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Efficacy of Communication Interventions for Amyotrophic Lateral Sclerosis

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Efficacy of Communication Interventions for Amyotrophic Lateral Sclerosis

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of the requirements
for the Murray State University Honors Diploma

Gracie Rightnowar

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Abstract

Efficacy of Communication Interventions for Amyotrophic Lateral Sclerosis

The purpose of this literature review is to analyze the efficacy of various communication interventions for amyotrophic lateral sclerosis (ALS). This research will seek to determine the role of a speech language pathologist in the treatment of an individual with a progressive neurological disease. It will specifically examine different approaches and methods of communication interventions. Research will further dive into the neurological and motor impacts of amyotrophic lateral sclerosis, also known as ALS. The progression and presentation of disease are also investigated. Specifically, the impact of ALS on an individual's communication abilities are evaluated. This review seeks to determine the overall effectiveness of communication interventions, as well as which methods of services have proven to be the most impactful and effective in the lives of patients. This will specifically look into the efficacy of various methods of augmentative and alternative communication (AAC), which can be used to prolong communicative abilities beyond that of the motor capabilities necessary for speech. This will examine the accessibility of intervention options into the later stages of disease progression, as well as associated benefits and limitations of implementation. Ultimately, this review seeks to determine the most effective communicative treatment options for amyotrophic lateral sclerosis and better understand the implications associated with each treatment plan.

Introduction

Amyotrophic lateral sclerosis, commonly referred to as ALS, is a progressive neurodegenerative disorder. It causes the degeneration and death of motor neurons in the brain and spinal cord. As a result, individuals with ALS experience a decline in voluntary muscle movement until they eventually experience complete loss of motor ability. Some associated symptoms with disease progression include: twitches, cramps, tightness, and weakness to the muscles. Other commonly experienced symptoms are difficulties walking, speaking, eating, swallowing, and breathing. Amyotrophic lateral sclerosis is a terminal illness and the average life expectancy is typically three to five years post symptom-onset. Respiratory failure associated with disease progression is most often attributed to cause of death. There is currently no cure for ALS and the majority of cases have no known cause (National Institute of Neurological Disorders and Stroke, 2024). According to the Centers for Disease Control and Prevention, in 2017, it was estimated that over 31,000 people in the United States are living with ALS (Centers for Disease Control and Prevention, 2017).

The Communication Bill of Rights states that, “all people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence” (Brady et al., 2016). In other words, everyone has the right to communicate in an effective manner. However, for individuals with ALS, this ability to express themselves through meaningful communication can be extremely hindered. In fact, “at some point in the disease progression, 80 to 95% of people with ALS are unable to meet their daily communication needs using natural speech. In time, most become unable to speak at all” (Beukelman et al., 2011). Thus, this deterioration of speech-motor abilities in individuals with ALS presents a need for effective communication interventions to help provide a successful avenue for communication.

Speech Language Pathologists (SLPs) are healthcare professionals who work specifically to diagnose and treat communication disorders. They are equipped to provide interventions for a wide range of speech, social, language, swallowing, and cognitive-communication difficulties. (American Speech-Language-Hearing Association, n.d.i). SLPs are an integral part of providing speech and swallowing interventions for individuals with ALS (The Amyotrophic Lateral Sclerosis Association, n.d.b.). For the purposes of this study, the role of an SLP will only be considered in regards to communication interventions for ALS. Responsibilities for speech language pathologists in this include: monitoring reductions in speaking rate, anticipating speech deterioration, recommending interventions, and implementing interventions. Moreover, there is a primary emphasis on compensatory strategies and for augmentative and alternative communication (AAC) implementation (The Amyotrophic Lateral Sclerosis Association, 2020; Beukelman et al., 2004; Beukelman et al., 2011; Boostani et al., 2023). The goal of SLPs for communication intervention in ALS is to maintain or improve the quality of life for the patient (American Speech-Language-Hearing Association, n.d.g.). This is accomplished through the provision of interventions which seek to support and prolong meaningful communication abilities (American Speech-Language-Hearing Association, n.d.c; Beukelman et al., 2011).

There are numerous communication intervention options for patients with amyotrophic lateral sclerosis. This literature review examines the implementation of several intervention options. Some interventions which have been suggested for patients with ALS include lingual exercise, respiratory exercise, palatal lift prosthesis, message banking, voice banking, AAC devices, speech-generating devices, eye-tracking technology, and brain computer interface systems (Beukelman et al., 2011; Hanson et al., 2011; The Amyotrophic Lateral Sclerosis

Association, 2020). This research seeks to further examine the impacts of these interventions on people with ALS, as well as their overall effectiveness.

According to Rule K of Principle I in the ASHA Code of Ethics, “Individuals who hold the Certificate of Clinical Competence shall evaluate the effectiveness of services provided, technology employed, and products dispensed, and they shall provide services or dispense products only when benefit can reasonably be expected” (American Speech-Language-Hearing Association, 2023). As a result of this standard, it is the responsibility and obligation of SLPs treating individuals with ALS to evaluate the efficacy of interventions. Moreover, the goal of this research is to determine the effectiveness of various communication interventions in the treatment of amyotrophic lateral sclerosis. Limitations to interventions will also be considered. This will investigate current research regarding various interventions, the means for determining efficacy for interventions, and the overall impact of interventions on individuals with ALS.

Review of Literature

What is Amyotrophic Lateral Sclerosis?

Amyotrophic lateral sclerosis, also known as ALS, is a progressive degenerative neurological disorder. It is characterized by its gradual decline of voluntary muscle movement in affected individuals (National Institute of Neurological Disorders and Stroke, 2024). The ALS Association further explains the impact of the disease through the origins of its name, "amyotrophic lateral sclerosis." The word "amyotrophic" can be broken down into three parts: "a," "myo," and "trophic." The beginning, "a" means no. "Myo" means muscle and "trophic" describes nourishment. Together, "amyotrophic" is indicating a lack of muscle nourishment, which results in its deterioration. Next, "lateral" is a directional description of the areas an individual with ALS is experiencing muscle degeneration. This is specifically referring to regions of the individual's spinal cord which house the nerve cells responsible for sending signals to the muscles; this is essential for the coordination and control of muscle movement. Finally, "sclerosis" refers to the formation of scar tissue in the body, as a result of nerve cell degeneration (The Amyotrophic Lateral Sclerosis Association, n.d.c). This definition provides an in-depth explanation for the disease's presentation. Ultimately, ALS is a disease which causes a continual loss of voluntary muscle movement throughout the body. It is characterized by its gradual declination of health in affected individuals, specifically relating to the nervous system. Amyotrophic lateral sclerosis specifically impacts the motor neurons of the brain and spinal cord. The progression of this disease causes these neurons to deteriorate and die. This results in muscle waste (atrophy), sclerosis, and weakness of voluntary muscle movement. This eventually leads to loss of bodily control and full paralysis (National Institute of Neurological Disorders and Stroke, 2024).

In 2017, an in-depth estimation was conducted to determine prevalence of amyotrophic lateral sclerosis in the United States. ALS is not a reportable disease at most state and local levels, meaning it is not required for individuals to notify health officials of a diagnosis. As a result, records regarding ALS have not been consistently held throughout the country. This means that there is no way to know a definitive number of ALS cases at the time. However, utilizing resources through the National ALS Registry, voluntary enrollment, and capture-recapture sampling techniques, it was estimated that there were somewhere between 17,800-31,843 cases of ALS in the US at the time (Mehta et al., 2022). According to the Centers for Disease Control and Prevention, there are on average 5,000 new diagnosed cases of ALS in the US each year (Centers for Disease Control and Prevention, 2017). Approximately 5-10% of these cases are familial, meaning there is a family history of the disease (The Amyotrophic Lateral Sclerosis Association, n.d.c). However, the remaining majority of diagnosed ALS cases are sporadic. Sporadic cases seemingly occur at random, with no clearly identifiable risk factors or history of disease within the family (National Institute of Neurological Disorders and Stroke, 2024). While ALS does impact people from a variety of backgrounds and ethnicities, there are some associated risk-factors. In regards to age, most individuals tend to start experiencing symptoms between 55 and 75 years of age. Men tend to be at a higher risk of developing ALS than women (National Institute of Neurological Disorders and Stroke, 2024). In familial cases, ALS tends to impact men and women in nearly equal quantities (Centers for Disease Control and Prevention, 2017). Additionally, individuals of a white or non-Hispanic background are more likely to develop ALS than individuals of other races or ethnicities. Research has also shown that military veterans are at an elevated risk for developing ALS (National Institute of Neurological Disorders and Stroke, 2024). Due to the progressive nature of the disease, amyotrophic lateral

sclerosis is fatal. There is no known cure for the illness at the time. However, new treatments are constantly being researched, experimented, and reviewed. Much progress has been made over the recent years and some treatments have demonstrated potential to slow disease progression and prolong survival. The average life expectancy for an individual diagnosed with ALS is 3-5 years after symptoms first begin. This time varies from person to person. Individuals with amyotrophic lateral sclerosis typically pass away as a result of respiratory failure, related to the illness (National Institute of Neurological Disorders and Stroke, 2024).

Etiology

Although the overwhelming majority of ALS cases do not have a known cause, research has indicated that genetic mutations are responsible for disease onset in many familial cases. According to the National Institute of Neurological Disorders and Stroke, defect in the C9orf72 gene, which is responsible for protein production in motor neurons and nerve cells, is linked to 25-40% of all familial cases (National Institute of Neurological Disorders and Stroke, 2024). Additionally, 12-20% of familial cases are linked to genetic mutations in the SOD1 gene, which is responsible for enzyme production (National Institute of Neurological Disorders and Stroke, 2024). There have been over 20 other genes linked to the disease (Masrori & Van Damme, 2020). In most cases, ALS has been associated with the presence of protein aggregation related to the TAR DNA-binding protein 43 (TDP-43) (Mead et al., 2022). There is ongoing research to determine other related factors which could be contributing indicators or causes of ALS. Potential links include injury, diet, environmental, and hereditary factors (Centers for Disease Control and Prevention, 2017).

Diagnosis

Although there is no cure for amyotrophic lateral sclerosis, receiving treatments and compensatory strategies early on can be essential for effective interventions (Beukelman et al., 2004; The Amyotrophic Lateral Sclerosis Association, 2020; Beukelman et al., 2011; Londral et al., 2015). Thus, receiving a diagnosis in the early stages of disease progression is essential. There is no singular test responsible for diagnosing ALS. Rather, there are a variety of resources utilized by healthcare providers to determine whether or not an individual should be diagnosed with ALS (National Institute of Neurological Disorders and Stroke, 2024). This diagnosis is based upon the progressive nature of an individual's muscle weakness, as well as signs of degeneration of the upper and lower motor neurons (Masrori & Van Damme, 2020). Upper motor neurons originate in the brain and are attributed to rigidity in ALS patients. Lower motor neurons originate in the spinal cord and their degeneration is characterized by muscle weakness, loss, and twitching (Department of Neurology, n.d.). Overall, a diagnosis is ultimately determined through order of elimination, meaning individuals would receive a thorough medical history review; as well as physical and neurological examinations. Some muscle and imaging tests utilized in this process consist of an electromyography (EMG), nerve conduction study (NCS), needle exam, and magnetic resonance imaging (MRI) test. These are primarily used to determine nerve and muscle functioning, although specific purposes vary by test. Additional testing, such as spinal taps, muscle biopsies, blood and urine tests, may also be conducted to distinguish ALS from other muscular diseases (National Institute of Neurological Disorders and Stroke, 2024). Due to the eliminating nature of this process, receiving a diagnosis may be time consuming. After symptom onset, individuals with ALS often endure a diagnosis delay of nearly a year (Masrori & Van Damme, 2020). Having input from a specialist who is familiar with the

disease can be beneficial in receiving a diagnosis quickly after symptoms begin presenting themselves (National Institute of Neurological Disorders and Stroke, 2024).

Presentation of Disease

There can be a varying range of symptoms present in individuals with ALS. However, marked characteristics which are consistent among those with a diagnosis are muscle weakness, atrophy (muscle waste), fasciculations (twitches), cramps, stiffness, and an increased slowness of movement (Masrori & Van Damme, 2020). Respiratory and cardiac abilities are also impacted by disease progression (Wexler, 2023). Muscle weakness often begins in a specific region of the body and progressively spreads from there. The region of onset for these characteristics separates amyotrophic lateral sclerosis into two primary subtypes: spinal and bulbar ALS (Masrori & Van Damme, 2020). Spinal ALS accounts for the majority of cases, impacting nearly two-thirds of individuals with ALS. This form of disease initially impairs the limb muscles. It is marked by initial weakness and fasciculations in the hands, feet, calves, and forearms. Conversely, bulbar-onset ALS accounts for nearly one-third of ALS patients. This variant primarily impacts the muscles surrounding the mouth and throat. It presents itself through difficulty with speaking and swallowing. These characteristics first occur in the early stage of ALS specific to their region of onset. However, as the disease progresses to affect more regions of the body, the difficulties associated with each subtype will eventually be experienced by both bulbar-onset and spinal-onset individuals. (Wexler, 2023). In addition to weakness and atrophy of the voluntary muscles of the body, ALS is also known to impact 35-40% of individuals through behavioral and cognitive changes (Masrori & Van Damme, 2020). Examples of these changes could include notable differences in impulsivity, apathy, social and emotional cognition (Caga et al., 2019). Additionally, 10-15% of individuals diagnosed with ALS will also receive a diagnosis of

frontotemporal dementia (FTD) due to the severity of degeneration to the frontal and anterior temporal lobes. This is known to lead to language and executive function impairments, as well as behavioral changes (Masrori & Van Damme, 2020). Despite some individuals experiencing impairment to executive function, it is important to note that most people with ALS are still cognitively aware of their progression of bodily impairment. While they may slowly lose their ability to verbally communicate, these individuals are still typically able to understand, reason, and remember. This is significant in the treatment process, especially for speech language pathologists when considering communicative intervention approaches. Additionally, it is important to consider how this physical awareness may impact an individual's emotional and mental wellbeing (National Institute of Neurological Disorders and Stroke, 2024).

Progression of Disease

Due to variation in the progression of ALS throughout the body and symptom presentation, there is a lack of a definite staging system to measure an individual's progress. The regions of the body affected, symptoms experienced, and rate of progression varies from person to person. As a result, the existing staging systems differ in their assessment and application to individuals with ALS. These differences have made it difficult for one system to become the standard for staging the disease progression. However, progression of disease in individuals with ALS can be broadly segmented into four stages. The Muscular Dystrophy Association has narrowed the progression down to early, middle, late, and end stages (Wexler, 2023). For the purposes of this analysis, these stages will be used in reference to various communicative interventions. These stages encompass the progression of ALS from symptom-onset to end-of-life care and death (Wexler, 2023).

Early-Stage

The early stage of ALS, as explained by the Muscular Dystrophy Association, is marked by symptom onset. This stage is outlined by the physical progression of an individual's symptoms. During this period, it can be expected to experience weakness, tightness, and rigidity of the muscles. Cramping, fasciculations, and the beginning of atrophy of the muscles can also be expected (Muscular Dystrophy Association, n.d.). For individuals with spinal-onset ALS, associated symptoms commonly consist of: difficulty walking, gripping, balancing, and completing fine motor tasks. Conversely, symptoms of ALS may first present themselves to individuals with bulbar-onset ALS through difficulties articulating, swallowing, chewing, and projecting one's voice. This variant can also cause slurred speech. During the early stage, symptoms are rather mild and are limited to one region of the body. Overall, during the early stage of ALS, patients are typically able to maintain a significant level of their independence. While the progression of disease and timing of stages vary from person to person, the early stage of ALS lasts approximately a year (Wexler, 2023).

Middle-Stage

The middle stage of ALS progression is primarily marked by increased severity of muscle weakness, as well as the widespread of symptoms to new regions of the body. At this stage, various muscles will likely be experiencing differing stages of disease progression. While one area may be experiencing complete paralysis, others may only be weakened or even remain unaffected. As a result of muscle paralysis, contractures may occur. Contractures describe the shortening and hardening of muscle. Due to this, individuals with contractures may also experience pain and rigidity around the joints. In general, the continuation of cramping and fasciculations can be expected, as well as increased severity of muscle loss. As a result of weakened muscles, individuals may also experience increased difficulty breathing, speaking,

eating, and managing saliva. Individuals may also experience the pseudobulbar affect; this is characterized by periods of uncontrollable laughing or crying. In the middle stage, individuals are still able to maintain some level of functionality. However, individuals at this stage will increasingly require more assistance in their daily lives. Levels of dependence will vary by person, but it is typical for an individual to be introduced to a feeding tube, respirator, and wheelchair or walker at this stage. These individuals are typically no longer able to drive. This stage could last anywhere from several months to over a year of time (Wexler, 2023).

Late-Stage

During this stage of ALS progression, most of the voluntary muscles of the body are paralyzed. Mobility at this stage is very restricted or impossible. As a result, eating, drinking, and speaking may be either extremely limited or not possible. Additionally, continued weakness to the chest muscles can make breathing progressively more difficult. Fatigue, headaches, blurred thinking, and increased risk of pneumonia can be attributed to low oxygen levels, as the result of difficulty breathing. To combat this, most individuals at this stage will also need some sort of ventilatory support to compensate for inadequate breathing function. The timeline of this stage varies, but it typically begins around two to three years post symptom-onset. During the late-stage, individuals generally require nearly round-the-clock assistance (Wexler, 2023).

End-Stage

As amyotrophic lateral sclerosis is a terminal illness, the end-stage of ALS primarily consists of end-of-life care. In addition to constant support for everyday motor functions, care at this stage emphasizes comfort for the individual's physical, emotional, and spiritual needs. After symptom-onset, an individual with ALS will typically live for two to five years (Wexler, 2023). However, this expected timeline varies. Nearly one tenth of ALS patients survive for ten years or

more after symptom onset (National Institute of Neurological Disorders and Stroke, 2024). Bulbar-onset ALS is attributed to having a shorter survival rate. Other factors which may contribute to a more limited timeline include older age, a quicker decline of functionality, and frontotemporal dementia (Masrori & Van Damme, 2020). Respiratory failure due to lack of oxygen is the most common cause of death for individuals with ALS. This is the result of difficulty breathing as a result of muscle loss, related to the disease's progressive degenerative nature. Other causes of death attributed to ALS symptoms include malnutrition, pneumonia, blood vessel blockage in the lungs, and atypical heart rhythms (Wexler, 2023).

Relation of Disease Progression to Communication Intervention

While bulbar ALS initially impacts the muscles necessary for speech production from the early-stage at symptom-onset, the majority of all ALS cases will ultimately result in communication difficulties (Masrori & Van Damme, 2020). Due to the progressive nature of ALS, the majority of patients will undergo the loss of function to most voluntary muscles of the body (Wexler, 2023). Thus, communication interventions can be impactful for both spinal ALS and bulbar ALS patients. However, the inherent urgency of such interventions and the nature they take on may differ based upon disease presentation and progression. While interventions can be effective in prolonging meaningful communication for individuals with ALS, it is important to be aware of the deteriorating nature of the disease when considering treatment plans (Beukelman et al., 2011). According to the American Speech-Language-Hearing Association (ASHA), the goal for a speech language pathologist when working with an individual in an end-of-life condition is to extend and enhance successful communication. This is achieved through compensatory strategies. Interventions are meant to allow an individual to express themselves as well and as long as possible, not to make improvements in their abilities. As a result of these

expectations for communication interventions, the means and method of compensatory strategies may change as the disease progresses throughout the various stages (American Speech-Language-Hearing Association, n.d.g).

What is a Speech Language Pathologist?

A speech language pathologist (SLP) is a healthcare professional who works to diagnose and treat a wide range of communication and swallowing disorders. More specifically, this range of communication disorders covers difficulties with social, language, and speech abilities. Additionally, their scope of practice covers cognitive-communication disorders, which may be related to brain injury (American Speech-Language-Hearing Association, n.d.i). An SLP treating a cognitive-communication disorder works specifically to combat difficulties with executive function. Examples of this include problem-solving, planning, and organization. In relation to social disorders, an SLP may work to help the individual grow in their understanding and responsiveness to various communicative social cues and rules. An SLP's role in treating speech disorders often covers speech production, fluency, and voicing. Language disorders can be either receptive or expressive in nature; an SLP is equipped to work in treating individuals who may struggle with either. Receptive language deals specifically with an individual's ability to understand the communication of others. Expressive language deals specifically with communicating an individual's thoughts and feelings to the world around them. Swallowing disorders and feeding difficulties are also addressed by speech language pathologists (American Speech-Language-Hearing Association, n.d.i). An SLP's scope of practice ranges from birth to death. There is a wide variety of settings speech language pathologists are needed in. Hospitals, private practices, and educational settings are common places of practice for an SLP. Additional responsibilities for SLPs may consist of multidisciplinary collaboration, aural rehabilitation,

accent modification, augmentative and alternative communication (AAC) systems provision, and providing training to caregivers. Ultimately, the role of an SLP is to work with individuals so that communication and swallowing can be effectively conducted (American Speech-Language-Hearing Association, n.d.i).

Implications of ALS on Communicative Abilities

The effects of amyotrophic lateral sclerosis are detrimental on an individual's ability to communicate with the world around them. Although affected communicative abilities may present themselves in a variety of ways, the primary area affected is an individual's speech production. "At some point, 80 to 95% of people with ALS are unable to meet their daily communication needs using natural speech" (Beukelman et al., 2011). This deterioration of speech ability occurs rapidly and typically leads to an overall inability to speak. Progression often begins with a slower speaking rate and leads to reduced speech intelligibility as disease advances (Beukelman et al., 2011). These deficits can be characterized initially through dysarthria of speech in bulbar ALS patients (Masrori & Van Damme, 2020). Dysarthria is a general term referring to neurogenic speech disorders of varying abnormal characteristics regarding strength, steadiness, tone, accuracy, speed, and range of speech movements. It often adversely affects an individual's speech intelligibility, or how understandable their speech is (American Speech-Language-Hearing Association, n.d.e). Since ALS causes the degeneration of both upper motor neurons (UMN) and lower motor neurons (LMN), the resulting difficulties can vary in presentation. Dysarthria of speech in individuals with bulbar ALS can demonstrate itself either through spastic or flaccid dysarthria. Spastic dysarthria is related to UMN dysfunction and presents itself through distorted, strained, and slowed speech. The degeneration of bulbar LMN is related to flaccid dysarthria, as well as tongue twitches and muscle reduction (Masrori & Van

Damme, 2020). Flaccid dysarthria is characterized by a deterioration of speech intelligibility, as well as hypernasality, related to nasal emission, and breathiness of speech (American Speech-Language-Hearing Association, n.d.d). Although bulbar ALS only accounts for a small percentage of ALS cases, the vast majority of cases eventually progress to display these difficulties in speech production (Masrori & Van Damme, 2020). As the disease continues to progress, dysarthria becomes more severe and weaknesses may be characterized through reduced phonation and the diminished movement of speech muscles (Beukelman et al., 2011). Another common characteristic in individuals with ALS is quiet and shortened speech. This is the result of a diminished forced vital capacity (FVC), which is necessary for forced exhalation and coughing. With a hindered ability to move air in and out of the lungs, the pressure and expiratory airflow needed for intelligible speech production is also diminished (Harkawik & Coyle, 2012). Such impaired speech characteristics continue to progress until the loss of motor speech function leads to a complete inability to speak. Furthermore, approximately 95% of individuals with ALS will experience full loss of speaking abilities (Beukelman et al., 2011).

In addition to impaired speech, an approximate 50% of ALS patients will also experience some level of impairment in executive function and language, or will show behavioral changes. Each of these abilities are essential for an individual to communicate effectively with others. Although these differences may not be as explicit, they are still worth acknowledging. Furthermore, individuals with ALS who have also met the criteria for ALS-FTD consists of 10-15% of patients. Associated communicative abilities which may be impacted include rhythm of speech, grammar, object knowledge, word-finding, single-word comprehension, sentence comprehension, and empathy (Masrori & Damme, 2020).

Additionally, the implications of this loss in speech-motor abilities may negatively affect the individual's overall quality of life. Research suggests that "when it becomes difficult to talk to communicate, individual and social identity can be negatively affected, increasing the risk of social withdrawal" (Cave & Bloch, 2020). Moreover, evidence suggests that an increase in speech difficulties have been associated with a decrease in quality of life for people with motor neuron disease (Cave & Bloch, 2020). This further intensifies negative attributes associated with ALS progression and reiterates the importance of effective communication interventions.

The Role of an SLP in ALS intervention

When considering treatment plans for individuals with ALS, speech language pathologists are responsible for providing interventions to assist with both speaking and swallowing difficulties (The Amyotrophic Lateral Sclerosis Association, n.d.b). However, for the purposes of this research, the role of an SLP will only be considered in regards to communication interventions. While swallowing interventions are encapsulated in the responsibilities of an SLP treating ALS, interventions related to swallowing difficulties are not discussed in this paper. In regards to communication, SLPs are often involved in the intervention process from as early on as before noticeable speech changes. Responsibilities in the early stages of disease progression consist of measuring and monitoring an individual's speech rate for indications of reduction (The Amyotrophic Lateral Sclerosis Association, 2020). Tracking the progressive decrease in speech rate can be especially helpful. Research has shown that the speaking rate in an individual with ALS tends to diminish before the intelligibility of speech is impaired. Furthermore, a quick decrease in intelligibility is noted in most patients once the speaking rate approaches approximately 45% to 65% of a typical speaking rate. This occurs at around 85 to 125 words per minute. By monitoring this progression of rate in regular intervals,

SLPs are able to somewhat accurately anticipate speech deterioration (Beukelman et al., 2004). As a result, augmentative and alternative communication (AAC) interventions can be referred to and implemented in a timely manner (Beukelman et al., 2011). During these beginning stages, some compensatory strategies may be encouraged by the SLP to prolong speech abilities and increase intelligibility (Boostani et al., 2023). As the disease progresses into the later stages, the role of the SLP shifts to focus more primarily on the use of AAC devices. The speech language pathologist is responsible for evaluating, recommending, training, and assisting in the use of AAC for individuals with ALS. Ultimately, it is the role of the SLP to ensure individuals are able to communicate competently throughout the development of ALS and to ensure access to the tools needed to do so (The Amyotrophic Lateral Sclerosis Association, 2020).

The American Speech-Language-Hearing Association (ASHA) is the accredited association headed over the speech language pathology profession. This organization is responsible for creating and maintaining guidelines. ASHA promotes accessibility, integrity, diversity, inclusion, and excellence in standard of care for SLPs to adhere to (American Speech-Language-Hearing Association, n.d.a). According to Rule K of Principle I in the ASHA Code of Ethics, SLPs have a responsibility to evaluate the effectiveness of services provided and only provide such services that can be expectantly beneficial (American Speech-Language-Hearing Association, 2023) The provision of services to individuals with speech, language, and progressive neurological disorders are listed as a role for speech language pathologists (American Speech-Language-Hearing Association, n.d.i). Moreover, amyotrophic lateral sclerosis is specifically listed as a potential etiology for communication disorder under ASHA's Scope of Practice in Speech Language Pathology (American Speech-Language-Hearing Association, 2016). Thus, determining the efficacy of communicative treatment options for ALS

is not only important for providing useful services for clients, it also falls under their obligations and responsibilities as SLPs.

Goal of Intervention

ALS is progressive and terminal in nature (National Institute of Neurological Disorders and Stroke, 2024). It is appropriate to consider this in regards to end-of-life approaches and treatment plans. According to ASHA, the goal of intervention for a SLP in end-of-life care is not to restore an individual's speech ability through rehabilitation. Rather, the role of an SLP is to maintain or improve the quality of life for the individual (American Speech-Language-Hearing Association, n.d.g). This is accomplished through providing accomodations which support efficient and effective communication. Thus, the expected result of communication interventions is to prolong and support communicative abilities as long as possible. This may be accomplished through adaptation of interventions as the disease progresses (American Speech-Language-Hearing Association, n.d.c). Ultimately, the goal of interventions for individuals with ALS is to allow accessible communication and limit communication barriers (Beukelman et al., 2011).

Importance of Early Response

Because of the rapid deterioration of communicative speech abilities in individuals with amyotrophic lateral sclerosis, an early response is vital. Particularly, anticipatory strategies help pave the way for preparation in the intervention process, even before major communication difficulties arise (Beukelman et al., 2004). Implementing proactive steps and well-timed interventions allows for effective communicative abilities to be maintained for as long as possible. An early response can be useful for a number of approaches to speech changes, especially those which help preserve the voice through banking systems (The Amyotrophic Lateral Sclerosis Association, 2020). Immediate responses upon diagnosis or speech changes is

primarily important for the utilization of augmentative and alternative communication (AAC). Such a response can allow for the process of referral, screening, and assessment to occur efficiently. This becomes increasingly important as this technology is acquired and implemented. Early response times can help prepare the individual for this new means of communication before they are entirely unable to speak effectively on their own. This is essential for meeting the daily communication needs of the individual with ALS (Beukelman et al., 2011). An in-depth study assessing the effect of the early initiation of AAC technology on the quality of life was reviewed. The research utilized a number of resources, including a performance analysis and a quality-of-life questionnaire. This study sought to determine the impact of this early introduction on quality of life for not just patients with ALS, but also their caregivers. Overall, the results indicated that early intervention could be useful for patient intervention acclimation, skill improvement in more complex AAC strategies, technology acceptance, and overall quality of life (Londral et al., 2015).

Overview of Communication Interventions

Since ALS is progressive in nature and leads to certain fatality, benefits of intervention are limited. As a result, associated interventions focus primarily on compensatory strategies rather than disease progression (Harkawik & Coyle, 2012). Speech interventions tend to progress alongside symptom progression in levels of patient dependence on intervention. In the early stages of degeneration, treatment plans may consist of exercise strategies to increase mobility, strength, and speech abilities (Beukelman et al., 2011). However, such interventions are controversial. Varying opinions debate whether or not the additional use of declining muscles may be counterproductive, especially in individuals with severe fatigue (Harkawik & Coyle, 2012). As a result, compensatory communication strategies are most often recommended for

individuals in the early stages of disease progression. Such strategies place an emphasis on conserving energy and adjusting environmental factors. These allow for easier communication with minimal effort. Examples of this consist of environmental changes, speech adjustments, and low-technology AAC devices, such as an alphabet board (Beukelman et al., 2011). Another less-discussed option for the patients in the early stage is a palatal lift prosthesis to increase intelligibility. This is accomplished through a reduction in hypernasality (Hanson et al., 2011). As the loss of speech function progresses, there is an emphasis on AAC devices, particularly high-technology. This use of AAC interventions is considered the standard of care for speech loss in individuals with ALS (Hanson et al., 2011). In regards to high-technology AAC interventions, eye-tracking technology has demonstrated itself to be one of the most beneficial for patients (Beukelman et al., 2011). Additional interventions include message banking and voice banking, which can be useful in speech generating devices (SGD) and text-to-speech (TTS) technology (The Amyotrophic Lateral Sclerosis Association, 2020). Brain computer interface (BCI), as well as head-tracking technology, are also beneficial in allowing for successful communication avenues for individuals with ALS (Beukelman et al., 2011). These interventions are further reviewed throughout this literature review.

Exercise

Until recently, the use of exercise has been strongly discouraged by healthcare professionals for individuals with amyotrophic lateral sclerosis (Harkawik & Coyle, 2012). In fact, a 2020 study surveyed 49 SLPs in general clinical practice and found that only 14.6% of the group would use oral motor strengthening exercises in treatment plan (Epps et al., 2020). This historic disapproval is related to a number of factors. Although the exact cause for ALS remains unknown, some studies have shown a correlation between previous participation in intense

physical activity with disease onset. Moreover, research has also reported a high incidence of ALS in individuals with physically-demanding professions (Bello-Hass et al., 2007; Chio et al., 2005; Haley, 2003; as cited in Harkawik & Coyle, 2012). While these reports do suggest a relationship between exercise prior to onset with disease presence, this is not necessarily indicative of the effects of exercise on symptom progression post-onset. Additionally, because fatigue is commonly experienced by individuals with ALS, it is widely recommended that energy conservation is prioritized. This was especially recommended so that the already-declining muscles are not unnecessarily overworked (Harkawik & Coyle). Despite these accusations, the idea that exercise should be avoided in individuals with ALS to prevent overuse and additional decline has not been sufficiently tested. There is not adequate data to conclude this theory regarding the harmful effects of exercise on individuals with ALS (Plowman, 2015).

Recent research suggests that moderate exercise can be useful for maintaining and prolonging motor function in individuals with ALS. Research also suggests that the lack of musculature usage and physical activity associated with exercise avoidance may lead to further weakness. Due to this recent change in general opinion, little experience has been associated with the practice of speech exercises as an intervention plan for ALS (Plowman, 2015). As a result, suggestions for speech treatment plans utilizing exercise are broad and information regarding implementation is limited. Respiratory and lingual exercise are both recommended as treatment options for individuals with ALS (Boostani et al., 2023). Lingual exercise is typically demonstrated through the use of tongue strengthening exercises through resistance training. Similarly, respiratory exercise associated with potentially beneficial ALS treatment consists of expiratory resistance training (Plowman, 2015).

Efficacy of Exercise

It is worth noting that exercise differs in purpose from other speech intervention strategies. Rather than compensate for communication loss through supplementary tools, this approach seeks to preserve the natural voice, slow symptom advancement, and lessen the intensity of inevitable speech-motor loss. With this in mind, it is important to realize that the nature of the disease will naturally prohibit this approach from entirely preventing declination. (Harkawik & Coyle, 2012). As aforementioned, there is extremely limited research examining the role of exercise as an active intervention for individuals with ALS in regards to speech function. However, there is an increasing amount of research which suggests that general exercise could be beneficial in maintaining motor function. Additionally, studies in other diseased individuals have shown promising results regarding lingual and respiratory strengthening exercises (Plowman, 2015).

While the effects of exercise on individuals with ALS is overwhelmingly limited, there are some studies which suggest it could be beneficial in a number of areas. A study researching the impacts of mild-moderate aerobic exercises in mice with SOD1 ALS was conducted. It demonstrated positive effects including delay of disease onset, an increased life span, improved motor performance, and improvement in motor neuron function (Plowman, 2015). A separate study examined the impact of exercise in humans with ALS. This study consisted of 25 individuals. 11 patients performed regular daily activities and were a part of the control group. 14 individuals participated in regular exercise. The results of this study showed that the exercise group did not experience a faster decline in muscle strength or increased fatigue. Rather, these individuals experienced decreased rigidity at three months and were clinically less disabled than their peers at three and six months (Harkawik & Coyle, 2012). Furthermore, a study researching the benefits of a resistance exercise program found that participants experienced significantly

greater scores concerning their upper and lower extremity function compared to their peers, according to the ALS functional rating scale (Harkawik & Coyle, 2012). While these may not explicitly outline speech implications as a result of exercise, it is contrary to previous beliefs regarding exercise and ALS (Harkawik & Coyle, 2012). Recent studies have suggested that limb and respiratory exercise may be beneficial in maintaining motor neuron health, motor function, and overall survival for individuals with ALS. While these are not explicit towards speech communication abilities, it does suggest that these benefits overlap to aid these areas. Speech intelligibility, air pressure, and tongue strength are among the abilities thought to be potential recipients of lingual or respiratory exercise (Plowman, 2015).

Loss of speech intelligibility in individuals with ALS is related to the slowed movement and decreased strength of the articulators, including the tongue. Thus, lingual strengthening exercises, which works to combat reduced tongue strength, could potentially aid patients in maintaining speech intelligibility (Plowman, 2015). Progressive lingual resistance training has been researched in a number of populations, including animals, healthy adults, and disordered clients. Such interventions have demonstrated improved tongue force in both rodents and healthy humans. Moreover, lingual resistance training has also demonstrated increased lingual strength and performance in diseased individuals. A stabilization in tongue pressure and preservation of swallowing abilities was also noted in an individual with a neurodegenerative disorder. Although this research is not specific to amyotrophic lateral sclerosis, it is thought that these might be indicative of potential benefits for this treatment plan (Plowman, 2015).

Weakness of the expiratory muscles, as a result of ALS, can be attributed to a decrease in expiratory pressure, airflow, and forced vital capacity. In consequence, the ability to speak loudly and with significant length of utterance are also hindered. Both of these factors are

considered important for speech intelligibility. Thus, if respiratory exercise is able to demonstrate effectiveness in maintaining or improving expiratory pressure, then associated factors could be speech intelligibility (Harkawik & Coyle, 2012). In regards to respiratory exercise studies on individuals with ALS, research is limited. Such trials have demonstrated non-significant and temporary improvements in inspiratory pressure, but the impact of treatment was determined to be unclear. It was noted, however, that inspiratory strength training was identified as an indicator for patient survival. In 18 clients, it was reported that this inspiratory strength training was related to an increased survival of 14 months in comparison to similarly attributed peers (Plowman, 2015). Rather, there is more conducive study researching the impacts of expiratory muscle strengthening exercises on individuals with bulbar dysfunction. While this is not specific to ALS, it does have significant findings which could demonstrate potential benefits for individuals with ALS. This study examined the use of expiratory muscle strength training (EMST) on a wide range of individuals, including those with Parkinson's disease, multiple sclerosis, and healthy adults. This intervention uses daily resistance training through expiration. It has been associated with benefits in expiratory generation capacity and improved airway protection. This exercise intervention is believed to be able to provide these same benefits in individuals with ALS (Plowman, 2015).

As of 2017, only two case studies demonstrated the effects of exercise interventions specifically on speech abilities in ALS. In both studies, the individual demonstrated worsened speech function over time. However, it was decided in both cases that no general conclusions regarding these speech treatments could be made. This was attributed to the quick progression of disease in one individual and to a lack of controls in the other case. While these both provide insufficient research to provide conclusions regarding the efficacy of exercise on speech abilities,

both demonstrated the rapid nature of disease progression in ALS (Plowman, 2015). This similarity is a good reminder that while exercise may be a contender in treatment plans, the long-term result of ALS is communication loss and death. While exercise may be beneficial in delaying speech loss, it is also important to recognize that this treatment plan has limitations. As ALS progresses, it is important to be mindful of when exercise is no longer beneficial and to begin implementing AAC (Harkawik & Coyle, 2012).

Palatal Lift Prosthesis

The use of a palatal lift prosthesis is recommended for ALS patients experiencing a loss of speech intelligibility as the result of hypernasality (The Amyotrophic Lateral Sclerosis Association, 2020; Plowman, 2015). According to the American Speech-Language-Hearing Association, hypernasality is characterized by excessive nasal resonance on voiced, oral sounds. This particularly impacts vowels (American Speech-Language-Hearing Association, n.d.h). This hypernasality is often attributed to ALS, as it is related to the deterioration of velopharyngeal function, which is an important system in resonance (Eshghi et al., 2021). A palatal lift prosthesis is a prosthetic device similar to a dental retainer. It goes within the mouth to provide a lift to the soft palate and prevent nasal emission while speaking (Cleveland Clinic, 2021). This device is often used to reduce the hypernasality of speech (Ohno et al., 2017). It helps accomplish this reduction by providing structural support in individuals with damage to this region of the body (American Speech-Language-Hearing Association, n.d.b).

Efficacy of Palatal Lift Prosthesis

Palatal lift prosthetics are not commonly requested by neurologists for individuals with ALS. However, there is evidence to suggest that it is a beneficial treatment option for experiencing improved speech intelligibility for individuals with ALS. A study was conducted

which evaluated the effectiveness of palatal lift/augmentation prosthetics in 25 individuals. Of this group, 84% demonstrated a decrease in hypernasality and overall improvement in relation to difficulties of dysarthria. Moreover, 60% of these individuals also demonstrated articulatory improvement. As a conclusion of this study, it was recommended that palatal lift/augmentation prosthetic devices be given thought when determining intervention plans for ALS (Esposito et al., 2000). It is important to note that while this tool may be beneficial for increasing speech intelligibility, it is limited in its usage. This intervention is meant to be utilized when oral communication is still possible. AAC should be considered as speech deterioration progresses (The Amyotrophic Lateral Sclerosis Association, 2020).

Augmentative and Alternative Communication

Although research regarding interventions such as exercise and palatal lift prosthesis suggest positive effects for individuals with ALS, they are limited in effectiveness by duration of use. In other words, the efficacy of such strategies are confined by the progression of ALS (Plowman, 2015). Thus, there is a need for interventions which continue to allow communication when the natural ability to speak becomes increasingly insufficient (The Amyotrophic Lateral Sclerosis Association, 2020). Hence, the use of augmentative and alternative communication (AAC) interventions for individuals with ALS experiencing speech-related loss is considered to be the standard of care. Such interventions are often utilized over an extended period of time and are typically made with adjustable accessibility to coincide with the individual's progressive deterioration of motor function Moreover, a recent data analysis from the Nebraska ALS Database demonstrated that many individuals with ALS who have utilized AAC have continued to do so up until the last few weeks of life (Beukelman et al., 2011). On average, individuals with bulbar ALS used AAC technology 24.9 months and those with spinal ALS used this technology

approximately 31.1 months (Beukelman et al., 2011). When considering potential reasoning for this disparity, it is worthwhile to mention that individuals with bulbar-onset ALS tend to have a shorter life expectancy. This subset of ALS is characterized by rapid decline (Masrori & Damme, 2020).

Augmentative and alternative communication (AAC) is explained by ASHA as a type of supplementary or compensatory practice. This aids in spoken and written forms of communication for individuals with speech-language production or comprehension impairments. This form of interventions covers a wide range of tools and strategies but is overall meant to improve daily functioning for affected individuals. AAC ranges from unaided forms, such as gestures or verbalizations, which do not require an external tool, to aided AAC which utilizes external tools. Aided AAC could be low-technology (nonelectronic), or high-technology. High technology options utilize electronic tools and could consist of speech generating devices, computers, and digitized speech (American Speech-Language-Hearing Association, n.d.c). For the sake of this literature review, there will be an emphasis on high-technology AAC devices. These high-tech AAC devices are especially beneficial for ALS patients because they require minimal motor ability and can be utilized with little to no head or limb movement (Linse et al., 2018).

Determining Efficacy of AAC

Based upon research conducted, there is no recognized set of standards by which efficacy of AAC for ALS can be determined. However, using ASHA's responsibilities for SLPs in AAC services, as well as palliative and end-of-life care, a set of standards can be deduced. First and foremost, it is important to note that the evaluation of outcomes for AAC interventions using evidence-based practice is specifically outlined as a role for SLPs (American Speech-Language-

Hearing Association, n.d.c). Evidence-based practice (EBP) is an evaluative process which utilizes patient perspective, clinical expertise, and evidence in order to make informed care decisions (American Speech-Language-Hearing Association, n.d.j). Moreover, some considerations in AAC use for end-of-life care include flexibility of accessibility to meet changes in patient mobility and to allow the individual the ability and access to functional communication for as long as possible (American Speech-Language-Hearing Association, n.d.c). Ultimately, in end-of-life care, the primary role of an SLP is to provide intervention which helps improve or maintain an individual's quality of life. Treatment plans may vary person-to-person, based on the client opinion, and disease progression and presentation (American Speech-Language-Hearing Association, n.d.g). Thus, while other implications may be reviewed, quality of life for the individual was the primary standard by which efficacy of AAC interventions was determined.

Limitations of AAC Interventions

Contributing factors which may potentially cause limitations on efficacy of AAC interventions include inadequate training and support, environmental factors, cognitive impairments, timing of recommendation and implementation, and rate of progression (Beukelman et al., 2011). Other factors could include patient opinions, caregiver opinions, lack of acceptance, lack of motivation, and equipment breakdowns (American Speech-Language-Hearing Association, n.d.c).

Speech-Generating Devices

A speech-generating device (SGD) is the form of high-technology AAC which allows individuals with partial or full limb paralysis the ability to successfully communicate. SGDs create an avenue for communication by generating speech for the individual. This can be accomplished through synthesized speech or by utilizing a previously recorded voice. This

option allows the person with ALS (pALS) to communicate using their own speech. This opportunity is available as a result of voice and/or message banking. While banking is not necessary, it does offer individuals a more personal communication avenue (Roman et al., 2021). In the case that an individual's natural voice is not stored, SGDs often allow an individual to select a voice which reflects their own age, ethnicity, gender, and race (American Speech-Language-Hearing Association, n.d.c). SGDs also offer a wide range of accessibility, allowing for pALS to select letters, words, and messages through alternative methods to typing. Some options include eye and brain-computer interface technology. Overall, speech-generating devices are popularly accepted by individuals with ALS, offer significant communication abilities, provide a personal avenue to utilize one's own voice after speech-motor loss, and offer a wide range of modalities for varying levels of mobility (Roman et al., 2021).

Moreover, the utilization of speech generating devices in ALS intervention plans is significant. As of July 29, 2015, "Medicare recognized speech-generating devices (SGDs) as Durable Medical Equipment, which is a covered benefit for Medicare beneficiaries under the Social Security Act (Section 1891)" (American Speech-Language-Hearing Association, n.d.f). This is inclusive of devices which assist in meeting functional speaking needs and speech generation (American Speech-Language-Hearing Association, n.d.f). This allows for more wide-range accessibility for SGDs in ALS treatment. Additionally, Medicare has historically referred to AAC devices as speech generating devices. This occurred when Medicare first began aiding in communication device payment. As a result, these terms have often been used interchangeably (The Amyotrophic Lateral Sclerosis Association, n.d.a). This connection was reflected in my research. Thus, allowing the implication that studies demonstrating the efficacy of speech-

generating devices were often, but not always, indicative of high-technology AAC interventions as a whole and vice versa.

Efficacy of Speech-Generating Devices

According to a 2021 research article, speech-generating devices have demonstrated a significant number of benefits for individuals living with amyotrophic lateral sclerosis. Generally, SGDs provide pALS with an avenue to continue functional communication even after patients have experienced severe speech-motor loss or even full body paralysis. SGDs have been widely accepted by individuals with ALS for communication in face-to-face interactions, e-mail, phone communication, and social networking. In regards to their impact on users, SGDs have demonstrated positive impacts on family, work, and community participation. Furthermore, SGDs have been shown to help aid in communication between pALS and their healthcare providers. Furthermore, the article indicates "enabling these communication functions has been shown to decrease anxiety, depression, and fear, and to improve self-determination, autonomy, intimacy, and quality of life for pALS" (Roman et al., 2021, p. 2099). The implementation of SGDs in pALS is also beneficial to caregivers. SGDs have been shown to decrease caregiver burden, increase social life, and improve interactions between caregivers and patients (Roman et al., 2021). While this research is indicative of associated benefits in relation to SGD implementation for pALS, there is a lack of quantitative research for speech generating devices in general. Rather, most studies were limited to a specific avenue or method of intervention for SGD usage. Thus, more specific research was conducted to account for this.

Speech-generating devices offer individuals with a wide range of alternative selection options to better accommodate limited accessibility associated with a loss of motor ability (Roman et al., 2021). The following research seeks to better understand the efficacy of some

SGD accessibility options. It also reviews the impacts of voice and message banking options. These interventions are additional avenues for SGD utilization which could provide for more effective and meaningful communication for pALS (Roman et al., 2021).

Voice Banking

Voice banking is a process by which individuals are able to record and store a collection of their speech. These recordings are then used to create synthesized speech. The purpose of voice banking is to create a synthetic voice which comes close to the natural voice and characteristics of the individual's sample recordings. This new synthesized speech is then implemented into speech generating devices. This service is recommended prior to significant speech loss (American Speech-Language-Hearing Association, n.d.c).

Efficacy of Voice Banking

The research conducted for this literature review did not find any studies examining the value or effectiveness of voice banking on individuals with ALS. This overwhelming lack of research is consistent with the conclusion of a 2020 study reviewing the views and expectations regarding voice banking. While there is no known clinical research regarding the value of voice banking, some potential advantages and disadvantages can be considered (Cave & Bloch, 2020). In this, it is important to note that the overall utilization of this service is limited by remaining speech-motor abilities and banking should occur while speech skills are still intact (American Speech-Language-Hearing Association, n.d.c).

The primary goal of voice banking is to allow the individual to have a more personalized synthesized voice. The intended benefit is to provide a means of voiced communication which is a more unique option to the individual than a generic synthetic voice may allow. However, the created synthetic voice is not capable of entirely recreating the individual's natural speech. The

created voice is incapable of properly replicating the natural intonation, timing, emotion, sarcasm, and irony which are naturally conveyed through speech. These are crucial elements in communicating meaning through speech. Moreover, the absence of these characteristics has been regarded as sounding robotic and may seem impersonal or unfriendly to individuals accustomed to natural speech (Cave & Bloch, 2020). Additionally, some patients who have utilized voice banking have indicated that they do not perceive the recorded voice to be their own. Even more, patient relatives have demonstrated difficulty accepting that the synthesized speech utilizes the voice of the patient for communication (Linse et al., 2018).

A study regarding the use of voice banking for a personal synthetic voice was conducted on individuals undergoing a laryngectomy procedure. The study claimed that this voice banking positively contributed to the patients' quality of life. However, it was determined that there is a need for more verifiable evidence to support this claim (Cave & Bloch, 2020). Another small-scale study determined that this personalized synthetic voice could be beneficial to the significant others of pALS by reducing stress associated with forgetting the sound of their loved one's voice (Cave & Bloch, 2020).

While there is an absence of current research regarding implications of voice banking, a 2020 study sought to determine why individuals with motor neuron disease chose for or against voice banking. Individuals who opted for voice banking viewed it as a way to preserve a sense of identity, control over their life, and maintain more personal social connections. On the contrary, patients who chose not to bank their voice often attributed it as an unnecessary waste of time. These individuals also indicated that the lack of natural speech characteristics in synthesized voice and an inability to preserve a complete sense of identity made it not worthwhile (Cave & Bloch, 2020). These associated factors could provide insight into potential effects of voice

banking on individuals with ALS. Personal experiences with voice banking may be investigated on a small scale, but vary person to person. However, there is an overwhelming need for further research studying the effects of voice banking on pALS and implications for overall quality of life. This can be best summarized by the words of a significant other to an individual with a motor neuron disorder regarding voice banking. They stated, "'we're making this commitment without knowing anything about what benefits it will have really'[CP6]" (Cave & Bloch, 2020).

Message Banking

Message banking is a process by which individuals record and store a collection of frequently utilized or meaningful utterances (Roman et al., 2021). These recordings could consist of sounds, words, sentences, or phrases. Message banking is unique because it allows SGDs to reproduce the individual's natural speech, rather than a synthesized version. In other words, this gives the individual the opportunity to utilize their own voice to communicate with those around them. This is significant in allowing speech individually characterized to the pALS, specifically in terms of natural voice, inflection, and intonation (American Speech-Language-Hearing Association, n.d.c). Moreover, these recorded messages can sometimes be used by voice banking services to create a synthetic voice (The Amyotrophic Lateral Sclerosis Association, 2010). In the case that the individual with ALS does not bank messages themselves, someone else may record such messages in their place (American Speech-Language-Hearing Association, n.d.c). Similar to voice banking, messages are intended to be recorded while the individual maintains a significant level of intelligibility and then later utilized after speech-motor loss (Majmudar et al., 2014).

Efficacy of Message Banking

Similar to voice banking, there was no identifiable study researching the implications of message banking on pALS. However, this resource does allow the individual to have some remaining use of their natural voice through recorded phrases. Message banking differs from voice banking in that the unique and natural characteristics of the individual's speech can be preserved in certain phrases. Moreover, message banking does not require as much energy or precision of speech as voice banking, as it is not inherently being used to create a synthesized voice (The Amyotrophic Lateral Sclerosis Association, 2020). However, this task of banking messages can still be labor and time intensive. Additionally, it is limited in accessibility by disease progression and message banking must occur early in ALS progression (Zhao et al., 2019). Another limitation of message banking is the number of possible utterances available. This number is restricted to the recorded messages (American Speech-Language-Hearing Association, n.d.c). However, there is a flexibility of message banking to also be utilized by voice banking for synthesized voicing (The Amyotrophic Lateral Sclerosis Association, 2010). This could be significantly advantageous in determining an intervention plan.

While there is a lack of empirical evidence supporting the effectiveness of message banking on quality of life, a podcast interview with SLP Emily Kornan may provide insight to the implications of message banking on the pALS and their family. She explained the significance of being able to communicate emotion through message banking and how it allows a sense of control in how one sounds in various situations. She goes on to explain that message banking helps to nurture and sustain connections with family members through preservation of the voice (Gray, 2022). In the interview, ALS patient, Brian Jeansonne, explained the importance of still being able to tell his children he loves them. He also expressed gratitude for an early start in the message banking process. Finally, his wife talked about how she still feels like his voice

has not been lost, because she hears it every day (Gray, 2022). While this may not be indicative of the effects message banking has on pALS on a large scale, it does provide insight to some possible positive implications regarding this form of voice preservation and communication.

Eye-Tracking Technology

Eye-tracking technology systems are an accessibility option by which individuals with ALS are able to utilize speech generating devices (Linse et al., 2018). Essentially, these devices are able to track eye movements, which are then used to control cursor control with computer technology or high-technology AAC devices (Beukelman, 2018). These eye-tracking devices can also be useful for navigating the internet and for typing on custom screens as a means of communication (National Institute of Neurological Disorders and Stroke, 2024). This technology primarily tracks eye movements and gaze in order to provide an avenue for successful communication (Beukelman, 2011). In order to use such devices, the user must be able to have remaining muscle control regarding upper, lower, and lateral eye movements (The Amyotrophic Lateral Sclerosis Association, n.d.a). This accessibility option utilizes an invisible infrared light to track eye movement. This light then reflects on the pupil of the eye (Ball et al., 2012). The infrared light also produces a reflection on the cornea. Both of these reflections are received using an infrared sensitive camera sensor to produce images. These are then utilized to calculate where the individual is looking on a computer screen (Linse et al., 2018). This allows for item selection when an individual's gaze remains at a specific location on screen. This can be used to construct messages and pair with speech generation to vocalize communication for the pALS (Ball et al., 2012). This technology is extremely commonly utilized as a form of direct access to AAC technology, as the use of eye movement is typically preserved in individuals with ALS. Thus, eye-tracking technology can often be utilized even into the later stages of disease progress

and motor function loss (Ball et al., 2012). Moreover, the movement of the eye muscles is generally not fatiguing and eye-tracking is thought to be the least fatigue-inducing access method for AAC technology in pALS. Additionally, eye gaze is natural and may be the only voluntary movement accessible for individuals in later-stages of ALS (Beukelman, 2011).

Efficacy of Eye-Tracking Technology

In 2013, a study was conducted to determine the impact of eye-tracking communication technology on individuals with amyotrophic lateral sclerosis. This study sought to determine the effects of this intervention on pALS communication abilities and quality of life. It is one of few studies which have examined such implications. Participants of this study were in late-stage ALS, had complete loss of speech abilities, and were paralyzed in the upper and lower body. In order to qualify for this study, participants had to demonstrate severity of symptoms by receiving a score of 0 on the speech section of the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised. This indicated maximal disability in speech abilities. This study administered three assessment scales to determine the effects of eye-tracking technology on patients. The Individually-Prioritized Problem Assessment (IPPA) evaluated the provision of eye-tracking technology to diminish problems in daily activities through the patient's perspective. The Psychosocial Impact of Assistive Devices Scale (PIADS) is a questionnaire which was used to evaluate the effect of eye-tracking technology on functional independence, well-being, and quality of life. Finally, the Quebec User Evaluation of Satisfaction with Assistive Technology measured the pALS overall satisfaction with eye-tracking technology. These surveys were sent out to patients and completed with the use of eye-tracking technology by 35 participants (Caligari et al., 2013).

Results of the study indicated that eye-tracking communication devices were “effective in reducing communication disabilities (as measured by IPPA), improving QoL (quantified by PIADS subscales), and producing high user satisfaction (QUEST 2.0-Dev)” (Caligari et al., 2013, p. 549). Moreover, results from the PIADS demonstrated a positive impact of eye-tracking technology in regards to competence, adaptability, and self-esteem. Each of these factors were attributed as indicators of positive impact on the patient's quality of life. Additionally, the IPPA indicated a significant decrease in communication difficulties when conveying a message, one’s feelings, opinions, and medical decisions. This was determined in comparison to communication without a device or using only a caregiver-reliant eye-tracking board. The QUEST 2.0-Dev results indicated high satisfaction for the pALS in regards to device weight, safety, durability, effectiveness, comfort, simplicity of use, dimension, and adjustments. Overall, this study determined that eye-tracking technology can be beneficial in providing individuals with an effective option in managing communication difficulties, improving quality of life in the late stages of ALS, and allowing continued meaningful communication (Caligari et al., 2013).

This positive impact on quality of life attributed to eye-tracking technology has also been supported by a number of studies. “Several cross-sectional and two longitudinal studies found a positive association between higher psychosocial wellbeing or quality of life and the use of eye tracking computer systems” (Linse et al., 2018). Furthermore, the first study to evaluate the connection between quality of life and eye-tracking computer systems on pALS who are experiencing upper and lower body paralysis determined that this intervention is useful in preserving independence. This patient autonomy is important in allowing social interaction and quality of life. The findings of this study further imply that eye-tracking devices are beneficial in maintaining high quality of life for individuals with ALS (Linse et al., 2018).

The effectiveness of eye-tracking technology may be negatively impacted by dysfunction in oculomotor abilities. In the case that an individual progresses to a total locked-in-stage and is unable to control eye movement, the use of eye-tracking computer systems would become obsolete (Linse et al., 2018). Other limitations to this technology may include eye-gaze fatigue, difficulty holding a stable head position, and pupil dilation as the result of medication use (Vansteensel et al., 2023).

Brain-Computer Interface

A brain-computer interface (BCI) is an avenue by which individuals with ALS are able to access speech generating devices (Roman et al., 2021). This technology detects brain activity and transforms it into meaningful commands, useful for computer operation (Linse et al., 2018). BCI technology can be utilized through invasive or noninvasive means. Invasive methods utilize implantable electrodes to track brain activity. Conversely, noninvasive methods may utilize electroencephalography (EEG), magnetoencephalography (MEG), fMRI, and near-infrared spectography (NIRS) technology (Beukelman et al., 2011). EEGs measure electrical activity of brain neurons through electrodes which are placed on the individual's scalp (Light et al., 2010). MEGs analyze the magnetic fields produced by neural electricity. It measures this using a system of highly sensitized magnetic sensors (Cleveland Clinic, 2023). An fMRI analyzes brain activity through changes in the magnetic field as a result of oxygen concentration and blood flow (Glover, 2012). NIRS analyzes brain activity through monitoring the oxygenation of tissue (Moerman & Wouters, 2010). In theory, BCIs could be extremely beneficial for communication in pALS who have experienced significant motor loss or experience fatigue holding a gaze. This could be extremely beneficial for individuals with hindered oculomotor abilities, causing difficulty controlling eye movements. Furthermore, BCIs would be the only remaining option for

individuals who are experiencing full-body paralysis, also known as total locked-in-state (TLIS). This stage prevents a total loss of voluntary muscle movement, including the eye muscles. Thus, BCIs would be the only remaining beneficial communication intervention for individuals who progress to this stage, as it utilizes brain activity for computer operation and is not dependent on motor ability. Moreover, these devices are not dependent on a still or specific body positioning for the individual. This aspect is advantageous over eye-tracking computer systems. However, while BCIs could be a promising intervention for future utilization, current studies on use are primarily limited to an experimental setting and further research on BCIs is needed (Linse et al., 2018).

Efficacy of Brain-Computer Interface

Brain-computer interfaces differ from other communication interventions in that they allow the individual with ALS to continue communication even after the patient has experienced full-body paralysis, including the loss of controlled eye movement. In other words, the use of this intervention is not limited by lack of voluntary muscle movement (Linse et al., 2018). While this could prove to be advantageous for pALS, BCI technology is relatively new and lacks significant research to indicate the effects of utilization on a widespread scale (Vansteensel, 2023).

A study researching the implications of brain-computer interfaces pALS was published in 2013. This study sought to assess the reliability and usefulness of this technology through independent use by pALS in the home. Participants in this study were referred by the US Department of Veterans Affairs. Some qualifications for participation included a life expectancy of a year or more, the ability to read and give informed consent, a home environment suitable for BCI operation, an available BCI system assistant over the age of 18, and a complete loss of verbal and written communication skills. The study began with 42 consented individuals.

However, only 27 participants had the BCI systems implemented in their home and received training to utilize it. This disparity is the result of a lack of criteria met, inability to use technology, or lack of assessment for use. Moreover, 12 of the original participants left the study due to disease progression or fatality and 6 left as the result of diminished interest. As a result, a total of 14 individuals completed the necessary training and utilized the BCI system in their home independently. Participants in the study, as well as their system assistant, received adequate system training and then entered into a 12-18 month period to utilize this technology within the home. The BCI system included in this study was the Wadsworth BCI home system. This specific system monitors brain activity through EEG technology to make selections from a 72 item response list. These selections allow the participant to operate a full keyboard with complete functionality. Overall, this study sought to determine the accuracy, and usability of BCIs in the home. Additionally, it assessed the impacts of such technology associated with quality of life on the pALS and their caregiver (Wolpaw et al., 2018)

This study used the Internet to track device usage and the McGill Quality of Life (MQoL) questionnaire to evaluate the impact of the technology on the pALS quality of life. On average, the BCI was used 26% of the days over the course of the study for an average of 1.3 hours per day. The BCI technology was considered accessible, or in working order, 98% of the time. The accuracy of copy-spelling using BCI technology averaged 73% over the course of the in-home study. Additionally, all in-home participants of this study were able to utilize the brain-computer interface for independent communication. Overall, the results of this study indicated that the majority of participating pALS and their system assistants expressed that the benefits regarding BCI usage outweighed burdens. Additionally, the average results of the MQoL did not indicate a decline in quality of life, despite a notable decrease in neuromuscular function. At the end of the

study, 7 users decided to continue use of the brain-computer interface system (Wolpaw et al., 2018). While these results are not indicative of brain-computer interfaces as a whole, they do offer a glimpse into the BCIs ability to allow for extended communication skills past speech-motor loss and to maintain the individual's quality of life.

However, other studies have indicated varying results regarding the accuracy of BCIs for communication and potential implications for pALS. One study sought to evaluate accuracy using the overall spelling speed and percentage of accurate target selection. This research group evaluated 25 patients. Of this group, 17 achieved a high accuracy level with an average of 92% accuracy in target selection. However, 8 members of the group received an average score below 40%. This disparity might indicate that BCIs are not quite usable across the board as a means of communication. Moreover, some studies have indicated average spelling rates of 2.1 to 5 words per minute. Some BCI systems which utilize EEG technology have reported scores as low as one letter per minute. In comparison, a spelling rate of 15-19 words per minute has been indicated to be satisfactory by persons with ALS. While these results indicate that some individuals may still have a level of autonomous and accurate communication through BCIs, the need for improved speed and accuracy is essential. While this approach could be beneficial at providing an avenue of communication for individuals in a total locked-in state, limitations regarding accuracy could be critical for pALS making end-of-life care decisions (Linse et al., 2018).

A limitation which may impact the effectiveness of BCIs is the lack of time for the extensive training required for accurate use. This could be hindered by the rapid progression of disease (Linse et al., 2018). Another limitation specific to EEG BCIs could be the required effort on behalf of the system assistant in order to place the electrode cap and initiate the system. This process of set up, removal, clean up, and other related tasks has been reported to take a total

average of 32 minutes. This requirement creates an additional level of dependence on the caregiver for accessible communication abilities (Wolpaw et al., 2018). Furthermore, patients with visual dysfunction may require a different modality of stimulus for BCI utilization. Overall, while BCIs could be a promising intervention for individuals with significant motor function loss, there is a prevalent need for technological improvements to provide more established benefits in use (McFarland, 2021).

Discussion

The purpose of this literature review was to investigate the efficacy of various communication interventions for individuals with amyotrophic lateral sclerosis (ALS). This study evaluated the effects of disease progression on communicative abilities for affected individuals. It further reviews the role of speech language pathologists in intervention plans, as well as the goal of communication interventions for ALS. It also discusses the importance of understanding the effectiveness of interventions. A means for determining efficacy for augmentative and alternative communication is discussed. This study evaluates various recommended intervention options and the implications associated with each plan. This research intends to determine the most effective and impactful interventions for patients. Overall, this analysis seeks to analyze the overall efficacy of communication interventions for ALS. This study has an overall emphasis on compensatory strategies and acknowledges the overall limitation on efficacy of interventions as a result of disease progression.

Overview of Results

Due to the progressive nature of amyotrophic lateral sclerosis, the continued loss of voluntary movement severely inhibits the effectiveness of all interventions on communication gain. Ultimately, the end point of ALS is death for all patients. Thus, any associated benefits attributed to communication interventions are finite. While there is no intervention which will be able to successfully rehabilitate or preserve natural speech abilities in individuals with ALS, there are some interventions which seek to prolong communicative abilities (Harkawik & Coyle, 2012). Moreover, some communication interventions were successful in their intended purposes for maintaining quality of life and prolonging meaningful communication throughout disease progression.

Of the interventions evaluated in the literature review, exercise and palatal lift prosthesis differ in that they are dependent on remaining speech-motor abilities and are extremely limited by disease progression (Harkawik & Coyle, 2012; Ohno et al., 2017). Furthermore, exercise differs significantly from every other intervention researched in this literature review, as it is not a compensatory strategy. Rather, the goal of lingual and respiratory exercise is to preserve the natural voice for as long as possible and to prevent further loss of speech skills (Harkawik & Coyle, 2012). Comparatively, the role of palatal lift prosthetics in ALS communication intervention is to provide increased intelligibility and reduced hypernasality in remaining natural speech. While this is still reliant on remaining motor function, the purpose of this intervention is to provide structural support to accommodate for muscle loss (The Amyotrophic Lateral Sclerosis Association, 2020; Plowman, 2015; Ohno et al., 2017; American Speech-Language-Hearing Association, n.d.b). Unlike exercise, palatal lift prosthetics are not used with the intention of prolonging the ability to speak. Rather, this intervention is utilized for increased intelligibility of remaining ability (The Amyotrophic Lateral Sclerosis Association, 2020; Plowman, 2015). In comparison, other interventions examined in this research have an emphasis on prolonging communication ability through the utilization of high-technology augmentative and alternative communication methods. These interventions consisted of speech-generating devices, voice banking, message banking, eye-tracking technology, and brain-computer interfaces (Beukelman et al., 2011; The Amyotrophic Lateral Sclerosis Association). As a result, the evaluation of efficacy for these compensatory interventions is dependent on their ability to maintain quality of life and prolong the ability to communicate. In comparison, efficacy of exercise is respective to its goal in preserving natural speech ability and efficacy of palatal life prosthetics is based on the ability to increase speech intelligibility (Harkawik & Coyle, 2012;

The Amyotrophic Lateral Sclerosis Association, 2020; Plowman 2015, Ohno et al., 2017; American Speech-Language-Hearing Association, n.d.c; American Speech-Language-Hearing Association, n.d.g).

At the moment, there is a lack of research evaluating the effects of exercise on speech-motor ability in individuals with ALS. However, research has recently been conducted which indicates a positive effect of general exercise on patients with ALS. Results suggest that moderate exercise is beneficial in maintaining upper and lower extremity motor function (Harkawik & Coyle, 2012). Additional research examining the impact of exercise on rodents, healthy adults, and disordered clients has also been conducted. These findings have demonstrated that lingual exercises have been beneficial in increasing lingual strength, performance, and stabilized pressure in diseased patients. Studies investigating the impacts of respiratory exercise on patients with bulbar dysfunction demonstrated promising findings. Associated benefits consist of increased expiratory generation capacity and improved airway protection (Plowman, 2015). While this research is not specific to the role of exercise on speech-motor function in patients with ALS, it is thought to be generally indicative of potential benefits associated with the intervention (Plowman, 2015). The associated results of lingual and respiratory exercise could be prolonged speech-motor function and increased intelligibility. However, this treatment intervention is limited by disease progression (Harkawik & Coyle, 2012; Plowman, 2015). Overall, more research is needed to conclude whether or not exercise could play a role in prolonging natural speech ability.

Palatal lift prosthesis is limited in effectiveness by disease progression, but has demonstrated an ability to improve speech intelligibility for individuals with ALS. The use of

this intervention has been associated with an 84% decrease in hypernasality and a 60% increase in articulatory improvement (The Amyotrophic Lateral Sclerosis Association, 2020).

Overall efficacy of augmentative and alternative communication (AAC) devices were determined based on the intervention's ability to maintain or improve quality of life for the individual. Additionally, its sustained accessibility for patients who have experienced motor function loss was also considered (American Speech-Language-Hearing Association, n.d.c; American Speech-Hearing Association, n.d.g).

Speech generating devices (SGDs) have demonstrated a positive impact on social participation, independence, self-determination, and quality of life. Moreover this intervention has also been shown to decrease caregiver burden. SGDs allow for individuals to continue communication even into the later stages of disease progression and full body paralysis. SGDs also offer a variety of modalities for target selection to accommodate for varying levels of user mobility (Roman et al., 2021).

Voice and message banking both lack clinical studies which examine their value or effectiveness for patients with ALS. However, voice banking services have generally mixed reviews regarding potential implications for patients. Research indicated that it could be beneficial in preserving unique characteristics of an individual's voice and a sense of identity. However, the inability of synthetic voices to replicate natural intonation and emotion were potential negative implications. Moreover, some individuals noted that this intervention might be an unnecessary waste of time (Cave & Bloch, 2020). Comparatively, message banking is able to preserve the natural inflection of the individual's voice and does not require as much precision of speech. However, it is still labor and time intensive (The Amyotrophic Lateral Sclerosis Association, 2020; Zhao et al., 2019). While there is no empirical evidence investigating the

effectiveness of message banking on quality of life, an individual interview expressed its ability to sustain family bonds and preserve the patient's unique voice (Gray, 2022). Both banking interventions are limited in effectiveness, as both services require the recording of words with speech skills intact (American Speech-Hearing-Language Association, n.d.c; Zhao et al., 2019).

Eye-tracking technology has been researched in a number of studies. It has demonstrated an effectiveness in preserving autonomy, prolonging meaningful communication, reducing communication difficulties, providing high patient satisfaction, and improving overall quality of life (Linse et al., 2018; Caligari et al., 2013). Limitations to this intervention include a lack of accessibility attributed to oculomotor dysfunction (Linse et al., 2018). Eye-tracking technology is typically able to be utilized by patients with ALS even after severe disease progression and paralysis of the upper and lower extremities. Preserved eye movement allows for success in this intervention and extended communication abilities beyond that of natural speech (Ball et al., 2012; Beukelman, 2011).

Brain-computer interfaces could potentially be the most effective avenue for prolonged communication and quality of life in individuals with ALS. This intervention allows for patients with full-body paralysis to continue communication through augmentative and alternative communication. Moreover, it allows this continued communication after the loss of controlled eye movement. It has also been shown to maintain quality of life in individuals with ALS, despite a decline in neuromuscular function. However, this intervention is relatively new and lacks consistent accuracy in target selection. Additionally, it requires extensive training, utilization can be time-consuming, and may require dependence on a system assistant for operation. This option is promising for individuals who are unable to use other forms of alternative communication because of a loss in motor-function. However, its lack of consistent

accuracy and significant time requirements demonstrate a need for further improvements. This option should not yet be considered over other communication interventions if motor function is still intact (McFarland, 2021; Wolpaw et al., 2018; Linse et al.,)

Results of these studies indicate that high-technology AAC methods such as speech-generating devices are most useful for prolonging meaningful communication in individuals with ALS (Roman et al., 2021). Additionally, eye-tracking technology and brain-computer interfaces have demonstrated significant effectiveness in maintaining and/or improving quality of life in clinical studies (Caligari et al., 2013; Linse et al., 2018; Wolpaw et al., 2018). Further research studies are needed to better understand the implications and efficacy of message banking, exercise, and voice banking on communication abilities for individuals with ALS. However, while some interventions may provide temporary benefits in their respective fields of quality of life or a prolonged ability to communicate, these benefits are limited. Even augmentative and alternative communication are typically only utilized up until the last few weeks of life (Beukelman et al., 2011). Ultimately, no intervention will be able to provide complete communication gain because of the terminal and progressive nature of ALS (Harkawik & Coyle, 2012).

Research Limitations

There is an overwhelming lack of research regarding the efficacy of communication interventions, as well as how they impact individuals with amyotrophic lateral sclerosis. Continued studies could be beneficial for each intervention to better understand associated implications. More specifically, there is a significant need for further research in regards to the effectiveness of lingual and respiratory exercise, message banking, and voice banking.

Additionally, there is a need for a standard staging system to track disease progression and a standard method of evaluating efficacy of communication interventions.

Conclusion

The purpose of this literature review was to evaluate the efficacy of communication interventions for people with amyotrophic lateral sclerosis. The findings of this study concluded that communication interventions are not effective for sustaining or restoring natural communication abilities. Furthermore, any benefits associated with these interventions are limited by the progression of disease and death of the individual. There is no evidence to conclusively support the use of restorative interventions for ALS. Compensatory strategies have demonstrated the most significant positive attributions of communication interventions. Moreover, high-technology augmentative and alternative communication interventions have demonstrated to be the most beneficial in extending the use of effective communication. They are associated with increasing quality of life. These standards are integral for end-of-life considerations in communication interventions. Additionally, eye-tracking technology appears to have the most significant evidence in fulfilling its goal of increasing quality of life and prolonging meaningful communication in individuals with ALS. While these interventions may be beneficial in their respective fields, the overall effectiveness of the interventions to provide communication gain for the person with ALS is ultimately made obsolete by disease progression.

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