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Viewpoint

Shifting Tides Toward a Proactive Patient-Centered Approach in Dysphagia Management of Neurodegenerative Disease

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Purpose: Persons with neurodegenerative disease frequently develop comorbid dysphagia as part of their disease process. Current "reactive" approaches to dysphagia management address dysphagia once it manifests clinically and consist of compensatory approaches. The purpose of this article is to propose a paradigm shift in dysphagia management of patients with neurodegenerative disease from a "reactive to proactive" approach by highlighting amyotrophic lateral sclerosis (ALS) and dementia as case examples.

Method: The authors present several areas of special consideration for speech-language pathologists (SLPs) treating dysphagia in patients with neurodegenerative disease. The drawbacks of historical "reactive" approaches to dysphagia management are described. Concepts of functional reserve for swallowing and homeostenosis are discussed. A "proactive" patient-centered paradigm of care for these patients is proposed with evidence to support its importance. A rationale for use of this approach in patients with ALS and dementia is provided with strategies for implementation.

Results: When treating dysphagia in patients with neurodegenerative disease, SLPs must balance a variety of factors in their decision making, including disease severity and expected progression, cultural considerations, goals of care, patient empowerment, and caregiver support. Reactive approaches to dysphagia management in these populations are problematic in that they disempower patients by focusing on use of compensatory techniques (e.g., diet modification, postural changes, feeding tube placement). Proactive approaches that employ rehabilitative interventions to increase functional reserve, such as resistance training, may result in improvement or maintenance of swallowing function longer into disease progression. An interdisciplinary team with early SLP involvement is necessary.

Conclusions: SLPs play a critical role in the management of dysphagia in patients with neurodegenerative disease and should be integrated early in the care of these patients. By focusing on a proactive patient-centered approach, patients with neurodegenerative conditions, such as ALS and dementia, will experience improved quality of life and health outcomes for a longer time.

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Dysphagia, or swallowing dysfunction, has an estimated prevalence of approximately one in 25 or 9.4 million individuals in the United States annually (Bhattacharyya, 2014). Data from the Agency for Healthcare Research and Quality Healthcare Cost and Utilization Project National Inpatient Sample revealed that over 2.7 of 88 million (3%) of all adult inpatients over the age of 45 years had a diagnosis of dysphagia with the prevalence increasing by approximately 1% from 2009 to 2013. Of significance were the findings that inpatients with a dysphagia diagnosis experienced significantly longer hospital stays, had substantially higher health care costs (approximately $6,243), had a greater likelihood of discharge to a health care facility, and demonstrated a 1.7 times higher mortality rate (D. A. Patel et al., 2018).

Given that dysphagia is a symptom of an underlying disease process, the cause for dysphagia varies widely, which,

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in turn, impacts the accuracy of these prevalence estimates. Advancing age is a known risk factor for dysphagia due to age-related changes to swallowing-related musculature (sarcopenia) and the governing sensorimotor neural control processes. Medical conditions that commonly lead to dysphagia, often in combination with these age-related swallowing changes, include stroke, head and neck cancer, and neurodegenerative disease. The understanding that dysphagia has different etiologies is critically important when designing treatment plans that will be most effective.

Dysphagia is prevalent among neurodegenerative conditions, such as amyotrophic lateral sclerosis (ALS), Parkinson's disease, Alzheimer's disease (AD), oculopharyngeal muscular dystrophy, and multiple sclerosis (Aghaz et al., 2018; Coates & Bakheit, 1997; Tabor et al., 2018; Takizawa et al., 2016). While prevalence estimates vary depending upon stage of disease progression, method of assessment (clinical bedside evaluation of dysphagia vs. endoscopic evaluation vs. videofluoroscopic evaluation), and the definition of dysphagia ascribed, estimates are high for those with neurodegenerative conditions. In this article, we will focus on patients with ALS and AD as case examples of patients with neurodegenerative disease who frequently experience dysphagia. For those with an ALS diagnosis, dysphagia prevalence estimates vary from 48% to 86%, with an estimated 85% of individuals eventually experiencing swallowing impairment at some point during the disease progression (Carpenter et al., 1978; Chen & Garrett, 2005; Ruoppolo et al., 2013). Similar to ALS, persons with AD experience a high occurrence of dysphagia, with estimates varying from 32% to 84% (Horner et al., 1994; Volicer et al., 1989). While dysphagia is common at end of life in those with AD, biomechanical changes in swallowing and neural activation during swallowing have been reported to occur in the mild phase of AD progression (Humbert et al., 2010).

Dysphagia-Related Complications in Persons With Neurodegenerative Disease

Consequences of dysphagia in persons with these neurodegenerative conditions are serious. Dysphagia can result in social isolation and decreased quality of life (Alali et al., 2018; Ayres et al., 2016; Lindroos et al., 2014; Paris et al., 2013; Tabor, Gaziano, et al., 2016). Additionally, dysphagia has been shown to lead to malnutrition, dehydration, pneumonia, and mortality in those with ALS and AD (Alali et al., 2016; Chen & Garrett, 2005; Chiò et al., 2009; Fávaro-Moreira et al., 2016; Kühnlein et al., 2008; Manabe et al., 2017; Paranji et al., 2017; Sorenson et al., 2007; Suttrup & Warnecke, 2016). These complications of dysphagia have been found to account for 26% of mortality in persons with ALS, resulting in a 7.7-fold increase in risk of mortality (Chiò et al., 2009; Yang et al., 2011). For those with AD, pneumonia is the most common cause of mortality with dysphagia-related aspiration underlying a high proportion of these pneumonia episodes (Campbell-Taylor, 2014; Foley et al., 2015; Manabe et al., 2017). Dysphagia-associated sequalae in those with neurodegenerative disease highlight the importance of early detection and management of dysphagia.

Special Considerations in Dysphagia Management for Those With Neurodegenerative Conditions

When evaluating and treating dysphagia in persons with neurodegenerative disease, there are various factors that must be considered and incorporated into a well-designed plan (see Figure 1). It is important to understand the nature of the disease process and the underlying neuropathology. For instance, ALS is a motor neuron disease that is characterized by the progressive death of upper and lower motor neurons throughout the body, leading to progressive paralysis and eventual death once progression impacts the thorax and associated functions of breathing and airway defense mechanisms (Tsitkanou et al., 2019). Given that ALS is considered a primary motor disorder, most individuals with ALS have spared cognitive involvement (although a reported 30% may also demonstrate a frontotemporal dementia). As an example, progressively worsening weakness experienced by patients with ALS due to the upper and lower motor neuron death may result in swallowing impairments such as poor lingual pressure generation in the oral cavity and decreased base of tongue retraction resulting in increased amounts of oropharyngeal residue (impaired efficiency). AD is the result of cortical neuropathology and specifically the increasing deposition of beta-amyloid plaques and twisted strands of the protein tau known as neurofibrillary tangles (Lane et al., 2018).

Figure 1. Management of dysphagia in persons with neurodegenerative disease requires special consideration of various factors highlighted in this figure. The speech-language pathologist is responsible for carefully balancing these factors when making decisions regarding dysphagia treatment for these patients.

Due to early involvement of the hippocampus, memory impairment represents one of the first signs of AD (Lane et al., 2018). As an example, deposition of these cortical plaques and tangles in areas important for motor planning for swallowing (e.g., the insula) may disrupt appropriate timing of swallowing events, including laryngeal closure, which can lead to airway invasion during the swallow. By understanding the specific pathological processes underlying the governing disease contributing to dysphagia, one can predict the swallowing impairments most likely to occur, when they will occur, and how they may evolve and progress to tailor evaluation and treatment accordingly.

Another important factor to consider when working with individuals with neurodegenerative conditions is the expected natural progression of the disease process. Does the disease progress rapidly or slowly over time? Is this progression variable in terms of symptoms or a steady decline over time? While those with AD live an average of 8 years following diagnosis (with a range from 3 to 20 years), the majority of individuals with ALS only live 3–5 years after diagnosis (Brookmeyer et al., 2002; Marin et al., 2016; National Institute of Neurological Disorders and Stroke, 2019). Progression rates of both ALS and AD are variable. Progression is known to be more rapid for those ALS patients with a bulbar onset (symptoms beginning in the head and neck region), and, although progressive, patients are known to have fluctuations with periods of steady functioning and others with declines in function. The majority of patients with AD experience a steady and slow progression (Haaksma et al., 2018); however, those with a diagnosis of vascular dementia may experience more of a "steplike" progression where there is an acute change followed a period of stability (O'Brien & Thomas, 2015). It is important to consider these factors in relation to expected treatment trajectories, goals, and outcomes. Given that dysphagia, which is associated with neurodegenerative conditions, is expected to worsen over time as compared to poststroke dysphagia or swallowing impairment in an individual with a traumatic brain injury, treatment goals need to be focused on maintenance of swallowing function longer into disease progression rather than recovery of swallowing function over time.

In addition to the type of neurodegenerative condition and prognosis for rate and process of decline, one must also take into account a variety of other important factors for dysphagia management planning (see Figure 1). Eating, being a function of everyday life, is often the centerpiece of many of our family gatherings, meetings for business, and holiday or religious traditions (Padilla et al., 2019; Shune & Linville, 2019). The eating process as a whole, which includes feeding and swallowing, can be affected in those with ALS and AD and, as a result, can take away the pleasure of mealtimes, impact quality of life, and lead to disease-related stigma (Padilla et al., 2019; Shune & Linville, 2019). Unique aspects of an individual's culture and the degree to which acculturation has taken place for that individual (interaction of two cultures; e.g., American and Mexican) can also play a role in decision making regarding approaches to dysphagia treatment (Mackie, 2001; Padilla et al., 2019). For example, feeding tube placement may be viewed differently depending upon one's culture and/or religious beliefs (Mackie, 2001; Ngan et al., 2019). Cultural aspects may influence quality of life and stigma in the presence of dysphagia, and is therefore an important part of the evaluation process and consideration in treatment planning for each patient (Padilla et al., 2019).

Aligned with respecting the individual's values based on culture, it is important that dysphagia-related recommendations are consistent with the patient's own "goals of care." Goals of care are defined as appropriate health expectations established between the patient-seeking medical care and the health care arena (Stanek, 2017). In order for health expectations to be considered appropriate, they should align with the patient's desires while also being ethical, clinically feasible, and avoiding unnecessary medical treatment. It is imperative that care is based on the goals of the patient and caregiver and not the implicit goals or unilateral treatment decisions of clinicians who have not communicated with the patient or family (Stanek, 2017). It is also necessary for goals of care to be thoroughly documented, as this ensures that treatment decisions and planning, code status preferences, and advanced directives are communicated to all members of the patients' interdisciplinary health care team to improve communication among providers and quality of care (Narasimhan et al., 2006; Stanek, 2017). In order to ensure this, facilitation of shared decision making and effective communication are critically important. Shared decision making does not mean that every interaction or decision requires deliberation as this would be impractical, but rather that a deliberative approach is used when reasonable alternatives justify informing patients and caregivers so they can form and share their preferences (Elwyn et al., 2016). An example would be the recommendation for thickened liquids. Reasonable alternatives to this do exist, and the factors that weigh into this decision may be different for an individual with a neurodegenerative condition than one who expects marked improvement in swallow function over time or with rehabilitation. Therefore, deliberation with the patient and family in this case may be beneficial to facilitate a plan to align with the patient's goals of care (Askren & Leslie, 2019).

Yet, another important factor is the level to which a patient feels confident and is empowered to manage their own health care. "Perceived self-efficacy" refers to an individual's ability to implement behaviors that are specific to a situation in order to accomplish goals or to meet expectations or certain outcomes (Hoffman, 2013). This involves having insight into one's own condition, skills necessary for the task, and confidence in one's ability to self-motivate and draw upon cognitive resources needed to perform the task (Marks et al., 2005). While an individual may have perceived self-efficacy for one task but not another, higher self-efficacy does contribute to positive outcomes in patients with chronic disease (Marks et al., 2005). Accordingly,

a patient's perceived self-efficacy will influence how empowered or activated they are to manage their own health condition (e.g., dysphagia). The term "patient activation" refers to the degree to which a patient understands that they need to actively manage their own health care and the extent to which they feel they are able to do so (Hibbard & Mahoney, 2010). A patient's level of activation specific to managing dysphagia in the context of neurodegenerative disease is important to assess and understand clinically as it will likely influence implementation of treatment recommendations. For example, if a clinical recommendation is to use a chin tuck posture consistently when drinking liquids to prevent airway invasion but the patient is not activated to manage their dysphagia, they may have difficulty following this recommendation consistently and may need additional support to do so.

While it is clear dysphagia impacts quality of life (Plowman, 2015), dysphagia treatment recommendations may have their own negative influence on quality of life as well. As a result, patients may not follow or "adhere" to recommendations. For example, adherence to thickened liquid recommendations is low, ranging from 22% to 52% (Krekeler et al., 2018). Patients report that drinking thickened liquids is "unpleasant" largely due to lack of sensory appeal (McCurtin et al., 2018). Optimizing quality of life will likely be a priority in dysphagia-related treatment decisions for many patients with a neurodegenerative condition who expect a decline in function as the disease progresses (Simmons, 2015). Additionally, for disease processes with rapid decline and limited life expectancy, quality of life in the limited remaining years is particularly important. Caregivers can also be impacted by dysphagia and the ascribed treatment programs with dysphagia identified as a significant independent predictor of increased physical and emotional burden. Specifically, 40% of caregivers with aging parents reported moderate-to-severe physical and/or emotional burden in a recent caregiver survey (Namasivayam-MacDonald & Shune, 2019). Examples of emotional stressors include guilt with eating while the patient is on a restricted diet or fear of the patient choking and not knowing how to handle it (Namasivayam-MacDonald & Shune, 2019). Examples of physical stressors include assistance while eating or the need for separate meal preparation (Namasivayam-MacDonald & Shune, 2019). Given that various aspects of mealtime change along with the onset of dysphagia (e.g., behavioral issues during mealtime, changes in food/taste preference, and agnosia), many similar stressors have been described by caregivers of family members with dementia specifically (Keller et al., 2006). Caregivers for patients with ALS report that a supportive multidisciplinary care team helps them to cope with the situation, but a shortcoming in multidisciplinary ALS care can be the lack of evidence-based interventions to guide family caregivers (Creemers et al., 2016).

Finally, the care environment and resources available to the patient with a neurodegenerative condition and/or the caregiver may have an impact on dysphagia management and treatment decisions. If the individual resides in an institutional setting, there may be issues with the environmental infrastructure that limit a well-intentioned and educated caregiver's ability to provide support needed during mealtime (Hammar et al., 2016). Financial resources available to the patient and/or caregiver may also be an issue. Thickened liquids or nutritional supplements, as an example, can be costly for patients and families whether they are prepared in the home or commercially prepared (Kotecki & Schmidt, 2010). Additionally, some patients and caregivers may not have the resources to prepare modified diets, as these require certain equipment (e.g., blenders) and adequate dedicated time.

The speech-language pathologist (SLP) evaluating and treating the individual with a neurodegenerative condition for dysphagia needs to carefully balance all of these factors while making evidence-based recommendations for the patient. This can be particularly challenging while taking into account the patient's wishes. It is the clinician's responsibility to consider all of these potential issues and to work with the patient and caregiver(s) to develop a treatment plan that is both feasible and aligned with their individualized goals of care. Early involvement in the patient's care and a consistent presence throughout disease progression will be key to accomplish this.

Historical Approaches to Dysphagia Management in Neurodegenerative Populations

Historical approaches to dysphagia management in patients with neurodegenerative conditions have been primarily "palliative" in nature. The goal of these interventions has been to minimize symptoms and consequences of dysphagia without actually addressing the underlying cause(s). The most commonly implemented interventions are "reactive" in nature, in that they are applied only after dysphagia has already manifested. These include compensatory approaches to dysphagia management, such as feeding tube placement, dietary modifications, changes to the environment to facilitate safe swallowing, postural adjustments during swallowing, and patient education. While these approaches are often successful and necessary to minimize symptoms and consequences of dysphagia (e.g., early feeding tube placement to prevent malnutrition), they do not result in lasting change in the underlying biomechanics of swallowing. They essentially compensate for (e.g., dietary modifications, postural changes) or bypass (e.g., feeding tube placement) the impaired swallowing physiology. "Reactive approaches" also include rehabilitative regimens implemented only after dysphagia manifests clinically and is diagnosed, which can be later in disease progression for both patients with ALS and AD.

Use of only "reactive approaches" to dysphagia management may be problematic in that they do not address subclinical swallowing impairment known to exist in these patient populations. Patients with ALS tend to underreport swallowing difficulty during the early stages of the disease, likely due to progressive adaptation or compensation

to subtle changes that are occurring (Plowman et al., 2017; Solazzo et al., 2014). Additionally, they may exhibit abnormal swallowing under imaging even without clear symptoms of dysphagia (Goeleven et al., 2006; Kawai et al., 2003; Perry et al., 2018). Despite this, a recent survey from the Northeast ALS bulbar committee revealed that referral for a videofluroscopic swallowing study occurred in only 27% of sites (Plowman et al., 2017). These issues also have been found to occur for patients in the mild stage of AD who exhibit decreases in hyolaryngeal displacement as well as neural activation during swallowing prior to the onset of clinical symptoms of dysphagia (Humbert et al., 2010, 2011). However, the current understanding of dysphagia in persons with AD remains largely that it is a late stage or even terminal stage sequelae; therefore, there is not a standard process for dysphagia screening or evaluation for patients receiving ongoing geriatrics care. Additionally, SLPs may be basing their treatment planning decisions on the misconception that there is no capacity to change a degenerating system or that rehabilitative approaches, specifically exercise, can result in worsening function, especially for patients with ALS.

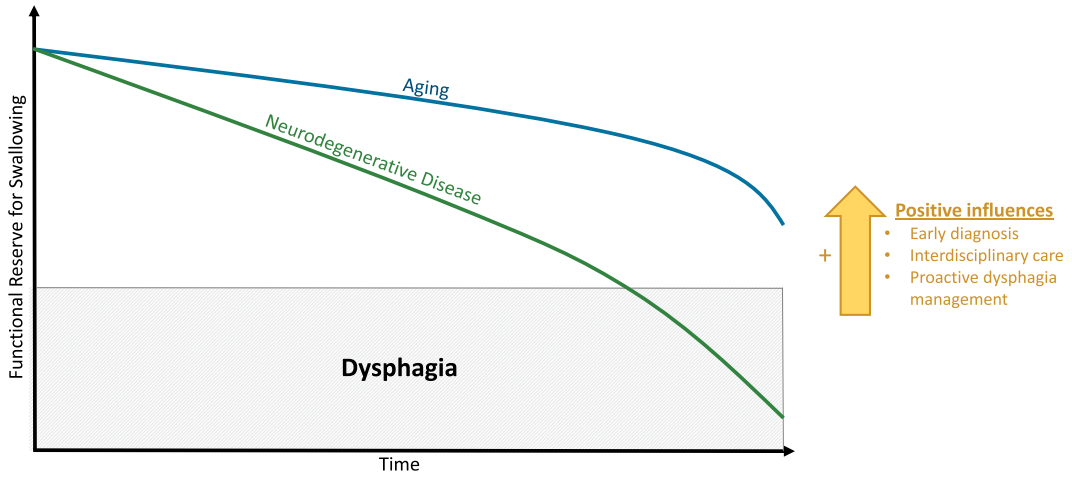
Given the high likelihood of dysphagia in these patient groups, "reactive" approaches do not take advantage of the early potential to maintain (or improve) the governing bulbar mechanism and swallowing function (Plowman, 2015). Patients with neurodegenerative conditions, including ALS and dementia, may experience a reduction in muscular strength, timing, or coordination that impacts swallowing function. The reason(s) for these changes will depend upon the specific condition. In the case of ALS, spasticity and atrophy from upper and lower motor neuron degeneration respectively underlie decreases in strength, force, speed, range of motion, and coordination. This often results in increased effort during swallowing with a system functioning with reduced physiological reserve that results in increased mealtime durations, fatigue, and physiologically in impairments in swallowing efficiency and safety.

"Functional physiological reserve" is an organ's ability to fulfill its physiological activity when under stress (e.g., disease, aging). Specifically, it is the difference between the maximum capacity of an organ or body part and the minimum activity necessary to function on a daily basis (Arnett et al., 2008; see Figure 2). The overall functional demand must be matched to the size and nature of the organ or body part in order to be able to facilitate the highest expected needs (Murray & Sullivan, 2006). In order to prevent the body system from failing when it is overloaded by physical exertion, infection, or disease, there must be a safety margin or "reserve" in place (Murray & Sullivan, 2006). Given that approximately 30% of the normal capacity of a body system is used to perform daily activities, there is typically a 70% margin of loss before the body cannot sustain functioning (Murray & Sullivan, 2006). The amount of physiological reserve available within a particular system may predict how long that system can continue to perform its necessary functions. In the case of swallowing in an individual with a neurodegenerative condition, it may predict how long an individual can maintain oral intake and optimize quality of life into disease progression.

Swallowing has been shown to be a "submaximal" task in that the full capacity of the muscles involved is not necessary for a functional swallow to be achieved (Rogus-Pulia & Connor, 2019). As an example, the amount of pressure produced by the tongue against the hard palate during a swallow is less than the amount produced when an individual is pressing maximally with their tongue during an isometric task (Nicosia et al., 2000). This difference between the maximal production of pressure and the pressure produced during swallowing has been termed "tongue pressure functional reserve" (Nicosia et al., 2000; Steele, 2013) or "lingual physiological reserve" (Robison, 2015). Maximum isometric tongue pressures have been shown to decrease with advancing age (Nicosia et al., 2000) and in those with neurodegenerative conditions (Hiraoka et al., 2017; Minagi et al., 2018; Namasivayam et al., 2016), which likely influences functional reserve. "Homeostenosis" is a narrowing of functional reserves that occurs naturally due to aging or secondary to disease. This depletion of functional reserves makes individuals more susceptible to adverse health outcomes and a decreased capacity to maintain optimal function (Troncale, 1996; see Figure 2).

Given that reduction of functional physiological reserve for swallowing is expected to occur, an opportunity not previously exploited in speech-language pathology could be to build, increase, or maintain this reserve earlier in the degenerative process. Traditional rehabilitation programs in our field rather have utilized "reactive" approaches to dysphagia management that do not support early or active involvement of the SLP in the care trajectory of these patients. In fact, one of the consequences of a "reactive" approach is that patients frequently are not seen by an SLP for their swallowing issues until they are admitted to the hospital, often with dysphagia-related sequelae such as pneumonia or malnutrition. In many cases, a hospital admission is the first time a patient is diagnosed with dysphagia. This results in increases in hospital readmission rates and medical care costs as well as unexpected dietary restrictions that negatively impact quality of life for these patients. Patients with dementia and dysphagia, compared to those without dysphagia, being discharged from the hospital are at higher risk for feeding tube placement, pneumonia, malnutrition, sepsis, and discharge to a facility (Paranji et al., 2017). Once dysphagia is identified, evidence-based practice recommendations are for use of compensatory approaches that conserve energy and improve swallow safety and efficiency during meals (Heffernan et al., 2004). Such a "reactive" approach to treatment means that the disease dictates the management plan in terms of timing and interventions used following clinical identification of dysfunction. We propose change in the way dysphagia management is practiced from a "reactive" to a "proactive" approach that empowers the patient to

Figure 2. The process of declining functional reserve (homeostenosis) with advancing age and even more so in persons with neurodegenerative disease is shown on this graph. Factors that will either result in increased functional reserve and improved functioning longer into disease progression are highlighted, as well as those factors that will have the opposite negative effects.



take ownership of the disease course and related management decisions.

Proposed Paradigm Shift: Patient-Centered Proactive Approach to Dysphagia Management

In order to address these issues and optimize outcomes for patients with neurodegenerative conditions, a paradigm shift in the approach to dysphagia management should be considered. Thus, we propose utilization of a "proactive" approach in dysphagia management that empowers the patient to partake in early management decisions before the inevitable decline of swallowing function. The goals of a "proactive" approach include (a) increasing and/or maintaining the governing bulbar and respiratory mechanism strength and swallowing-associated physiological reserve (e.g., respiratory and airway defense physiological capacity), (b) maximizing oral intake into disease progression, (c) maintaining and optimizing quality of life into disease progression, (d) actively engaging the patient in their disease process, and (e) empowering the patient to make choices in their disease path. By utilizing a "patient-centered approach," the patient's self-efficacy for managing their own condition and activation to do so will improve and ensure alignment of treatment decision making with the patient's goals of care. The intent of this approach is to target underlying physiological function "early," before the development of dysfunction. Once the patient has advanced disease progression, it may no longer be possible or appropriate to apply rehabilitative interventions, but rather compensatory approaches may be necessary.

Improving Physiological Reserve for Swallowing

Strength or resistance training can be used as a method to address declining functional physiological reserve that results in muscular weakness, reduced force, and impairments in swallowing efficiency (i.e., residue due to reduced base of tongue retraction and/or pharyngeal constriction) or safety (i.e., inability to adequately protect the airway or expel tracheal aspirate due to reduced peak cough flow). As mentioned previously, the process of aging alone results in declines in physiological reserve and homeostenosis throughout various body systems (Goldspink, 2005; see Figure 2). Frailty, a clinical state of increased vulnerability in older adults, results from decreased functional physiological reserve across multiple body systems and a reduced ability to regain physiological homeostasis after a destabilizing event (Chen et al., 2014). Specific to muscle strength, the effects of sarcopenia (changes in muscle mass and quality with advancing age) lead to a decrease in the reserve of muscle function in older adults (Cruz-Jentoft & Michel, 2013; T. P. Ng et al., 2018). Sarcopenic effects are commonly measured through tests of physical function, such as grip strength, jump power and/or height, and gait speed (Cruz-Jentoft & Michel, 2013). These measures are incorporated in the phenotypic definitions of frailty as well (Chen et al., 2014).

Exercise-based approaches to increase muscular strength and force generation have been the interventional modality that has most consistently shown benefit in treating frailty by reversing or minimizing its effects (Clegg et al., 2012; Crocker et al., 2013; Fiatarone et al., 1994; Gill et al., 2002; Theou et al., 2011). Resistance training for older adults has been proven to attenuate age-related intramuscular adipose infiltration (Goodpaster et al., 2008), increase muscle fiber area (Hakkinen et al., 2002), improve muscle quality and bone density (Evans, 2002; Marques et al., 2012), improve metabolic capacity of skeletal muscle (Evans, 1997), and reduce risk of falls and fractures (Silva et al., 2013). By building reserve, the patient develops greater resilience for when they experience a

disease-related event that may negatively affect their muscle function.

Resistance training also has been used to counteract the effects of aging on swallowing-related musculature (termed "presbyphagia") and as a rehabilitative approach in patients with dysphagia. Most of the research in this area has focused on strength training of limb musculature with a number of important functional and structural differences existing between limb and cranial muscles that include lower innervation ratios for cranial musculature, differential regenerative capacities and responsiveness to aging, and disease processes (Rogus-Pulia & Connor, 2019). However, studies focused on the response of cranial muscles involved in swallowing reveal that these muscles also respond positively to strength training. Various approaches have been used to strengthen swallowing-related musculature and governing bulbar structures within a defined exercise regimen, and studies with varying levels of quality in terms of design have shown promise in terms of enacting change in related swallowing biomechanics. Non–load-bearing approaches include the "effortful swallow" (Clark & Shelton, 2014; J.-W. Park et al., 2012), the "Mendelsohn maneuver" (voluntary prolongation of laryngeal excursion at the midpoint of the swallow; McCullough et al., 2012; McCullough & Kim, 2013), and the "Shaker exercise" (Easterling et al., 2005; Shaker et al., 2002, 1997). Progressive load-bearing approaches include lingual strengthening (Robbins et al., 2005, 2007; Rogus-Pulia et al., 2016; Steele et al., 2016), expiratory muscle strength training (EMST; Chiara et al., 2006; Pitts et al., 2009; Plowman et al., 2016; Troche et al., 2010), and the McNeill Dysphagia Therapy Program (Carnaby-Mann & Crary, 2010; Lan et al., 2012). Several of these load-bearing approaches (lingual strengthening and EMST) have been used in patients with neurodegenerative conditions to stabilize and preserve swallowing function (Chiara et al., 2006; Malandraki et al., 2012; Troche et al., 2010).

ALS as a Case Example

In the case of patients with ALS, degeneration of upper motor and lower motor neurons leads to spastic and atrophic bulbar pathophysiology that manifests as a spastic–flaccid dysarthria and dysphagia (Plowman, 2015). Declines in functional physiological reserve relevant to swallowing function are manifested as decreased oral and pharyngeal muscle strength leading to reduced pressure generation throughout the swallow (Hiraoka et al., 2017; Solazzo et al., 2014; Suh et al., 2019; Tomik et al., 2017; Waito et al., 2018). It is also apparent that the weakness of axial (respiratory and ventilatory) musculature impacts airway protection by reducing expiratory pressure generation capacities needed for an effective cough (Ackrivo et al., 2019; J. H. Park et al., 2010; Plowman et al., 2016; Ruoppolo et al., 2013). Indeed, Plowman et al. (2016) noted that cough volume acceleration was 3 times higher in individuals with safe swallowing versus those who aspirated providing support for improving related aspects of strength and physiological reserve for airway defense mechanisms in this patient population.

Traditional treatment approaches for patients with ALS have been based on the idea that exercise could result in overuse injury that would result in worsening of function and should therefore be avoided (Bello-Haas et al., 2007; Plowman, 2015; Sinaki & Mulder, 1978). However, this premise requires further study, and data are currently insufficient to conclude that exercise has a negative impact in patients with ALS (de Almeida et al., 2012; Pinto et al., 2012; Plowman, 2015). Physical inactivity may lead to disuse atrophy, which may actually be more detrimental for these patients (de Almeida et al., 2012; Plowman, 2015). In fact, it may be that exercise has beneficial effects on motor neuron function (cellular and morphological changes) that may help to prolong function longer into disease progression if applied early and at the appropriate intensity and dose (Adkins et al., 2006; McCrate & Kaspar, 2008; B. P. Patel & Hamadeh, 2009; Plowman, 2015).

Specific to swallowing function, the governing assumption that energy conserving and compensatory approaches are the best options to care still exist. Recent preliminary research has shown strengthening-based approaches to be beneficial for maintenance and improvement of function when applied early in the disease process. A recent case series of two individuals with ALS with differing bulbar profiles who underwent an 8-week lingual resistance training program revealed that this approach was feasible. Results showed no change in lingual strength but improvement in lingual endurance (Robison, 2015). No change was observed in airway invasion (penetration–aspiration scale scores), and no additional swallowing outcomes were reported. Furthermore, four recent reports ranging from case studies (Tabor, Rosado, et al., 2016; Robison et al., 2018), a delayed intervention cohort design (Plowman et al., 2016), and a randomized sham-controlled trial (Plowman et al., 2019) document promising findings for implementation of EMST in individuals with ALS to increase and prolong swallowing-associated physiological reserve. In one such report, an individual with a bulbar onset ALS implemented a combined expiratory and inspiratory muscle strength training program for 24 months that lead to increases in maximum inspiratory pressure (from 71 to 134 cm H_2O), maximum expiratory pressure (from 108 to 197 cm H_2O), and peak cough flow (from 331 to 655 L/min). The latter was noted to represent a significant functional improvement in the patients' physiological airway defense capacity and airway clearance abilities, which represents a common impairment in this patient population (Robison et al., 2018). In the randomized sham-controlled trial, 48 patients with ALS underwent 8 weeks of either an active (n = 24) or sham (n = 24) EMST program. Results indicated that EMST was well tolerated and led to improvements in maximum expiratory pressure and improvements in the Dynamic Imaging Grade of Swallowing Toxicity total scores as well as Efficiency subscale scores (Plowman et al., 2019). Patients included in this study were noted to

have early disease progression and had a forced vital capacity greater than 65% predicted and ALS Functional Rating Scale–Revised (Cedarbaum et al., 1999) scores of greater than 30. While clearly high-quality additional research is needed to validate these preliminary promising findings, these studies suggest that strengthening-based exercise paradigms to improve physiological reserve could be beneficial in ALS.

Dementia as a Case Example

Despite limited evidence, clinical practice recommendations for individuals with dementia also focus on use of "reactive approaches" to dysphagia management that involve mainly compensatory approaches (e.g., dietary modification, postural changes; Alagiakrishnan et al., 2013; Flynn et al., 2018). One large clinical trial focused on patients with dementia and Parkinson's disease found these approaches (e.g., chin tuck posture, thickened liquids) to be effective in minimizing the occurrence of aspiration under videofluoroscopy; however, it is also known whether these interventions may negatively impact quality of life for persons with dementia (Flynn et al., 2018; Wang et al., 2016). Additionally, while data are limited, it is possible that thickened liquid recommendations, in particular, may contribute to adverse health outcomes (e.g., pneumonia development, dehydration, urinary tract infections; Murray et al., 2014; Robbins et al., 2008).

As mentioned previously, changes in the neural control of swallowing and swallowing biomechanics begin early in the progression of dementia. Humbert et al. (2010) found that hyolaryngeal displacement (taken from videofluoroscopic images) and neural activation during swallowing (measured with functional magnetic resonance imaging) are decreased in individuals with mild AD as compared to age-matched controls. Therefore, similar to ALS, swallowing changes begin prior to the development of clinical symptoms, and patients as well as their families may be unaware (Namasivayam-MacDonald et al., 2019). Despite these changes early in the course of the disease, SLPs are not typically involved until later in the progression when dysphagia has been clinically diagnosed and dysphagia-related consequences have already occurred (e.g., pneumonia, malnutrition, dehydration). This may be due to the perception that dysphagia is not manifested until the individual is suffering with more severe or even end-stage dementia. This misperception likely leads to more reliance on compensatory approaches given that rehabilitative strategies may no longer be feasible later in progression due to the severity of cognitive impairment.

The factors leading to dysphagia development in individuals with dementia are multifactorial. The neuropathology of dementia, depending upon dementia subtype, will influence neural control of swallowing. Through use of functional magnetic resonance imaging, Humbert et al., (2010) found decreased neural activation in important swallowing network areas in individuals with early stage AD, such as the primary sensorimotor cortex and the Rolandic and frontal opercula bilaterally. While these areas are not typically atrophied in early AD, they do receive input from the insula, which is involved in the preparation to swallow and atrophies in early AD (Augustine, 1996; Dziewas et al., 2003; Foundas et al., 1996).

Additionally, individuals with dementia are more likely to be physically frail compared to healthy age-matched controls, which leads to decreased functional physiological reserve (Grande et al., 2019; Rogers et al., 2017). The prevalence of sarcopenia and related dynapenia (age-associated loss of muscle strength) has been shown to be greater in individuals with AD as compared to healthy controls (Ogawa et al., 2018; Yazar & Olgun Yazar, 2019). Sarcopenic effects lead to decreased physical function and increased fall risk in individuals with dementia, even those in the early stage (Allali & Verghese, 2017; Lach et al., 2017). Decreased skeletal muscle mass in individuals with AD has been shown to relate to poor swallowing function (Takagi et al., 2017). Long-term care residents, many with dementia, have been found to produce lower maximum isometric tongue pressures and saliva swallow pressures than healthy older adults, and these decreased lingual pressures are associated with longer meal durations and clinical signs of dysphagia (Namasivayam et al., 2016; Namasivayam-MacDonald et al., 2017). Pharyngeal residue in individuals with dementia, which is more pronounced in the vallecular region, may relate to decreased pharyngeal pressure generation, but this requires further study (Namasivayam-MacDonald & Riquelme, 2019).

Exercise-based approaches have been used to address physical frailty in individuals with dementia with positive outcomes (Forbes et al., 2015; Karssemeijer et al., 2017). Individuals with AD, in particular, have been shown to maintain intact implicit motor-learning capabilities that can be used in rehabilitation (van Halteren-van Tilborg et al., 2007). Hauer et al. (2017) conducted a randomized controlled study of a 6-week strength and functional home training regimen with 58 geriatric patients with cognitive impairment. Results revealed improved functional performances on the Short Physical Performance Battery, reduced gait and balance deficits, and increased physical activity (Hauer et al., 2017). Another study conducted by Morris et al. (2017) assessed the effect of 26 weeks of a supervised aerobic exercise program in 76 individuals with probable AD and found cardiorespiratory fitness gains that were associated with improved memory performance and reduced hippocampal atrophy. Taylor et al. (2019) recently completed a pilot feasibility study of a home-based fall prevention exercise program in individuals with dementia and found that this particular program had acceptable usability, scored well on enjoyment, and was feasible for all participants. These studies collectively support the feasibility of exercise-based approaches with this population. Additionally, these effects are sustainable in individuals with dementia when implemented in the early stages. Zieschang et al. (2013) conducted a study to determine the sustainability of motor training effects in individuals with mild–

moderate dementia following a 3-month progressive resistance and functional group training program. Even after 9 months without training, the gains in functional performance observed directly after training were maintained (Zieschang et al., 2013). While it remains unclear whether the positive effects found in studies focused on the limbs would translate to the bulbar-innervated musculature of the head and neck, these results remain promising (Rogus-Pulia & Connor, 2019).

Despite this, exercise-based approaches are not commonly used in clinical practice to provide "proactive" rehabilitative interventions for individuals with dementia. A paucity of research focused on these types of approaches in terms of feasibility or efficacy in this population exists. However, based on these literature focused on exercise more broadly, there appears to be potential for building functional physiological reserve in individuals with early-stage dementia that would likely result in maintenance of swallowing function longer into disease progression through the implementation of "proactive" approaches to dysphagia management.

Implementation of a Patient-Centered Proactive Approach

Interdisciplinary Care

To enact change or a shift from a "reactive" to a "proactive" management approach, an interdisciplinary team approach that includes the SLP is needed. Interdisciplinary or transdisciplinary care is highly recommended for patients with neurodegenerative conditions. While the term "multidisciplinary" is often used interchangeably with "interdisciplinary" or "transdisciplinary," there are important differences in these models of care with more highly integrated or collaborative care occurring with interdisciplinary/transdisciplinary models (Howard & Potts, 2019).

Jointly published guidelines from the American Academy of Neurology and the American Academy of Neuromuscular and Electrodiagnostic Medicine support team-based care for patients with ALS and other neuromuscular conditions (Howard & Potts, 2019). Interprofessional care for patients with ALS is associated with increased survival, decreased frequency of hospitalization, and improved patient satisfaction (Chiò et al., 2006; Howard & Potts, 2019; L. Ng et al., 2009). For patients with ALS, this team typically consists of medical specialists from a variety of disciplines given that the disease impacts multiple modalities. This team most often includes speech-language pathology, respiratory therapy, occupational therapy, physical therapy, social work, dietetics, psychology, and neurology (Hogden et al., 2017). Interprofessional care is also recommended for patients with dementia given the complexity of their needs. A memory care clinic may be set up in a primary care practice or as a stand-alone clinic. The team most often consists of a physician, nurse practitioner or physician assistant, registered nurse, social worker, neuropsychologist, physical therapist, occupational therapist, and/or pharmacist (Galvin et al., 2014). This model improves access to care; provides timely diagnosis, holistic treatment, care coordination, and community referrals; improves quality of life; facilitates shared decision making; and reduces adverse health outcomes for patients with dementia (Callahan et al., 2006; Galvin et al., 2014; Ganz et al., 2010). Given that there is so much involved in a successful mealtime experience for patients with dementia (Keller et al., 2014), an interprofessional approach that considers optimization of the experience, nutritional intake, and swallowing safety is necessary.

Early Involvement of the SLP With Standardized Tracking of Outcomes

Early involvement of an SLP as part of the patient's care team is critically important. This involvement needs to begin at the time of the medical diagnosis so that the SLP can be aware of the diagnostic process and specifics of the patient's disease (e.g., dementia subtype, severity of disease, bulbar vs. spinal onset in ALS patient). Given that swallowing changes have been found to begin often before they are manifested as clinical symptoms, regular evaluations for dysphagia by the SLP beginning at the time of diagnosis are crucial. These evaluations should include tracking of standardized outcomes using validated tools and instrumental assessments of swallowing (videofluoroscopy and fiberoptic endoscopic evaluation of swallowing). Screening tools and clinical assessments for dysphagia are lacking in adequate sensitivity and specificity, and, while it may not be necessary to validate a tool in every patient population, it is important to note that many of the available tools have not been validated for use with neurodegenerative populations who experience declining function over time (O'Horo et al., 2015).

A recent survey of current practice patterns for the evaluation of speech and swallowing function within the Northeast ALS bulbar committee revealed that 92% of sites offer speech-language pathology services (Plowman et al., 2017). While this is encouraging, the ALS Functional Rating Scale–Revised and body weight were the only parameters routinely tracked at greater than 90% of sites. Additionally, referral for videofluoroscopy was only routinely used in 27% of sites (Plowman et al., 2017). Practice patterns for SLPs evaluating and treating patients with dementia require further study, but it remains infrequent that SLPs are automatically part of the dementia care team in a systematic way. By involving the SLP in the interdisciplinary care team from the disease onset, the clinician is able to develop relationships with the patient and family, as well as educate them early in a proactive rather than reactive manner, which in turn may lead to less stress on the family who can be empowered to handle or prepare for subsequent dysfunction or declines in health. This facilitates open discussion regarding advanced care planning (e.g., does the patient want a feeding tube placed in the end stages of the disease?) and supports the notion of shared decision making.

Disease Progression: Optimization of Health in the Context of Dysphagia

As the disease progresses, the clinical focus will shift to optimization of health in the context of a known dysphagia diagnosis. This also requires a "proactive" approach in that close involvement and education from the SLP before there is bulbar involvement allows the clinician to anticipate issues that may occur later in the disease that could jeopardize the health of the patient. An example of this may be maintenance of adequate oral care. Poor oral health has been shown to be an independent predictor of pneumonia development in older adults (Langmore et al., 1998) and is an issue for patients with neurodegenerative conditions (Nakayama et al., 2018; Ribeiro et al., 2012; Rozas et al., 2017). Saliva production, which plays an important role in supporting oral health, is known to decline with advancing age and in patients with neurodegenerative disease (Affoo et al., 2015; Ship et al., 1990). In the way that muscular reserve decreases with advancing age, functional physiological reserve of the salivary glands is also affected by age (Ghezzi & Ship, 2003). "Secretory reserve" refers to the process by which salivary gland acinar cells are lost with advancing age while salivary production remains age-stable in healthy adults (Ghezzi & Ship, 2003). Some patients with neurodegenerative conditions report "too much" saliva, termed as "hypersialorrhea." In many cases, this increased perceived volume of saliva that results in drooling is due to a reduced baseline swallowing frequency rate rather than overproduction of saliva. By targeting maintenance of swallowing function proactively, saliva will continue to be stimulated through eating and drinking, which will help to increase and maintain this reserve that is important for oral health. Maintenance of healthy swallowing function will also aid patients in managing the saliva that is produced through regular and efficient swallowing.

Additionally, education of nutritional intake, the inherent risk for developing malnutrition, and the need to increase caloric intake has the potential to reduce subsequent rates of malnutrition. This is particularly important in ALS whereby individuals are known to have a higher resting metabolic rate (approximately 30%) that necessitates increased caloric consumption (Plowman, 2014, 2015). If not educated on this important fact at time of diagnosis, an individual with ALS can easily slip into a vicious cycle of malnutrition and muscle cachexia that overlays their inherent ALS muscle-wasting disease process that is known to exacerbate disease progression by approximately eightfold (Chiò et al., 2009). Furthermore, once patients become malnourished, their functional physiological reserve is affected, and the potential for rehabilitation decreases. Patients with dementia often experience changes in appetite and impairments in the self-feeding process along with dysphagia that impact their nutritional intake (Priefer & Robbins, 1997). The SLP can work in conjunction with a dietitian to develop strategies and recommendations to ensure patients meet their nutritional needs. For patients with ALS, placement of a feeding tube may be necessary to avoid the onset of malnutrition while simultaneously working on maintenance and improvement of swallowing function (Plowman, 2014). By being involved "proactively," SLPs will be aware of declines in nutritional intake that can be addressed quickly. Additionally, given that the mealtime experience involves much more than swallowing (Keller et al., 2014), an interdisciplinary approach that incorporates professionals involved in supporting mealtime (e.g., nursing assistants who are feeding patients with dementia, occupational therapists who can support patients with self-feeding) will need to be taken to support adequate oral intake and quality of life.

Conclusions

Patients with neurodegenerative disease are at high risk for dysphagia and require special considerations by the SLP. Current dysphagia management practices for patients with neurodegenerative conditions focus on "reactive" compensatory approaches that do not result in maintenance or improvement of swallowing function. A paradigm shift to a "proactive and patient-centered" approach to empower the patient and their family to have active involvement in treatment planning and decision making as part of the interdisciplinary team has been proposed. While more data are needed, taking advantage of a critical window prior to the development of bulbar impairment may represent a key and previously overlooked opportunity to improve physiological reserve for the bulbar and respiratory mechanism and lead to maintenance of swallowing efficiency and safety further into the disease progression.

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