices		77

Appendix A Recruitment Information Sheet.....	77
Appendix B Participant Consent Form.....	78
Appendix C Themes, Subthemes, and Representative Quotations	86

List of Tables

Table 3.1 Participant Demographics	18
Table C.1 Themes, Subthemes, and Representative Quotations for “Psychology is a Big Part of It”	88
Table C.2 Themes, Subthemes, and Representative Quotations for “Recovery is a Team Effort”	94

List of Figures

Figure 3.1 Schematic Representation of Themes	20
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List of Abbreviations

AES	Advanced encryption standard
COVID/COVID-19	Coronavirus disease 2019
CT	Computerized tomography
FEES	Fiberoptic endoscopic evaluation of swallowing
GF	Graduate student researcher
GFS	GF Strong rehabilitation centre
GPC	George Pearson centre
h	hour
HNC	Head and neck cancer
ICU	Intensive care unit
ID	Interpretive description
Int	Interviewer
IPA	Interpretive phenomenological analysis
NG	Nasogastric
NPO	Nil per os (nothing by mouth)
OT	Occupational therapy
PCC	Patient-centered care
PMV	Prolonged mechanical ventilation
PT	Physical therapy
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
SAS	Thesis supervisor

Si-Lab	Swallowing Innovations Lab
S-LP	Speech-language pathologist
TA	Thematic analysis
UBC	University of British Columbia
UES	Upper esophageal sphincter
US	United States
VCH	Vancouver Coastal Health
VFSS	Videofluoroscopic swallow study
VGH	Vancouver General Hospital

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Por Monker

...and Cracker

Chapter 1: Introduction

Food is our common ground, our universal experience.

– James Beard

The single biggest problem in communication is the illusion that it has taken place.

– George Bernard Shaw

Patients requiring artificial airways and mechanical ventilation while in critical care frequently suffer from various iatrogenic complications during and after hospitalization. One of these is dysphagia, or disordered swallowing, which can affect more than 90% of this population (Skoretz et al., 2020). Patients with dysphagia following critical illness and artificial airway use are at risk of various negative physiological sequelae, including, but not limited to, pulmonary pathologies. However, dysphagia also frequently results in deleterious effects on psychosocial well-being and quality of life when the enjoyment of eating and drinking, especially with loved ones, is altered because of necessary, life-saving medical treatment. To date, no study has examined the lived experiences of this population with respect to their dysphagia. Understanding their perspectives of dysphagia and the treatment they receive will improve research in this area and inform better clinical practice.

1.1 Swallow Physiology

Swallowing is a complex and finely coordinated process, involving voluntary and involuntary actions of more than 30 pairs of muscles throughout the oral cavity, pharynx, and larynx (Matsuo & Palmer, 2008; Shaw & Martino, 2013). Controlling these movements are multiple cranial and peripheral nerves, as well as cortical, subcortical, and brainstem regions (Shaw & Martino, 2013). The coordinated process of swallowing serves two critical biological functions: 1) protecting the airway, and 2) transporting food and liquid from the oral cavity to the

stomach (Matsuo & Palmer, 2008). While individual variation exists, particularly with differing bolus textures, consistencies, volumes, and tastes, the physiology of a normal swallow consists of an expected event sequence.

The swallow is commonly described as a four-stage process comprising an oral stage subdivided into preparatory and transit phases (Malandraki & Robbins, 2013; Perlman 1994), a pharyngeal stage, and an esophageal stage (Logemann, 1983; Matsuo & Palmer, 2008; Shaw & Martino, 2013). In the oral preparatory phase, food or liquid is ingested into the oral cavity, masticated (in the case of solid food), formed into a cohesive bolus, and held between the surface of the tongue and the hard palate (Matsuo & Palmer, 2008; Shaw & Martino, 2013). The bolus is contained in the oral cavity with the airway protected when muscles of the face, tongue, and soft palate prevent anterior spillage from the mouth as well as posterior spillage into the oropharynx, (Perlman, 1994; Shaw & Martino, 2013). During the second, oral transit phase, the bolus is transported from the oral cavity to the pharynx, via a wavelike anterior-to-posterior squeezing movement of the tongue against the hard palate. This propels the bolus posteriorly through the fauces to the oropharynx (Matsuo & Palmer, 2008; Perlman, 1994; Shaw & Martino, 2013).

In a normal swallow, when the bolus passes approximately the anterior faucial pillars, the oral stage gives way to the pharyngeal stage (Perlman, 1994; Shaw & Martino, 2013). The pharyngeal swallow is a brief (approximately one second) sequence of involuntary movements during which the bolus is propelled through the pharynx and upper esophageal sphincter (UES) into the esophagus, and the airway is protected from invasion by food or liquid (Matsuo & Palmer, 2008). As the bolus enters the pharynx, the soft palate elevates to close off the nasopharynx, preventing bolus escape into the nasal cavity.

The pharynx shortens, the base of the tongue retracts against the posterior pharyngeal wall and the pharyngeal constrictor muscles contract in sequence to propel the bolus caudally towards the UES, which relaxes to allow passage of the bolus into the esophagus (Martin et al., 1994; Matsuo & Palmer, 2008). As the pharynx elevates, anterior and superior movement of the hyoid bone leads the larynx under the tongue base and passively inverts the epiglottis, covering the laryngeal inlet and directing the bolus towards the esophagus (Malandraki & Robbins, 2013; Shaw & Martino, 2013). Elevation of the larynx and hypopharynx creates a negative pressure below the bolus which helps to move the bolus caudally (Shaw & Martino, 2013). It also pulls the cricoid cartilage away from the posterior pharyngeal wall, opening the UES. With the lips and nasopharynx sealed, this opening creates an additional negative pressure, sucking the bolus into the esophagus while it is squeezed from above by the pharyngeal stripping wave (Shaw & Martino, 2013). The esophageal phase begins when the bolus has passed through the UES and entered the esophagus. Once the bolus has passed, the UES contracts, sealing the proximal esophagus and preventing the bolus from re-entering the pharynx (Shaw & Martino, 2013). The bolus is then propelled caudally via esophageal peristalsis, taking from 8 to 13 seconds to reach the stomach in healthy adults (Shaw & Martino, 2013).

It is critical that during the swallow, the airway is protected to prevent aspiration of food or liquid. If that does not occur, the individual is at risk of multiple airway complications, including pneumonia or even death (Marik, 2001). Airway protection is facilitated by timing and coordination of the swallow relative to respiration, protective movements that occur during the swallow itself, and sensory-mediated reflexes (Martin et al., 1994; Matsuo & Palmer, 2008; Shaw & Martino, 2013). While airway compromise is not the only characteristic indicative of

swallowing impairment, the prevention of prandial aspiration (or penetration) is often the main focus of swallowing rehabilitation.

1.2 Disordered Swallowing

1.2.1 Physiological Impacts

Dysphagia can result from various structural or functional deficits of the oral cavity, pharynx, larynx, or esophagus (Malandraki & Robbins, 2013; Matsuo & Palmer, 2008; Palmer et al., 2000). Dysphagia's effects on the individual may range from uncomfortable or painful sensations to more serious complications including dehydration, malnutrition, reduced rehabilitation potential, and respiratory compromise (Dodds et al., 1990; Malandraki & Robbins, 2013; Matsuo & Palmer, 2008; Palmer et al., 2000; Sura et al., 2012).

Especially concerning to clinicians are penetration and aspiration events that may occur despite the various protective mechanisms built into swallow physiology, (Marik, 2011; Matsuo & Palmer, 2008). Penetration is defined as the presence of food, liquid, oral secretions, or gastric contents in the larynx but above the vocal folds (Malandraki & Robbins, 2013; Matsuo & Palmer, 2008). Aspiration is defined as passage of that material through the vocal folds (Dodds et al., 1990; Logemann, 1983; Smith et al., 1999) and into the respiratory tract (Marik, 2001); it can occur before, during, or after the swallow (Dodds et al., 1990; Logemann, 1983; Matsuo & Palmer, 2008). While individuals with a normal swallow may aspirate microscopic quantities of food, liquid, or oral secretions without adverse effect (Marik, 2003; Matsuo & Palmer, 2008), aspiration of large quantities is dangerous to health (Langmore, 1998; Marik, 2003). Critically ill patients are at particularly high risk of aspiration and related pathologies, due to several factors including multiple medical comorbidities, tenuous respiratory status, infrequent ambulation, and gastrointestinal motility issues (Marik, 2001).

Individuals with a normal swallow respond to aspiration by coughing or clearing their throat (Marik, 2003; Smith et al., 1999). However, impaired laryngeal sensation, common among individuals with severe dysphagia (Matsuo & Palmer, 2008; Smith et al., 1999), often results in a lack of response, or an abnormally high sensory threshold (Garon et al., 1996). Silent aspiration, the passage of material beyond the true vocal folds without eliciting a cough reflex or other appreciable signs of difficulty and/or effort to eject material from the airway (Garon et al., 1996; Leder et al., 1998; Smith et al., 1999), has been reported to occur in from 40% (Garon et al., 1996; Logemann, 1983; Matsuo & Palmer, 2008) to 59% (Smith et al., 1999) of individuals with dysphagia, and as much as 77% of ventilator-dependent patients (Leder et al., 1998).

The consequences of aspiration for any given individual range from inconsequential to life-threatening, and are determined by several factors, including volume of aspirate, its bacterial load, its physical and chemical properties, the depth to which it penetrates the airway, and the effectiveness of clearing mechanisms (Marik, 2001, 2003, 2011; Matsuo & Palmer, 2008; Palmer et al., 2000). Among the potentially more severe consequences of aspiration are airway obstruction (Matsuo & Palmer, 2008) and pulmonary pathologies such as aspiration pneumonia (Langmore, 1998; Marik, 2001, 2011; Palmer et al., 2000). Aspiration pneumonia is a leading cause of morbidity and mortality among hospitalized patients (Marik, 2003; Tada & Miura, 2012), particularly the elderly (Hibberd et al., 2013), for whom up to 48% of all infections are attributable to aspiration pneumonia (Langmore, 1998).

Prevention or mitigation of adverse outcomes such as these generally requires intervention, and it is common for speech-language pathologists (S-LPs) and other professionals to recommend restricting and/or modifying diet textures and consistencies for patients with dysphagia while the swallow is rehabilitated. In addition to rehabilitation approaches,

compensatory modifications may include thickened fluids, for example, and/or softening, mincing, or pureeing solid foods (O’Keeffe, 2018). In more severe cases, NPO (nil per os – nothing by mouth) status may be indicated, and a nasogastric (NG) or gastrostomy feeding tube used for feeding (Marik, 2001). Patients demonstrating risk or signs of dysphagia may experience some or all of these interventions while in acute care, and even beyond.

1.2.2 Psychosocial Impacts

Eating and drinking are inherently social activities (Carey et al., 2015), and enjoyment of eating is an important component of overall health (Vogel & Mol, 2014). As a result, the physiological ramifications of dysphagia may also carry adverse social and psychological consequences (Manor et al., 2013; Plowman-Prine et al., 2009). For patients in acute or long-term care facilities whose swallow dysfunction poses a medical risk, associated interventions often result in a loss of enjoyment of eating and drinking. Many patients dislike fluid modifications, who report significant negative effects on their quality of life (O’Keeffe, 2018). Modified solid textures are also unpopular; with complaints regarding texture, appearance, and taste amply recorded, and patients often refusing to comply altogether (O’Keeffe, 2018; Swan et al., 2015). A patient who is precluded from oral intake (NPO) and who is receiving nutrition via feeding tube is often prevented from enjoying any aspect of eating or drinking. In hospitals, mealtimes are especially important for patients and their families, providing caregivers with the opportunity to bring preferred foods for the patient, and to provide care and support for their loved one (Carey et al., 2015). To lose this opportunity likely has significant adverse effects on individuals’ emotional, mental, and even physical health.

Dysphagia rehabilitation is not always focused on prevention of prandial aspiration. Even for individuals experiencing dysphagia outside of a healthcare setting, impacts on psychosocial

health and well-being may be present for other biomechanical swallowing impairments. For example, oropharyngeal residue may cause discomfort, be ejected during coughing or speech, and interfere with oral hygiene (Tada & Miura, 2012). Spillage of food or liquid from the mouth or nasal passages due to impaired swallow physiology may cause discomfort and embarrassment (Malandraki & Robbins, 2013; Robbins et al., 2006). Compensatory modifications to posture, or specialized equipment may cause self-consciousness and lead to social isolation (Malandraki & Robbins, 2013; Robbins et al., 2006). Dysfunctional eating and drinking can often impact families and relationships, since mealtimes provide not only physiological nourishment, but also help organize daily routine and provide opportunities for connection with loved ones (Moss, 2016).

An individual for whom eating or drinking has become effortful, uncomfortable or painful, or for whom eating and drinking is a source of anxiety due to concerns over safety, may eventually eat less, or avoid eating altogether (Sura et al., 2012). This is problematic not only in terms of nutrition and personal satisfaction, but also in terms of social function. It is not surprising, then, that swallowing dysfunction has been identified as an independent risk factor for depression in long term care facilities (Chow et al., 2004). We eat not only to sustain ourselves, but to enjoy the sensations that accompany eating, to commune with others, and to structure our time (Carey et al., 2015). When eating and drinking is restricted because of safety issues or if it becomes difficult, uncomfortable, or dangerous due to disordered swallowing, an individual is faced with the risk of physiological effects compounded by psychosocial consequences, including depression, isolation, exclusion, anxiety around meals, and diminished quality of relationships – all of which are detrimental to confidence, dignity, self-esteem, and overall health (Chow et al., 2004; Ekberg et al., 2002; Plowman-Prine et al., 2009).

1.2.3 Populations at Risk

Dysphagia is not a disease in and of itself; rather it is a symptom of a medical condition, or a complication following (often lifesaving) medical interventions (Skoretz et al., 2010).

Populations at particularly high risk of dysphagia include stroke patients (Martino et al., 2005; Paciaroni et al., 2004), individuals with neurogenic disorders (Buchholz, 1994; Warnecke et al., 2020), and head and neck cancer patients (Dawson et al., 2019; Manikantan et al., 2009).

Dysphagia is also common among the elderly (Logemann, 1990; Logemann et al., 2013; Sura et al., 2012), due more to comorbidities associated with aging than to aging itself (Logemann, 1990; Sonies, 1992). Another population at especially high risk of dysphagia is patients with critical illness, particularly following artificial airway use (Skoretz et al., 2020; Zuercher et al., 2019).

1.3 Critical Illness and Artificial Airway Use

1.3.1 Mechanical Ventilation

Nearly a quarter million Canadians were admitted to intensive care in 2013-2014 with one third requiring mechanical ventilation (CIHI, Canadian Institute for Health Information, 2016). Mechanical ventilation is indicated when a patient has inadequate oxygenation, inadequate ventilation, and/or compromised airway status (Tung, 1997), and is often necessary for a variety of morbidities and interventions, including critical illness (Patsaki et al., 2013; Skoretz et al., 2020), high spinal cord injury (Como et al., 2005; Kirshblum et al., 1999), surgery and anaesthesia (Branca et al., 2001; Skoretz et al., 2014) progressive and/or end-stage neurogenic disease (Tung, 1997), and severe SARS-CoV-2 infection (Möhlenkamp & Thiele, 2020). Prior to the global SARS-CoV-2 pandemic, it was estimated that in Ontario by 2026, there would be an 80% increase in patients requiring prolonged mechanical ventilation (PMV,

>48h) (Needham et al., 2005). While these estimates may vary as a result of the current pandemic, it is estimated that 10-20% of patients with severe SARS-Co-V-2 infection will require ventilatory support, and between a quarter and a third will be admitted to the intensive care unit (Grasselli et al., 2021). As of February 2021, 4,663 Canadians have required mechanical ventilation secondary to this illness (CIHI, Canadian Institute for Health Information, 2021).

1.3.2 Dysphagia following Artificial Airway Use

Reported incidence of dysphagia following artificial airway use varies widely (Skoretz et al., 2010). Following critical illness and artificial airway use, the incidence of dysphagia has been reported to be as high as 93% (Skoretz et al., 2020). In the United States in 2004 and 2005, dysphagia was a reported complication in 0.35% of all hospitalizations overall (Altman et al., 2010), but in 84% of cases involving mechanical ventilation (Macht et al., 2011). For those with tracheostomy, the frequency of dysphagia is even higher, at 94% (Fernández Carmona et al., 2015). In spite of variation in reporting, it is generally accepted that disordered swallowing occurs among patients following endotracheal intubation (Barker et al., 2009; Brodsky et al., 2018; de Larminat et al., 1995; Macht et al., 2013; Skoretz et al., 2010), tracheostomy (Elpern et al., 1994; Skoretz et al., 2020; deVita & Spierer-Rundback, 1990), and prolonged mechanical ventilation (Schefold et al., 2017; Skoretz et al., 2014; Tolep et al., 1996).

Among other etiologies, dysphagia following endotracheal intubation may be related to changes in swallowing physiology (Brodsky et al., 2018; Skoretz et al., 2014), muscle weakness and atrophy (Brodsky et al., 2018; de Medeiros et al., 2014), and reduced or altered sensation due to injury related to intubation (de Medeiros et al., 2014; Mencke et al., 2003; Sue & Susanto, 2003; Tolep et al., 1996). Dysphagia following tracheostomy may be attributed to restrained

hyolaryngeal excursion due to the tethering of the trachea to infrahyoid musculature and the skin of the neck (Bonanno, 1971; Elpern et al., 1994; Tolep et al., 1996), or to weakness and incoordination related to muscle disuse and atrophy (deVita & Spierer-Rundback, 1990). Overall, the relationship between dysphagia and artificial airway use is complex. Patients in critical care present with complex medical histories and comorbidities which predispose them to iatrogenic swallowing difficulties (Skoretz et al., 2020) requiring interventions, including surgical procedures and artificial airways, that substantially increase that risk (Langmore et al., 2020; Macht et al., 2013; Skoretz et al., 2014; Skoretz et al., 2020; deVita & Spierer-Rundback, 1990). Thus, it is difficult to determine the exact etiology of the dysphagia whether it is acute or critical illness itself, or the medical treatments necessary to sustain life (Tolep et al., 1996; Zuercher et al., 2019). Regardless of the cause, dysphagia following mechanical ventilation is associated with poor patient outcomes, including delayed return to oral feeding and hospital discharge (Barker et al., 2009), the need for feeding tube placement (Macht et al., 2013), and discharge to long term care (Macht et al., 2013), with further implications for nutrition, resources, and patient quality of life (Barker et al., 2009).

1.4 Patient-centered Care

Patient-centered care (PCC) is integral to current conceptions of healthcare delivery (Hudon et al., 2011; Maassen et al., 2017). Ethical considerations including respect of patient autonomy – regardless of outcome (Duggan et al., 2006; Epstein et al., 2010) – and patient dignity (Epstein et al., 2010) are fundamental to this approach. The US National Academy of Medicine defines PCC as a “partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own

care” (Institute of Medicine, 2001, p. 7). PCC is based on understanding that the patient as a unique, individual person (Duggan et al., 2006), with consideration of their perspective and experience of illness within the larger psychosocial context, is essential for optimal health outcomes (Epstein, 2000). Equipped with this understanding, health care professionals can engage in shared decision making with the individual and their family in an effort to improve patient outcomes and satisfaction, and reduce healthcare costs (Maassen et al., 2017).

1.5 Epistemology and Methodology

This study was conducted within a social constructionist epistemology. With this approach, realities are related to specific social, cultural, moral, ideological, and political contexts (Braun & Clarke, 2013), and accounts offered by participants reflect their interpretations of the realities they experienced through whatever contexts were most available and relevant to them. Crucially, a social constructionist position is also predicated on the idea that knowledge is constructed through human interactions (Gergen, 1985). We acknowledge therefore that, as researchers, we have an active role in the production of knowledge. Not only is the subjectivity and influence of the researcher conceded in qualitative research, it is valued (Braun & Clarke, 2013). In their discussion of subjectivity and reflexivity in qualitative research, Braun and Clarke explain that “we, as researchers, bring our own histories, values, assumptions, perspectives, politics and mannerisms into the research – and we cannot leave those at the door” (2013, p.48). For this reason, we locate our position of inquiry such that we recognize that whatever knowledge is generated here is necessarily the product of all persons involved.

Thematic Analysis (TA) as outlined by Braun and Clarke (2006) is “a method for identifying, analyzing, and reporting patterns (themes) within [qualitative] data” (p. 79). It is a flexible technique that can be used to analyze data under multiple theoretical frameworks, and is

well suited as an analytic strategy for patient and caregiver interview data, while being relatively easy to use and learn for those new to qualitative research (Braun & Clarke, 2006).

1.6 Patient Perspectives of Dysphagia: State of the Science

Patient and/or caregiver perspectives of dysphagia have been examined in some contexts, for example among the elderly in nursing homes and clinics (Chow et al., 2004; Eckberg et al., 2012), and in the context of head and neck cancer (Dawson et al., 2019; Ganzer et al., 2015; Nund et al., 2014). Although dysphagia is a primary issue for patients following critical illness, it has been a recent research focus relative to other illnesses (Skoretz et al., 2010). As a result, early research in this area is focused on swallowing biomechanics and health outcomes rather than individual perceptions (Dawson et al., 2019). However, to understand the individual experience so as to inform and maximize clinical efficacy (e.g., Dawson et al., 2019), it is crucial to investigate patient perspectives. No known study has explored patient perspectives of dysphagia following critical illness, prolonged mechanical ventilation, and artificial airway use (Skoretz et al., 2020). Consequently, little is known about this population's experience of their illness and its treatment, what impacts it has on their quality of life, what barriers and facilitators to recovery they encounter, and how they view the process and trajectory of recovery. Without that information, clinicians are limited in understanding how best to enhance outcomes, or what they can do to optimize the patient's experience.

1.7 Rationale and Objectives

The swallow is a highly complex and vulnerable mechanism. Swallowing impairments have deleterious effects on nutrition, pulmonary health, emotional well-being, social function, and quality of life. We have identified patients with critical illness who require artificial airway use as a population at particularly high risk of dysphagia; moreover, we expect, especially in the

context of COVID-19 and potential future pandemics, that this population will grow significantly. We acknowledge that an understanding of patient and caregiver perspectives concerning dysphagia and its treatment is pre-requisite for truly patient-centered care, yet research dedicated to acquiring this understanding is scarce in general, and non-existent for this particular population. This study, therefore, aims to address this shortfall by investigating this population's perspectives and experiences of dysphagia and its treatment in order to inform our clinical practice, our delivery of care, and our research priorities.

Chapter 2: Methods

2.1 Study Process

We conducted a qualitative study using semi-structured interviews; Thematic Analysis (TA; Braun & Clarke, 2006) was used to report themes identified across participants' accounts.

2.2 Participants

Patient participants included English-speaking adults (18 years of age and older) who had required prolonged mechanical ventilation (PMV), were experiencing (or had experienced) dysphagia necessitating any or all of the following: tube feeding, diet modification, and/or *nil per os* (NPO; nothing by mouth) status, and were physically and cognitively capable of participating in a 45-60 minute interview. Prolonged mechanical ventilation is defined as ventilation durations exceeding 48 hours (Ajemian, 2001; Skoretz et al., 2010; 2014). Given the differences in dysphagia etiology, those patients with dysphagia secondary to head and neck cancer (HNC), neurological impairments, or neurodegenerative diseases were not invited to participate. We also excluded patients with altered levels of consciousness.

2.3 Participant Recruitment

We recruited patient participants at three sites within the Vancouver Coastal Health (VCH; Vancouver, BC, Canada) authority: Vancouver General Hospital (VGH; tertiary acute care hospital), G.F. Strong Rehabilitation Centre (GFS), and George Pearson Centre long-term residential care facility (GPC). Due to COVID-19-related restrictions on non-essential in-person visitation at these sites, patient participant recruitment was conducted by seven on-site speech-language pathologists (S-LPs). This included the VCH S-LP Professional Practice Lead, who conducted and oversaw recruitment from all three sites, and six clinicians practicing at their respective sites. The S-LP practice lead did not carry a clinical caseload and was not engaged in

clinical service delivery at any site. The practicing S-LPs recruited patient participants from clinical units different from those they covered, and did not provide clinical service to those patients who met study inclusion criteria. On a rotating schedule, these points of contact screened admissions at their respective sites and approached potential participants who met eligibility criteria with information about study participation (Recruitment Information Sheet, Appendix A).

2.4 Consent and Enrollment

Once eligibility and interest in participating was confirmed, the on-site point of contact provided patient participants with a copy of the consent form (Consent Form, Appendix B) and allotted 24 hours for the patient to read (but not sign) the form. Following that, the point of contact returned to review the consent form details with the patient, including the purpose of the study, what participation would entail, and possible risks, benefits, and discomforts that could result from participating. The S-LP practice lead collected signed consent forms from all sites once a month for transport by GF to the Swallowing Innovations Lab (Si-Lab) at the University of British Columbia (UBC), where they were accessible only to essential research staff. Once they were consented and enrolled, we assigned patient participants a unique de-identifying study number. Participation was entirely voluntary, and participants could withdraw from the study at any point without consequence.

2.5 Data Collection

2.5.1 Demographics

Demographic data collected from patient participants included age, sex, and disposition/interview setting.

2.5.2 Semi-structured Interview

We conducted a semi-structured interview for all patients, developed based on previous work (Dawson et al., 2019; King et al., 2019; Letawsky et al., 2019) and patient-partner contributions (see Dawson et al., 2019). Comprising 18 open- and closed-ended questions, the patient interview explored: 1) the patient's understanding of dysphagia; 2) physical, emotional and psychosocial effects of dysphagia; 3) patient opinions regarding assessment and treatment approaches, as well as their level of involvement in treatment planning; and 4) perceived impact of current pandemic conditions on dysphagia and its treatment. A provision was made for brief follow-up interviews in case some clarification was required by the interviewer, or at the request by the participant for the purpose of adding new information.

Due to COVID-19-related restrictions on in-person research and data collection, we conducted interviews via video conference on Zoom or by telephone, depending on participants' preference and/or access to communication devices. Interviews were audio recorded using an Olympus DS-9000 encrypted voice recorder with password-protected AES 256-bit encryption.

2.6 Data Analysis

2.6.1 Transcription

Interviews were transcribed verbatim by GF. A second reviewer verified transcription accuracy on 20% of interview data.

2.6.2 Theme Identification and Analysis

Following guidelines outlined by Braun and Clarke for TA (2006), the first phase of analysis consisted of immersion in the data via multiple readings and listenings to the interview data in order to gain an appreciation for the scope of the data set. Using NVivo (released in March 2020) software, each line of the transcripts was then coded, both for semantic ("surface")

content, and for latent, inductive themes, which were subsequently checked, both against each other and against the data set for coherence, consistency, and distinctiveness. The study supervisor (SAS) reviewed the themes generated inductively in this first phase to ensure that they accurately represented the data set. (See Appendix C for table of representative data, codes, and themes).

2.6.3 Peer Debriefing

Peer debriefing was conducted with the author's supervisor (SAS) in order to enhance rigour of the study findings. This process consisted of review and assessment of transcripts, emergent codes and themes, and final findings.

2.6.4 Reflexivity

Key throughout the analytic process was the practice of reflexivity; that is, to reflect continually on our own understanding and positions with respect to participants' descriptions of their experience. To that end, and following the recommendation of Braun and Clarke (2013), the researcher kept a reflexive journal which recorded thoughts, feelings, and reflections about their role in analyzing and reporting the accounts and experiences of others.

Chapter 3: Results

3.1 Participants and Interviews

Four patient participants, all male, consented to be interviewed. We assigned each a pseudonym to ensure anonymity in reporting data. Interviews lasted on average approximately 43 minutes and ranged from just over 18 minutes to almost 100 minutes. Recency of the dysphagia experience varied as well, occurring from within a few weeks of the interview to 2 or more years in the past. All but one participant had resolution of their dysphagia at the time of the interview. Per participants' preference, we conducted all interviews over the telephone.

Participant demographics and interview setting are given in Table 3.1.

Participant Pseudonym	Sex	Age	Interview Setting/ Disposition
Peter	M	59	Rehabilitation Centre
Amar	M	59	Home
Robert	M	69	Long-term Residential Care Facility
Jay	M	47	Long-term Residential Care Facility

Table 3.1 Participant Demographics

Though provided for and consented to by participants, neither the interviewer nor any participant required follow-up interviews.

3.2 Theme Identification

We identified two overarching themes, eight subordinate themes and two subthemes (Figure 3.1). Themes, sample codes from which they were derived, and portions of the data generating these codes are provided in Appendix C.

The first overarching theme, *Psychology is a Big Part of It*, comprises five themes, aligning with a five-stage process through illness towards recovery. Participants' perspectives of the roles of patient, care team, and family are represented in the second overarching theme, *Recovery is a Team Effort*, comprising three subordinate themes. Here, participants reflected on what they needed to accomplish their goals: what helped them, and what held them back. Transcribed interview data, illustrating themes and codes, is provided throughout the analysis. Where not explicit in the surrounding text, speaker identity is given in parentheses () following each quoted item. Line numbers from interview transcriptions are similarly provided in parentheses () following each item. For ease of reading, disfluencies, fillers (e.g., “um,” “uh,” “you know,” etc.) and unnecessary repetitions have been edited out without indication. In some cases, for the sake of brevity and coherence, portions of dialogue have been omitted. Where this has taken place, it is indicated by ellipses in braces [...].

3.3 Psychology is a Big Part of It

The first overarching theme describes participants' experiences of their illness and recovery – and their dysphagia in particular – in terms of the psychology underlying their unique perspectives. Five themes compose this overarching theme; they are *Mealtime: Enjoyment*, *Connection and Structure*; *Loss*; *Under Pressure*; *Acceptance*; and *Empowerment*.

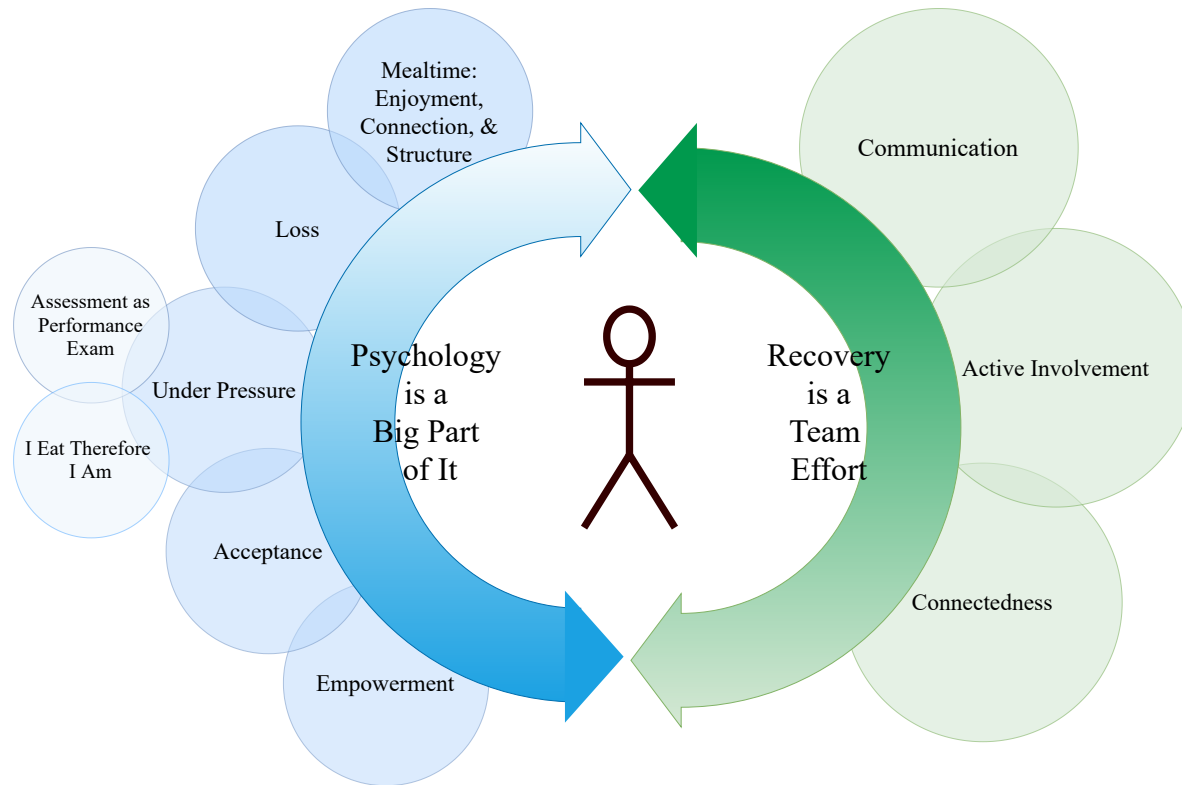


Figure 3.1 Schematic Representation of Themes. The patient is represented in the center. Themes identified in this report are arranged around the patient to represent the multi-directionality and overlap between them.

3.3.1 Mealtime: Enjoyment, Connection and Structure

The mealtime theme reflects participants' attitudes and values around normal eating and drinking, in particular its importance to the structure of their lives and connection to loved ones. Participants reflected on the importance to their lives of eating and drinking. Like most of us, they loved to eat for its own sake. "I love eating," Robert commented, "I love food, and if I have a chance to eat something special, I'm all for it" (57-58). As far as Jay was concerned, this was a universal truth. "Yeah I think everybody... it's just a commonality," he remarked (131). Peter agreed that "as far as food goes, yeah, it's a beautiful thing, isn't it?" (853).

In addition to being enjoyable sensory experiences, mealtimes afforded connection with loved ones, opportunities for caring for others, and daily structure. For some participants, making a point of having family together for meals was a matter of tradition:

From day one we always eat especially supper together if everybody's home. [...] I was brought up like that because my dad [...] always insist to sit together and eat and stuff like that. So it's the same thing I do with my own kids and same way [...] (Amar; 77-81)

Mealtimes with loved ones were "very important; we can eat together, discuss things, and it's satisfying; you got a loved one beside you" (Robert; 238-239). Mealtimes also offered family members an opportunity to care for their loved ones in hospital. Peter's wife, for example, "tends actually to bring food every day [...] she comes every day [...] she wants to be here every day, so we tend to have dinner together for sure" (358, 367-368). Eating with family was important to participants, and to their families. Even Jay and his family, who, while he was in hospital

actually didn't share meals, still regularly had at least coffee together. Consistently economical with his words, he remarked: "It just... it's a good thing to do" (93).

Mealtimes also provided ritual and daily structure. "There's something to be said about that routine" (Peter; 757). Hospital staff recognized the importance of this, as they tried to provide as close to a normal mealtime experience as possible to patients under COVID-19 restrictions. "I mean, the whole ritual of food and the meal, yeah it does mean a lot. I mean, even here they know the importance of it because you have the option of getting served in your room or to go to the cafeteria [...] Because they know it's a social event, right?" (Peter; 754-755). One of many drawbacks associated with a feeding tube, from Peter's perspective, was that "there's no meal time or ritual around that, something you've had all your life" (313-314).

3.3.2 Loss

Participants expressed the emotional impact of the loss of their ability to eat and drink normally, among other things. The suddenness with which their circumstances changed was not something they were prepared for. As Peter commented, "You don't think your life can change in [...] literally a heartbeat – or no heartbeat" (742-743).

For all participants, the inability to eat or drink normally as a result of their illness represented a loss. Jay reported missing eating and drinking when he was unable to: "I missed drinking coffee. I missed water and food, yeah. Just good tasty food" (128-129). Robert felt that loss as well. "When I started eating, it did feel good to eat. I can't deny it felt good to be eating again," he said (58-59). The loss had an impact on participants' mental well-being:

Int: [...] when you were not able to eat or drink normally did it affect you in other ways? Like –

Jay: Well it made me sad.

Int: It made you sad.

Jay: Yeah I just wanted to eat and drink water real bad. (121-125)

While sharing meals with family was important to participants, it might occasionally have been taken for granted. “You know, they definitely meant something. Now, that wasn’t an observation I made at the time. I didn’t realize it at the time but looking back, you know, I miss that” (Peter; 341-342). In addition, when the freedom to share mealtime with family was lost, either because of illness, or restrictions on gathering associated with a pandemic, the loss was felt keenly. “When I was in hospital [...] you didn’t have that luxury” (Amar; 81-82). Speaking on the subject of pandemic-related restrictions on family gatherings, Peter also pointed out that “family get-togethers and things are completely messed up because of COVID as well [...] They’re not getting together really as much and the kids hardly come in with the grandkids and it’s difficult” (407-408, 410-411). Amar, now at home with family, still felt the impact of restrictions on his ability to connect with his family:

So now I’m back home and we try ((chuckles)) to do the same thing again. But because of this COVID thing my kids they stay little bit far from me and they always wear face mask and stuff like that. And because my immune system is not quite as great as it should be the doctor advised me to stay away from people and stay away as much as possible so I can get better. (82-87)

Though participants did not feel that their relationships had been negatively impacted by their swallowing difficulty per se, they did generally observe that being unable to spend mealtimes with their family, either because of restrictions or because of their health status, was difficult.

For each participant, the loss of their ability to safely swallow, and thus receive oral nutrition, meant having a feeding tube for some period. Some reported feeling more or less neutral about it, mainly because it was one of many concurrent issues. “Well, really I had so many other problems going on, I really didn’t pay too much attention to the tube feed at all,” recalled Robert (35-36). For some, however, recollections were distinctly more negative. “Terrible,” said Jay. “It didn’t go over well with me” (52). Peter also felt strongly: “Oh my God it’s like having a clothesline up your nose, right?” he said (882). He described it as “devastating when you can’t [eat] or when you slip back into having a feeding tube. It’s devastating” (674-675). From Peter’s perspective, “the worst thing you hear is ‘Oh, you know, you gotta go back on the feeding tube’” (307). When the results of an instrumental swallowing assessment indicated that he would not yet be able to return to an oral diet, Jay felt “disheartened; it really brought me down [...] I was looking forward to eating” (69).

Not only did participants feel disappointment at not being able to eat preferred foods, the experience of tube feeding had an effect on their motivation. Peter reported that it did not “really spark your appetite to uh wanna sustain yourself” (179). Further, the ritual around mealtimes was lost. “[...] the only ritual around your feeding tube is somebody opening a tetra pack and throwing it into your feeding bag” (Peter; 311-313).

For some participants, the feeding tube was also associated with other supports, the necessity of which represented a loss of independence and dignity as well. “Demeaning, right?”

said Peter (301). “You know, it’s very disgusting but it was just...you can’t get up. You’re too weak and you’re on a feeding tube and...” (303-304). For Peter, being unable to eat, to ambulate, or to manage other routine body functions reflected on his independence, and his manhood.

“I mean, here I am, I’m a fifty-nine-year-old man with a feeding tube in their stomach saying ‘Well how do I go to the washroom?’ [...] you learn a lot about yourself, the people around you, things you’ve taken for granted for years like food, utensils, sleeping, bathing, or bathroom routine. It becomes all different [...] you don’t know how happy I was the day I could get up out of bed and go to the washroom. (Peter; 300-301, 295-298).

The loss of independence and autonomy represented the loss of a sense of dignity that some participants viewed as essential to humanity:

To eat yourself, [...] to have control of what you really wanna eat on a plate, to make those decisions again. You don’t know how much you miss them until you can’t do them. It’s a part of dignity, it’s a part of being a human, your choice. (Peter; 659-662)

3.3.3 Under Pressure

The theme *Under Pressure* captures pressures felt by participants as they tried to come to terms with their illness, and as they attempted to take control of outcomes. Subordinate to this theme are two subthemes: *Assessment as Performance Exam*, and *I Eat Therefore I Am*. The first explores participants’ perceptions of instrumental swallowing assessments, and the pressure they felt to perform well. The second reveals a complex dynamic between eating normally and returning to health.

3.3.3.1 Assessment as Performance Exam

Participants viewed instrumental assessments such as the videofluoroscopic swallowing study (VFSS) or fiberoptic endoscopic evaluation of swallowing (FEES) as a test of volitional performance (to be either passed or failed), for which one could and must prepare. This perception was reflected in the language participants used when talking about the instrumental assessments. Robert, for example, described being “put to the test” in “the X-Ray department” (76). Amar related how his clinicians “did the test there, swallowing test on me which I passed [...]” (38-39). Not only did he “pass” the “test”, but according to Amar, “[the clinician] was quite happy with the performance” (145-146). Jay, on the other hand, recalled: “The first time I failed a buncha times and I finally passed it the second time. I did fairly well... or I failed again and I passed again after a couple tries” (63-64). Referring to the process not only as an exam but as a “fight”, Peter explained what was at stake, and the pressure that generated for him:

Peter: Yeah it was a bit of a fight for sure, and fighting for your place, knowing that if you don’t learn to swallow again and chew proper that you’re gonna slip back and it’s gonna happen pretty quick cause they’re not gonna stand by and watch you lose that much weight.

Int: Did you feel like there was pressure on you?

Peter: For sure. (278-284)

When the results of his assessment indicated that his swallowing was not yet safe enough for a full return to regular consistencies, Robert was “upset. I really was upset. I really thought I did a bang-up job, but they said no” (111-112). He went on, “I was really mad but by the time I

got my second test I was calm, collected, and I really wanted to pass it. So I concentrated quite a bit on my swallowing and I made it” (113-114).

Some participants believed that prior experience with the procedure might also help one’s performance:

“So I knew what a lot more to expect come your second, third time when you’ve had the tube out and back in; you know what markers and what they wanna see and and how to approach the whole testing phase, cause I mean the first time it’s ((pause)) very foreign.” (Peter; 271-273)

They also felt that, like exams, successful assessments were a matter of preparation. After “failing” a couple of times, Jay “practiced and re-took the exam” (71). Robert likewise credited his eventual success to having practiced for a month. Peter felt that clinicians could have supported his preparation by telling him ““Ok, today’s the twelfth. On the twenty-fifth we’re doing testing so you have that many days to prepare”” (535-536), going on to say that ““if I’ve got two weeks I can cram on the last week, right?”” (545-546).

Knowing what clinicians wanted to see on the assessment was considered important for a positive outcome. “You know, I’ve approached that test a couple ways and I think on any given day I could have done differently,” Peter explained (452-453). Asked to expand on that, he told the following story:

Peter: So I went for a barium test and of course my swallowing was fine but they asked me to suck through a straw and of course it landed the wrong way which can happen with a straw.

Int: Yup.

Peter: I just happened to land the wrong way and I felt that if I were to clear my throat at that point they would know that I had failed to swallow properly and penalize me for it.

Int: Hm.

Peter: But the technician said ‘Listen that landed the wrong way. How come you didn’t clear it?’

Int: Right.

Peter: ‘I would have expected you to clear that’ and I said ‘Well I thought if I would have admitted to it you would have thought I wouldn’t know how to swallow.’ She said ‘No no, it’s fine but I have to mark you down that you didn’t know enough to clear your throat.’ That’s why I have no straw on my drinking instructions. My own fault, but that’s just an example of, like, within the test you’re trying to please so you can progress. (460-474)

3.3.3.2 I Eat Therefore I Am

Eating and drinking safely was not something participants had given much thought to before their illness.

Yeah, no, it wasn't something I ever considered [...] maybe not chewing my food well enough, I thought that was about as major as it got. Eat too fast, that kind of thing. Eat too much [...] but not as far as impeded swallowing [...] I guess anybody who's had any kind of facial injury or maybe even perhaps ulcers or something might have a little more insight but [...] as a fifty-something male who had a job and a family of 18 when we all got together...no, just eat your food and be thankful you have it, but no problems around getting it down the gullet, that's for sure. (Peter; 831-843)

As they did with assessment, some participants felt pressure to eat in order to maintain adequate nutrition, lest they be required to stay on a feeding tube. The participants felt that pressure came not only from within, but from care team members as well. Peter describes the feeling he had as “more of a ‘You better do this or you know what happens; you’re back to it, right? So get it together and stay off the tube,’ right?” (275-276). He reported that his physicians in particular seemed determined that he should eat as close to a regular diet as possible, as soon as possible.

“I must say though through the process the doctors were always like, well the doctors really push for you to get on solid food [...] They were the one pushing, saying ‘Well, you know, I don't wanna mess around with puree, like, he looks like he can swallow, we gotta get him stronger.’” (Peter; 238-239)

There seemed to be an equivalence drawn between overall wellness and strength and eating what would be considered a “normal” diet. Peter recalls his physicians saying ““Get him up out of bed;

we can't have him lay there; like, if he can't get up, put him in a chair, get him to eat something. You know what I mean? I can't have him lie there" (512-514). Importantly, Peter goes on, "And he was right" (514-515). At the same time, however, Peter tells us, having not had any oral nutrition in some time, "Oh my God, if you go those many months with a feeding tube and to have to chew again... I mean pieces of meat would stump me. I would chew for five minutes, like, my jaw would get tired, right?" (188-190). So despite feeling too weak to chew, Peter also felt that

Maybe that's the key to get stronger, which is correct I think. The quicker you can get somebody managing their food, swallowing for themselves, making decisions around food, the stronger they'll get. I don't know if that's a I eat therefore I am kind of thing, I don't know what it is, but I noticed with my own care [...] I seemed to get stronger when my diet went from a feeding tube. (241-246)

From Peter's point of view, having the autonomy to eat normally would lead to his overall improved health status. In fact, he asserted that "the changing of my diet and the ability to eat my own food, not to sound too dramatic, but it might have saved my life, cause up until that point your dignity is just so scattered [...]" (657-659). However, when one is that unwell, it may not always be their desire to eat a great deal – if at all. Robert recalled that he "didn't have any cravings to eat anything at the time [...] I really don't recall cause I was really out of it quite a bit at the time" (36-38). Even if the desire were there, it was not always that simple. In spite of wanting to eat, Jay said, "[...] really, I was exhausted for it. So [...] a lot of it was try and then just rest. I was just tired, so it was just a lot of coming to" (193-194). In other words, the process

of returning to regular eating was not something that participants felt they could rush, even if they wanted to. “Yeah, your mind’s ready to go before your body’s ready,” admitted Peter, “[...] you may wanna do it with all your being but if you’re not ready and you’re not prepared to do those exercises to get stronger in the chewing and the swallowing, you won’t be successful” (1180, 193-195).

3.3.4 Acceptance

The theme of acceptance represents the mental, emotional, and spiritual endurance that participants demonstrated as they progressed through the recovery process. It represents a yielding of sorts – not a capitulation, but a willingness to acknowledge and accept the situation as it is, within a larger picture. It is a recognition by participants of the limits of their own power and control, and some of the realities constraining the health care system. It is an understanding that the process of recovery takes its own time, and that the best way through it is with a positive outlook.

Peter: [...] it’s just not that easy to come back. It’s just not something that’s so... it’s just not natural the... boom, you wake up one morning, they take the tube out, you get a plate of food, and you’re back at it. It just doesn’t work that way.

Int: No.

Peter: There’s a lot of steps in between lot of it and they must be different for everyone.

(287-292)

Participants recognized, at least in hindsight if not at the time, that recovery was going to be a lengthy process and that regaining the ability to eat and drink normally would be part of it.

I just knew it was gonna take time. I knew everything about the recovery in my accident was... everything was gonna take like years to settle. So I knew it was just gonna take time and it was [...] just comin back to life [...] so it was just part of the ordeal for me.
(Jay; 168-171)

Jay recognized that, as discouraging as it had been for him not to be able to eat or drink, returning to that would come with time as his general health improved.

Int: And the swallowing eventually came along too.

Jay: Yeah, it was just a process a little bit more with that. (162-163)

Participants also recognized that the road to recovery would be neither straight nor smooth. Amar recalled, “I went through lots so... I mean, when you’ve been in a coma for few months you expect some up and downs” (245-246). Success and failure accompany each other during the course of recovery, and sometimes progress was hard to recognize. Peter explained: “Well, the only thing I could add is that coming through the experience, that it is quite normal [...] to succeed and then to have a failure, and that failure may even lead you back to where you started” (1083-1085). As a result, patients carefully guarded whatever progress they did make. “[...] It’s a journey from... you rebuild from nothing so you get to know your strengths and then you become very protective of how much you’ve come” (Peter; 304-306).

Importantly, this journey is different for every patient, and a patient’s outlook has a significant role in the course of recovery. Looking back on his own road, Peter reflected on how

far he had come. “Yes,” he said, “psychology’s a big part though” (1027). An important facet of that psychology was a certain trust, or faith, that recovery would be achieved eventually. Many participant comments reflected this belief. Jay, for example, recalls that “It sucked but you know, I always kinda just thought things will happen. I still do” (192-193).

Participants’ comments revealed an eventual acceptance of the timeline of recovery. As much as they wanted to return to health and strength, and to eating and drinking normally again, they understood that they would need to be patient. “[...] Again, it’s patience with the whole ordeal” (Jay; 189-190). In fact, participants admitted that to push too hard, or to rush some part of the process, might actually set them back. As Amar explained, “I mean, this is better, to take every each and every step and then rushing into, then go wrong way” (176-178). Here he demonstrated a willingness to let go, to be patient, and to trust the timeline of his recovery. Jay agreed that slow and steady would win the race. “Bit by bit made sense,” he said (198). It was also important to look back from time to time and consider how far they had come.

I’m just thinking that I really had to fight [...] to get to where I am now. When I first got into the wheelchair, I could barely move my arms and now I’m able to get some of my ability back to move my arms. I don’t have full range of lifting my arms up or out to the side but at least it’s better than what it was in the beginning. (Robert; 244-248)

Some comments demonstrated participants’ willingness to trust the process, and those delivering care. Amar trusted that the feeding tube, though unpleasant, was there for his benefit. “But because it was my own good and I took everything positively,” he said (71-72). Robert also

expressed that while he wanted to be involved in decision making, he trusted that his care providers had the experience and knowledge to make decisions in his best interest.

Well, I'd like to know what is going on, I would like to voice my opinion. I would trust the doctor; whatever they recommended and or the therapists, you know? Normally I would trust them to make a good decision on whatever my case is, so I do trust them [...]
I would think they'd be able to have the experience or the knowledge to make these decisions for me so it's fine with me, whatever they decide. (Robert; 165-168, 209-210)

One of Robert's comments, however, did suggest a slightly unsettling basis for that trust. "I trust them. If I don't trust them then I've got nothing, I've got no help at all. So I have to trust them" (203-204).

Participants acknowledged that the health care system at large was constrained by realities they might not understand, and that their care providers were doing all they could, even if not every desire was met. "I think they did whatever they could do in in their power," Amar reported (130). Though Peter felt that his therapists could have spent more regular one-to-one time with him, he also acknowledged that there were limits to what was available.

Int: So you weren't getting enough follow-up or enough treatment?

Peter: I think I was getting what they're designed to do and what they're allowed to do.

(583-584)

This comment, as well as Amar's, recognized that care providers have only so much power, latitude, and resources. Asked if, overall, he would have had his care team do anything differently, Peter's response was "Oh, jeez no. My first reaction is: who am I to say? They're so kind" (681). Peter also recognized that COVID-19 had its impact on the care that clinicians were able to provide, and that "things might be different in a COVID-free world" (1193).

Peter: So it's hard to speak to that. Anything done differently... I would love to have seen em more.

Int: Mhm.

Peter: But that coulda been COVID-driven [...] I know, a lot of restrictions around who could come see what at the time, you know? (689-694)

Peter also acknowledged that in addition to systemic realities and COVID-19 restrictions, his care team may have also been constrained by his own readiness:

I mean, maybe at the time I wasn't well enough to take advantage of [rehabilitation services], who knows? The doctor never let us know, the nurses never let us know. Maybe only speech and PT got involved at the times that were appropriate physically for me. Maybe I was too weak [...] (Peter; 1174-1177)

Recognition of the limitations placed on the care team also allowed participants to view them with a sense of appreciation and gratitude.

Well, treatment was excellent; I don't have no complaint whatsoever. They did everything in their power and the staff was very friendly. I don't have any complaint whatsoever. Doctor was so nice, the nurses was great, especially in ICU, and I [...] have no words to thank them and they were so great to me. (Amar; 95-98)

As general recovery progressed, feeding and swallowing became ever more important to participants. However, in the early stages of recovery, swallowing was not their only concern. As shown earlier, Robert scarcely paid attention to his feeding tube, since, like all participants, he “had so many other problems going on” (35). Peter commented that returning to normal feeding was only one aspect of recovery, which depended on “where you're at physically and mentally, if you're exhausted. And other things happen as well. It's not the only thing you're you're doing right?” (568-569). He went on to say later that, while important, swallowing recovery was at times necessarily subordinated to other things. “So there's other things you've gotta... [...] like your your exercises can go in the backseat or whatever right? Although it's important to you” (Peter; 577-581). Others shared this perspective. Jay recalled that “the swallowing eventually came along too [...] it was just part of the ordeal for me” (162, 170-171), and Amar related how he felt early in his illness, and how he kept the feeding tube in perspective:

Int: Did that change anything else that you did on your day to day? Did it affect your sleep or your mood or – [...]

Amar: No, not really because I knew that the tube was for reason and I totally understand that because ((laughs)) it wasn't only one feeding tube. I had another tubes in my both nose ((laughs)) in my neck, in my throat ((laughing)) some in my arms

((laughing)). I had so many tubes it was just a different experience, right?

Because I'd never been through all that kind of stuff. (63-71)

Having a positive outlook was important. "All I know, I think the main thing is, you have to be positive" (Amar; 244). Robert didn't let seeing others eating get him down. "No, no, I would see other people eating and it didn't affect me at all," he said, "I figured one of these days I'll get back to eating myself, so it really didn't matter" (40, 42-43). Amar told the same story:

When I wasn't eating, [...] I saw people with a cup of coffee in their hand and they're walking around, and I'd like to have a cup of coffee but I know I can't. So I said 'Well, no problem my time will come; no big deal, you know, it's alright.' [...] so just to one day at a time and I did it and it's all great. (255-259)

According to Amar, taking a positive stance made things easier to bear. Besides, from his point of view, having a negative outlook would do little good anyway:

[...] thing is, if you keep yourself positive and take everything positively and I think everything's easier for you. This is the main thing: I keep myself positive, I'm always positive person and then that way... like even you have, let's say you you have a stomach ache, and if you gonna keep crying 'Oh my god I'm dying,' ((laughs)) not gonna help you. ((General laughter)) You just take it easy and say 'Hey ok, I got a stomach ache. No problem, maybe I need a glass of water or maybe I need some kind of medication' and just go from there. (Amar; 246-251)

Jay agreed. “There’s only what you can do,” he said (196-197). After all, as Peter remarked, “even setbacks are just successes with cheap dressing on, you know?” (1108).

3.3.5 Empowerment

The theme of empowerment captures the patient having agency. In spite of not having as much control as they might have liked, there were, in fact, things within their power to do.

First among these was to persist. When asked what advice they might give another person in a similar situation, all participants stated first that not giving up was essential.

I would just give em encouragement not to give up, just to [...] keep trying and if I could help em any way with advice, I’d help em. But the main thing is don’t give up, keep on, keep on trying and hopefully you’ll get some of your movement back or you’re able to swallow whole foods. I’d encourage em, just never give up. (Robert; 258-261)

Peter’s response was the same. “Just don’t give up man,” he said emphatically (1106). This might not always have been easy, however. “I don’t know. I think ((pause)) yeah not giving up, it’s so difficult” (Peter; 1160). In the following, he explained why:

I think [...] maybe people give up in that respect when they can’t really... when you don’t win your first 4 or 5 times, you may have a tendency to back off and give up a little bit. And it’s just not that easy to come back. (Peter; 285-288)

To Robert, “the will to try and get better” was essential (250).

Participants thus turned to setting goals as a means of taking some measure of control over the recovery process. Peter counseled that one should “empower yourself. Talk to your doctor, talk to your nurses of where you wanna be as a goal. Always set goals for yourself, whether it’s the smallest of goals” (800-801). Sharing those goals with the care team was important because “if they know your goals they have the expertise how to get you there and how to establish certain things that you can do” (Peter; 1101-1102). Robert agreed that “even the care aides and nurses, they’re very helpful in helping you get to what you want” (251-252).

[...] Establish goals and those goals are the end. Not the setbacks, not the exercises. Those are all just part of the journey to the goal that hopefully you set with professional people and the disciplines that are important to your improvement have had input as well into what you should be doing and your goals and establish those as early as possible and put as much effort as you can into those. Cause those are the things that will lead you out and back to where you need to be to be successful at recovering. (Peter; 1086-1093)

Another way a patient could exercise some agency throughout the process was to practice the exercises given them by their therapists.

[...] My involvement was to prepare myself for testing with with exercises or tasks that they gave me and not cheat on them [...] You can’t not do them. If you don’t do them you’re not gonna be successful, I learned that the first time. (Peter; 528-531)

Jay practiced exercises, though he could not recall what they were exactly. Robert also described how he was taught “different ways to exercise my throat and practice swallowing” (69-70). Exercises were important to do “whether it suits you or not or difficult or...” (Peter; 618-619), both because they facilitated recovery and got the patient involved, even if they seemed “ridiculous” (Peter; 605).

3.4 Recovery is a Team Effort

The second overarching theme is *Recovery is a Team Effort*. It represents the integration of the patient into the care team, alongside their family and care professionals. It comprises three themes: *Communication*, *Active Involvement*, and *Connectedness*.

3.4.1 Communication

Communication describes the degree to which participants felt their care team provided them not only with information, but the opportunity to share in a dialogue around the course of recovery. Robert, for example, reported that his swallowing difficulty was well explained to him. “I would say so, yes,” he said, “I was first tested at [Hospital] and the lady there [...] would come and tell me what I was doing wrong when I was swallowing” (95-97). Although Amar felt as though he could safely tolerate an oral diet, his care team saw it differently but helped him understand why. “They explain me everything,” he said (182).

I was quite confident that I’m gonna be fine [...] I can feel that I can able to eat but I think they was doing their job. They want to make sure there’s nothing will go wrong because it’s very hard to reverse those things. And they explained that to me, they says ‘You know if something goes into your lungs then you can get pneumonia and we don’t want to go that route.’ (Amar; 169-175)

Peter also felt as though the rationale behind the course of assessment and treatment was, for the most part, well communicated to him.

Int: If you didn't see the purpose of what was being done, did you have an opportunity to to ask that?

Peter: Oh I think so [...] the speech pathologists and the people that were in charge of the swallowing very open, very educational [...] anything that you didn't understand they would certainly explain, cause those tests – well, the one test with the camera through the nose and down the mouth, it's not that easy to administer never mind be a participant in. (220-228)

Understanding why certain interventions were taking place, and what they represented in terms of the course of his recovery also helped Peter to accept the situation and to be patient with the process.

When I got to [Hospital] they said 'Ok well we're gonna do the tests, see if you can have any food at all, hard food. And so we went with puree and they cut my feeding tube to forty percent, monitored my weight and said, 'Once you can replace sixty percent of your diet with pureed food then we'll take you off the feeding tube.' And I just found that approach worked so much better with me. (Peter; 210-215)

By contrast, Peter's recollection of a different, previous site, was that the goal of adequate oral nutrition was framed much differently:

'If you can't take in forty percent of your calories then this tube's going back, in do you understand?' That's the approach that I felt was taken and it translated into my interpretation of my food. I didn't enjoy it; it was a fight and I wasn't successful. (Peter, 207-210)

Being informed in terms of intervention timelines and rationale was important for someone who was used to feeling in control:

Peter: I wasn't given a timeline like that, although that could have been COVID-related, who knows?

Int: Would you have liked that kind of information? [...]

Peter: For me yeah, cause I'm kind of a write-it-down-in-a-book control guy, right?
(538-543)

Robert also felt that clinicians should keep patients well briefed on the situation. Asked what he felt clinicians' priority should be, he replied, among other things, "Try and advise people of what is happening or what's going to happen" (267). Like Peter, Robert wanted to understand the rationale that drove his care team's decisions. "If I don't agree with em, I will talk to them until I totally understand what they're thinking and why they're thinking what they're thinking" (201-

202). Once he was able to have that conversation, and to have the reasoning for his course of treatment explained to him, he was able to accept it and participate in it more willingly.

Good communication with the care team also extended beyond the period of hospitalization as well. Amar was pleased to report that “communication lines [were] still open,” (201-202) even after he had been discharged home:

Any information, like ((laughs)) even right now, this morning I get a call from [Hospital site] and they’re still monitoring me, so I do have the contact number and I can always, I could reach them. She even asked me for my diet, what I’m eating, how I’m doing and that they still doing the follow-ups and I think communication lines are still open and I feel that if I need anything I can always, I can reach them no problem. (Amar; 198-203)

From the patient’s point of view, communication between team members was also important; however, it was not always evident to some participants. “I don’t know how well the disciplines talk to one another in acute,” Peter wondered, “I’m not sure whether it’s a jointed effort for rehabilitation or not. I don’t know” (1170-1171). This observation reflects his perception, at least, of the care team not being totally coordinated in their approach.

I don’t know how much they actually spoke to each other. I was never privy to that. There was never any team meeting either at [Hospital] or at [Hospital] so I don’t really know if speech, PT, OT nursing really ever... Maybe there was a lot more talking going on and consultation between them than I was ever aware. (Peter; 683-687)

In addition to this, it was not always perceived that the availability of resources was well communicated either. Peter, for one, felt that there might have been more treatment available than he was made aware of at the time:

Int: Do you think that they could have made that information more available to you?

Peter: Yes, but that being said, did I miss something where it could have been available to me?

Int: Well, that's what I mean; do you think that information could have been more clear?

Peter: Yes [...] I believe there could be an improvement on that, wherever I was. What a speech pathologist did, what the OT can do, what the PT can do. Even though you're prone and sucking liquid, maybe there's something that can be done – you never know, right? (1181-1190)

Peter didn't feel that various disciplines' scope of practice, or what they could offer him in terms of treatment, were well communicated to him, which might also have contributed to his perception of the team's coordination overall. On the other hand, however, Amar told a different story. "Every time they did something they will tell me. Even doctor, nurses, when they have morning meetings they usually come to my room and they discuss everything front of me which was great because I was feeling I'm a part of it" (182-185). For Amar, the perception that communication was open and visible to him helped him to feel involved.

3.4.2 Active Involvement

The theme of active involvement represented participants' view of their own role in the care team, in particular their participation in shared decision making, and their responsibilities. Participants expressed that they wanted not only a voice in the discussion around their treatment, but the deciding vote as well. "I'd like to know what is going on. I would like to voice my opinion," Robert commented, "[...] if they suggest something for me, I will try it, and if it doesn't work or I don't like it, I'll let em know. Maybe we can try something else" (204-206). Overall, participants felt involved in the process. "Oh yeah, I was totally involved and satisfied with what happened through the whole process. I talked to the S-LP, I talked to my nurses and I totally understand what was involved" (Robert; 127-129). Inclusion and involvement meant that they had a responsibility to do their part as well. On the subject of prescribed dysphagia therapy, and swallowing exercises in particular, Peter said "If you don't do them you're not gonna be successful [...] So you are included that way" (534-535).

Another key responsibility for participants was to communicate with their care team. "Yes," advised Peter, "listen to the people very carefully. Don't be afraid to ask for help with your exercises [...] if they know your goals they have the expertise how to get you there" (799-800, 1101).

3.4.3 Connectedness

The final theme of connectedness represents how support from participants' families was central to their recovery. Unfortunately, restrictions on visitation due to the COVID-19 pandemic presented a barrier to that, which had a negative impact on participants' mental health.

Beginning of COVID, my God, just wondering what's gonna happen with this COVID. But when it finally settled down it got pretty lonely here and especially in the fall and winter when it was raining and cold, [...] mentally it was pretty hard. (Robert; 219-222)

Peter felt the same way. "Well, it's really been a minefield," he reported. "I was taken off a ward that eighty percent of them had COVID [...] and the visitation from my wife was restricted to twice a week for a couple hours. It really affected me mentally" (699-702). These comments illustrated the impact that isolation had on participants at a time when they were critically ill and unable to have the physical presence of their loved ones.

The presence of family, to the extent that it was permitted, was of real value to participants. "Well, I was lucky, you know. I had a good family around me," Jay said, when asked what helped him stay positive (196). To Amar, the support of his family was what kept him going.

Absolutely, it's lovely. It's lovely, my family is very supportive, and because of them, I'm here. Even when I was in ICU they always come and, you know, and gave me positive stuff and they was just wonderful, especially with the family when you all together [...] (Amar; 263-266)

Robert credited his recovery to "the will to try and get through this COVID business, the will from family and friends" (251-252). Peter was glad when restrictions were lifted as well, because his wife could visit him regularly, coming, as described earlier, "every day" (358).

Chapter 4: Discussion

This study was the first to investigate patient perspectives of dysphagia following critical illness and artificial airway use. While dysphagia was but a part of many challenges the participants were facing during their recovery from critical illness, we have identified several themes reflecting participants' common beliefs and values around eating and drinking, especially as they relate to 1) connectedness with family, 2) recovery and overall health, and 3) personal autonomy and dignity. We further identified latent patient perceptions of swallowing and instrumental assessment – in particular that swallowing was a volitional action, and that assessments were a test of ability with a binary outcome. We learned that these perceptions contributed to pressure felt by participants to expedite their return to normal feeding, and created, for some, tension between themselves and their care providers. Consistent with previous research, we observed the importance participants place on positivity, perseverance, and active involvement in treatment planning. Additionally, it was demonstrated that the support of family is critical to the well-being of patients and to the success of their recovery. While a theme in its own right, communication among all members of the care team (including the patient, their family, and health professionals) was also found to be of central importance within these findings. The S-LP has a vital role to play in fostering this multi-directional communication, thus the nature of this role and implications for clinical practice are discussed, along with a need for further examination of all stakeholders' perspectives.

4.1 Perspectives of Eating and Autonomy

Participants aligned the importance of eating and drinking with their sense of well-being, connectedness, and normalcy. Reminiscences of family mealtimes and togetherness reflected the value participants placed on these events and demonstrated the impact of losing their ability to

participate normally. For participants, eating with others was a social event, and an important part of daily routine. Without that ritual and social context, feeding, especially via tube, became nothing more than sustenance.

When their inability to eat and drink normally was coupled with the myriad of other treatments required for their survival, and especially when they required tube feeding, these participants felt the loss of many things: loss of enjoyment, loss of hope of eating normally again, and loss of something even more fundamental: their dignity. All participants required tube feeding at some point, due to either safety or nutrition concerns. For some, the nasogastric (NG) tube represented the loss of comfort and independence. As a result, they were eager to return to an oral diet as soon as possible and were likewise discouraged when this process was prolonged. For some, the experience of the NG tube further represented a loss of dignity and personhood. Having the choice of what to eat, or when to eat – or whether to eat at all – represented an inalienable, fundamental dignity. Losing the ability to eat and drink contributed to a loss of autonomy, and an essential part of that which made one human. As clinicians, given that we understand the importance and value that people place on eating and drinking in social and structural terms, we expect that patients would grieve the loss of their inability to do so normally. Addressing this grief and giving the patient the opportunity to express their experience is part of patient-centered, compassionate intervention. Furthermore, patients value the opportunity to participate in their own nutritional care, and make decisions about food based on several factors, including ideologies, experience, and trust in their care providers (Rattray et al., 2019). The basis of that trust lies in how well information regarding safe swallowing and feeding is communicated to them. Substantial time is spent in training S-LPs to appreciate the personal impacts of communication disorders. Training for clinicians who work with these patients and who

prescribe such interventions (physicians, dieticians, and S-LPs) may be improved by providing support in areas such as grief counseling as well as enhancing student training on the psychosocial impacts of dysphagia.

4.2 Perspectives of Swallowing Assessment

One of the most striking perceptions among participants was that instrumental assessments were exams, creating an adversarial relationship with the swallowing assessment process. Participants referred variously to instrumental assessment as a “test”, an “exam”, and a “performance,” and related how they “passed” or “failed” these assessments. Further, some participants also believed that success after repeated attempts at assessment was attributable not to having progressed in their overall recovery, but to knowing what clinicians were looking for, and performing to meet those expectations.

What a clinician sees on an instrumental assessment plays a large part in determining the appropriate diet and feeding modality. As with tube feeding, eating a modified diet was not an experience participants relished. This, along with the perception of assessment as a test, resulted in participants feeling pressure to perform. It was revealed that not only were participants frustrated when unable to return to a baseline diet, but also somewhat disconnected in terms of perceptions of their swallowing and the reality of it. Robert, for example, was upset because he thought he did “a great job” but his clinicians did not agree. This reflects two important points, one being the aforementioned negative psychological impacts of feeding tubes and modified diets experienced by some. The second is that participants considered swallowing ability to be a matter of volitional control; Robert attributed his eventual success to the fact that he 1) was calm and collected, 2) really wanted to pass, and 3) really concentrated on his swallowing.

While the process of instrumental swallowing assessments and the specifics of swallowing physiology – in particular its reflexive aspects – are unfamiliar to most, swallowing in general is not. Instrumental assessment procedures do not involve unusual tasks; one eats and drinks as they are currently able to, and the physiology of their swallow is observed directly through imaging (i.e. videofluoroscopy or nasendoscopy). However, interview data reflected the perceptions that 1) an individual has volitional control over the complex and coordinated actions that compose the swallow, and 2) assessment is an inquisitorial affair that can only be “passed” with the benefit of experience and preparation. Peter’s anecdote regarding one assessment experience most clearly illustrated this. He reported that he intentionally did not cough to clear something that he sensed had gone “the wrong way” because he calculated that coughing would make him appear impaired, and that he would be “penalized” for it. What is more, he believed that by not coughing, he could hide from the clinician the fact that something had entered his airway. This indicates a lack of understanding of the procedure as well as the reflexive nature of airway protection: it is not possible to for a patient to volitionally conceal airway invasion. However, it also reflects that participants felt pressure surrounding what they felt was a high stakes and demanding assessment process. This supports a need for vigilant communication with the patient, ongoing education and shared investment in the process beginning with informed consent. Specifically, it is important that clinician-to-patient and/or family communication practices regarding swallow physiology and assessment continue throughout care delivery. Engaging with patients to determine their understanding of both swallowing and the assessment process will help the clinician determine how best to frame their explanations as well as redirect any misconceptions.

Patients' perceptions of their illness are particularly sensitive to information given after an assessment (Devcich et al., 2011). Altering the language used when discussing assessment and its results – in particular avoiding the use of terms like “test,” “pass,” and “fail” – would support patient understanding. As with other diagnostic imaging in medicine (e.g. chest X-ray or head CT), instrumental swallowing assessments do not have a “pass” and “fail” outcome; rather they are a means by which to determine impairment severity. Further, explaining the purpose of assessment, and the implications of any results, even multiple times, will help patients better understand the process and alleviate the pressure to perform that some seem to feel. Patients are naturally disappointed upon learning that their swallow is unsafe. Managing expectations and addressing the emotional impact of suboptimal results, even pre-emptively, is a key component of the process for clinicians. Doing this relies on open communication with patients. It will also be important also to provide opportunities for patients to ask questions following the assessment, as well as over time, particularly when they are discouraged by the results.

4.3 Perspectives of Eating, Health, and Recovery

Participants' ability to eat normally was, for them, a reflection of their overall health status. For some, the perception of both participant and reportedly the attending physician was that they would get stronger once they progressed to an oral diet, not the other way round. However, participants struggled to reconcile that with constraints on their ability and desire to do so. This resulted in competing pressures: on one side, the belief that eating normally would facilitate real recovery, along with the threat of requiring a feeding tube because of insufficient oral intake, and the desire to experience the connection, satisfaction, and ritual associated with mealtimes. In opposition were constraints imposed by illness, creating a complex relationship for participants with eating and recovery. They believed that one must eat to get well, but also

recognized that one must get well before they can eat. Therefore, patients may benefit from dialogue with clinicians about navigating these contradictions in the context of patients' desires, beliefs, health status, and goals of care.

4.4 Acceptance, Empowerment, and the Power of Positivity

Better health outcomes are related to the individual having positive rather than negative beliefs and feelings (Street, 2009). All participants reflected on the importance of a positive attitude throughout the course of their recovery. The basis of this lay largely in individual outlooks and beliefs in eventual recovery, but also on acceptance of the realities of the situation: the trajectory of recovery, one's current status therein, and patient and care provider limitations.

Certain psychological factors, such as a patient's attitudes and expectations regarding their recovery, have a significant influence on health outcomes (Mondloch, 2001). Participants ultimately accepted that their recovery would take time, and would involve many phases, challenges, successes, and failures. Amar, for example, expected to have some "highs and lows" after having been critically ill; recovery would not be linear, nor would progress be consistently evident. Interestingly, participants did not prioritize their swallowing difficulties relative to other concerns and progress made; particularly in the early stages of recovery, swallowing was subordinate to survival and participants felt that eating would come along with the rest. In fact, several participants cited patience as an important component of their mindset around recovery. Further, perseverance in the face of setbacks was critical to how these participants navigated their illness; all participants expressed the importance of not giving up.

Trusting that their care providers' decisions were based on experience and made with patients' best interest in mind was key to participants' faith in the process. Further, they acknowledged that health care providers operate under myriad constraints related to time,

energy, and resources. Accepting these realities facilitated patient trust in their care providers, and may have helped reduce felt tension and conflict. Looking back on their experience of critical illness and recovery, participants described it as a series of successes and failures. Throughout, it was important for them to accept the situation as it was, to trust the process, recognize limitations, and keep the big picture in mind. Clinicians providing clear and honest information, highlighting progress, and supporting empowerment and perseverance will help to foster such an outlook while building trust and facilitating shared decision making.

4.5 Patient Involvement in Care

While participants expressed the importance of trusting that care providers were acting in their best interests, they also wanted an active role in making decisions. In particular, they prioritized shared goal setting as an important component of involvement and participation in their own care.. Goals gave participants a way to see the full trajectory of recovery, and a sense of moving forward, especially when setbacks occurred. Setting goals and sharing them with the care team also gave participants a sense of accountability and of involvement. Goals were actionable, which stood in stark contrast to their illness(es), where so much of their own agency, control, and independence had been lost.

Having the opportunity to participate – and taking advantage of it – is important not only psychologically, but tangibly: patient involvement can lead in practical ways to better outcomes through shared decision making based on and suited to each unique patient’s needs and circumstances (Street, 2009). Educating patients on the nature and etiology of their swallowing difficulty, on recovery trajectory, and how they can contribute to their own care will support their participation. Patients must also be given options, while understanding associated risks and benefits relevant to decision making. This education can come directly from the clinician;

however an alternative may be to help patients actively seek and find relevant information themselves. This may afford patients a greater sense of autonomy and self-efficacy, empowering them to determine and express their treatment goals, manage their illness, and comply with treatment protocols (Street, 2009; Williams et al., 1998).

4.6 Family Support

Participants unanimously endorsed the value of family support in their recovery. Anyone who plays a significant role in an individual's life is a family member, and while family composition may be endlessly diverse, a family's members are invested in one another's well-being (Blackstone, 2015). Consequently, when an individual confronts illness, family often becomes quite involved, be it by attending appointments and therapy sessions, visiting in hospital, or acting as decision makers and advocates (Blackstone, 2015). Each of the four participants attributed much of their recovery to their family's involvement, whether it was through their presence (in person or remotely, as circumstances allowed), taking up responsibilities at home, or advocacy with health care providers.

Support from family has numerous impacts on health, recovery, and quality of life. Family members may provide practical assistance, encouragement, and social support, all of which have positive effects on a patient's emotional well-being (Street, 2009). Clinician support of this connection may include communicating with family members, educating them about the patient's illness and recovery, and involving them in the patient's care. Further, they may also connect them with counselling services when family members are struggling to cope or experiencing caregiver burnout.

In the context of the COVID-19 pandemic, connectedness with family became difficult to maintain. All participants reflected on the impact of visitation restrictions on their mental health,

particularly in the early stages of their illness. When participants were unable to spend time with their loved ones (e.g. shared mealtimes), their well-being was negatively affected. Given the increasing prevalence of technology-mediated health care, S-LPs are well positioned to facilitate patient-family interaction, particularly in times of restricted in-person access. This is an important role, since for some participants remote connection was immensely beneficial despite the physical distance.

4.7 Communication: The Key Ingredient

4.7.1 Importance of Patient-Clinician Communication

Care providers' communication skills are a significant factor in determining patients' satisfaction with their healthcare experiences, adherence to treatment plans, and improved health outcomes (Berman & Chutka, 2016; Heisler et al., 2002; Street, 2009). Such communication practices are also essential for providing social support to patients as they navigate their illness and recovery, and coordinating the efforts of various care team members (Kreps, 1994). Patients rate open communication as the single most important component in their relationship with clinicians; further, this communication depends on trust (Riedl & Schlüßler, 2017). As a result, to ensure effective communication, clinicians should establish a relationship in which they are trusted. Failing to achieve this may actually have negative consequences for the patient's health (Moffat et al., 2006). Additionally, in order to understand the patient's situation and to provide effective and appropriate support, family members also require information and education from clinicians (Riedl & Schlüßler, 2017).

4.7.2 Barriers and Bi-Directionality

Our participants prioritized bi-directional flow of communication. Unfortunately, barriers to successful communication invariably exist. These barriers may include novel communication

partners/circumstances, time constraints, and emotionally charged situations. Individual-level challenges (e.g. language and/or communication difficulties, cultural differences, limited health literacy), or those related to context (e.g. environmental factors) can also contribute to unsuccessful communication (Blackstone, 2015). So what does effective communication in this context look like? The Joint Commission (2010) guideline for hospitals in the United States defined communication as follows:

Effective communication is the successful joint establishment of meaning wherein patients and health care providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood. To be truly effective, communication requires a two-way process (expressive and receptive) in which messages are negotiated until the information is correctly understood by both parties. Successful communication takes place only when providers understand and integrate the information gleaned from patients, and when patients comprehend accurate, timely, complete, and unambiguous messages from providers in a way that enables them to participate responsibly in their care. (p.1)

In sum, for patient-clinician communication to be effective, it is critical that: 1) it is bi-directional; and 2) patients understand the information being presented to them, and their role in the recovery process. Ensuring that all parties understand what was communicated, and that the patient and their family believe that their concerns, values, beliefs, and goals have been heard

and integrated into the care plan is necessary for successful collaboration and adherence to treatment.

4.7.3 Communication: Implications for Clinical Practice

Throughout this analysis, it has been apparent that participants' experiences were significantly shaped by communication, either done well, or less well. When communication was effective, participants felt included and cared for. When communication was felt to be lacking, it affected the perception of the care team's overall effectiveness and coordination. When processes or decisions did not make sense, or were thought arbitrary, the unfortunate consequences were tension, resentment, and a (perceived) adversarial relationship between some participants and their care team. S-LPs, as trained specialists in communication, have a unique role to play in advocating for and facilitating communication amongst all team members. This includes educating other professionals, who may not be aware of the misconceptions that patients have with regard to swallowing and assessment; doing so may prevent consequences of those misconceptions.

Participants all felt that communication between care providers and themselves was as good as it could be, given the circumstances. While this is a testament to clinician quality, there are areas which could improve. Time and resource constraints, for example, may prevent thorough and effective consultation with patients and their families. As a result, it may be difficult for S-LPs to determine individualized situations and perspectives, while also effectively communicating the information necessary information for facilitating patient understanding and empowerment. Acute care caseloads in particular are large and growing, while staffing may be chronically insufficient or underfunded. Consequently, for those experiencing dysphagia

following critical illness, a disparity exists between the needs they're reporting and what S-LPs are able to provide. For a solution to this, shifting attention to larger scale questions around resource allocation within care sites and health authorities may be warranted however, this is beyond the scope of this project. It is important that this shortfall be identified, so that it may be addressed in the future.

4.8 Limitations and Lessons Learned

While novel findings were obtained during this study, inherent constraints led to some limitations. Firstly, its sample size is small, and recruitment was from a single geographical location and health region. Although we did recruit participants from multiple institutions, the findings are still limited to the participants and settings studied. While a certain homogeneity among participants is appropriate for Thematic Analysis, the experiences described here reflect a limited perspective, owing to the fact that only four participants were enrolled, and they were all males. Therefore some views are likely not represented in our sample, particularly those of a sample with greater sex and gender diversity. Further, no participants were experiencing dysphagia at the time they were interviewed. Half of the participants experienced dysphagia within weeks to months of the interview, and in contrast, the experience was remote (i.e. 2-4 years in the past) for the remainder. It is possible that recollections were therefore less vivid and/or accurate. While the information collected herein is no less valuable to our understanding, continuation of this research would benefit from the inclusion of perspectives of those currently experiencing dysphagia.

Secondly, the analytic approach chosen for this study is not typically used with such small samples. Thematic Analysis, in its ideal conceptualization, identifies thematic patterning across larger datasets. For our sample, an approach like Interpretive Phenomenological Analysis

(IPA; Smith et al., 2009) or Interpretive Description (ID; Thorne, 2016), may have been more appropriate. However, this project was conceived and largely designed prior to the curtailment of research activities secondary to the COVID-19 pandemic, and with the intention of a larger number of interviewees. Research questions, interview schedules, and analytical frameworks were informed from the outset by Braun and Clarke (2006)'s prescriptions for TA, and, though perhaps not ideal given the eventual circumstances, they were suitable for a novice qualitative researcher whose project's scale and scope were constrained by the time remaining following the resumption of research activities.

4.9 Role of the Researcher

It must also be acknowledged that the writer's own perspectives and biases had a significant impact on the data that was collected, and the way that data was analyzed. The questions asked, the way that interviews were conducted, the types of data points deemed interesting, the way they were interpreted, and the overall message presented in this report all reflect the personal experiences and lenses through which the writer views this topic. Benefit is also gained; however, with this approach. Given the investigators' experience in dysphagia and communication, collectively this offers a rich understanding of the patients' medical condition as well as underlying pathophysiology of dysphagia itself along with an ability to successfully navigate the interview process and analyses.

4.10 Future Directions

"Good research generates more questions than it answers" (Epstein, 2000, p.806). We have taken a modest step towards a better understanding of patient perspectives of dysphagia following critical illness. However, much remains to be done so that clinicians can more fully appreciate patients' experiences and priorities. We have seen here a small sample of what these

patients experienced, and what their attitudes towards that experience may be. In the future, continuing patient enrollment as well as expanding to caregiver and clinician perspectives would lead to a richer and more nuanced view of the spectrum of this population's experiences. It is often the case that caregivers experience negative psychosocial effects of their loved ones' illness, including stress, anxiety, and depression (Hawken et al., 2018; Sullivan & Miller, 2015). Further, examining S-LPs' perceptions of swallowing, assessment and dysphagia recovery, the challenges they face, and how they perceive their role in patient education and interdisciplinary communication, could support clinicians in delivering patient-centered care. Finally, including patients and their caregivers throughout the research process, including conceptualizing, planning, conducting, and dissemination will help determine patient priorities for research and foster improvements in delivery of care and patient outcomes (Boivan et al., 2018; Hewlett et al., 2006; Pill & Jarden, 2016; Skovlund et al., 2020), while mitigating the risk of bias inherent in researchers' own points of view, questions, agendas, and priorities. Collectively, incorporating the perspectives of these stakeholders in future work will help to inform practical recommendations.

Chapter 5: Conclusion

Investigating patient perspectives of dysphagia following critical illness and artificial airway use revealed a “journey,” experienced by each of the four participants. The themes identified in this report represent different aspects of this journey. Participants lost the ability to participate in something they valued highly, but persevered through pressures and frustrations, and, with the support of family and effective multi-directional communication within the care team, empowered themselves to take an active role in their recovery. Although participants’ individual experiences of illness and recovery were unique, there were many similarities in terms of perception, opinion, and attitude that became evident, especially as we explored latent themes. In particular, this study has revealed novel findings in beliefs and attitudes around eating and drinking in the context of health, autonomy, and family. Important patient misperceptions of swallowing and assessment were also identified, supporting a need for improved communication and education around these topics.

The patient perspectives reported herein point with regularity to the critical role of communication between clinicians and patients and their families. Communication was the basis of patient trust in care providers and facilitated understanding and acceptance of recovery trajectories and limitations. Crucially, it was the basis of participants’ active involvement in their own care. Patient-clinician communication supported participants’ sense of agency and autonomy as they created goals for themselves, participated in shared decision making, and became active members of the care team. This study represents an important step towards understanding the perspectives of this population and highlights the essential role of the S-LP in supporting care team communication. Specifically, the S-LP contributes to more effective care by 1) discussing patients’ perspectives, goals, and priorities regarding their swallowing with

them; 2) educating patients, their families, and other team members about the swallow and swallow assessments; 3) supporting open and multi-directional communication between all members of the care team, including the patient and their family; and 4) supporting family involvement in care.

Ultimately, this role is based on a compassionate understanding of patients' experience. The insights gained from these patient perspectives, augmented by further investigations, will contribute to such an understanding, and will inform and enhance patient-centered care delivery, empowering our patients, and improving overall health outcomes.

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Appendices

Appendix A Recruitment Information Sheet



PARTICIPANTS NEEDED FOR SWALLOWING RESEARCH

We are looking for participants to take part in a study on
***patient and care partner perspectives of swallowing difficulty
and its treatment.***

Who can participate?

We are looking to recruit adults (18 years and older) who:

- Required a breathing machine for longer than 48 hours
- Have difficulty swallowing requiring tube feeding or diet modifications
- Are able to communicate fluently in English (written and oral)
- Have not had surgery for head/neck cancer
- Do not have a neurological and/or neurodegenerative disease

AND Adult care partners of the above participants

What's involved?

As a participant in this study, you would be asked to:

- 1) Participate in an interview about your experience with difficulty swallowing and your treatment, including in the context of COVID-19.
- 2) Complete a standard questionnaire about your swallowing difficulty.

Your participation is *entirely voluntary* and would take ***approximately one hour.***

What are the benefits of participating?

By participating in this study, you would help us to better understand, manage, and treat swallowing disorders. We believe that your perspective can benefit other individuals with disordered swallowing as well as their care partners.

If you are interested in participating in this study, you may:

1. Indicate your interest to the on-site Speech-Language Pathologist

OR

2. Contact Geoff Fullerton at

email: [redacted] **or phone:** [redacted]

This study is supervised by Dr. Stacey Skoretz [redacted]
School of Audiology and Speech Sciences, Faculty of Medicine, University of British Columbia

Appendix B Participant Consent Form



Participant Information and Consent Form

**Exploring patient and caregiver perspectives regarding dysphagia
following critical illness and artificial airway use**

Principal Investigator: Stacey Skoretz; PhD, RSLP, SLP(C), CCC-SLP
Assistant Professor
School of Audiology and Speech Sciences
Faculty of Medicine
The University of British Columbia
421-2177 Wesbrook Mall
Vancouver, BC V6T 1Z3
T: [REDACTED]
[REDACTED]

Co-Investigator: Geoff Fullerton; BA (Hons)
MSc Research Student
School of Audiology and Speech Sciences
Faculty of Medicine
The University of British Columbia
321-2177 Wesbrook Mall
Vancouver, BC V6T 1Z3
[REDACTED]

INTRODUCTION AND STUDY PURPOSE

You are invited to participate in a study being conducted through the University of British Columbia and Vancouver Coastal Health that is investigating the opinions and perspectives of patients 18+ years of age who have been unable to eat or drink normally due to swallowing difficulty following prolonged use of an artificial

airway. This research is being conducted by the Swallowing Innovations Lab at the University of British Columbia as part of a student Master's thesis.

YOUR PARTICIPATION IS VOLUNTARY

Your participation in this study is entirely voluntary; if you do not wish to participate, you do not need to provide a reason, nor will your decision have any impact on the medical care or other services to which you are entitled or are presently receiving. If you decide to participate, you may still choose to withdraw from the study for any reason at any time without any negative consequences whatsoever.

Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts. Your involvement in the study is additional to the care you would otherwise receive. The information acquired during the study is meant to provide new information that will help other patients in the future but will not benefit you directly during your hospitalization. The researchers have a duty of care to all participants and will inform you of any information that may affect your willingness to remain in the study.

If you wish to participate in this study, you will be asked to sign this form.

Please take time to read the following information carefully and, if you wish, discuss it with your family, friends, and doctor before you decide.

WHY IS THIS STUDY BEING DONE?

It is important that clinicians understand the experience and perspective of patients with swallowing difficulties and their caregivers in order to provide the best possible care to them. Further, by expressing their views and experiences, patients with swallowing difficulties and their caregivers may influence the direction and priorities of future research as well as hospital policy. We are also investigating the experience of patients with swallowing difficulty in the context of the COVID-19 pandemic, since COVID-19 can lead to critical illness requiring artificial airway support and potential disordered swallowing as a result. Further,

COVID-19 has had a significant impact on the functioning of our health care system and on the way we interact with it. It is hoped that what is learned from this study will benefit patients and caregivers like yourself in the future.

WHO CAN PARTICIPATE IN THIS STUDY?

You may be able to participate in this study if you are 18 years of age or older and were/are unable to eat or drink normally following use of a breathing apparatus. You may also participate if you are 18 years of age or older and are a caregiver of a person who is eligible for this study.

WHO SHOULD NOT PARTICIPATE IN THIS STUDY?

Patients who are unable to communicate during a 30-45 minute interview due to physical or neurological impairments or altered levels of consciousness should not take part in this study. Patients with head/neck cancer should also not participate in this study.

WHAT DOES THE STUDY INVOLVE?

If you decide to participate in this study, a researcher will interview you for 30-45 minutes either on the phone or via Zoom video conference, depending on your preference. You will be asked questions about your experience while not being able to eat or drink normally, your perspective on the care you have received and/or are receiving, and your opinions on what care workers and researchers should focus on with respect to people with swallowing difficulties. You will also be asked about how you perceive the COVID-19 pandemic affecting your experience. As with all questions, those related to COVID-19 may be omitted if you do not wish to answer them.

Interviews will be audio recorded.

You can take a break at any point during the interview. If you'd like to conduct the interview over more than one session, you may request to do so, and the researcher will arrange that with you.

Within four weeks of the interview, you may be asked by the researcher to participate, at your convenience, in a brief follow-up interview. This would be only be done in the event the researcher needed clarification of some information you provided in the main interview, and is not anticipated to require more than 10-15 minutes. You may decline to participate in this follow-up interview if you so desire.

You may also **request** a follow-up interview with the researcher within four weeks of the main interview if you want to revise or clarify any information you provided, or if you think of something you'd like to add. You are not required to do this, but the opportunity will be available to you.

You will also be asked to complete a questionnaire in your own time that will help us further understand the impact that your swallowing difficulty has had or is having on your day to day life.

Some health information, such as your age and gender will be collected in study data forms. Information about your medical history, current hospital admission, swallowing difficulty, and treatment will also be obtained from your patient records and recorded. This information will be collected by the Vancouver Coastal Health Speech-Language Pathology Acute Practice Lead. Study personnel may need to access your health records after the study is complete to confirm and verify any specific health information directly related to your participation in the study. **No health information not directly relevant to your participation in this study will be accessed.**

WHAT ARE THE POSSIBLE RISKS AND INCONVENIENCES OF PARTICIPATING?

There are no physical or economic risks to you in participating in this study. However, you will be asked questions that may be of a sensitive nature to you, and it is possible that you may experience some emotional discomfort while speaking about your experiences. You may decline to answer any question(s)

you do not want to answer, and you may further choose to end the interview at any time.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

There are no anticipated direct benefits to you from taking part in this study. However, we hope that the information gathered from this study may be used to benefit others like yourself who are experiencing swallowing difficulties, and their caregivers.

WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE?

You may withdraw from this study at any time and for any reason, including no reason. If you enter the study and then choose to withdraw at a later time, there will be no penalty or loss of benefits to which you are otherwise entitled.

If you choose to enter the study, and then decide to withdraw at a later time, you have the right to request the withdrawal of data collected about you during the study. This request will be respected to the fullest extent possible. Please note, however, that there may be exceptions wherein data cannot be withdrawn, for example whereby the data has been anonymized and is no longer identifiable, or has been merged with other data. It is important to understand that in such cases, this data cannot be connected in any way to your identity. If you would like to request the withdrawal of your data, please let the study researcher know. If your participation in this study includes enrolling in any optional studies, or long term follow-up, you will be asked whether you wish to withdraw from these as well.

WHAT WILL THE STUDY COST ME?

You will not incur any expenses by participating in this study, nor will you be compensated for your participation.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Your confidentiality will be respected. However, research records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the Behavioural Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law. De-identified data gathered during this study may be used in research publications in medical journals and/or scientific presentations.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you (e.g. your Personal Health Number, SIN, initials, etc.). Only this number will be used on any research-related information collected during the course of this study, so that your identity (i.e. your name or any other information that could identify you) as a participant in this study will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study number that is used on your research-related information will not be removed or released without your consent unless required by law.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request from your study researcher.

Zoom Video Conference

If you elect to have your interview conducted via Zoom video conference, confidentiality of your identity and personal information will be maintained. A UBC-licensed version of Zoom will be used, rather than the publicly available version. You will be sent a link and a password for a locked meeting that only you and the interviewer will have access to. You will be given a unique study identifier to use instead of your real name, and you are encouraged to use it. Instructions

for how to do so will be provided with the meeting link. You may further protect your identity by turning off your video if you wish.

Audio Recording

Whether your interview is conducted by phone or by Zoom video conference, it will be audio recorded on an encrypted and password-protected voice recorder. Your recorded data will be accessible only to study personnel. It will be assigned a unique study number so that no link may be made between it and your identity. Only the Principal Investigator and primary contact will have access to any information connecting your identity to your anonymous study number. Recorded data will be stored securely using encrypted computers requiring multi-level authentication in the Swallowing Innovations Lab at UBC. Per national and institutional requirements, recorded data will be kept at the lab for five (5) years and then destroyed. These materials will not be used for any purpose other than the research project described in this form without your separate consent.

WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions or desire further information about this part of the study before or during participation, you can contact Dr Stacey Skoretz (Principal Investigator) at [REDACTED] or at [REDACTED]

WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT DURING THE STUDY?

By signing this consent form, you are not giving up any of your legal rights.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

CONSENT TO PARTICIPATE

Exploring patient and caregiver perspectives regarding dysphagia following critical illness and artificial airway use

My signature on this consent form affirms that:

- I have read and understood the participant information and consent form.
- I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- I understand that my participation in this study is voluntary and that I am free to refuse participation or to withdraw from this study at any time, with no effect on the quality of care that I receive now or in the future.
- I understand that if I choose to withdraw from this study, I may request that any data collected on me up to the point of withdrawal be removed and destroyed.
- I understand that some data, such as that which has been anonymized or merged with other data, cannot be removed or destroyed. However, this data cannot be connected to my identity in any way.
- I authorize access to my health record as described in this consent form.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I will receive a signed copy of this consent form for my own records.

I consent to participate in this study.

Participant signature

Printed name of participant

Date

Appendix C Themes, Subthemes, and Representative Quotations

Table C.1: Themes, Subthemes, and Representative Quotations for “Psychology is a Big Part of It”

Theme	Sample Codes	Original Data
Mealtimes: Enjoyment, Connection, & Structure	Love of Eating	<p>Um I love eating I love food and uh if I have a chance to eat something special I’m all for it um at the time when I started eating uh it it did feel good to eat. I I can’t deny it it felt good to be eating again. (Robert, 57-59)</p> <p>Yeah I think everybody it’s just a commonality. (Jay, 131)</p> <p>But as far as uh food goes yeah it’s a beautiful thing isn’t it? (Peter, 853)</p>
	Importance of Family Meals	<p>Yeah yeah you know be like you know from day one like you know we always uh eat you know especially supper together try to eat supper together if everybody’s home. And then you know this was I I was brought up like that because my dad you know he [...] he always uh insist to you know sit together and eat and stuff like that. So it’s the same thing I do with my own kids and same way but when I was in hospital you’d be (alright if) you didn’t have that luxury. So now I’m back home and we try ((chuckles)) try to do the same thing again. But uh because of uh this COVID thing my kids they stay little bit far from me and uh they always wear you know face mask and stuff like that and because my immune system is not quite as great as it should be the doctor advised me to you know stay away from people and stay away uh you know as much as possible so I can get better [yeah]. (Amar, 77-87)</p> <p>So uh meals were big dinners were big. They meant something for sure. And of course we always like big meals with the family. (Peter, 336-337)</p>
	Importance of Mealtime Routine	<p>There’s something to be said about that routine and you know I don’t know (Peter, 757)</p> <p>There’s no meal time or ritual around that something you’ve had all your life. (Peter, 313-314)</p>

Table C.1 (Continued)

Loss	<p>Missing Eating & Drinking</p> <p>Loss of Family Connection through Eating Together</p> <p>Tube Feed Unpleasant</p> <p>Not Everyone Felt Strongly About Tube</p> <p>Discouragement When Tube Remained</p> <p>Loss of Ritual</p> <p>Choice = Dignity = Humanity</p>	<p>Um all sorts all of it I I I missed drinking coffee [I missed] water and food yeah just good tasty food. (Jay, 128-129)</p> <p>[...] when I started eating uh it it did feel good to eat. I I can't deny it it felt good to be eating again. (Robert, 58-59)</p> <p>You know they definitely meant something. Now that wasn't an observation I made at the time I didn't realize it at the time but looking back you know I miss that. (Peter, 341-342)</p> <p>So it's the same thing I do with my own kids and same way but when I was in hospital you'd be (alright if) you didn't have that luxury. (Amar, 81-82)</p> <p>Oh terrible it didn't go over well with me. (Jay, 52)</p> <p>Oh my God it's like having a clothesline up your nose right? (Peter, 882)</p> <p>Well really um I had so many other problems going on I really didn't pay too much attention to the tube feed at all. (Robert, 35-36)</p> <p>Uh disheartened it really brought me down I was looking forward to eating. (Jay, 69)</p> <p>You don't wanna slip back but I mean the worst thing you hear is 'Oh you know you gotta go back on the feeding tube.' I heard that a couple of times at [HOSPITAL] and it was like wow. (Peter, 306-308)</p> <p>Plus with the feeding tube the only ritual around your feeding tube is somebody opening uh a tetra pack and throwing it into your uh your feeding bag. There's no meal time or ritual around that something you've had all your life. (Peter, 311-314)</p> <p>To eat yourself to kind to have control of what you really wanna eat on a plate to make those decisions again. You don't know how much you miss them until you can't do them. It's a it's a part of dignity it's a part of being a human your choice. (Peter, 659-662)</p>
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Table C.1 (Continued)

Assessment as Performance Exam	Language of Assessment: “Pass, Fail, Test, Exam, Performance”	Um she put me to the test um I went to in for into the X-Ray department and they had me swallow different uh liquids and uh and uh food. (Robert, 76)
	Assessment Becomes Adversarial	Uh the first time I failed a buncha times and I finally passed and the second time I I I did fairly well or I I failed again and I I passed again after a couple tries. (Jay, 63-64) Um no I was mad because uh I I really thought I did a great job and uh and uh I started arguing with them not a big argument but I uh ‘Hey you guys I did a great job’ you know? (Robert, 111-112)
	Experience, Preparation, & Practice Would Lead to Success	Yeah it was a bit of a fight for sure and fighting for your place knowing that if you don’t learn to swallow again and chew proper that you’re gonna slip back and it’s gonna happen pretty quick cause they’re not gonna stand by and watch you lose that much weight. (Peter 278-281)
	Swallow is Volitional	So I knew what a lot more to expect come your second third time when you’ve had the tube out and back in you know what markers and what they wanna see and and how to approach whole testing phase cause I mean the first time it’s ((pause)) very foreign. (Peter, 271-273)
	Gaming the Assessment	Uh practiced and re-took the exam. (Jay, 71) Uh ‘What what did I do wrong?’ And uh that’s when they told me about the air bubbles with the milk so you know I I still uh I still remember I thought they were totally wrong I was very upset but uh uh I just waited again for another month for another test. (Robert, 122-124) I was really mad but you know by the time I got my second test I was calm collected and I really wanted to pass it so I concentrated quite a bit on my swallowing and I made it. (Robert, 113-114)

Table C.1 (Continued)

<p>I Eat Therefore I Am</p>	<p>Pressure to Eat for Recovery</p>	<p>But I did find it a lot more of a challenging environment in in [HOSPITAL A] for sure Yeah more of a ‘You better do this or you know you know what happens you’re back to it right? So ((pause)) get it together and uh ((pause)) stay off the tube’ right? (Peter, 273-276)</p> <p>They were the one pushing saying ‘Well you know I don’t wanna mess around with puree like he looks like he can swallow he loo- we gotta get him stronger.’ (Peter, 238-239)</p>
	<p>Oral Diet = Health</p>	<p>Like maybe (that’s the key) to get stronger which is correct I think. The quicker you can get somebody um managing their food swallowing for themselves making decisions around food the stronger they’ll get. I don’t know if that’s a I just eat therefore I am kind of thing I don’t know what it is but uh I noticed with my own care it seemed to get I seemed to get stronger when my diet went from a feeding tube. Plus after a while your body starts to have problems with a feeding tube. (Peter, 241-246)</p>
	<p>Mind Ready Before Body</p>	<p>I know I know it um I didn’t have um any cravings to eat anything at the time um and but really that’s about all I can say is uh um I really don’t recall cause I was really out of it quite a bit at the time. (Robert, 36-38)</p> <p>But it was just a matter of like really I was exhausted for it so it was a lot of it was try and then just rest. I was just tired so it was just a lot of coming to. (Jay, 193-194)</p> <p>Yeah your mind’s ready to go before your body’s ready. (Peter, 1180)</p>

Table C.1 (Continued)

<p>Acceptance</p>	<p>A lot of steps</p> <p>Recovery is not a straight line</p> <p>Swallowing not the only concern</p> <p>Acknowledging limitations of the system</p>	<p>And as if it's it's just not that easy to come back. It's just not something that's so it's just not natural the... boom you wake up one morning they take the tube out you get a plate of food and you're back at it it just doesn't work that way [...] there's a lot of steps in between lot of it and they must be different for everyone. (Peter, 287-292)</p> <p>Uh ((pause)) well the only thing I could add is that coming through the experience ((pause)) that it is quite normal to have suc- like to succeed and then to have a failure and that failure may even lead you back to where ((pause)) you started. (Peter, 1083-1085)</p> <p>There's a lot more to it than you might... Everything takes time and it's more complicated than what you've experienced in your life it's... (Peter, 813-814)</p> <p>Well really um I had so many other problems going on I really didn't pay too much attention to the tube feed at all. I know I know it um I didn't have any um cravings to eat anything at the time um and but really that's about all I can say is uh um I really don't recall cause I was really out of it quite a bit at the time. (Robert, 35-38)</p> <p>So there's other things you've gotta... Swallowing's not the only thing you're doing [...] Like your exercises can go in the backseat or whatever right? Although it's important to you. Just it's the way it is or it's just the way I am I don't think I was the only one. (Peter, 577-582)</p> <p>Things move at their own speed and at a certain way of working through the system. So when you have a goal you gotta make it known and be prepared that it involves other people and their timeline and that it could take longer than you've ever expected to get things done. (Peter, 814-818)</p> <p>No I think they did whatever they could do in their power. (Amar, 130)</p> <p>I think I was getting what they're designed to do and what they're allowed to do. (Peter, 584)</p>
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Table C.1 (Continued)

	Everything's easier if you take it positively	<p>You know that could have been COVID too. Things might have been different in a COVID-free world. (Peter, 1192-1193)</p> <p>All I know I I think uh the main thing is you have to be positive [...] when you've been in a coma for a few months you know you expect you know some up and downs uh but thing is is you keep yourself positive and uh take everything positively and I think everything's easier for you. (Amar, 244-248)</p> <p>Even setback are just they're just successes with cheap dressing on you know? (Peter, 1108)</p> <p>Well I was lucky you know I had a good family around me and stuff it was there's only what you can do. (Jay, 196-197)</p>
Empowerment	<p>Don't Give Up</p> <p>Setting Goals is Key</p> <p>Exercises As a Way to Get Involved</p>	<p>I would just give em encouragement not to give up just to keep s- keep trying and if I could help em any way with advice I'd help em but the main thing is don't give up keep on keep on trying and uh hopefully you'll get some some some of your movement back or you're able to swallow whole foods you know I'd encourage em just never give up. (Robert, 258-261)</p> <p>[Just] don't give up man. (Peter, 1106)</p> <p>Uh empower yourself talk to your doctor talk to your nurses of where you wanna be as a goal always set goals for yourself whether it's the smallest of goals. (Peter 801-802)</p> <p>[...] even the care aides and nurses they're they're very helpful in helping you get to what you wanna have uh done to you (Robert, 251-252)</p> <p>Um ((pause)) it's a g- my involvement was to prepare myself ((pause)) for testing with with uh exercises or tasks that they gave me and not cheat on them like not... You can't not do them if you don't do them you're not gonna be successful I learned that the first time. Like I mean there was times when I didn't do them they call it hard swallowing? (Peter, 528-531)</p>

Table C.2: Themes, Subthemes, and Representative Quotations for “Recovery is a Team Effort”

Theme	Sample Codes	Sample Original Data
Communication	What’s happening and what’s going to happen	Um the only thing I can think of is for them to [...] just uh just try and advise people of what is happening or what’s going to happen [...]. (Robert, 265-267)
	Tangible goals explained made a difference	When I got to [HOSPITAL C] they said ‘Ok well we're gonna do the tests see if you can have any uh ((pause)) uh food at all hard food and so we went with puree and they cut my feeding tube to forty percent monitored my weight and said you know ‘Once you can replace sixty percent of your diet uh with pureed or pureed food then we’ll take you off the uh the feeding tube.’ And I just found that approach worked so much better with me. (Peter, 210-215)
	Clinicians open and educational	Oh I think so in both cases in each [HOSPITAL A] and [HOSPITAL C] the speech pathologists and the people that were in charge of the swallowing very open very educational. (Peter, 222-224)
	Communication helped me feel included	No no they they they explain me everything. Every time they did something they will they will tell me even doctor nurses when when when they have morning meetings they usually come to my room and they discuss everything front of me which was great because I I was feeling I’m a part of it [...] (Amar, 182-185)
	Communication Between Care Team Members Important	<p>Then to say I don’t know well I don’t know how well the disciplines talk to one another in acute. I’m not sure whether it’s a jointed effort for rehabilitation or not. I don’t know. (Peter, 1170-1171)</p> <p>Every time they did something they will they will tell me even doctor nurses when when when they have morning meetings they usually come to my room and they discuss everything front of me which was great because I I was feeling I’m a part of it and you know every time they make any decision. (Amar, 182-185)</p>

Table C.2 (Continued)

Active Involvement	I would like to voice my opinion	Well I'd like to know what is going on I would like to voice my opinion [...] (Robert, 204)
	I Felt Involved and Included	I will uh if they suggest something for me I will try it and if it doesn't work or I don't like it I'll let em know maybe we can try something else. (Robert, 204-206)
	Communicate With the Care Team	Oh yeah I was totally involved and satisfied with uh uh what happened through the whole process uh I talked to the SLP I talked to my nurses and uh you know I totally understand what was involved. (Robert, 127-129)
Connectedness	COVID restrictions limited family visits and affected mental health	Yes listen to the people uh very carefully don't be afraid to ask for help with your exercises or... (Peter, 799-800)
	Family key to well-being and recovery	Um beginning of COVID my God you know um just wondering what's gonna happen with this COVID but when it when it finally settled down it got pretty lonely here and uh especially in the fall and winter when it was raining and cold and it was uh mentally it was pretty hard. (Robert, 219-222)
		Well it's really been a minefield uh [HOSPITAL A] I was taken off a ward that uh eighty percent of them had COVID ICU and I was taken to another heart ICU and uh the visitation from my wife was restricted to twice a week for a couple hours. Uh it really affected me mentally. (Peter, 699-702)
		Absolutely it's lovely it's lovely my family is very supportive uh and and because of them I'm here. You know uh uh even when I was in ICU they uh they always come and you know and gave me positive stuff and uh you know they was just just wonderful [...] (Amar, 263-265)
		I would say the therapies I got uh the will to try and get better the will to try and get through this COVID business um the will from family and friends. (Robert, 250-251)