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Thursday, November 3, 2016  
9:15 am – 10:15 am  
Track 1  

ALS and Augmentative Communication: Seeking Improved Outcomes through Early Engagement in Assessment, System Design and Implementation  
*John Costello, MA, CCC-SLP*  

**Background:** “This disease takes EVERYTHING away from me; early exploration of AAC is the ONLY hopeful part of the ALS journey”. This statement has been made in varied ways by dozens of people who have ALS as they leave our clinic.

Procedures and outcomes of our model of proactive intervention with AAC including: speech production enhancement strategies, voice amplification, creating quick access tools, completing early trials with alternative access, message banking and voice banking – including authentic examples of the presenter’s own voice created through both message banking and voice banking strategies, experiencing many AAC strategies and directing the selection of technology and language systems will be detailed.

**Objectives:**

1. Discuss benefits of proactive intervention to successful use of AAC strategies throughout the course of the ALS disease.
2. Describe at least six AAC strategies that can be introduced proactively to people facing the loss of functional speech.
3. Define message banking vs. voice banking and know resources for implementation for both.

Thursday, November 3, 2016  
9:15 am – 10:15 am  
Track 2  

Teamwork Makes the Dream Work: SLP/PT Collaboration for Optimal Swallowing, Breathing and Communication in Patients with ALS  
*Cathy Carver, MS, ATP, and Laura Royal, MS, CCC-SLP*  

**Background:** Patients with ALS have varying symptoms at varying times in the disease process. Since ALS affects the upper motor neurons and lower motor neurons, voluntary muscle control will be lost over time. This lecture focuses on the gradual loss of speech and swallowing and how therapists can help prolong these functions as long as possible. People with bulbar-type ALS (30% of people with ALS) experience this early in the process because the corticobulbar area controls the muscles of the face, head and neck. Loss of speech occurs in 93% and difficulty swallowing occurs in 86% of people with bulbar-type onset. (1) Those with limb onset will experience loss of speech and swallowing later in the disease process.
The optimal head/neck position for breathing, swallowing and communication should be a neutral head position. This position allows good tracheal alignment for adequate epiglottic depression and retroflexion for maximal airway protection, as well as optimal expansion of the intercostal muscles. In an average adult the estimated total salivary volume produced per day can reach two liters (2). Secretion management in a patient with ALS can be a challenge for two reasons: the weakening of the pharyngeal constriction muscles and decreased full expiratory pressure to achieve a productive cough. Delaying pulmonary compromise is essential for sustaining a positive quality of life for the patient with ALS.

One of the roles of the physical therapist (PT) for a patient with ALS (3) is to promote neutral alignment in each of the positions (supine, sitting on a variety of surfaces, side lying) someone with ALS will use. Clinical observation indicates that most people with ALS will begin to flex into a posterior pelvic tilt, thoracic kyphosis and/or poor cervical postures. These deviations can be caused by abnormal fluctuations in tone, pain, muscle weakness/imbalance, or habitual positioning. Since these deviations are typically flexible, a PT can assist in using supports in the above positions to promote proper postural alignment for swallowing, breathing and communication. In side lying or supine in bed, supports can be used to maintain a neutral spine. While sitting in a wheelchair a person should use a properly fitting backrest with the potential need for lumbar support and/or lateral support. Head/neck supports may be needed intermittently as someone begins to experience weakness in those muscles. Positioning cushions can also stabilize the pelvis so that the rest of the spine to the head and neck can be properly aligned while in a wheelchair or household seat. (Handouts will be provided).

Materials and Methods: Our team examined how we could enhance these desired functional tasks of swallowing, breathing and communicating for patients with ALS. In isolation a speech therapist (SLP) can establish the best swallowing program and access to augmentative communication devices (AAC), but if the person is not supported with optimal posture, these tasks will be limited at best. A PT must consider a person’s ability to swallow, breathe and communicate to be optimally functional. Assessing our clinic’s approach showed a gap in effectively assisting patients and their caregivers to maximize their ability to swallow, breathe and communicate.

We then developed a screening tool to assess the swallowing, breathing and communication difficulties our patients experience in their most common positions. Our findings showed that patients spend the majority of their days in a variety of chairs and positions other than the positions we see them in during clinic visits. As a result, we developed levels of follow-up based on a decision-tree that can be used to ensure carryover of proper positioning for swallowing and communicating in their environment(s). Potential options for follow up intervention included a phone call in 2-3 weeks, viewing photos, consideration of a “video chat”, home visit/home health referrals and/or a return to clinic.

Outcomes and Results: To begin our pilot study we administered a survey (see handout) to our clinic patients (n=3). Ranked responses gave an understanding of where patients spend their time and what difficulties they experience in various positions. The feedback showed that all three patients experience the highest level of difficulty with breathing and swallowing in the positions where they predominately spend time. Of our sample size, one patient required a follow up clinic visit with speech therapy, one
patient required a comprehensive communication assessment, and one patient required a follow up phone call to assure that swallowing precautions and energy conservation strategies were being utilized.

Another finding of our pilot was that people needed handouts for positioning in beds, household seating surfaces and in wheelchairs for reference to ensure good positioning for swallowing and either verbal communication or access to AAC. We discussed that video on a personal phone or tablet device for carryover with multiple caregivers will be a good option. These options for follow up would allow better carryover for swallowing, breathing and communication and maximize these important needs for a patient with ALS.

**Discussions and Conclusion:** This process has improved the team’s understanding of the need for ST and PT to collaborate to address these specific functions for patients with ALS, especially for those with bulbar-type ALS. It has provided improved carryover for caregivers to support patients with ALS for better swallowing and communication. It has given us an objective tool to determine a level of appropriate follow up. The subsequent follow up has been beneficial for caregivers to improve positioning and function in their environment. Perhaps other clinicians can enhance the continuity of care that their clinics provide using this patient-centered tool and caregiver-based approach as a starting point.

**References:**

2. Livescience.com October 15, 2012 How Much Saliva Does a Person Produce?

**Objectives:**

1. Identify ways to support neutral alignment in a variety of positions to promote optimal positioning for swallowing, breathing and communication in a patient with ALS
2. Describe the significance of neutral postural alignment as it relates to speech, varying means of augmentative communication and swallowing in a patient with ALS
3. Describe the process of developing a screening tool and relevant patient education information to assist caregivers with carryover of postural support for swallowing and communication in their environment(s)
Background: Working with and caring for people living with ALS and their family members is often very satisfying and rewarding knowing that our professional interactions may make a positive difference in their lives. However, our compassion and care will emotionally impact us which is a normal and predictable consequence of the work we do.

This presentation will define the conditions of burnout, compassion fatigue, and vicarious trauma and examine these conditions through the lenses of emotional resonance, mirror neurons and chronic stress. We will identify protective factors that individuals and professional staffs may use to increase the satisfaction of their work and to address these conditions should they occur. We will conclude with an introduction to the online and free tool, the “Professional Quality of Life Scale” (PROQOL) that professionals may use to assess their own (or their staffs’) compassion satisfaction and/or fatigue.

Objectives:

1. Describe three or more signs and symptoms of burnout, compassion fatigue, and vicarious trauma
2. Identify three or more protective factors to limit the effects of vicarious trauma
3. Utilize the PROQOL for assessing compassion satisfaction and fatigue

Thursday, November 3, 2016
10:30 am – 11:30 am
Track 1

Preparing Your Clinic for Research and Participation in Clinical Trials
Peggy Allred, PT, DPT

Background: Every clinic has important information to contribute to ALS research. Details regarding disease phenotypes, longitudinal ALSFRS scores, breathing measures, and disease duration are all valuable data points that when gathered together in a larger effort can aid in answering questions about ALS. Clinics or facilities without a research infrastructure may need guidance with the steps required to initiate data collection or how to become competitive as a clinical trial site. Targeted collection of clinical information provides a quick method to monitor clinic demographics and can be a first step in preparing for clinical research activities. This presentation will introduce methods for developing a clinical/research database, discuss biorepository development measures, and provide steps for preparing to be a clinical trial site. Information and guidance for the Allied Health Professional’s role in clinical research and their valuable contribution potential will also be discussed.

Objectives:

1. Describe the regulatory requirements of collecting clinical information for research purposes
2. Demonstrate the options and mechanisms for building a clinical database
3. Apply the mechanisms to becoming a clinical trial site
Power Wheelchair Features and Funding Options for the ALS Population

Pamela Glazener, OTR, and Gina Strack, OTR, ATP

Background: Amyotrophic lateral sclerosis, is a progressive disease resulting in limb muscle weakness, muscle atrophy, speech and swallowing difficulties and respiratory compromise. The site of onset, bulbar versus limb, can vary between patients and the progression of symptoms can be rapid, average, or slow. Power mobility plays a large role in the current care for these patients. Several patients will be presented in this course, each with varied symptoms, level of function, and abilities. Justification and reasons for wheelchair components will be reviewed focusing on the patient’s physical abilities, metabolic/nutritional status, respiratory decline/complications, endurance/energy conservation, fall history, need for head support, and overall progression of disease. This course will include documentation guidelines and justifications to assist with funding for custom power mobility which can be a challenge for this patient population.

Objectives:
1. Identify when power mobility is indicated for the bulbar onset ALS patient and describe two specific features that are appropriate
2. Interpret when power mobility is indicated for the upper limb (“man in the barrel”) onset ALS patient and describe three features that are appropriate
3. Illustrate when power mobility is indicated for the lower limb onset ALS patient and describe two specific features that are appropriate.
Life isn't over with ALS but it is different, to be perfectly clear I am living with ALS not dying from it! Approaching the disease with this perspective allows you to be proactive in your care striving to stay one step ahead of the challenges that we face by employing tactics to live a full and rewarding life. Many of the approaches we will discuss are you based on what I call the fire extinguisher analogy, you get it before you need it because if you don't it is probably too late.

Approach: I was diagnosed in November 2013, a little over two and a half years ago. This is a case study of the strategies that I have employed with the help of multidisciplinary care, collaboration with other pALS, research, and reaching out to experts in the field. I would like to share my story with clinicians and medical professionals in hope that I can share those things that can really help improve Quality of Life as well as help them understand obstacles and potential strategies in gaining acceptance by the person with ALS.

My Story: A brief synopsis of my diagnosis, symptom onset, and progression. Also including an introduction to changing perspectives, positive attitude, and participation in / taking control of my care.

Life Changing Strategies:

Battling Fatigue
The BiPAP is my best friend in battling fatigue. With a challenged respiratory system it is difficult to exhale against the constant pressure leaving to a buildup of CO2 and fatigue. I now use non-invasive ventilation every night, for naps, and sometimes just a pick me up when I feel overly tired. Patients often do not understand this benefit and get frustrated with the comfort of the mask. Don't give up!

Power wheelchairs are not just for those who cannot walk. I can walk although a bit unsteady however it is very tiring for me. I prefer to save my energy for the things I want to do. I describe the essential features of my wheelchair. I will also address the fear of giving in that many patients experience.

Being Proactive
The Cough Assist; an example of that fire extinguisher analogy gone wrong. The cough assist was recommended by my respiratory therapist and I chose not to get it believing that was not necessary yet since I was able to cough up mucus very well thank you. I woke up one morning unable to breathe due to mucous lodged in my windpipe. My clinic had one delivered that afternoon.

The PEG/MIC-KEY – the perfect example of the fire extinguisher analogy. The general public has been conditioned to believe that a feeding tube is an end-of-life measure. For ALS patients it is simply a tool to continue enjoying life when you lose the ability to swallow. It is not giving in.

Communication
Eye gaze computer - there is a learning curve for utilization. Though there have been great strides, it is not necessarily intuitive and takes a great deal of practice. If at all possible this needs to be required as soon as practical preferably while you can still communicate by other means during the learning process.
Voice banking - needs to be while the voice is strong. It is easy to put off when you have no problems speaking, and by the time it gets difficult it is too late to bank your voice. I will demonstrate my synthesized voice.

Clinical Trials
The most critical time for ALS patient trial eligibility is in the first two years. Many trials do not accept patients more than two years since the onset of symptoms. Since diagnosis can take a year or more the window is very small. Unfortunately in that first year patients are wrapped up with management of their disease and often put off participation in clinical trials thinking that they have plenty of time. The reality is that with a 2 to 5 year prognosis researchers want patients early in there diagnosis to assure they can survive the trial. Clinicians need to understand this urgency to make sure pALS do not miss the opportunity.

What can you do?
In summary, things that clinical professionals can do to encourage acceptance and strategies for improvement of the quality of life for ALS patients.

Objectives:
1. Distinguish between the obstacles and potential strategies in gaining acceptance by the person with ALS
2. Express the importance of quality of life, as told from an individual living with ALS
3. Discuss the equipment and technological needs associated with ALS, in order to maintain mobility, communication and quality of life

Thursday, November 3, 2016
1:15 pm – 1:45 pm
Track 1

The Holy Grail: Seeking Best Measures of Lung Function in ALS
Lee Guion, RRT, FAARC

Background: There is no consensus on the best measure of pulmonary function in ALS. The optimal evaluation of a diagnostic test requires comparison with the accepted “gold standard” measure. However, there is no “gold standard” bedside test for respiratory insufficiency in ALS. The tests commonly utilized in clinical and research settings, including forced vital capacity (FVC), maximum inspiratory pressure (MIP), and sniff nasal inspiratory pressure (SNIP) are effort-dependent and may be affected by bulbar and cognitive dysfunction. As a result, they have well-documented shortcomings in ALS.

Phrenic nerve conduction studies (PNCS) are an objective, non-volitional measure of diaphragm innervation. This test has been validated in normal subjects and has been shown to have a high discriminative value in predicting hypoventilation and mortality in ALS patients.
Purpose: To assess the relative performance of PNCS against a number of established, validated, and commonly utilized tests combined with signs and symptoms of respiratory dysfunction and propose it as a biomarker of respiratory function across the spectrum of ALS patients.

Materials and Methods: We prospectively evaluated all patients who attended the Forbes Norris ALS center during a 9-month period between 2013 and 2014. Of 126 patients screened 100 agreed to participate, met inclusion criteria, and were enrolled. Data obtained included: symptoms of respiratory insufficiency (dyspnea at rest or with exertion, orthopnea, unrefreshing or disturbed sleep, morning headache and excessive daytime sleepiness); upright and supine respiratory rate, oxygen saturation, and capnography; and FVC, MIP, and SNIP in accordance with the American Thoracic Society technical guidelines. Physician investigators with advanced neurophysiology training performed bilateral PNCS. The PNCS results were considered abnormal if phrenic CMAP amplitude (Pamp) was less than 0.3mV.

Outcomes and Results: Pamp correlated with symptoms and signs of respiratory insufficiency. With Pamp <0.3mV, the relative risk of orthopnea was 3.5 (95% CI 1.6-8.7, p<0.01); of dyspnea 2.4 (95% CI 1.4-4.0 p<0.01); and of tachypnea (RR > 18 BPM) 7.2 (95% CI 2.2-37.2, p<0.01). Pamp decline and FVC decline correlated well (R2=0.48, p<0.001). Significant correlations were also seen with MIP (R2=0.37 (p<0.001), SNIP (R2=0.28 (p<0.001), and ALSFRS-R (R2=0.28 (p<0.001). When the Pamp was abnormal (<0.3mV), all but 3 patients (94%) had a MIP below the standard threshold of 60cmH2O. However 26% of patients with normal Pamp (>0.3mV) also displayed MIP values <60cmH2O. Although thought to be a more sensitive measure of respiratory function that FVC, MIP may lack specificity and reliability in ALS.

Discussions and Conclusions: In patients with ALS, PNCS are objective, easy to perform, well tolerated, and independent of cognitive and bulbar dysfunction. In a large cohort, Pamp correlated closely with mortality and symptoms and signs of respiratory insufficiency and standard PFT measurements. Baseline-to-peak amplitude Pamp <0.3mV was more sensitive in detecting respiratory dysfunction than the PFT thresholds for NIV commonly utilized in the U.S. PNCS are worthy of further study as a potential biomarker in ALS.

Usefulness to ALS Clinical Practitioners: These results have practical implications for pALS, RCPs, SLPs, PTs, physicians, nurses, and other members of our multidisciplinary teams when assessing lung function and recommending treatments and symptom management. Objective non-volitional tests of lung function are useful when patient-reported symptoms of breathing and sleep do not match pulmonary function test results. Accurate lung function measures are difficult to obtain in patients with moderate-to-severe bulbar disease and those unable to follow instructions due to dementia. PNCS might be a useful biomarker of lung function and adjunct to our current practices.

Objectives:

1. Define components of ideal tests for respiratory insufficiency in ALS.
2. Describe the implications of accurate lung function testing in ALS.
3. Compare phrenic nerve tests to standard PFTs and clinical signs and symptoms of respiratory insufficiency in a broad cross section of ALS patients.
Thursday, November 3, 2016
1:45 pm – 2:15 pm
Track 1

CDC ALS Registry Update
Paul Mehta, MD

Background: An update from the congressionally mandated National ALS Registry covering updated national ALS prevalence estimates; how the Registry is connecting patients with researchers for studies and clinical trials; information/talking points on the fall launch of the National ALS Biorepository, research currently being funded, and informational materials available for chapters and clinics.

Objectives:

1. Explain the latest National ALS Registry updates
2. Define the importance of the National ALS Biorepository
3. Discuss recent Registry public awareness campaigns

Thursday, November 3, 2016
1:15 pm – 1:45 pm
Track 2

The Role of Child Life in Providing Developmentally Appropriate Interventions and Resources for Children of Adult Patients Diagnosed with a Chronic or Terminal Illness
Suzanne Berg, BS, CCLS

Narrative: Child Life programming in alternative settings is a rapidly growing area in which the unique skill set of child life specialists is implemented in a particular population or setting. This presentation will describe the traditional child life programming and the development of child life programming designed to meet the unique needs of children of adult patients who have been diagnosed with a terminally ill disease. The focus will be on program elements, funding, resources and interventions in a metropolitan adult hospital and outpatient clinics.

Background: Traditional child life programs focus on developmental, emotional and psychosocial needs of children and families within the health care environment. In some pediatric units or smaller programs located within a larger adult hospital, child life services may include consults for children or grandchildren of adult patients. Most often these consults are placed following a family members; traumatic injury, sudden or acute illness or end of life. Recognizing that child life specialists have the unique skills to help children and families, the interventions of child life are particularly appropriate in a time of new diagnosis or crisis. Unfortunately, these services are often accomplished in a brief and intense time and may not include follow-up or ongoing support.
Child life programming for children of adult patients has great potential to enhance services of medical staff in supporting families through all ages of adult illness progression from initial diagnosis through treatment and beyond. For many children, having an ill parent is not an acute, but rather, a chronic concern and children may experience different developmental needs throughout the illness. At each stage, child life is able to provide developmental appropriate interventions to assist the family.

**Purpose:** The purpose of this presentation is to describe the development of a child life program within a multidisciplinary clinic setting in a metropolitan adult medical center focusing on chronic, terminal illnesses such as ALS. Designed solely to meet the needs of children of adult patients, this program is facilitated by two experienced child life specialist who provide resources and interventions for the families of adult patients throughout the facility including intensive care units, a level 1 trauma center, large out-patient cancer center and out-patient specialty clinics including ALS. An overview of the program’s implementation, funding, available resources and ongoing interventions will be discussed. The expansion of child life programming to adult settings utilizes the unique skill set of child life specialists in areas of strong need, such as the ALS population. To provide developmentally-based psychosocial care for children of adult patients helps not only the adult patients who fear for their children’s coping, but also supports staff who may not possess the skills to meet the needs of the children. The expansion of child life programs into adult settings offers opportunities for future research documenting the value of child life while supporting vulnerable children in the stressful healthcare environment.

**Objectives:**

1. Examine the role of child life in the alternative setting of an adult hospital
2. Identify developmentally appropriate resources for children whose family member is chronically or terminally ill
3. Discuss elements of programing unique to children and ways to implement it in adult hospitals

**Thursday, November 3, 2016**
**1:45 pm – 2:15 pm**
**Track 2**

**Kids from 4-24**

*Laurie Fieldman, LCSW*

**Background:** The children in ALS families are different than their peers. It's inevitable. They are likely to learn about death before their friends, and in addition, they may have to do things that make them uncomfortable, upset, anxious, angry, or all of the above-mentioned emotions. A clinician may not have the opportunity to work directly with the children, but a great impact can also be made by providing information to the adults so that they can better guide their kids through this difficult time. In order to be able to do this, we must understand the developmental stages of young people, as well as the likely behaviors we might see in those stages. This presentation will provide that information, as well as case examples to illustrate some of the many ways that the kids in ALS families struggle in their own unique
ways. This presentation will also provide the clinician with practical tips to share with these families so that they can minimize the negative impact of the ALS as much as possible.

**Objectives:**

1. Classify how a child’s perception of how the loved one’s ALS threatens them at each developmental level
2. Identify the various coping skills most likely to be seen at each developmental stage
3. Provide parents with information regarding how to guide their children through the adult’s ALS journey

**Thursday, November 3, 2016**

**1:15 pm – 1:45 pm**

**Track 3**

**Computer Access Options for Individuals with ALS**

*Sara Feldman, PT, DPT, ATP*

**Background:** Individuals with amyotrophic lateral sclerosis (ALS) present with progressive weakness resulting in difficulty with usual daily activities including computer use. New technologies enable individuals with motor disabilities to have alternative access to their computers. The information regarding this technology is not always readily available to either the health care professional or the individual with ALS. Individuals with ALS who attend a multidisciplinary team clinic have access to health care professionals who can evaluate issues related to computer use and access.

**Purpose:** The goal of this presentation is to give allied health professionals information they can use in their own settings to address computer accessibility needs.

**Presentation:** The focus of the presentation will be to discuss in detail the broad spectrum of assistive technology that is available for alternate computer access. The difficulties individuals with ALS frequently encounter with using a standard keyboard and mouse will be described. The range of computer access options to address these issues will be covered, starting from accessibility options that are available within the computers operating system (Windows and Mac) all the way up to eye-gaze systems. The options that are more commonly used by individuals with ALS will be emphasized. The current state of iPad accessibility will be demonstrated. Ideas on how to establish a trial library will be included.

**Discussions and Conclusions:** The use of computers is pervasive in society today and that includes the individuals we see with ALS. As these individuals experience difficulty with computer access, they are likely to turn to the health care professionals they rely upon for so many of their needs for information. It is incumbent upon us to take the steps necessary to be able to be a resource for computer accessibility. It is anticipated that by attending this seminar, the health professionals will leave with information that they can take back to their clinical settings and begin to use immediately.
Objectives:

1. Identify the common difficulties with computer access encountered by individuals with ALS
2. Locate the accessibility options available in a familiar computer’s operating system
3. Identify at least one hardware or software option for alternate keyboard access and alternate mouse access

Thursday, November 3, 2016
1:45 pm – 2:15 pm
Track 3

Rapid Access Communication Systems
Alisa Brownlee, ATP, CAPS

Background: Approximately 75% of all people diagnosed with ALS will need some form of communication assistance. While progression of speech disturbance varies in each person with ALS, many people will experience a significant communication disorder during the last few months of life. In a retrospective study of 100 hospice patients with ALS, 28% were anarthric (unable to speak) and 47% were severely dysarthric (slurred speech) at the time of their deaths. Only 25% could speak understandably during the terminal stage of the illness.

As a group, people with ALS demonstrate a wide range of needs and preferences for communication strategies, including some of the more technologically sophisticated speech generating devices (SGDs). For many people with ALS, quality of life is linked to communicative effectiveness. These needs and preferences may change depending on what environment the PALS is communicating in, their positioning, their mood, and where they are in the course of the disease.

Access to easy and effective communication system is crucial in the medical management of ALS. Many PALS opt to use an electronic communication system. However, that system is not always available or accessible, (for instance, in the bathroom, or late at night!) so another method of communication is vital. Rapid access strategies such as use of a letterboard, picture board, laser pointer are quick and effective methods of communication. Families tell us that they appreciate electronic communication devices for in-depth conversations, but they rely heavily on rapid-access techniques to communicate and respond quickly to routine or immediate needs. Both rapid-access and electronic communication devices have a place in assuring communication in PALS.

Using Rapid Technology Methods may be:

- A personal preference since electronic communication is not a choice for everyone
- Used as a back up to SGD’s
- The only option due to cognitive function
Rapid-Access Methods include:

- Letterboards
- Laser pointer
- Picture Board
- Numbered phrase poster technique
- Megabee

Objectives:

1. Describe (3) different methods of Rapid Access Communication for People with ALS
2. Practice Partner Assisted Scanning with each other
3. Illustrate why there is a need for a “yes, no, maybe” communication system for people with ALS

Thursday, November 3, 2016
2:30 pm – 3:00 pm
Track 1

High Rates of Cognitive and Behavioral Impairment in a Large Prospective ALS Study
Jennifer Murphy, PhD

Purpose: To characterize the prevalence of cognitive and behavioral symptoms using a cognitive/behavioral screening battery in a large prospective multicenter study of ALS.

Materials and Methods: 274 patients with ALS completed two validated cognitive screening tests and two validated behavioral interviews with accompanying caregivers. We examined the associations between cognitive and behavioral performance, demographic and clinical data, and C9ORF72 mutation data.

Outcomes and Results: Based on the ALS-Cognitive Behavioral Screen (ALS CBS) cognitive score, 6.5% of the sample scored below the cut-off score for Frontotemporal Lobar Dementia (FTLD), 54.2% scored in a range consistent with ALS with mild cognitive impairment (ALSci) and 39.2% scored in the normal range. The ALS CBS behavioral subscale identified 16.5% of the sample scoring below the dementia cut-off score, with an additional 14.1% scoring in the ALS behavioral impairment (ALSbi) range, and 69.4% scoring in the normal range.

Discussions and Conclusions: This investigation finds high levels of cognitive and behavioral impairment in ALS patients within 18 months of symptom onset, comparable to prior investigations. This investigation illustrates the successful use and scientific value of adding a cognitive-behavioral screening tool in studies of motor neuron diseases, to provide neurologists with an efficient method to measure these common deficits and to understand how they relate to key clinical variables, when extensive neuropsychological exams are unavailable. These tools, developed specifically for patients with motor
impairment, may be particularly useful in patient populations with Multiple Sclerosis and Parkinson’s Disease, who are known to have co-morbid cognitive decline.

Objectives:

1. Relate the latest research on the prevalence and nature of cognitive and behavioral impairment in the ALS population
2. Explain what disease characteristics and clinical features cluster together for patients with cognitive and behavioral impairment
3. Explore what busy clinicians can do in clinic to help families who struggle with these issues

Thursday, November 3, 2016
3:00 pm – 3:30 pm
Track 1

Transitioning a Research Tool into Clinical Practice: Use of the Edinburgh Cognitive and Behavioral ALS Screen in ALS Clinic
Susan Walsh, RN, MSN, ACNS-BC
Author(s): Judy Lyter, RN, MS, LPC, NCC, Travis Haines, MA, CCRC, Susan Walsh, RN, MSN, ACNS-BC, Anne Morris, MPH, Sharon Abrahams, PhD, and Zachary Simmons, MD

Background: The presence of cognitive and behavioral dysfunction in ALS is well documented. Identifying such changes is an important part of clinical care, yet there is no consensus on the best instrument for screening for cognitive and behavioral dysfunction in an ALS clinic. An ALS-specific screen, the Edinburgh Cognitive and Behavioral ALS Screen (ECAS), has been developed and validated, but has not been tested for feasibility and usefulness in an ALS clinic setting.

Purpose: To evaluate the administration of the ECAS in an ALS clinic and the use of the results in the care of patients in a multidisciplinary ALS care setting.

Program Description: Two members of a university-based, multidisciplinary ALS clinic, a nurse counselor and research coordinator, were trained and certified in the administration of the ECAS by the developer, Dr. Sharon Abrahams. Patients were eligible for screening during their second or third multidisciplinary ALS clinic visit. Patients were excluded from screening if they had depression or a prior history of neurological or mental health diagnosis, were too fatigued or weak, or had limited clinic time. The behavioral portion of the screen was completed with the caregiver. The results were scored and reviewed with the clinic team. Screening results that demonstrated significant cognitive or behavioral changes were communicated to the caregiver with appropriate psychoeducational support from the counselor.

Clinical Outcomes: The ECAS has successfully been administered to 55 patients in clinic. Administration takes 15-20 minutes. Nonverbal patients can also be assessed. Scoring is completed and results reported to the clinic team for input. The results provide an important framework for the clinic team to make
recommendations for safety, monitoring, and follow-up care. The ECAS results assist clinicians in developing strategies specific to cognitive areas that are affected. Administration of the behavioral portion of the screen provides an opportunity to hear concerns from the caregiver that may not have been shared in front of the patient. It provides the screener an opportunity to educate the caregiver regarding potential behavioral problems that may require monitoring. The ECAS has been adopted as standard of care for screening cognitive and behavioral dysfunction in the ALS clinic.

Recommendations to the Field: The ECAS is a valid ALS-specific cognitive screen that can easily be administered and interpreted in a busy ALS clinic. It provides an opportunity for both patient assessment and caregiver teaching. The ECAS provides information to the multidisciplinary team to develop specific recommendations for care as they relate to cognitive and behavioral changes.

Objectives:

1. State the unique aspects of the ECAS cognitive screen in an ALS Clinic
2. Describe the application of the ECAS in the care of patients in an ALS Clinic
3. Discuss how the ECAS relates to assessment and care of cognitive dysfunction in ALS

Thursday, November 3, 2016
2:00 pm – 2:30 pm
Track 2

Engaging ALS Youth in Support and DME: Pilot Project in Wisconsin
Lori Banker-Horner, LPN, BA, Melinda Kavanaugh, PhD, MSW, LCSW, and Amy Scharmer, MSSW, CAPSW

Background: In a pilot study of ALS families, nearly 2/3 of patients with ALS have a youth (under the age of 18) in the family. The majority of these youth participate in caregiving activities including assisting with meals, bathing, communication and medications. Moreover, the majority of these youth receive little to no training in how to provide the care or how to use durable medical equipment (DME) or communication devices – despite the youth’s stated desire to learn about DME. Youth in ALS families have few outlets to discuss life with ALS with other youth, missing an opportunity to normalize their experience. Established programming across ALS Association Chapters traditionally focus on the adult as caregiver and target for supportive and educational programs. In recent years, numerous chapters have begun to draw attention to the needs and of youth in the families. Targeting adult caregivers, families, and ALS professionals, the ALS Association - Wisconsin Chapter (ALSA-WI) conducts an annual “ALS Care and Research Symposium”. In 2016, a youth track was added to engage youth and reach families who may not have attended past general programs and who may benefit from a youth specific program. The first ALS-WI pilot youth day took place in April. All youth ages 6-18 who have a current family member with ALS or who have recently lost their family member to ALS were invited to participate.

Methods and Materials: Youth Day was held in three rooms in a hotel venue, which allowed it to be held concurrently with the general symposium. A total of 6 youth participated in the day (1 female, 5 males), ages 6-15. The supportive program was run by two ALS experienced MSWs. The 6-year-old
engaged with most activities. However, during discussions about ALS, he went to a separate room with one of the leaders for one on one time given his young age. Activities included art, music and the youth making a video about ALS and their experience as in a family affected by ALS.

The DME portion consisted of an hour with 3 DME stations: Speech/communication, power wheelchair, and BiPAP machine. All youth spent time with each device, learning from the experts in each device. The goal of the DME portion was to create an atmosphere where the youth can ask questions and have hands on learning about devices without the parent present, or without the possibility of potential harm to the parent.

Outcomes and Results: The impact of the support group was multifaceted. Five of the six youth had never attended any ALS meetings or any youth focused programming. One youth, who lost his father last year, served as de-facto leader, starting conversations and engaging the other youth.

Youth attendees engaged with all DME, asking many questions and using all devices. Not only did they learn about the devices for themselves, they also brought back information to the parent. One parent followed up to say that she has now decided to use a speech device after her daughter attended the Youth Day, and encouraged her mom to re-consider. The day also provided one on one time with youth and the two leaders, seeking information on how to talk to siblings and parents. After the youth day, one father reported to the staff that not only did the day make a huge impact on his son, but that the father is now attending support groups; having seen the impact on the family as a whole. “My son had really good things to say about your interaction with him. Thank you for taking the time to specifically address our situation with him and also your helping him understand what [his sister] may be going through. Thank you for what you do. It really means a lot.”

Discussions and Conclusions: Several takeaways came from piloting a youth day: First, it is clear that youth need access to, and information about, the numerous DME options. Providing this information not only served to reduce anxiety in the youth, but also helped inform parents’ decision about using a device. Second, the day built community. With one exception the youth had never attended any meetings and did not know each other. Yet, by the end of the day, they were talking about ALS, families, and brainstorming ways to develop future youth focused programming – including a statewide conference for youth. The youth also requested programs with their families, highlighting the fact that these are youth value time with their parents. The pilot program also offered learning opportunities for professionals in developing future programming. The pilot highlighted the need for multiple leaders to address individual issues that arise, breakouts for youth of various ages and developmental levels and the possibility of collaborating with other neurological disease organizations – widening the scope of youth supportive programs across similar disorders.

Objectives:

1. Describe the Youth Day developed by the ALSA-WI Chapter
2. Discuss how the opportunity to learn about DME and have a hands on opportunity with the device/equipment under the guidance of a specialist, impacted the family as a whole
3. Identify youth generated specific future supportive and educational programs
Utilizing Home Caregiver Training Programs to Support ALS Caregivers

Cris Mammarelli

**Background:** The ALS Association, Arkansas Chapter has partnered with the Schmieding Home Caregiver Training initiative, a program of the Donald W. Reynolds Institute on Aging at the University of Arkansas for Medical Sciences, to provide ALS-specific caregiver workshops at their 8 locations throughout the state and to utilize their online caregiver directory as a resource for our families looking for privately paid home caregivers. The Schmieding program provides initial and continuing education for individuals seeking a career in home caregiving as well as training for family members and/or significant others caring for an older adult or disabled person in the home. Instructors for the program are licensed nurses selected for their knowledge and experience in home care.

On selected dates throughout the year the ALS Association, Arkansas Chapter hosts ALS Caregiver Workshops at the Schmieding training facilities in cooperation with the professional staff. This learning opportunity introduces the caregiver training program to ALS caregivers and provides a condensed version of the overall free training they can receive at a later date.

At the Schmieding training centers caregivers find a simulated home-like environment, complete with a living room, kitchen and bedroom model so they can receive hands-on learning with equipment such as Hoyer lifts, transfer boards, bathroom necessities, helpful products and more. The instructors also provide training for lifting, transferring, feeding demonstrations and many other caregiver skills. During the ALS Caregiver Workshops we offer all of this with the challenges of ALS in mind and a question and answer time period to address concerns ALS caregivers may be experiencing at that time.

In addition to the caregiver training, we also informational booths and speakers on ALS-related topics. Including speech, Medicare, hospice information, equipment, and more.

We’re able to provide an outlet for family caregivers to receive hands-on training in remote areas of the state; we’re able to offer interested non-family home caregivers an educational opportunity to receive a more extensive home caregiver certificate; and we’re able to share and access the online caregiver directory of those who have been trained through the Schmieding program throughout the state.

**Objectives:**

1. Explain of the benefit of collaborating with community programs that provide hands-on caregiver training
2. Coordinate with home caregiver training sites to offer occasional ALS-specific caregiver workshops
3. Foster and maintain relationships with caregiver programs throughout a service area
Thursday, November 3, 2016
2:30 pm – 3:00 pm
Track 3

Lessons Learned from the ALS Bedside
Marcia Obermann, RN BSN HRM

Background: 24-hour a day direct ALS caregiving gave new insight and intimate perspective and empathy to an experienced RN healthcare professional. When ALS professionals are aware of daily living challenges and caregiver aspects they can become more effective healthcare planning partners with the ALS primary caregiver and patient. This will be an enlightened conversation about simple but very important lessons learned from the bedside viewpoint that can help enhance approaches offered by the professionals.

Objectives:

1. Stimulate understanding about the realities of ALS caregiving
2. Expand on the caregiver viewpoint in regards to ALS challenges
3. Provide practical information on 5 everyday themes related to ALS caregiving

Thursday, November 3, 2016
3:00 pm – 3:30 pm
Track 3

Redefining the Role of the Physical Therapist at an ALS Clinic
Katelyn Sandy, PT, DPT

Purpose/Hypothesis: Patients with ALS benefit from the care provided by a physical therapist as part of a multidisciplinary team. Currently care is focused on evaluations and treatment during a clinic visit once every three months. However, there is opportunity for growth of the role of the physical therapist at this MDA/ALS clinic. The physical therapist could potentially lead groups, complete thorough power wheelchair evaluations and provide specialized one on one focus visits. As the program expands, patients with various neuromuscular diseases may be provided for.

Subjects: Patients treated at the Forbes Norris MDA/ALS Research and Treatment Center. On Mondays an average of eight patients are seen by the multidisciplinary team. Each Thursday morning, as part of the muscular dystrophy clinic, an average of 5 patients (out of the 15 to 20 seen by the neurologists) are referred to see the physical therapist.

Materials and Methods: The multidisciplinary team consists of an occupational therapist, a physical therapist, a respiratory therapist, a speech therapist, a research nurse, a nurse case manager, a dietician, and a neurologist. Initially, a physical therapist was placed at the clinic for four hours a day two days per week. Eight hours was an insufficient amount of time to complete power wheelchair
evaluations, provided training on stretching and passive range of motion as part of a home program, make equipment recommendations and to complete balance assessments along with fall risk education. Time spent directly with each patient, time for documentation and time to address insurance requirements and equipment recommendations was tracked. Time spent with each patient ranges from a brief fifteen minute consult to a sixty minute evaluation and treatment session.

**Outcomes and Results:** The results indicated a physical therapist as part of the multidisciplinary team has at least twenty hours of work to complete weekly. The clinic was able to increase the number of hours from eight hours per week to twelve hours per week. Insurance requirements demand detailed documentation for DME in order to ensure reimbursement and prevent delays in patients receiving the equipment they need.

**Discussions and Conclusions:** The physical therapist plays a significant role as a member of a multidisciplinary team caring for patients with ALS. Additionally, the physical therapist can provide expertise when assessing patients with abnormalities of gait to determine if custom orthotics or power mobility is warranted as part of the muscular dystrophy care team. There may be opportunities for increased services to be provided by a physical therapist including group therapy focusing on teaching home programs for range of motion and for teaching new power wheelchair users how to complete adequate pressure relief. The physical therapist plays a valuable role for justification of durable medical equipment, assessment of fall risk, and provides interventions which enhance quality of life.

**Scientific/Clinical Merit/Significance:** People with neuromuscular diseases including muscular dystrophy and ALS benefit from the direct care of a physical therapist to diagnose and treat movement impairments in order to enhance quality of life and prevent secondary disability. Physical therapists, as the movement specialists of a multidisciplinary team, are able to promote the highest level of function, prevent further disability and enhance each patient’s quality of life. A physical therapist is an integral part of the multidisciplinary team providing care for patients with neuromuscular diseases.

**Summary:** This presentation will include background on the Forbes Norris MDA/ALS Clinic and a vision for growth of the program. Included is how to expand the role of the physical therapist as part of a multidisciplinary team, a highlight of treatment interventions, and the importance of fall risk assessments.

**Objectives:**

1. Describe the role of the physical therapist for documentation and justification of durable medical equipment
2. Recall the role of the physical therapist for fall risk assessment
3. Recognize interventions delivered by the physical therapist to enhance quality of life
Track 1

BAYADA SIM Lab: Who’s Ready? Preparing Your Team for Independent Practice

John Morris, RN, BS, CSLI

Background: Determining readiness for practice combining adult learning theory with high-fidelity simulation to assess competence and confidence.

Repeated mistakes are worrying, sentinel events are devastating. How can we train consistent excellence into our care providers? An exciting review of adult learning theory integrated with real-world examples and a demonstration of new educational tools may provide the answer!

Evidence shows health care simulation to be a safe, effective educational tool to sharpen skills, replicate muscle-memory, instill confidence, and impart confidence. By using life-like mannequins in a realistic, psychologically-safe environment, providers can practice interventions, master machines, and recognize/respond to emergencies without the risk of harm. Health care systems around the world use simulation as an integral tool for assessing readiness. This session will cover adult learning theory and the unique training high-fidelity simulation offers, the science behind why it works, and the methodologies used to accomplish its objectives.

References:

Objectives:

1. Identify and overcome barriers to effective learning
2. Develop evidence-based educational framework
3. Utilize confidence and competence measuring tools

Thursday, November 3, 2016
3:45 pm – 4:45 pm
Track 2

Consumer Home Automation Use by PALS for Environmental Control
Antoinette Verdone, ATP, MSBME

Background: There are a number of consumer based home automation products on the market. This has opened up a lot of options for PALS to maintain control over their environment. The options are overwhelming and complicated. This presentation will attempt to demystify the current products on the market and how a PALS could be utilize this technology.

Objectives:

1. Name two commercial protocols for home automation
2. Describe at least one reason why a person with ALS would benefit from using consumer home automation equipment
3. Illustrate two apps that a person with ALS can use to control items in their environment
End of Life Options – Physician Assisted Death

Robert Osborne, RN

**Background:** California recently enacted the End of Life Options Act. This law was based on the current law in Oregon. Other states are considering similar laws. This presentation will look at the physician assisted death laws that currently exist, the requirements of both patients and physicians and the limitations of such laws as they pertain to ALS patients.

**Objectives:**

1. Identify which states currently have physician assisted death options
2. Name the requirements for both patients and physicians, as it relates to physician assisted death
3. Describe the impact of physician assisted death laws on patients with ALS

Maximizing Communicative Effectiveness in Individuals Diagnosed ALS and Cognitive Impairment

Kathleen Kaminski, MA, CCC-SLP, ATP

**Background:** The assessment of communication changes in individuals diagnosed with ALS is a dynamic process. As functional communication declines, augmentative and alternative communication (AAC) solutions are considered to maximize communicative effectiveness. In the presence of cognitive and behavioral impairment in individuals diagnosed with ALS, AAC acceptance and strategy use can be limited and additionally compromise day-to-day communication with a variety of communication partners and settings. Key responsibilities of the multidisciplinary team include education regarding potential barriers to successful use of frequently recommended communication strategies and speech generating devices, as well as identification of appropriate AAC solutions for this patient population.

**Objectives:**

1. Identify five stages of communication changes in ALS
2. Define two characteristics of cognitive and behavioral impairment in ALS
3. Describe two strategies to maximize communicative effectiveness of individuals with ALS and cognitive and behavioral impairment
Utilizing Modems and At-home Technology to Titrate Respiratory Support in ALS Patients

Micaela Sarazen, RRT, BSRT

Background: Advancing device technology at home has allowed ever increasing options in terms of the respiratory management of the amyotrophic lateral sclerosis, or ALS, patient. In ALS, where the progression of respiratory failure is highly variable, it is critical to have access to as much information as possible. Being able to securely and continuously monitor a patient’s noninvasive positive pressure ventilation data can facilitate compliance and ensure effective therapy. Modem downloads, coupled with at home overnight oximetry assessment can allow titration of settings in the comfort of the patient’s own home. This titration had previously been performed using a formal sleep study, guesswork, or not performed at all. As the disease progresses, access to this data can help determine the right time to advance to portable daytime ventilation. All of this can be done without a physical presence of the clinician interacting with the machine or a DME provider.

Purpose: To increase compliance, efficiency, and titration of respiratory support in ALS patients using modem downloads and home based studies.

Materials and Methods: We will discuss the benefit of having modems activated on all NIV devices at the initiation of therapy. The advantage of clinic permitted access to information for the life of the device, and how to access the online data and download information to the ALS clinic. Secure transmission of data to facilitate communication between the DME companies and clinic RT/RN/MD. A survey was conducted regarding initiation of NIV and titration of therapy in 50 ALS providers, respiratory therapists, physicians and nurses (Guion, 2015)

Outcomes and Results: Access to the most current information assists in evaluating the need for an increase in settings and initiating daytime ventilation for patients with a variable trajectory of respiratory failure. We believe this facilitates quicker intervention on symptoms preventing emergency initiation of respiratory support. Previous practice has not utilized modems to titrate respiratory support in ALS. Illustrative case examples from ALS patients using modems for titration of their respiratory support will be provided.

Discussions and Conclusions: Utilizing modem downloads and Bluetooth software for respiratory devices can greatly assist in the compliance, titration and effectiveness of noninvasive ventilation therapy in ALS patients. Easily accessible serial downloads can allow clinicians to increase settings, advance therapy and best facilitate evidence-based advancement of care including G-tube placement and end of life discussions. We believe that this improves care by the ALS clinic and their supporting DME companies. This can allow for safer initiation of therapy in the future and more complete follow-up in the context of Telemedicine programs. Studies evaluating the effect of these home based technologies may confirm benefit and can allow for creation of newer modes for respiratory support where current NIV modes frequently fail.
Objectives:

1. Illustrate current practice of titrating respiratory settings for ALS patients and the disease progresses
2. Explain the advantage of utilizing modem data in the clinic to titrate noninvasive ventilation settings
3. Outline the options for home based assessment of effective ventilation settings using overnight pulse oximetry
4. cognitive and behavioral impairment

Thursday, November 3, 2016
5:00 pm – 5:30 pm
Track 2

The Creation of an ALS Outreach Clinic in Iowa
Erin Springer, MSN, RN

Background: Multidisciplinary ALS clinics create a wonderful environment for patients, families and providers to combat this degenerative disease. They create an opportunity for a group of providers to collaborate in order to provide the best care possible for patients and families. Establishing a new ALS clinic, especially an outreach clinic, is challenging. This presentation will describe the process, goals and outcome of the creation of a multidisciplinary outreach clinic in Des Moines, Iowa. For the first time, three healthcare institutions—the University of Iowa, Mercy, and Unity Point—are collaborating to provide staff and care for these patients. Their dedication to this patient population is evident even with the challenge of creating the clinic in a new setting, with new providers from all 3 institutions, the ALSA and MDA, and in the out-of-clinic follow up care for ALS patients.

Objectives:

1. After viewing this presentation participants will be able to explain the basic process of the creation of a multidisciplinary ALS outreach clinic in Iowa
2. Identify key staff members needed for an ALS multidisciplinary clinic
3. Describe the complex nature of the creation of this clinic by bringing together 3 healthcare institutions, ALSA and MDA to work together to care for ALS patients and families

Thursday, November 3, 2016
5:30 pm – 6:00 pm
Track 2

The Impact of Early Collaboration between a VA ALS Clinic and an ALS Association Chapter
Marinella Galea, MD
**Background:** In 2014 the James J Peters VAMC was designated as the ALS Center for VISN 2 South. The Spinal Cord Injury/Disorder (SCI/D) Center was challenged to create a state-of-the-art ALS program within its structure. Our mission is to identify and provide patient centric care to all ALS Veterans residing in the southern NY, NJ and PA area, creating an opportunity to support them and their caregivers. To better understand the scope of the issue and the geographical impact of the disease we have sought early partnership with the ALS Association (ALSA) Greater New York Chapter. The representatives have offered guidance, extended their expertise, and shared in depth knowledge of the ALS resources available to the general population in New York. They have provided oversight of the initial operations and provided regular follow up. We have strengthened our collaboration to include outreach, education opportunities, and community support.

**Purpose:** To delineate the positive effects, outcomes and pitfalls of a partnership between VA and ALSA.

**Materials and Methods:** Since our ALS Clinic opened in June 2014 we have reached out to and enrolled 75 ALS Veterans, 12 (16%) patients were referred by ALSA and had never utilized VHA. All Veterans not already aware of ALSA, attending the ALS Clinic, are referred to ALSA for additional support and education in the community. Persons with amyotrophic lateral sclerosis (PALS) who are Veterans are prioritized, and the enrollment process expedited (1-2 weeks). They receive service connection within an average of 30 days (7 to 90 days), and can be scheduled for initial assessment on Mondays; transportation is offered to all service connected Veterans; we have no waiting lists. Our specialists (neurologist, palliative care and primary care) were invited to speak at the ALS support groups, resulting in additional referrals (2). To provide continuity of care we have established that all ALS Veterans in need of inpatient services are admitted directly to the SCI/D Unit. From June 2014 to date we have admitted 12 Veterans, 5 were ventilator dependent. While hospitalized, the patients and their families continue to receive ALSA support through regular visits, team discussion and advocacy at large. We currently provide inpatient care for 4 ventilator dependent patients who have no viable discharge options into the community.

**Outcomes and Results:** The ALS clinic at JJPVAMC has rapidly become the referral Center for ALS care for the South NY, NJ and PA area. The ALSA representatives identify the ALS Veterans at the first encounter and educate them to the broad spectrum of clinical, financial and coordinated services available to them. ALSA liaisons at the specialized NY non-VA clinics advocate for Veterans with a diagnosis of ALS and encourage referrals. ALSA deep understanding of the requirements for VA enrollment and service connection prerequisites has accelerated the process from referral to first visit. In fact, every ALS Veteran who is service connected is entitled to transportation to the ALS Center, eliminating the travel and distance burden. The SCI/D Unit provides clinical care, in a safe, and compassionate environment, however the outdated physical plan is not conducive to promote independence and allow the ALS ventilator dependent Veterans to live life to their fullest. With ALSA assistance we have selected 2 best practices for inpatient ALS ventilator dependent persons in the NY and MA area, we have visited sites and are establishing the feasibility of creating a dedicated ALS inpatient program. A plan to design a comprehensive ALS Model of Care at the JJPVAMC was presented in April 2016 to VISN 2 Leadership, for consideration.
Discussions and Conclusions: The collaboration between the JJPVAMC ALS clinic and ALSA has strengthened over time. The identification of a point of contact within the VA clinic has facilitated communication. Referred PALS who are Veterans reported being evaluated quickly and efficiently. This process included stakeholders learning the VA mission and scope, familiarizing themselves with VA operations, available resources, and identifying how to integrate VA services. ALSA representatives report that they feel confident in sending their PALS to the VA clinic, knowing that they will receive quality comprehensive care, including state-of-the-art equipment, stipends for home care services, and home modifications. This has expedited the enrollment process and provided a clear understanding, from the first encounter, of the support VA can provide. VA clinicians’ participation in the ALSA support groups, providing education in a friendly, supportive and non-threatening environment, has attracted more referrals. We are exploring alternative pathways to deliver care to the most disabled ALS Veterans (i.e. ventilator-dependent) to allow them to remain independent, when discharge home is not feasible. Future endeavors include collaborating with The Greater New York Chapter to have a liaison at the VA clinic, and seek ALS clinic certification.

Objectives:

1. Describe the implications of VHA and ALS Association collaboration
2. Clarify VHA and ALS Association chapter partnership roles
3. Identify outcomes and pitfalls associated with collaboration between an ALS VA clinic and ALS Association chapter

Thursday, November 3, 2016
5:00 pm – 5:30 pm
Track 3

ALS Databases and Spreadsheets: What’s on Your Dashboard?
Ileana Howard, MD

Background: Amyotrophic Lateral Sclerosis is a rapidly progressive condition requiring close management by the Interdisciplinary Care Team. There are well-established and widely accepted clinical practice guidelines to guide care, but there is little consensus on the best way to practically monitor adherence to the guidelines on an ongoing basis in individual clinics. Previously, large centralized databases provided a resource to standardize data collection and present intermittent feedback to practitioners regarding adherence to clinical practice guidelines. However, this type of solution is less than ideal due to the inability to integrate with the Electronic Medical Record, the inability to continuously update, and the inability to provide additional specific data for an individual patient. Therefore, these type of tool is more helpful for population data rather than individual patient care.

The Agency for Healthcare Research and Quality suggests that the presence or absence of adequate clinical support structure, such as a patient database, to promote quality care coordination is in of itself a quality metric. Although this quality indicator is not included in the aforementioned clinical practice
guidelines, this is an indispensable component of highly effective and proactive management of medically complex patient population.

**Materials and Methods:** This poster will outline the evolution of a patient management dashboard through various databases, starting from simple spreadsheet management through interactive “dashboards” interfacing with the Electronic Medical Record (EMR) within the Veterans Health administration.

**Discussions and Conclusions:** The presence of a patient management database is a commonly cited quality metric for complex medical populations and should be considered an indispensable tool for the interdisciplinary amyotrophic lateral sclerosis clinic. This pilot project demonstrates successful integration of a patient care dashboard for a regional ALS specialty program, one that can be replicated across the Veterans Health Administration.

Further work is warranted to align clinical database tools to allow future comparison of outcomes in the public and private sector.

**Objectives:**

1. Describe the category of structure as defined by the Agency for Healthcare Research and Quality, and cite two examples of structure that supports high quality clinical management in an ALS clinic
2. Name three potential benefits of keeping a database of patients enrolled in an ALS clinic
3. Describe two potential challenges to maintaining an accurate patient database in an ALS clinic, and solutions for how these can be overcome

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**Thursday, November 3, 2016**

5:30 pm – 6:00 pm

**Track 3**

**Continuity of Care and Community Collaboration in AAC Service Delivery**

*Trinity Deibert, MS, CCC-SLP*

**Author(s): Kendra McInturf, MS, CF-SLP, and Trinity Deibert, MS, CCC-SLP**

**Background:** Communication is a vital part of the human experience and one that is threatened by loss of motor function resulting from ALS. In recognition of the critical importance of PALS’ ability to communicate, many ALS Association chapters have AAC equipment loan programs and other resources for communication support. When the Oregon and SW Washington chapter began in 2002, its third hired staff member was a Speech-Language Pathologist to fill the role of Assistive Technology Services Coordinator. Since that time, the role of the AT Services Coordinator has changed and adapted to meet the evolving needs of the ALS Community in our chapter. One innovation that has come from this is a unique model of community collaboration in meeting AAC needs.
Purpose: This presentation seeks to offer a unique approach to meeting the AAC needs of people and families living with ALS through collaboration and partnership between community home health SLPs and Assistive Technology programs within the ALS Association. The model described by the authors promotes better continuity of care, as well as increased access to care, communication support, and excellent SGD implementation.

Materials and Methods: This presentation will describe the evolution of the current collaborative model with particular attention to 1) the partnership between the presenting authors, the Oregon and SW Washington Chapter’s Assistive Technology Services Coordinator and a home health speech-language pathologist who specializes in AAC and belongs to a part of a prominent system of care in our region; 2) the values that have driven and shaped this model; and 3) the distinctive benefits of this model. The authors will demonstrate that this model has improved the quality of AAC support for our areas’ PALS and families, as evidenced by case studies that demonstrate its application, as well as the testimony of PALS/families, other healthcare providers, and other professionals who serve in supportive roles.

Outcomes and Results: This model represents a unique approach to meeting PALS’ AAC needs across systems, one which has increased PALS’ access to AAC and SGDs, as well as to much-needed follow-up training and support. PALS and caregivers report feeling supported throughout the course of their journey with ALS and receive strong communication advocacy on their behalf. Other professionals also attest to the unique benefit of this approach.

Discussions and Conclusions: Each region, ALS chapter, and healthcare system encounters its own challenges. Commonly this includes providing adequate support for AAC education, equipment, and training for people and families living with ALS. The authors present one model of collaboration and partnership that has helped to bridge gaps and provide greater service to these PALS and families. It may not be appropriate for this model to be precisely replicated in every setting, but the authors hope that it can inspire and encourage formation of strategies and approaches that fit each community’s individual AAC needs.

Objectives:

1. Express the key values/needs driving the model presented by the authors
2. Describe the major hallmarks of this model, as described in this presentation
3. Discuss how aspects of this model could or could not be implemented within their own practice and service delivery models
4. and solutions for how these can be overcome

Friday, November 4, 2016
8:00 am – 9:00 am
Track 1

Walking a Tight Rope: To Infinity and Beyond Eyegaze
Lisa Bruening, MS, CCC-SLP
Background: ALS is a disease lacking a definitive diagnostic test and results in a poor prognosis. Estimates indicate severely reduced life expectancy of approximately 2 to 5 years; therefore, speech-language pathologists (SLPs) working with persons with ALS have a narrow window of opportunity in which to evaluate, recommend and obtain a speech-generating device (SGD) via insurance funding. Often, individuals who are referred to SLPs report onset of symptoms at least 6-12 months prior to the speech consult. Frequently, many individuals present at the initial visit with profound speech and communication deficits often with reduced respiratory support and poor capacity for maintaining adequate hydration and nutrition. Furthermore, many of these individuals have already exhausted all Medicare authorization for speech therapy via traditional speech and dysarthria therapeutic techniques, not including those sessions targeting the swallowing disturbance. The disease is often rapid in progression suggesting the need for additional support via hospice services and spiritual care. These factors may further restrict the timeline to gain much needed SGD via insurance coverage. In addition, recent changes to Medicare guidelines may make obtaining the appropriate SGD and access methods via insurance an even more difficult scenario. SLPs, therefore, must be good stewards of funding sources while still meeting the ever-changing needs of the person with ALS. This presentation will focus on the requirements put in place by Medicare for funding of a SGD and access methods as well as also considering standard off-the-shelf technologies and applications to meet immediate communication needs. Often overlooked access strategies will be discussed. The newest technology and seemingly least obtrusive access methods may not always be the least restrictive. Why should ethical considerations and costs matter?

Objectives:

1. Describe Medicare funding guidelines and requirements for a speech generating device
2. Describe the “access hierarchy” necessary in Medicare documentation
3. List at least two physical deficits or disease symptoms which may indicate need for alternative access methods

Friday, November 4, 2016
8:00 am – 8:30 am
Track 2

The Assessment of Bulbar Function in ALS
Richard Smith, MD

Author(s): Richard Smith, MD, Erik Piro, MD, PhD, FRCPC, Gary Pattee, MD, Jordan Green, PhD, Merit Cudkowicz, PhD, and Eric Macklin, PhD

Background: Historically, clinical trials in ALS have emphasized survival rather than symptomatic improvement as an endpoint. When symptomatic benefit is assessed, it generally focuses on the integrity of limb musculature. In fact, to our knowledge, objective measurements of bulbar functions, such as timed swallowing, have never been measured in a clinical trial.
**Purpose:** To evaluate the utility of measures which assess bulbar function in ALS: the ALSFRS-R, CNS-BFS (a self-report scale), visual analog scales (VAS), and timed measures of speech and swallowing.

**Materials and Methods:** Bulbar function was assessed in up to 120 subjects with probable or definite ALS as determined by El Escorial criteria. A clinical observer made a diagnosis of impaired speech, swallowing and salivation by making direct observations of the subjects. For example, the patients' speech was determined to be normal or abnormal based on three criteria: intelligibility, loudness, and nasality. Subsequently, subjects completed the self-administered CNS-BFS and VAS tests, and were also evaluated by raters who scored the various items comprising the ALSFRS-R. Speech rate for each subject was determined by reading a test passage, and the time to swallow both liquids and solids was recorded. Further, correlations were made between clinician diagnosis and each of the measures that were assessed. Based on this, we rank ordered each of these measures for their potential utility in a clinical setting.

**Outcomes and Results:** The self-report CNS-BFS was highly correlated with the bulbar subscale of the ALSFRS-R ($r = -0.896, p < 0.001$). Both the ALSFRS-R bulbar subscale and the CNS-BFS speech, swallowing, and salivation subscales were highly predictive of clinician assessment of bulbar dysfunction. The CNS-BFS subscales for swallowing and salivation were more highly correlated with the VAS than with the corresponding ALSFRS-R subscales. The CNS-BFS swallowing subscale was better correlated with the timed swallowing of liquids and solids than were the ALSFRS-R and VAS swallowing subscales.

**Discussions and Conclusions:** Both the CNS-BFS and the bulbar domain of the ALSFRS-R accurately predict impaired bulbar function in ALS patients, comparing favorably to clinician diagnosis. In general, the recently developed CNS-BFS outperforms both the ALSFRS-R and the VAS when correlations are made between these scales and timed reading and swallowing tests. Although the ALSFRS-R is the most frequently used scale, it is a rater-administered scale, a disadvantage in that the data is generated by an observer rather than the patient. The variability between raters does not need to be taken into account in the instance of a self-report scale, a considerable advantage since data provided by a patient is not filtered through an observer. At a minimum, the CNS-BFS could become a useful adjunct to the clinical assessment of bulbar function.

**Acknowledgements:** This was supported by grants from the ALS Association and Avanir Pharmaceuticals.

**Objectives:**

1. Describe tools available for evaluation of speech and swallowing
2. Summarize the utility of self-report scales versus “objective measurements”
3. Practice the validity of the Center for Neurologic Study Function Scale as an aid to diagnosis, management, and clinical investigation
Friday, November 4, 2016
8:00 am – 8:30 am
Track 2

“Breaking Bad” Connections: International Organization for Standardization (ISO) Enteral and Respiratory Connectors—Impact on Patients with ALS

Pamela Kittrell, MSN, RN, CCRC

Author(s): Karen A. Martin, MA, RDN, LD, FAND

**Background:** The Joint Commission has issued two Sentinel Event Alerts concerning misconnections. International device manufactures are standardizing connections to decrease interconnectivity between unrelated delivery systems. The infusion of enteral nutrition via the parenteral route has resulted in death and sentinel events. Luer connectors allow functional connections between unrelated delivery systems: vascular, enteral, respiratory, epidural, urologic, and intrathecal, leaving room for unacceptable risk.

Provision of supplemental or sole source nutrition/hydration via enteral feeding is the standard of care for ALS patients with dysphagia, respiratory compromise and weight loss. The potential for misconnections is real in ALS patients who may have respiratory devices and connectors as well as urinary tubes. Clinical teams that are aware of the changes in the connections will be able to educate patients regarding safe practices in enteral nutrition and other therapies.

Awareness, education and communication between facilities, pharmacies, prescribers, nurses, home suppliers, supply chain managers, patients and caregivers will enhance patient safety. Familiarize your organization with the new ISO standards, implement the standards via an interdisciplinary team. Utilize transition checklists to optimize safety in the process. Evaluate the transition process and report the impact of the changes seen in patients with ALS.

**Objectives:**

1. Summarize the Joint Commission’s Sentinel Event Alert concerning misconnections
2. Detail the Global Enteral Device Supplier Association initiative to decrease potential misconnection
3. Identify challenges with new connectors related to formula delivery of various thicknesses

Friday, November 4, 2016
8:00 am – 9:00 am
Track 3

Building Personal and Professional Resilience to Prevent Burn Out

Anne Supplee, MDiv

**Background:** Participants will be invited to try different methods of renewal to experience what might work best for them—meditation, gratitude, doodling, and breath work.
The presentation will be primarily experiential since we all already know we need to take care of ourselves, we just need to know how to integrate that awareness into our daily lives.

**Objectives:**

1. Identify ways of thinking about burnout both personally and professionally
2. Discuss what renews us professionally — experiences in clinics or support groups that enhance our understanding of what we do and why we do it
3. Practice at least 3 different methods of mindfulness — meditation, doodling/drawing, gratitude, breathing
4. Identify challenges with new connectors related to formula delivery of various thicknesses

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**Friday, November 4, 2016**

**9:15 am – 10:15 am**

**Track 1**

**Power Wheelchairs: What to Recommend and How to Get It Approved**

*Kristy Allen, DPT*

**Background:** The process of providing a power wheelchair to our patients with ALS is extremely complicated and requires a team approach. In a study of ALS patients, Bromberg (2010) reports that 96% of patients with LE onset, 63% of patients with UE onset and 46% of patients with Bulbar onset will require a power wheelchair at some point during the course of the disease. Unfortunately most practitioners working in our ALS clinics are not experienced in providing wheelchairs to patients or are unable to keep up-to-date with the evolving equipment and insurance demands as the only time they recommend a wheelchair is for their ALS patients.

One of the most difficult discussions for a PT/OT to have with a patient is when first discussing the wheelchair. However, Ward (2015) in their survey of ALS patients found that 33% of patients wished the conversation had been started sooner. This presentation will include my experiences in starting this difficult conversation and also insurance requirements to first qualify for a power wheelchair.

**Purpose:** Past power wheelchair presentations have focused mostly on the typically recommended equipment, but there are many more options available. During this presentation I will educate providers about equipment options from a multitude of sources. There are three different companies who manufacture group 3 power wheelchair bases and I have recommended each of them to various patients. I will explain the differences between the bases and why to choose one versus another. I will also discuss specialty controls, modifications and items not covered by insurance. In this category there are numerous manufacturers and I will discuss the variations and benefits of each. The presentation itself will include pictures throughout to use as references and I will also provide power wheelchairs and accessories for the practitioners to see in person.
While the equipment is a vital aspect of providing a wheelchair to our PALS, it is only one piece of the process. I feel that past presentations regarding power wheelchairs have not focused enough on insurance reimbursement. As practitioners it is our responsibility to provide our patients with the correct equipment and to not create a financial burden on the patient or their family. The average power wheelchair costs between $20,000-$30,000, which our patients cannot afford, nor can they afford not to get the specific equipment we are recommending due to insurance denials. This presentation will include specific documentation requirements and tips for the evaluating PT/OTs to ensure their recommendations are approved. I will also describe the documentation requirements of the referring provider from the initial visit through possible modifications. In the past year alone, Medicare/Medicaid and private insurance requirements have become even more stringent, specifically with getting both tilt and recline approved, something that is an absolute necessity for our patients. With improved documentation our practitioners will be able to get our patient’s power wheelchair and accessories approved.

**Discussions and Conclusions:** At this conference we all have a passion for helping patients with ALS; however our experience levels differ greatly. The goal is for this presentation to be a valuable tool for all levels of experience. At the conclusion of the presentation new practitioners will have a comprehensive guide and understanding of the equipment available and how to get it approved. For experienced practitioners they will be introduced to new or previously unknown equipment along with up-to-date insurance requirements. I hope that this will have an immediate impact on the care we all provide our patients with ALS.

**References:**


**Objectives:**

1. Explain the different power wheelchair base options, power options and accessories available for patients with ALS
2. Differentiate between insurance requirements and coverages for Medicare, Medicaid and private insurances for power wheelchairs and their accessories
3. Describe and document the required elements in the chart note, prescription and justification letter for Medicare, Medicaid and private insurance approval of all recommended equipment
Laryngotracheal Separation in ALS: The Why and How
Ileana Howard, MD, and Abigail Potts, MS, CCC-SLP

**Background:** Laryngotracheal Separation (LTS) is a surgical procedure which separates the esophagus from the trachea, providing a definitive treatment to prevent aspiration of oral contents into the airway. Several case series have been reported regarding the use of this procedure for persons with ALS, however, there is a paucity of literature regarding patient selection, education, and pre-procedure counselling as well as post-procedure education and follow-up.

**Purpose:** In this session, we will discuss the role of LTS surgery in the armamentarium of the ALS clinician, among other strategies to optimize respiratory hygiene. We will present case examples to highlight clinical management options in challenging respiratory situations. We will describe our experience with assessment, referral, and follow-up of individuals with ALS for the LTS procedure including pre-procedure education and counselling, caregiver and healthcare team education, aftercare, and follow-up.

**Discussions and Conclusions:** Although at first LTS may appear to be an extreme solution to improve respiratory management in ALS, it is an important tool for select patients who otherwise are at high risk of morbidity and mortality due to intractable aspiration and our experience suggests it can promote improved quantity and quality of life for these individuals.

**Objectives:**

1. List three non-surgical interventions to decrease the risk of aspiration in ALS
2. Describe the indications for laryngotracheal separation surgery
3. Describe two benefits and two risks of the laryngotracheal separation procedure
4. Letter for Medicare, Medicaid and private insurance approval of all recommended equipment
This session will address this gap in care and answer the remaining Medicare benefit questions identified through a pre-conference nationwide ALS Association Chapter Survey. Information will be gathered through a survey of skilled home health service agencies in Iowa and Nebraska to address these remaining benefit questions as well as the identified gap in hours of care. Additionally, this session will address “best practice” tips that health care professionals and families can utilize to ensure home health service benefits are maximized.

Objectives:

1. Address Medicare home health benefit questions with input from skilled home health service agencies
2. Identify barriers to patients accessing the maximum hours of their Medicare skilled home health services benefit
3. Outline at least three interventions that can assist families in maximizing their Medicare benefits for skilled home health services

Friday, November 4, 2016
10:30 am – 11:30 am
Track 1

Psychosocial Assessment across the Life Span of an ALS Patient
Brenda Edelman, LCSW, BCD

Background: This presentation will review developmental milestones associated with the individual’s life cycle, according to Erik Erikson’s stages of psychosocial development. The discussion will include the impact on the patient and family while dealing with the diagnosis of ALS and the progression of the disease.

Objectives:

1. Identify developmental milestones that are effected by chronic illness by utilizing Erik Erikson’s theory of psychological development
2. Describe how professionals evaluate patients’ psychosocial needs utilizing this model
3. Demonstrate how to utilize this model in the ALS continuum of care
4. for skilled home health services

Friday, November 4, 2016
10:30 am – 11:30 am
Track 2

Barriers to Normalcy: An ALS Patient and Caregiver
Don Akers and Berkley Akers
**Background:** Getting a terminal diagnosis of ALS really knocks the wind out of your sails and puts your long range plans on hold. You need to continue to deal with the normal aspects of life as long as possible, knowing what you are likely going to face. For many who have had this diagnosis, the desire is to continue with life as normal as possible until that is no longer an option. In doing so, we have found many resources, but we have also found several gaps where some work could be done to help families dealing with ALS. These gaps range from informational to practical to technological areas. Filling some of these gaps may also increase the quality of life for many others with similar diseases. In many cases, solutions exist today, but is not associated closely with the ALS community. We hope to help the community understand our perspective and to understand some things that could be very beneficial to the community.

**Objectives:**

1. Describe practical ways for the ALS community to approach technological gaps
2. Recognize how information be gathered and made accessible to the ALS community
3. Develop ways to meet large ticket practical needs of ALS patients

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**Friday, November 4, 2016**

10:30 am – 11:30 am  
Track 3  

**Care Manager's AAC Tool Kits Help People with ALS Reach Vital Communication Goals**  
*Amy Roman, MS, CCC-SLP, Daniel Potapshyn, MA, and Michelle Longo, MSW, ASW*

**Background:** This presentation describes and provides the training tools, strategies and reproducible materials for a successful, time-efficient and cost-effective, AAC Toolkit Project which:

1. Empowers ALSA Care Managers, who have frequent contact with patients including those who don’t go to clinics, to provide simple but essential AAC tools and strategies.

2. Is guided by the ALS Functional Communication Scale that is applicable to people at all stages of ALS. This tool will be introduced during the presentation and provides multidisciplinary team members an understanding of the communication abilities people with ALS should always expect to maintain. We will demonstrate Kit tools and strategies which can be easily utilized by participants of any professional discipline.

3. Focuses on inexpensive but effective communication solutions that enable patients to alert others when they have a need, conserve energy, maintain communication via multiple access methods, communicate in emergencies with unfamiliar partners, and prepare for future changes in communication.

4. Is increasing the number of people receiving helpful communication tools from the ALSA Golden West Chapter’s AAC Lending Library.
Objectives:

1. Describe and locate the training materials and resources available online to reproduce this successful, time-efficient and cost-effective project to expand patient exposure to communication strategies and tools by equipping ALSA Care Managers and other non-AAC specialists with tools and training.

2. Observe demonstrations of and then describe at least 2 AAC tools or strategies the participant can use immediately with clients with whom they are experiencing communication challenges.

3. Describe and reference seven communication competencies that every person with ALS should expect to maintain throughout the course of their disease.

Friday, November 4, 2016
2:30 pm – 3:00 pm
Track 1

ALS Telemanagement: Development and Evaluation
Susan Walsh, RN, MSN, ACNS-BC

Background: There is currently no published research on the outcomes associated with Telemanagement as a mode of care for individuals with ALS. Live at-home telemanagement for ALS has received little research attention largely due to obstacles that are involved in planning this type of study, which include factors related to insurance coverage and reimbursement for services, patient health information confidentiality, video conferencing software and public internet security, liability, funding, and technology support for the video conferencing software and its connectivity. This pilot program has been designed for videoconferencing to be used to deliver remote multidisciplinary care to patients as an alternative for in-clinic visits. It is currently unknown whether using live remote presence software to deliver health care to ALS patients will be acceptable and perceived as effective by patients and their caregivers. It is also unknown if health care providers will believe they achieved their goals of the visit through Telemanagement or if they would consider Telemanagement to be an adequate proxy for an in-person office visit in delivering medical care. This presentation will detail the development of Telemanagement for patients at the Hershey ALS clinic and the results of the pilot project. It will discuss strategies for approaching Telemanagement within institutional settings and the next steps for evaluation and development of Telemanagement as a feasible patient care option.

Objectives:

1. State the rationale for use of Telemanagement in ALS care
2. Describe the critical components for a Telemanagement program
3. Describe patient, caregiver and provider responses to Telemanagement as an ALS clinic
Telemedicine and ALS Caregiver Burden

Monique Washington, RN, MS, APHN-BC, and Valerie Fluellen, MS, LISW-S, C-SWHC

Author(s): Monique Washington, RN, MS, APHN-BC, Stephen Selkirk, MD, PhD, Frances McClellan, RN, and Valerie Fluellen, MS, LISW-S, C-SWHC

Background: Caregivers of Amyotrophic Lateral Sclerosis (ALS) patients experience a multitude of strain and stressors, putting them at risk for high caregiver burden (CB). It is estimated that a primary caregiver of an ALS patient spends more than eleven hours daily providing care for their loved one, separate from hired services. CB is also concerning since it can negatively impact a patient’s physical and mental well-being, as well as their quality of life (QOL). Virtual ALS care may impact the development and degree of CB in caregivers of those with ALS. The purpose of this analysis was to determine if ALS care delivered via telemedicine impacted CB.

Materials and Methods: This cross-sectional analysis included 33 patients with ALS that received either traditional face to face clinic (n=15) or telemedicine (n=18) care from an interdisciplinary team at a tertiary ALS Center. Telemedicine patients received real time interactions with ALS center staff via Clinical Video Telehealth at a local clinic or using Video-to-Home technology from the home using a personal computer, laptop. CB was determined by the Zarit Caregiver Burden Interview (Zarit). The Zarit rates CB using a 5-point Likert scale (0 = never, 5 = always), with higher scores reflecting higher caregiver burden.

Data Analysis: Median total Zarit scores (0=none to 16=high burden) were calculated. Total Zarit scores were also dichotomized as no/low burden vs. high burden. To account for differences in CB that may be attributed to quality care and severity of ALS, the proportion of patients receiving Riluzole, NIPPV, Home Health care, Communication Device, PEG, Hospice, multidisciplinary care plan, nutritional screenings, assessments of respiratory sufficiency, and ALS Functional Rating Scale-Revised (ALSFRS) scores was determined for both groups. The Student’s t test was used to detect differences between continuous variables and the χ2 or Fisher’s exact test to detect differences between categorical variables. The Mann-Whitney U test was used to detect significant differences median CB. Significance was determined by a p-value ≤ 0.05.

Outcomes and Results: The majority of the sample was male (clinic =94.6%, telemedicine =100%) and there were no significant differences in the length of diagnosis (clinic =20.4, SD= 31.7; telemedicine =35.7, SD= 70.9), ALSFRS (clinic =30.1, SD= 0.98; telemedicine =31.7, SD= 0.91), or quality measures. Median CB was higher in the clinic care group (20.5 vs. 16.0) and the proportion of caregivers with high CB was significantly higher in the clinic group (33%) compared to the telemedicine group (5.6%).

Discussions and Conclusions: Caregivers of ALS patients who received care via telemedicine had significantly lower caregiver burden than those that were followed in a traditional outpatient clinic setting. This may have resulted from mitigating the stress related to traveling a patient with high-level
Are A telemedicine platform provides an additional level of care that when combined with local primary care provides a more concise, coordinated care plan that is reassuring to the caregiver and patient, in turn relieving stress. This data supports the expansion of telemedicine modalities in the ALS population. This care delivery platform has the potential to lower caregiver burden, provide high quality care, and improve the QOL of people diagnosed with ALS.

**Objectives:**

1. Evaluate how caregiver burden is measured
2. Describe how caregiver burden impacts patient’s quality of life
3. Illustrate how telemedicine impacts caregiver burden

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**From PALS to Provider: A Model of Wellness Life Dimensions to Support Quality of Life**

*Donna McArthur, PhD, APRN, FNP-BC, FAANP, FNAP*

**Author(s): Donna McArthur, PhD, APRN, FNP-BC, FAANP, FNAP, and Dagmar Munn**

**Background:** Recognizing personal and professional expertise within PALS provides opportunities for interprofessional engagement in creating resources for use among team members, PALS, and CALS. The concept of resilience – the ability to transition through, cope with, and survive change – is inherent in this process. Dagmar Munn, a patient currently living with ALS, experienced personal success in tapping into her resilience by applying the fundamental principles of wellness drawing from the principles she taught to others during her past 25 years managing a hospital-based wellness program in Iowa. With the encouragement and input from ALS clinic team members and the Arizona ALS Association, Dagmar wrote a self-help eBook for other PALS using a series of humorous anecdotes to describe her first year living with ALS. The book received positive attention world-wide and led Dagmar to create and author an online blog that continues to share ALS-related wellness motivation, inspiration and humor. While no two journeys with ALS are alike, the ability to maintain resilience throughout the ongoing changes and challenges of ALS, to practice checking-in and balancing physical, emotional, intellectual, spiritual, and social life dimensions impact quality of life (QoL). Studies support that patient and caregiver psychological well-being impacts overall QoL in patients with ALS.

**Materials and Methods:** A simple model proposed by Dagmar Munn will be presented. This model is based on the traditional wellness wheel developed in the 1960s by Dr. Bill Hettler, co-founder of the Wellness Institute. The model depicts six interdependent life dimensions. For PALS, five key life dimensions will be highlighted: physical, emotional, intellectual, spiritual, and social. Definitions of each dimension with exemplars will be provided as well as ALS life dimension tenets.

**Outcomes and Results:** Application of the five ALS Life Dimensions within the context of clinic visits will be described to include opportunities for patient self-reflection. Integration of this resource among
caregivers and other family members to facilitate discussions in problem solving will be explored. More broadly, topics or themes for discussion during support group meetings will be identified.

**Discussions and Conclusions:** The proposed presentation is unique because it gives voice to one special patient living with ALS and her mission to impact QoL among other PALS. Health care providers will have the opportunity to share her work/resources in myriad formats.

**Objectives:**

1. Discuss application of ALS life dimensions with individuals, within clinic, and community settings
2. Describe a new model addressing quality of life in PALS using wellness life dimensions
3. Discuss patient engagement in creating resources for PALS
4. Illustrate how telemedicine impacts caregiver burden

**Friday, November 4, 2016**
**2:30 pm – 3:00 pm**
**Track 3**

**Increase the Quality of Life for People Affected by ALS by Utilizing Volunteers in the Home**  
*Laura Winterstein, CVA*

**Background:** In 2000, the Minnesota Chapter was approached by one of its board members who lost her brother to ALS. She asked that a program to provide more assistance in the home for people affected by ALS be created. With a two person staff, she thought utilizing volunteers would help them better meet the needs of the people they served. She funded the start of the program with a $2000 donation which was used to hire a part-time staff person. The family assistance program was created and served six people living with ALS in the first year.

**Purpose:** The family assistance program furthers the mission of The ALS Association by utilizing volunteers to provide support to families affected by ALS in their homes. Using volunteers allows the chapter to provide more individualized support than staff alone is able to.

**Materials and Methods:** The family assistance program is available to anyone affected by ALS or PLS who lives in our service area. Families learn about the program through a brochure in their welcome packet, by talking with a care services coordinator at an ALS clinic, or by visiting our website. Families can request any type of help, outside of medical or personal care, on a weekly, biweekly, monthly, or as needed basis. The most popular requests are cleaning, lawn mowing, and companionship.

The screening process for volunteers includes an application, an interview, two professional references, and a background check. Once volunteers are accepted into the program they go through orientation to the chapter and training for the program.

Both the families and volunteers must sign an agreement to participate in the program which outlines the program’s guidelines and boundaries.
Once a request for assistance has been submitted, volunteers are paired with families based on geography, the frequency of visits, and the type of request. The preference is to match trained volunteers first but should none be available, recruitment of a new volunteer is necessary.

When both the family and volunteer agree to a pairing, identities are revealed and contact information is shared. Two weeks after this information is shared, both receive a phone call from the volunteer manager to inquire about their first meeting and answer any questions that have come up. After that, families are contacted every six months and volunteers are contacted monthly.

**Outcomes and Results:** The program has consistently grown since its inception. In FY2016, 45 people affected by ALS utilized the program and were assisted by 58 volunteers who gave 1,768.5 hours of their time.

There are a myriad of benefits of the program. On the face of it, families receive the help they requested and those needs are met. Behind that, the stress of having to complete certain tasks is eliminated for the entire family. Since the family doesn’t have to spend time doing these tasks, they can use that time to be together while they’re still able. A gentleman with ALS said of the program, “Having help and support in these kinds of areas has really taken some of the pressure off on a daily basis. When I know that [volunteer] Gregg is coming, I do not worry about how and when the lawn work will get done. When [volunteer] Deb calls and says she is on her way with a meal, I know that takes pressure off of [my wife] Kathy, and gives her time to focus on other things.”

Additionally, families’ support systems are expanded. Many families find people drift away after the diagnosis; having someone who wants to help is extremely meaningful. The consistent visits often lead to friendships between the family and the volunteer. The same gentleman mentioned above said, “It has also been very touching to get to know these two people – who we would not have met if not for the ALS volunteer program. They have enriched our lives in many ways.” Volunteers feel similarly; one volunteers said, “On my last visit we went for a “walk” and Sherm (the gentleman living with ALS) introduced me to other residents as his friend which I consider a true honor.”

**Discussions and Conclusions:** Offering the family assistance program has brought innumerable benefits to the people we serve, the volunteers who participate in it and the chapter staff. We have been assisting other chapters on an individual basis with their implementation of the program. The clinical conference is the perfect forum and the most efficient way to disseminate information on the program and how it can be implemented. The attendees will also benefit from the opportunity to have discussion with other chapter staff in attendance which is something that individual consultations lack.

**Objectives:**

1. Describe How the Family Assistance Program Increases the Quality of Life for People Affected by ALS
2. Identify the Specifics of the Family Assistance Program and How to Coordinate It
3. Implement the Family Assistance Program Locally
The ALS Association Philadelphia Chapter's Visiting Volunteer Program: Suggestions for How to Start a Program

Gail Houseman, RN, CNS-BC

**Background:** Many non-profit organizations rely on volunteers to support their missions: the ALS Association Greater Philadelphia Chapter utilizes volunteers for events, fundraisers and as friendly visitors for some of the PALS (Person with ALS) in our community.

The Chapter's Visiting Volunteer program has been a consistently helpful program for the PALS we serve. In addition, most of the Visiting Volunteers report feeling good about being able to give back to the ALS community. The goal of this presentation is to teach the participants how they may be able to set up and run this program in their ALS communities.

**Objectives:**

1. Indicate an awareness of how to identify possible Visiting Volunteers
2. Identify key issues, including do's and don’ts and limits of the role, to be addressed with possible Visiting Volunteers
3. Indicate an awareness of providing on-going support to the Visiting Volunteer

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**Voice Activation Options for PALS**

Antoinette Verdone, ATP, MSBME, and Alisa Brownlee, ATP, CAPS

**Background:** Although ALS often affects the voice, there is a segment of the ALS population than maintains good voice control for an extended period of time while losing extremity control. This presentation will discuss tools and methods for using voice activation to control a computer, environmental controls, and other voice activated assistive technology.

**Objectives:**

1. Name two criteria in favor of using voice control
2. List two voice activated devices for telephone operation
3. Illustrate two voice activated devices for environmental control
Dysphagia Strategies
Lakshmi Boyle, MS, CCC-SLP

**Background:** Patients with ALS are in a unique situation where strategies implemented must change on a consistent basis in accordance with disease progression. Focus is on balancing swallowing safety combined with quality of life. Working in tandem with the patient, the interview, including motivational interviewing techniques, combined with the Dysphagia evaluation, assessment and education help motivate and guide patients and families so they can feel in control of the process, while they are losing function.

**Objectives:**

1. Employ motivational interviewing techniques to help guide the patient towards safe swallowing techniques, while focusing on quality of life
2. Identify 5 signs/symptoms of swallowing difficulties
3. Explore 3 techniques in facilitating safe and/or increased oral intake

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Issues of End of Life Care: Non-invasive Ventilation – To Use or Not to Use?
Heather Meehan, BSRC, RRT-NPS

**Background:** This presentation examines the role of Non-Invasive Ventilation from initiation to end of life, management techniques and therapy goals as they relate to disease progression. There is good evidence to show that early implementation of NIV therapy improves survival, quality of life and pulmonary function. Home non-invasive ventilation has become the standard of care for respiratory management in persons with ALS, yet there is much controversy surrounding the use of non-invasive ventilation during hospice/end of life. To explore the role of non-invasive ventilation at end of life, this presentation will provide an in-depth review of the pathophysiological indications for NIV therapy as they relate to ALS, contraindications, mechanism of action, adverse effects that may result from disease progression and most importantly strategies to employ at end of life. Non-Invasive ventilation plays a vital role in improving quality of life in patients with ALS just as it improves quality of life, NIV therapy when properly managed provides the ALS patient and their family with enhanced comfort as they transition to end of life.
Objectives:

1. Explain the minimal qualification criteria for home non-invasive therapy and describe the indications, contraindications, adverse effects of NIV therapy
2. Differentiate the strategic goals of therapy and NIV management techniques as they apply to early intervention vs. end of life care
3. Conclude for yourself, NIV during hospice/end of life or no NIV during hospice/end of life

Friday, November 4, 2016
5:00 pm – 6:00 pm
Track 1

Supporting Medical Decision Making and End-of-Life Communication Needs
Richard Hurtig, PhD

Author(s): Richard Hurtig, PhD, and Brooke Slayman, CCC-SLP

Background: Neuro-degenerative diseases and spinal cord trauma leave many individuals locked-in and unable to speak or write. As a consequence, these individuals are unable to actively participate in their care or in decisions about their care. Furthermore, the barriers to effective communication can lead to significant isolation and a dramatic shrinkage in the individuals’ social world. The inability to speak make individuals all the more susceptible to our society’s paternalistic approach to dealing with individuals with a disability. All too often professionals and lay-persons treat the non-speaking individual as if they were cognitively impaired. They use “baby talk” or “elder speak” which assumes diminished capacity and they will speak loudly because they assume the person may also be hearing impaired. Patients with impairments as well as healthy elders find these behaviors are demeaning. To overcome the loss of control and the demeaning behavior of their healthcare providers, caregivers, family and friends, it is essential that we address the communication rights of all individuals irrespective of their physical condition.

With the evolution of Augmentative and Alternative Communication tools and strategies, from their origins in the treatment of children with developmental disorders to their application to individuals with acquired speech and language disorders, we now have the ability to support better communication for individuals with Neuro-degenerative diseases and spinal cord trauma that leave them locked-in and unable to speak or write. Unfortunately, the development of the range of low to high tech AAC solutions has not eliminated the problems many individuals face in managing their care and maintaining their social world. Complicating things for pALS may be their initial reluctance to start using an AAC strategy that uses stored phrases. Furthermore, even when individuals have prepared advanced medical directives and have designated a healthcare proxy, they may not have been able to anticipate how they would react to a significant change in their ability to take oral sustenance or to breathe independently. Thus providing a means for individuals to remain active participants in their care and in control of medical decision making is essential.
Finally, it is important that the AAC tools and strategies not only cover critical care and decision making but also provide individuals with means to maintain their social relationships and meet their psychological and spiritual needs.

**Purpose:** In order for individuals who are unable to speak and write to participate in their care and in decision making, they need to be able to demonstrate that they are competent. To that end they must be able to demonstrate that they understand their situation and that they can articulate their preferences when it comes to their care. Reliance on yes/no responses is not only a challenge because it may introduce a bias based on what questions or options the individual is presented with but because it prevents the individual from easily trying to solicit the critical information necessary to make an informed decision. Our aim was to develop a range of communication templates that would enable non-speaking individuals to not only indicate their preferences but more importantly to solicit information about the consequences of both making or not making a particular decision. The goal was to make it easy for individuals to demonstrate an understanding of the consequences of certain decisions about their care thereby insuring that their wishes on medical and spiritual issues could be as unambiguous as possible and clearly grounded in their current situation.

**Materials Methods:** Informed by the literature on medical decision making as well as interviews with patients, critical care providers and spiritual counselors, we developed communication templates to support individuals’ ability to participate in their care and also engage in extended conversations on key life sustaining options ranging from pain management to invasive treatment options. The templates provide individuals to specifically ask a range of follow-up questions about the consequences of choosing or not choosing to pursue a particular treatment option (e.g. mechanical ventilation, dialysis, percutaneous endoscopic gastrostomy tube placement). While information about such options is readily available on the internet (i.e. http://www.alsa.org/als-care/resources/publications-videos/factsheets/feeding-tubes.html), it is important that the pALS can effectively solicit information and either make, change or postpone having to make decisions. To that end, the templates include both questions and a range of action options. The templates have been designed for implementation as part of low tech communication boards or as menu options on speech generating devices.

**Outcomes and Results:** The presentation will provide illustrations the templates and provide case study descriptions of their implementation.

**Discussion and Conclusions:** This approach to empowerment of individuals who may be unable to speak and who may only be able to generate a single intentional gesture has enabled individuals to remain engaged with their caregivers and to actively participate in medical decision making even in terminal end-of-life scenarios. While the decision to accept or terminate life-sustaining treatment is always a painful one for patients, caregivers and their family members, allowing the patients to have a significant role in those decisions not only preserves their autonomy, but also can reduce the stress of the caregivers and family members.
Objectives:

1. Describe the value of being able to participate in medical decision making and the risks associated with the inability to participate in medical decision making
2. Differentiate the strategic goals of therapy and NIV management techniques as they apply to early intervention vs. end of life care
3. Identify key conversational content areas that enable individuals to enhance their quality of life and remain socially engaged

Friday, November 4, 2016
5:00 pm – 6:00 pm
Track 2

“Rectangularizing” Quality of Life during the Progression of ALS

Charles Robinson, DSc, PE

Background: Almost 500 people attended the Rehabilitation Research at NIH: Moving the Field Forward Conference held on the NIH campus near the end of May 2016. Many of the issues presented and discussed were of interest to those serving persons with ALS (pALS) and their caregivers (cALS). The goal was to help the NIH develop a strategic plan for its future sponsorship of rehabilitation research. One concern was the basic definition of “rehabilitation” (i.e., “restoration”). All agreed that it included “habituation” (i.e., adding a function not present), and some pushed for including “optimization” (i.e., doing the best with what residual is left). For those with ALS and their caregivers, maybe “increasing, maintaining, adding or slowing the loss of” a function is a more inclusive term. A unique mindset presented by a speaker at the conference was that of the “rectangularization” of a function during the end year(s) of a person’s life. That talk was focused on the geriatric population, but the term applies equally well to our pALS. Thus the aim of rectangularization with respect to a pALS would be to “slow the loss of” a function (i.e., to provide the highest possible level possible of functionality for as long a duration as possible), before a “cliff” is reached near the end of the disease progression. The judicious use of technology can make rectangularization possible for many with ALS by applying a new rehabilitation technology mantra termed “ABBA” (not the rock band!) — Appropriate, Beneficial, Beautiful, and Affordable. I was my wife Rosemary’s principle caregiver during the 2.5 years from her symptom onset with bulbar ALS until her death. But I was also a university educator and director in the rehabilitation engineering, science and technology (REST) field. I found myself needed to apply many of the techniques that I taught to my students, but often in unconventional ways as we together tried to optimize what she could do as the ALS progressed, but also to help teach hospice that pALS need not be “warehoused” in a darkened room with the shades drawn. In essence, we were practicing rectangularization without knowing about it! Thus this talk is about how we used technology in this rectangular framework to maintain the best quality of life possible given her stage of ALS progression. We even managed to travel 20,000 miles throughout the United States in that time span, all the time involving more and more appropriate technology.
Objectives:

1. Articulate the concept of “rectangularizing,” a function during the end year(s) of a person’s life, and illustrate how it applies to persons living with ALS and their caregivers.
2. Employ ways to help a patient clarify and communicate his/her wishes to his/her loved one and healthcare team.
3. Develop knowledge of advanced care planning documents and professional resources, including palliative care and hospice, in helping to ensure the patient’s treatment preferences are honored.

Friday, November 4, 2016
5:00 pm – 6:00 pm
Track 3

Challenging Talks about a Challenging Disease: Honoring the Patient’s Wishes throughout their Healthcare Trajectory
Kellie Branch-Dircks, MSW, LCSW

Background: Knowing when and how to talk with people about advanced care options, including death, is uncomfortable for the professional, the patient, and their loved ones. Unfortunately, social workers and nurses are often left to answer questions and present topics that do not get addressed by other healthcare professionals. End-of-life planning is often avoided for many reasons, leaving loved ones to make difficult decisions without the knowledge to do so. This presentation will help you know how to approach the topic of end-of-life care, how to help support the patient in communicating their preferences for care, and how to mediate family meetings.

Objectives:

1. Discuss how to start a conversation regarding a patient’s advanced care treatment preferences.
2. Employ ways to help a patient clarify and communicate his/her wishes to his/her loved one and healthcare team.
3. Develop knowledge of advanced care planning documents and professional resources, including palliative care and hospice, in helping to ensure the patient’s treatment preferences are honored.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 101

Effects of ALS on Sex and Intimacy: Clinic Team Perspectives
Valerie Saha, RN

Author(s): Mona Shahbazi MSN, BC-NP, OCN, Shara Holzberg, MS, CCC-SLP, and Gioia Ciani, OTR/L, OTD
**Objective:** Effects of ALS in intimacy is an area of need that could but is rarely addressed at clinic. This study was designed to assess clinic team's perception, knowledge and comfort regarding sex in ALS.

**Materials and Methods:** An online questionnaire was anonymously distributed to clinic staff, assessing thoughts & comfort and knowledge regarding intimacy in ALS.

**Outcomes and Results:** 89 completed responses were received. 100% felt ALS impacts intimacy & agree it should be addressed; opinions varied on who is considered appropriate. 44% initiated such conversations, only 15% have been approached. 83% feel comfortable discussing this and 43% of those would do so with/out intervention strategies. 22% are aware of such strategies, positioning & equipment.

**Discussions and Conclusions:** ALS and sexuality is an often neglected area. Nearly all who responded agree intimacy is affected by ALS & should be discussed in clinic, yet only half have initiated this due to lack of information. Addressing this may enable better QOL for PALS.

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**Friday, November 4, 2016**
**1:15 pm – 2:15 pm**
**Poster 102**

**Right Service Right People Right Time**
*Mary C. Riggs, MS, CRC, LPC, and Tara Klucker, MA, CRC*

The objective of this poster is to show trends in enrollment in chapter's nutrition, respite, and counseling program comparing the 2011, 2012 and 2013 non standardized testing enrollment to the 2014 and 2015, 2016 standardized testing enrollment qualifications. Data for the assessments is a self-completed survey completed by the enrollee at a chapter affiliated clinic and at a center of excellence. The results of these surveys led to better psychological care for patients and caregivers and nutritional support for patients thru increased participation in the chapter's programs. It also led to a redesign of the respite program -to include a non-medical weekly support program which was identified upon completion of a needs assessment form with the patient family and the chapter case manager.

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**Friday, November 4, 2016**
**1:15 pm – 2:15 pm**
**Poster 103**

**ALSA/AFTD Phone Group for Caregivers: Support for Caregivers of People with Both ALS and FTD**
*Gail Houseman RN, CNS-BC*

**Author(s):** Gail Houseman RN, CNS-BC, and Bridget Moran, MPH

Caregivers of people with both ALS and FTD have the challenging responsibility of caring for their loved one's physical changes due to ALS, along with the cognitive and/or behavioral changes inherent with the diagnosis of FTD. AFTD (The Association for Frontotemporal Degeneration) and the ALS Association
Greater Philadelphia Chapter have teamed up to provide on-going phone support for this group of caregivers by offering monthly meetings. Participants live across the country; participant responses have been quite positive, as noted below."

"...A tremendous comfort and help to me to be able to talk to other people who know what I am going through…”

"I appreciate the subtleties of what people share..."

"...it’s great to hear that I am not alone."

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 104

A Six-week "Mindful Living with Compassion" Course for Persons and Caregivers Living with ALS
Kate Morris, PhD, and Tom Tower, MS

Objectives: Research supports the benefits of mindfulness meditation to improve many aspects of health and well-being (Keng, Smoski, & Robins, 2011; Davis & Hayes, 2011) but research specific to ALS is sparse and suggests that a formal meditation practice may be difficult to instigate and sustain (Pagnini, et al., 2014; Marconi, et al., 2015). Mindfulness practices encompass informal, formal and compassion exercises (Kabat-Zinn, 1990; Seigel, 2010; Germer, 2009)). All levels of practice (i.e., informal, formal, and compassion-based) were included in this pilot program, combining in-class practices with summaries accessible in participants’ notebooks and online references that supported and extended practices. This pilot program tested the feasibility of a six-week “Mindful Living with Compassion” class for caregivers and persons living with ALS. This program incorporated practices of mindfulness and compassion to improve emotional regulation, quality of life, and daily pleasure. These skills were set within a narrative context of the mythic "Hero's Journey" to clarify and expand the use of skills.

Materials and Method: 19 people (9 patients and 10 caregivers) enrolled in the class series and 12 completed (5 patients, 7 caregivers) at least four of the six classes. Those that did not complete the class series gave the following reasons: 1-ALS made it difficult to get ready on time; 2 felt they had a mindfulness practice and needed no further instruction, 2 felt it conflicted with religious beliefs, and 1 lost interest. Each class was 90 minutes long and included one break each class. Pre and post assessment of mindfulness (Boder & Langer, 2001) and a single item Quality of life measure were administered. Post measures of participants' beliefs that their practices benefited their sleep, daily pleasure, level of compassion expressed towards self and others, their ability to be with painful emotions, how they identify with the Hero's journey and the use of the Hero's journey to generate curiosity and open possibilities as well the frequency of their skill practice was assessed.
Outcomes and Results: 63% of participants completed four or more classes. Of the seven pairs that complete pre-post data, a paired t test revealed a significant increase in mindfulness scores $x=8.14$, $p>.05$ while no significant difference was found for the QoL single item. On the 5pt. Likert scale measures of utility that 11 of 12 participants completed: 73% of the sample reported at least somewhat improved sleep, while 91% stated their daily pleasure, the compassion shown themselves or others improved somewhat to significantly, and 100% stated their ability to be with painful emotions increased somewhat to significantly. 72% reported that the Hero’s journey supported their use of mindfulness skills and 90% felt the Hero’s journey helped them view their life with curiosity and open possibilities. Finally, 72% of the sample reported practicing skills nearly daily or daily (further delineation provided in table form).

Discussions and Conclusions: This pilot project supports an array of mindfulness and compassion practices (informal, formal, and compassion-based) may benefit both caregiver and persons living with ALS. For all participants class summaries were provided along with supportive online resources to supplement practices which all who missed classes reported benefiting from. Mindfulness scores significantly improved. Several measures indicated greater adaptability and utility of skills following this six week program. Significantly, while in previous research has adapted to ALS the Mindfulness Based Stress-Reduction model for mindfulness meditation, the present project revealed high rates of nearly daily practice were possible with the inclusion of informal, formal, and compassion-based practices. While the sample size was small, as a pilot project, results are positive and further replication and refinement may yield increased benefit.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 105

The Potential of Telehealth in ALS Support Programming: Reaching the Underserved

Paula Morning and Randy Berd

Few community resources have harnessed the potential of telehealth as a methodology to reach the underserved rural communities in northern Michigan. Telehealth involves the use of technology to facilitate an interaction between patients and providers that promotes health. As an emerging health care delivery method, telehealth is generally thought of within the context of facilitating a health care visit between a single provider and the patient via videoconferencing. To best serve the ALS patient population that resides in northern Michigan or those who are in advanced stages of disease, an expansion of this context and capacity is necessary.

The ALS Association Michigan Chapter is presently in phase two of the implementation of a telehealth initiative to serve our northern Michigan patients and families and those who have disease that has advanced to the point at which travel to necessary health services is now impossible. In the northern part of the state, harsh weather and extremely limited availability of skilled providers frequently results in patients in this region becoming isolated or presenting to our Chapter in crisis due to lack of local
resources. Upon intake, these patients express a lack of access to specialty providers, an inability to access resources such as educational sessions and support groups and profound social isolation. Caregiver burnout is a common phenomenon among these families. Additionally, these patients frequently experience extreme difficulties in accessing care from ALS-knowledgeable providers at the end of their lives. The telehealth program initiated by the Michigan Chapter seeks to address some of these issues and improve quality of life for these patients and their caregivers by improving access to care and Chapter services.

The telehealth program to be implemented has several objectives. First it will offer patients the opportunity to consult with a multi-disciplinary ALS clinic, an intervention that has been linked to greater survival and quality of life. The ALS Association Michigan Chapter has three ALS Certified Centers of Excellence - at Henry Ford Health System Harry Hoenselaar ALS Clinic, the University of Michigan ALS Clinic, and the Hauenstein ALS Clinic. This Chapter also has two recognized treatment centers at Spectrum Hospital and Bronson Methodist Hospital. Combined, these five Clinics serve over 500 ALS families. Has the potential to offer not only improved access to ALS clinics, but the ability of patients to actually participate in valuable caregiver and patient education, support groups and visits with Chapter Care Services staff. The telehealth program places a ruggedized multimedia device in both the patient’s home and in the clinic setting to facilitate face-to-face communication between the patient and these specialists, including Chapter staff. Provided through secure wireless connection with capabilities to serve the most remote areas of our state, the delivery method allows access to patients without financial or technological means and protects privacy.

This is accomplished through a partnership with a technology provider specializing in telemedicine device construction and service and funded through the generous support of private foundation gifts. Secondly, the program seeks to connect patients, and their caregivers, to supportive services by allowing them to participate in support groups and educational seminars. This is superior to simply providing videos of educational sessions as telehealth participants will have the opportunities to ask questions and receive answers in real time. Additionally, facilitators gain a greater ability to assess the condition, emotional state and knowledge level of both the patient and their support persons.

Finally, the program will be inclusive of those with advanced disease that prevents them from traveling to access care or supportive services. At present, patients with advanced disease often experience a gap in care as they become unable to travel to their ALS clinic, but are not yet ready to make a hospice decision. The telehealth program will allow their clinic team to continue to manage their care as their disease advances and, when they are ready, provide them access to ALS-knowledgeable hospice providers regardless of their geographic location. This is accomplished through partnerships with a network of hospice providers and the ALS multidisciplinary clinic teams.

For a state that is largely comprised of medically underserved areas, the potential impact of telehealth on patient quality of life is essentially limitless. The success of the program is predicated on the strength of relationships with community partners who are equally committed enhancing quality of life for geographically and pathologically isolated ALS patients. The ALS Association, Michigan Chapter looks
forward to the continued implementation of this program as an expansion of our Care Services programming.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 106

Improving the Clinic Experience: Wait Time
Valerie Saha, RN

Author(s): Mona Shahbazi MSN, BC-NP, OCN, Shara Holzberg, MS, CCC-SLP, and Gioia Ciani, OTR/L, OTD

Objective: Multidisciplinary care clinics have shown to improve both QOL and length of survival for PALS. However, as complexities of visits grow, so does the time needed for the visit. The 3-4 hour visits are difficult for PALS in wheelchairs as well as their families.

Materials and Methods: This was a time survey study conducted in 2 clinics in NYC. “Non-value” time was defined as time not spent face to face with a provider in clinic. This was anonymously measured for 3 months in clinic 2 days a week.

Outcomes and Results: The average wait time in clinic of non-value time per 4 hour visit was 33 minutes. This included time in waiting room, and in between staff visit.

Discussions and Conclusions: Strategies to improve non value time in clinic could benefit both the institution financially and make the patient experience more comfortable and efficient. A process improvement project is now being worked on to improve this methodology to improve wait times.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 107

Clinical Management of Oral Hygiene for Patients with ALS
Mallory Riggs, MS, and Lori Banker-Horner, LPN, BA

Author(s): Michelle McDonagh, RD, Mallory Riggs, MS, Lori Banker-Horner, LPN, BA, Paul Barkhaus, MD, Darryl D. Stich, DDS, Agnieszka Domagala, DDS, and Dominic Fee, MD

Background: To date there are no practice parameters for oral hygiene as a component of ALS management. As ALS progresses and care burden increases oral hygiene can often be overlooked. Barriers to routine oral care include general fatigue, upper extremity weakness, inability to maintain open-mouth posture, sialorrhea, and ultimately dependency on others for oral care. Oral hygiene remains important even when the oral cavity is no longer used for nutrition. Oral hygiene is imperative to minimize risk for dental caries, halitosis, to control bacterial build up which could enter upper airways and lead to respiratory infection, as well as to maintain the patient’s quality of life. The ALS Association-Wisconsin Chapter (ALSA-WI) has partnered with the Froedtert and Medical College of Wisconsin (F-
MCW) ALS Multidisciplinary Clinic (MDC) and Marquette Dental School Advanced Care Clinic (MDSACC) in Milwaukee, Wisconsin to assess the need for support for oral hygiene in patients with ALS (PALS).

**Objectives:**

1. Assess how PALS are maintaining their oral health at home
2. Identify barriers to receiving routine dental care
3. Provide education and resources to PALS and their caregivers to maintain routine oral care

**Materials and Methods:** A thirteen question survey was created to assess if PALS are able to maintain their oral health at home, if they are receiving routine dental care and what barriers exist to maintaining oral hygiene. Our MDC’s Speech Language Pathologist and Dietitian administered the survey to thirty PALS attending the F-MCW MDC. Participants ranged in age from 41-81 years, ALSFRS-R ranging from 4-45, seven PALS had bulbar onset and twenty three had limb onset ALS, fourteen were male and sixteen were female.

**Outcomes and Results:**

1. Seven of the PALS surveyed did not have a regular dentist and their last appointment coincided with onset of ALS symptoms. Twelve PALS had not seen a dentist in over a year.
2. Sixteen PALS did not schedule a follow up appointment. Reasons cited were cost (4), lack of insurance coverage (2), transportation (2), ALS diagnosis (2), and concerns regarding excess saliva (2).
3. Three out of the sixteen PALS without a follow up appointment confirmed that they had oral discomfort.
4. Twelve patients were interested in a referral to the MDSACC.

**Discussions and Conclusions:** There are multiple barriers to maintaining oral hygiene in PALS. The ALS clinic must educate patients and their caregivers on the importance of oral hygiene and provide resources to maintain oral care at home to reduce secondary oral health complications. The preliminary survey results are generating an evolving list of resources for patients seen in the Froedtert and MCW ALS MDC including basic educational materials, a list of special needs dentists, grant information for transportation costs, and routine referrals to the MDSACC for affordable basic dental care.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 108

**Multidisciplinary ALS Clinic Development at the Ralph H. Johnson Veterans Administration Hospital:**
**Keys to Success**
*Jerome Kurent, MD, MS, MPH*

**Background:** The Institute of Medicine (IOM) report, Amyotrophic Lateral Sclerosis in Veterans: Review of the Scientific Literature, was released on November 10, 2006. It summarized evidence in support of a
1.5 to 2 times increased incidence of ALS in association with military service. ALS was declared to be a 100% service-connected disability on September 8, 2008. In 2010, the Ralph H. Johnson VAMC became one of the earliest Multidisciplinary ALS clinics to be established within the Veterans Administration. The Amyotrophic Lateral Sclerosis (ALS) System of Care Procedures is the VHA Handbook 1101.07 which describes the essential components and procedures of the ALS System of Care to ensure that all enrolled Veterans have access to specialized care.

Objectives:

1. Describe the process of planning and organizing the RHJ ALS Multidisciplinary Clinic
2. Identify key stakeholders in determining success of the ALS Clinic
3. Describe the process of ensuring ongoing success and continued growth of the VA ALS Multidisciplinary Clinic

Materials and Methods:

1. Planning the first meeting: Emails to all key stakeholders, including service chiefs and other potential participants in the ALS clinic were sent to enlist their interest and to schedule the first meeting. In preparation for the meeting, authorization was provided to conduct a chart review of all the veterans in our region who were provided with a diagnosis of ALS from May 2005 to May 2010.
2. Key participants included: Neurology Nurse Practitioner/clinic coordinator; Neurologist/neuromuscular specialist (presently two physicians); Physical Therapist; Physiatrist; Occupational Therapist; Speech and Swallowing specialist; Dietician; Respiratory technician; Social worker; VA Paralyzed Veterans of America (PVA) representative; ALS Association (ALSA) representative; physician representative from the VA Home Based Primary Care (HBPC) service also frequently joined the clinic, as well as rotating neurology residents or fellows. A volunteer from the local community with previous experience as a caregiver for a veteran with ALS.

A Palliative Care physician and Psychiatrist subsequently joined the ALS Multidisciplinary team.

3. Process Improvement: An ALS patient satisfaction survey was mailed to patients being provided active care, as well as to a designated surviving family member of veterans who had succumbed to ALS. Completed surveys were returned anonymously to the ALS Clinic Coordinator, and results subsequently analyzed and incorporated into the clinic operation.

Outcomes and Results:

1. Virtually all invited subspecialty consultants became committed and active participants in the clinic from its inception through the subsequent six years up to the present.
2. ALS patient satisfaction surveys submitted anonymously indicated that the clinic is meeting its goals of providing multidimensional services to veterans with ALS and their families.
3. The RHJ ALS Clinic initially met once monthly for one-half day, but has subsequently expanded to one full–day because of an increasing veteran ALS patient population referral base.
4. The RHJ VAMC ALS Clinic has provided patient-centered care to 82 veterans with ALS and their families during its period of operation, and continues to meet the needs of an increasing number of patient referrals.

5. Efforts are ongoing to meet criteria for status as an ALSA Certified Treatment Center of Excellence

Discussions and Conclusions:

1. The RHJ ALS Multidisciplinary Clinic continues to expand while meeting the needs of an increasing number of veterans with ALS since its inception six years ago.

2. The mission of the VA ALS System of Care as implemented at the RHJ ALS Multidisciplinary clinic is to manage the multiple medical, physical, functional, psychological and social effects impacting veterans with ALS.

3. Goals include making symptoms more tolerable while enhancing quality of life of the veteran with ALS through patient-centered clinical care along with education of the patient and family caregivers. Plans are also in place to engage in collaborative research.

References:


4. VHA Handbook 1101.07
excellence, we met with the local and national ALS Association (ALSA) representatives to discuss eligibility criteria and timeline to achieve Certified Treatment Center of Excellence (CTCE). The MUSC-ALS clinic team members were available to the ALS patients, but not necessarily on site or in the clinic. Here we present our experience and the steps taken from 2015 to 2016 to establish an interdisciplinary collaboration between neurology and therapeutic rehabilitative services, to provide a truly comprehensive and individualized care program for ALS patients seen at MUSC.

Objectives:

1. Describe challenges at implementing a multidisciplinary clinic within an institution, with complex business practices
2. Discuss factors needed towards success
3. Discuss plans and schedule to validate our goal in providing quality care for ALS patients,

Materials and Methods:

1. Identify obstacles that prevent rehabilitative therapists (PT/OT/SLP) from regularly attending the multidisciplinary clinic. (a) Conduct meetings with each manager of the Therapeutic Services; (b) Identify staff availability and resources; (c) Review Medicare and other payer reimbursement practices; (d) Compare different models of care delivery to determine ownership of the services for our institution.
2. Design a new model at MUSC where the ALS clinic encompasses the rehabilitative therapists (PT/OT/SLP) to deliver their expertise to the patients in ALS clinic visits. (a) Conduct group meetings among neurology, neuroscience service line administrators, and the therapeutic service manager to evaluate existing business practices, maintain open communication channels, and reach a common goal in centralizing the delivery of care in the Neurology Clinic; (b) Negotiations with Therapeutic Services to provide therapists to evaluate patients in the ALS clinic; (c) Modify clinic schedules from the 60/30-minute model for a new/return patient to 120-minute model to ensure adequate time for team member’s evaluation of an established ALS patient; (d) Reconfiguring one examining room to facilitate the physical therapist and occupational therapist’s assessment of the patient and install necessary equipment.
3. Optimize the delivery of care for the ALS patients both in the clinic and at home. (a) Improve the communication and care coordination between providers in the clinic and home health care agencies; (b) Improve documentation in the electronic health records on the home health services patients are receiving; (c) Hold pre-clinic meetings to facilitate the evaluation of patients in the clinic; (d) Hold post-clinic meetings to initiate individualized management plan for patients.

Outcomes and Results:

1. Table illustrating various staffing and billing models
2. Timeline of actions and steps taken from 2015 to May 2016
• Feb 2015: ALS Clinic Medical Director met with each manager of the Therapeutic Services and team members of the ALS multidisciplinary clinic; attended local ALSA support group; modified clinic schedule to 90-minute sessions per patient
• Mar 26, 2015: MUSC-ALS team met with ALSA representatives, along with Ralph H. Johnson VAMC-ALS team
• May 12, 2015: MUSC Neuroscience leaders/ Neurology/ Therapeutic Service meeting
• Summer 2015: met with the national ALSA president; MUSC initiated discussions with ALSA regarding Business Associate Agreement
• Oct 1, 2015: MUSC team and ALSA representatives met to further discuss eligibility criteria and timeline to achieve CTCE status
• Jan 2016: Neurosciences and Therapeutic Services established a new business plan for additional therapeutic service staffing in the ALS clinic
• Feb 2, 2016: FTE requests approved
• Apr 2016: consistent OT/ SLP presence in the clinic
• Jun 2016: Modified clinic schedule to 120-minute sessions per patient; converted one examining room to include a murphy mat for PT/OT evaluation; PT presence in clinic

**Discussions and Conclusions:**
1. Challenges to deliver an integrated multidisciplinary care in the existing healthcare system may be overcome. 2. How ALS clinics incorporate numerous disciplines to provide the critical services to patients are different for different institutions and business systems. There is no single path to success. 3. Communication and sharing of experiences and results is the key to improve and progress towards delivery of consistency and quality care to ALS patients in a multidisciplinary clinic. 4. This is a work in progress. We plan to survey patients and caretakers to assess how the on-site Therapeutic Services affect their care and quality of life, and how we may continue to enhance them.

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**Friday, November 4, 2016**
1:15 pm – 2:15 pm

**Poster 110**

**Quantifying Oropharyngeal Dysphagia in Patients with ALS and Association with Functional Decline**

*Amy Chen, MD, PhD*

**Author(s):** Amy Chen, MD, PhD, and Kendrea Garand, PhD, CScD, CCC-SLP, BCS-S, CBIS

**Background:** Amyotrophic lateral sclerosis (ALS) is a progressive, degenerative neuromuscular disease that primarily involves motor neurons in the cortex, brainstem and spinal cord. Thus, impaired corticobulbar control leads to disordered volitional swallows. Swallowing impairment (dysphagia) is a frequent patient complaint and radiographic finding in patients with ALS. Bulbar dysfunction can lead to lingual impairment, which results in difficulty in poor bolus control, bolus manipulation and transport resulting in premature spillage of the bolus into the pharynx prior to initiation of the swallow. Poor pharyngeal function resulting from reduced/absent hyolaryngeal excursion and pharyngeal contraction can result in poor upper esophageal segment opening and poor bolus clearance through the pharynx.
These impairments place the patient at higher risk of bolus airway invasion (penetration/aspiration). Dysphagia can lead to social isolation, depression, poor nutrition and overall health, and early mortality related to aspiration pneumonia.

The modified barium swallow study (MBSS) is the gold standard for evaluation of oropharyngeal swallowing function and is the most commonly used method for assessment by speech-language pathologists and radiology teams. Previous reports of swallowing impairment in patients with ALS are limited in their interpretation and generalization since variable, non-standardized interpretation methods are used with reliability infrequently reported, or the measurements reported are often not feasible in the increasingly fast-paced clinical setting (e.g., temporal and kinematic measures). The Modified Barium Swallow Impairment Profile (MBSImP) is a standardized and validated scoring system for the quantification of swallowing impairment from MBSS recordings (Martin-Harris et al., 2008), which requires clinicians to undergo extensive training and reach 80% reliability.

Objectives:
1. Explain how ALS affects swallowing physiology
2. Identify 3 common swallowing impairments in patients with ALS
3. Describe the relationship between pulmonary function and swallowing impairment

Materials and Methods: A retrospective review of patients with ALS who had undergone MBSSs between January 2013 and March 2016 were eligible for inclusion. ALS diagnosis was made by a neurologist specializing in neuromuscular diseases based upon electrophysiologic and neuroimaging findings after exclusion of other diseases. 23 MBSSs were analyzed for the current project.

MBSS files were interpreted using consensus scoring by two dysphagia clinicians reliably trained in using the MBSImP interpretation approach. This MBSImP has an ordinal scoring schema that permits quantification of 17 components of swallowing physiology. The scale for each component ranges from 0-2 to 0-4. The highest score comprises the Overall Impression (OI) score for each component.

Primary outcome measures included 17 MBSImP component OI, and composite (Oral Total (OT) and Pharyngeal Total (PT)) scores. Descriptive measures were calculated. Comparisons of patients’ composite scores with age (+/- 1 year) and gender-matched healthy controls were analyzed using Mann-Whitney U tests. Analyses examining the associations between pulmonary function (e.g., forced vital capacity) and MBSImP scores, and functional outcome measures (e.g., ALSFRS-R) and MBSImP scores are currently underway and will be completed prior to conference.

Outcomes and Results: 23 patients (11 males) with ALS were included for analysis. Mean age was 64 (±11) years (range: 45 – 92 years). Highest rates of impairment (>90%) were observed for bolus transport, oral residue, initiation of pharyngeal swallow, anterior hyoid excursion, pharyngoesophageal segment opening, tongue base retraction, pharyngeal residue and esophageal clearance. The mean ± SD OT was 11.8 ± 4.2 (median: 12; range: 5 – 18). The mean ± SD PT was 10.4 ± 1.6 (median: 10.5; range: 8 – 12). A significant difference was observed in OT and PT scores between patients with ALS and healthy
controls (p-value <0.0001 and p-value = 0.005, respectively), with higher scores (greater impairment) observed in patients with ALS.

**Discussions and Conclusions:** To our knowledge, this is the first study quantifying swallowing impairment using a standardized, validated, and reliable MBSS interpretation approach. In contrast with previous reports, our study demonstrates impairment across both oral and pharyngeal physiologic components. Our findings are readily translatable to the clinical setting since the outcome measures reported here are increasingly being used and reported worldwide. Providing optimal, evidence-based care for patients with ALS requires specific attention to oropharyngeal swallowing function which can assist the other multidisciplinary team healthcare professionals increase life expectancy and quality-of-life in these patients.

**Friday, November 4, 2016**
**1:15 pm – 2:15 pm**
**Poster 111**

**Videofluoroscopic Assessment of Swallowing Dysfunction in ALS**
*Denise Epps, MS, CCC-SLP*

**Background:** Dysphagia is one of the most critical problems in ALS patients. Early diagnosis and treatment of dysphagia is important to avoid complications such as undernourishment, dehydration, and/or aspiration pneumonia. Careful follow-up of the clinical progression of dysphagia is necessary to determine the appropriate timing for interventions. Therefore evaluation of the swallowing function at the initial diagnosis is necessary (1). Clinical diagnosis of dysphagia by history and bedside examination has low specificity and often requires confirmation by videofluoroscopy (VFS). Videofluoroscopy is currently the recommended examination for evaluating swallowing disorders. The exact timing for a radiographic evaluation of swallowing in ALS patients has not been well-studied and videofluoroscopy does not have a defined role in the assessment of swallowing disorders in amyotrophic lateral sclerosis (2).

**Objectives:**

1. To determine whether videofluoroscopic assessment of swallowing function in patients who do not have bulbar symptoms can detect subclinical aspiration
2. To determine the severity of swallowing dysfunction on a videofluoroscopic assessment in ALS patient who do not have bulbar symptoms
3. To determine which functional guidelines for the diagnosis and management of swallowing disorders in ALS patients is the appropriate

**Materials and Methods:** A retrospective chart review was conducted for all ALS patients diagnosed at University of Maryland ALS Clinic between 2008 and 2015. Information extracted includes: ethnicity, gender, revised El Escorial diagnostic criteria classification at the time of diagnosis, date of symptom onset, date of diagnosis, site of symptom onset, clinical measures of motor function, ALSFRS-R, forced
vital capacity. Videofluoroscopic studies between 2008 and 2015 were reviewed. In ALS patients who have a score of 5 or above using the Penetration Aspiration Scale (PAS), non-oral methods to provide nutrition is strongly recommended. ALS patients who have ALSFRS-R bulbar score of 6 or above are considered to have mildly abnormal bulbar function not requiring gastrostomy tube.

**Outcomes and Results:** Of the 74 patients who had a VFS study, 15 studies reviewed thus far included a full PAS. In 11 patients, the VFS study showed dysphagia as defined by score 3 or above on the 8-point PAS. Five of the patients have bulbar onset ALS, 5 have limb onset ALS, and 1 has onset in other regions. In 13 of the VFS studies, the patients have an ALSFRS-R bulbar score greater than 6. Among these patients, 6 studies show a PAS score of 5 or greater.

**Discussions and Conclusions:** In this preliminary analysis, the ALSFRS-R bulbar score may be an insensitive method for determining the need for non-oral feeding.

**References:**


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**Standard of Care for Dysphagia Management in ALS Patients**

Denise Epps, MS, CCC-SLP

**Background:** Dysphagia contributes to declining respiratory status and causes considerable distress which may lead to altered ingestion patterns causing malnutrition and dehydration in ALS patients. Early diagnosis and management of dysphagia is important to avoid complications such as undernourishment, dehydration, or aspiration pneumonia. To date, no clear or specific guidelines for dysphagia management or treatment in ALS has been offered or established.

**Objectives:** The purpose of this study is to determine the evaluation and recommendations of speech-language pathologists in the care of ALS patients.

**Materials and Methods:** A 15 question survey was sent to speech-language pathologists (SLPs) who are active in clinical practice. The survey queried each practitioner’s perception of the current standard of care provided by SLPs to ALS patients with symptoms of dysphagia.

**Outcomes and Results:** Forty-five SLPs completed the survey. A variety of dysphagia protocols in the initial assessment of ALS patients were being used. Most respondents (82%) performed a FEES or MBS in ALS patients. Forty-three percent recommended a baseline FEES or MBS in ALS patients who did not have bulbar symptoms. Respondents varied greatly in how soon they would recommend a FEES or MBS
after the initial assessment, with some SLPs recommending an instrumental assessment immediately and others recommending an instrumental assessment within a specified time frame or as symptoms arise. All responding SLPs reported that they would provide consultative information on aspiration precautions to ALS patients even if the swallowing function was normal.

**Discussion and Conclusions:** There is currently no uniform recommendation for the timing and method to evaluate dysphagia in ALS patients. Most SLPs perform FEES or MBS to evaluate dysphagia in ALS patients. There is no agreement on the need for FEES or MBS in ALS patients who do not have bulbar symptoms.

**References:**

Questions:

- What methods do you use to evaluate adequacy of NIV settings?
- How frequently do you assess NIV settings?
- If using NIV download data, which parameter(s) do you find most useful in evaluating ventilation?
- What other download data do you find useful in gauging patient response to NIV?
- Which waveforms and graphic data do you find most useful in assessing patient-ventilator asynchrony?
- What clinical signs and symptoms do you use to assess patient response to prescribed NIV settings?

Outcomes and Results:

- 52% of respondents were RCPs working in ALS clinics or in homecare
- 34% of respondents were physicians with a specialty in neurology or pulmonary medicine
- More than 90% of respondents use patient-reported symptoms of nocturnal hypoventilation (morning headaches, frequent awakenings, daytime sleepiness) and daytime energy levels and fatigue to evaluate patient response to therapy
- 74% of all respondents use ventilator download data to evaluate patient response to therapy
  - 58% use waveforms/graphs and find volume response to be the most useful.

Discussions and Conclusions:

The use of NIV has increased over the past 20 years and is now standard of care in the treatment of respiratory insufficiency in ALS. New-generation microprocessor ventilators and bi-level respiratory assistive devices with built-in software allow for the collection and display of patient response to ventilation settings. Survey responses of physicians, nurses, and RCPs show that clinical specialists in ALS care utilize patient-ventilator interface data to assess patient response to therapy. However, clinicians use different information and combinations of information to gauge success of treatment with NIV.

Next steps: Moving toward a best practice model

By evaluating current practices and our perception of benefit we can begin to determine:

- Physiological measures, tests, signs, and symptoms that best capture respiratory insufficiency in ALS;
- Data that is most reliable in assessing patient response to NIV therapy; and
- Data that best alerts us to patient-ventilator asynchrony.
Using Evidence Based Respiratory Management of NMD Patients through Telehealth Modalities

Micaela Sarazen, RRT, BSRT

Background: Efficiently applying these measures can help relieve the frustration of equipment issues, prevent admission to the hospital and provide interim support for patients between multidisciplinary clinic visits. Taking away the most common frustrations historically associated with respiratory support and DME companies, allows an overall improvement in quality of life. Additionally, an application on the iPad provided to each patient may assist them with reminders for medications and appointments. Finally, access to a patient-centered website for educational materials and other resources.

Objectives:

1. Using home technology to allow communication between the patient and provider. This allows for real time education, provision of resources, and emotional support outside of physical clinic visits
2. Providing direct access to respiratory durable medical equipment, or DME, providers allows quick answers to questions, equipment troubleshooting and titration of respiratory settings
3. Creating a protocol for home adjustment of noninvasive ventilation, or NIV, settings, cough assist titration and threshold for advancement to portable ventilation facilitates an understanding of expectations for the patients, clinic providers and DME providers

Materials and Methods: Created an evidence based protocol that allows titration of ventilator and cough assist settings using published white papers specific to neuromuscular patients. Patients are provided with a secure iPad, flow meter and pulse oximeter. Patients are able to use the pulse oximeter and peak cough flow anytime and are encouraged to track their measurements. Specialized Respiratory Therapists connect with patients monthly via Face Time and iChat which significantly reduces energy required to communicate for patients living with neuromuscular diseases, thus providing an improved quality of life. Additionally, video chat provides a unique glimpse of the patient in real time allowing for interventions to be communicated to both care providers and the clinics that support these patients for quick response.

Outcomes and Results: Single facility enrolled 8 patients in neuromuscular disease (NMD) program that were on portable daytime ventilation. Able to facilitate in one patient’s advancement from one non-invasive ventilator to two as they required additional respiratory support in between clinic visits. Able to provide technical support for patients in rural areas. Created a relationship with patients allowing providers to provide support between clinic visits. Overall we saw a 45% increase in equipment adherence, 47% decrease in dyspnea and complaints of SOB and a 30% decrease in complaints on pain leading to an overall increase in quality of life.
**Discussions and Conclusions:** Created tight-knit group of care providers for patients with degenerative neuromuscular diseases, including ALS. Choosing the patients that will benefit from the additional interaction with the DME companies and care providers. Facilitated effective closed loop communication including patient, caregivers, clinic providers and DME providers while minimizing response turnaround.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 115

**To Phonate or Not To Phonate: A Tale of SIP/PUFF Ventilation**
*Irvin Marquez, RRT, RCP, and Erin Singleton, MA, CCC-SLP*

**Background:** The mechanics of respiration involves the contracting of the diaphragm, which expands the lungs causing negative pressure. During speech, accessory muscles force the rib cage to move and enlarge the thoracic cavity. Speech then moves air out of the lungs to the vocal cords causing vibrations (phonation). This airflow must be constant in order for patients to phonate consistently. Patients with neuromuscular disorders involving respiration ultimately develop weakness of the intercostal muscles and diaphragm, affecting phonation. SIP and Puff ventilation has been effective in providing “sigh breaths,” and can decrease daytime hypercapnia and respiratory distress for patients that have respiratory insufficiency and require frequent daytime support with non-invasive positive pressure (i.e. BiPAP). SIP and PUFF ventilation is an alternative that is well tolerated and can facilitate communication where it was not possible otherwise with the continuous use of BiPAP.

**Objective:** We report our initial experience using SIP/PUFF ventilation in patients with a variety of neuromuscular diseases impacting ventilation and speech. These observations have resulted in our interest in developing a protocol to formally access the efficacy, impact on the quality of life and benefit of enhanced communication.

**Materials and Methods:** For our consideration of SIP/PUFF ventilation, patients must have good oromotor tone and strength and ideally adequate neck strength. Patients are accessed at baseline for their ability to phonate and on their overall respiratory indices. Phonation is regularly evaluated by the SLP to determine baseline of sustained phonation through syllable prolongation and passage reading. Baseline volume is evaluated with a sound level meter, through sustained syllable prolongation and passage reading.

The SIP/PUFF ventilation is facilitated through a Trilogy NIPPV machine using settings: Pressure control ventilation 15-20cmH2O, Rate of 1, EPAP 4cmH2O (Day mode)

NOC Mode: is current Bi-Level settings.
Patient Reports:

CM is a 32 yo woman with antibody positive myasthenia gravis (bulbar predominant). At onset FVC was 84% of predicted. Her speech was hypophonic and labored. Following her last disease exacerbation she became dependent upon use of BiPAP for 22+ hours / day resulting in uncomfortable skin breakdown due to the mask interface. She was essentially anarthric due to her inability to speak with the BiPAP mask in place and poor airflow.

RC is a 52 yo man with Becker’s muscular dystrophy. At baseline FVC was 30% of predicted, and speech was affected by marked dyspnea. BiPAP use was 12+ Hours per day with noticeable skin breakdown on the bridge of his nose.

JT is a 35yo man with Duchenne Muscular Dystrophy. At baseline his FVC was 9% of predicted with noted mild dysarthria. BiPAP use was over 12 hrs a day and patient began using a comfort care pad to alleviate the skin breakdown on the bridge of his nose.

BL was a 54yo with ALS. At baseline his FORCED VITAL CAPACITY was 31% of predicted. Use of Bi-level was over 12 hours a day. Although this patient had mild dysarthria, his speech became compromised only with fatigue and ultimately became short of breath.

The four patients we present adopted the regular use of SIP/PUFF ventilation allowing them the opportunity to speak, which was not readily possible at baseline. They all reported sufficient respiratory comfort associated with improved breath management necessary for adequate and functional speech production. Prior to consistent use of SIP/PUFF all targeted patients were observed to require excess effort to manage air supply for sufficient phonation in conversation. Following the start of SIP/PUFF intervention, patients quickly learned their phonation limitations and when to take a replenishing breath. Although each patient’s FVC’s were considerably divergent, prior to SIP/Puff intervention their speech was similarly challenged.

Discussions and Conclusions: Based on these observations, plans for a clinical study to evaluate the benefits of routine usage of SIP/PUFF ventilation to support functional phonation are underway. Interest from other sites in a multi-site investigation are welcome.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 116

SIP/PUFF Ventilation: Increasing Exercise Tolerance from Breath to Breath
Irvin Marquez, RRT, RCP, and Jeremy Fagundes, PT

Background: Patients with neuromuscular disease often become sidelined due to increased shortness of breath then ultimately become bedbound as a result of total muscle weakness and atrophy. SIP and Puff ventilation has been effective in providing “sigh breaths,” and can decrease daytime hypercapnia and respiratory distress for patients that have respiratory insufficiency and require frequent daytime support
with non-invasive positive pressure (i.e. BiPAP). SIP and PUFF ventilation is an alternative that is well tolerated and has been shown by multiple patients to decrease their work of breathing after exertion. SIP/PUFF ventilation has been proven to decrease recovery time after exercise, yet will the use during exercise increase the patient endurance time?

**Objective:** We report our initial experience using SIP/PUFF ventilation in patients with a variety of neuromuscular diseases impacting ventilation and exercise tolerance. These observations have resulted in our interest in developing a protocol to formally access the efficacy, impact on the quality of life with use of mouth piece ventilation during activities of daily living.

**Materials and Methods:** For our consideration of SIP/PUFF ventilation, patients must have access to MPV, decent extremity strength, and is able to ambulate on his/her own. For patients requiring assistance a walker or cane will be acceptable and will be noted during the study. Patients are accessed at baseline for their exercise tolerance and on their overall respiratory indices. Exercise tolerance and ROM is regularly evaluated by the Physical Therapist.

1. Patients will be assessed on distance traveled, SPO2, Heart rate, and respiratory rate without MPV (Baseline).
2. Patients will be reassessed on distance traveled, SPO2, Heart Rate and respiratory rate with MPV.

The SIP/PUFF ventilation is facilitated through a Trilogy NIPPV machine using settings: Pressure control ventilation 15-20cmH2O, Rate of 1, EPAP 4cmH2O (Day mode)

NOC Mode: is current Bi-Level settings.

**Conclusion:** TBD

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**Poster 117**

**Nutrition Management Methods Most Effective in Increasing Weight, Survival Time, and Functional Status in ALS Patients: A Systematic Review**

*Erin Arra, RD, and Frances Kozlowski, BS, MS*

**Author(s):** Erin Arra, RD, Frances Kozlowski, BS, MS, Jaylin Kellogg, MS, Stephen Selkirk, MD, PhD, and Lindsey Bottman, BS, MS

**Objectives:** The overall objective is to complete a systematic review of research conducted between 2006 to 2016, in order to determine the most effective nutrition interventions for the management of ALS. This systematic review will provide evidence summaries and conclusion statements that can be utilized for evidence-based course of action guidelines for practitioners to improve health outcomes.
Materials and Methods: The systematic review will include research regarding ALS and nutrition management to answer the following research question: What are the nutrition management methods most effective in increasing survival time and quality of life for ALS patients?

Trials will be identified through computerized searches of five databases: CINAHL, Cochrane, EMBASE, Medline, and PubMed. The review will include both retrospective and prospective randomized controlled trials conducted from 2006 to 2016 that are peer-reviewed and published in the English language. These clinical trials will consider the health status, living conditions, and comorbidities of ALS affected participants 18 years or older. The search terms that will be used for this systematic review are “ALS management” OR “Lou Gehrig’s” OR “amyotrophic lateral sclerosis” OR “ALS” OR “motor neuron disease” or “MND” AND “nutrition” OR “diet” OR “MNT” OR “medical nutrition therapy” OR “nutrition management” OR “nutrition support” OR “malnutrition” or “weight loss.”

All results obtained from the comprehensive search will be critically evaluated using the inclusion and exclusion criteria. Each study will be given a quality rating score. Once this is completed, the strength of the evidence and the quality of each individual study will be assessed.

The Academy of Nutrition and Dietetics web-based Data Extraction Tool (DET) will be used to extract and store information from the included trials. Statistical analyses will be performed with all available data that has significant homogeneity in order to strengthen the evidence, grading, and conclusions. The available data will include age, height, weight, BMI, quality of life, survival and overall function that will be gathered using the Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R).

Conclusion statements will be composed that aggregate all of the evidence found in the systematic review. These statements will provide scientifically based conclusions on the most effective nutrition interventions regarding initiation, duration, and methods of nutrition supplementation and nutrition support to prolong life expectancy and improve quality of life in ALS patients.

Outcomes and Results: This study is currently in process.
**Objective:** The objective of this analysis was to examine patient outcomes following DPS placement surgery at a single ALS referral center.

**Materials and Methods:** This is a non-randomized, observational study of ALS patients choosing DPS placement. Results will be presented.

The following data were collected for all patients undergoing DPS placement surgery at our institution:

- FVC every 3 months
- ALS Functional Rating Scale-R (ALSFRS-R) scores every 3 months
- Time from ALS symptom onset to death or tracheostomy
- Monthly patient reports of:
  - DPS
  - Work of breathing
  - Dyspnea
  - Voice volume
  - Energy
  - Sleep quality
  - Secretion management

- Description statistics, Spearman correlations, and Wilcoxon rank sum tests were performed.
- The study received Institutional Review Board (IRB) approval.

**Outcomes and Results:**

**Surgery Outcomes**

- To date, 19 patients followed at our site have undergone surgery for DPS placement (11 men, 7 women, mean age 56.9 years [range 34-69]).
- These patients have been followed for an average of 13.1 months post-surgery (range 0-23).
- Of the 19 patients, 8 have died, with an average time from DPS placement to death of 9.4 months (range 0-15 months).
- We continue to follow 10 living patients, who have been pacing for an average of 10.3 months (range 0-23 months).

**Patient Reported Outcomes**

- Patient reported outcomes are available from 14 patients who responded to post-surgery questionnaires.
- All patients report pacing for at least 8 hours per day at 3 months post-surgery.
- Patient reported changes included:
  - Improved work of breathing (n=1)
  - Improved pain in shoulders (n=2)
  - Improved quality of sleep (n=1)
• Worsened voice volume (n=1)

- No change was reported by any patient for: shortness of breath, energy level, or secretion management.
- Comments from patients were largely positive and indicated improved sleep duration and quality. No negative outcomes were reported.

Discussions and Conclusions:

- This small, non-blinded, non-randomized study did not identify any disease characteristics beyond age that might contribute to a more rapid disease decline after DPS placement surgery.
- The more rapid decline in ALSFRS-R and FVC observed after DPS surgery is based on a very small number of patients and cannot be generalized.
- We are analyzing outcome data for our larger cohort and speculate that the decline noted after DPS placement surgery could be related to multiple factors, such as: general anesthesia, progression of the disease from the time of evaluation to the time of surgery, or unpredictability of the disease.

Friday, November 4, 2016
1:15 pm – 2:15 pm
Poster 119

Evaluation of the Edinburgh Cognitive and Behavioral ALS Screen (ECAS) in a US Sample

Susan Walsh, RN, MSN, ACNS-BC

Author(s): Travis Haines, MA, CCRC, Judy Lyter, RN, MS, LPC, NCC, Susan Walsh, RN, ACNS-BC, Anne Morris, MPH, Sharon Abrahams, PhD, Zachary Simmons, MD

Background:

- Up to 50% of patients with ALS will exhibit cognitive impairment and 10-15% will meet diagnostic criteria for frontotemporal dementia (FTD).
- Identifying cognitive and behavioral change is an important aspect of clinical care, but comprehensive neuropsychological testing is impractical in a multidisciplinary ALS clinic.
- The Edinburgh Cognitive and Behavioral ALS Screen (ECAS) is a brief exam that was developed to assess impairment in ALS patients and includes:
  - An ALS-Specific Cognitive Score comprised of Language, Verbal Fluency, Executive domains,
  - An ALS Non-Specific Cognitive Score comprised of Memory and Visuospatial domains, and
  - A Behavioral Score derived through a caregiver interview
The ECAS has been validated in the UK, demonstrating high sensitivity (85%) and specificity (85%) for cognitive dysfunction.

- The ECAS has not yet been evaluated in the US or in a busy multidisciplinary ALS clinic.

**Objectives:**

1. Evaluate the administration of the ECAS in a multidisciplinary ALS clinic.
2. Compare US ALS clinic data to published UK data.

**Materials and Methods:**

- The ECAS was administered by certified personnel (a nurse counselor and a research coordinator) in a multidisciplinary ALS clinic during routine clinical care.
- Patients were eligible for testing after their initial visit to clinic.
- Exclusion criteria included: significant fatigue or weakness; severe or pre-existing neurological or mental health conditions; terminal stages of illness; or insufficient clinic time.
- Cognitive and behavioral data were analyzed retrospectively and descriptive statistics were compared to published UK data.

**Discussions and Conclusions:**

- The ECAS can be administered in a multidisciplinary ALS clinic by individuals undergoing relatively brief training.
- Cognitive abnormalities were found more frequently in the US clinic sample than in the published UK data.
- Similarities between the US clinic and published UK data included:
  - Trends of abnormal scores across cognitive components
  - ALS-Specific abnormalities found in ALS patients more often than ALS Non-Specific abnormalities
  - The relative frequency of reported behavioral changes and possible FTD
  - Higher frequency of abnormal cognitive scores in the US may be due to different patient populations (registry vs. clinic).

Further studies are warranted to establish US normative data and better describe this instrument’s clinical utility.

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**Friday, November 4, 2016**

**1:15 pm – 2:15 pm**

**Poster 120**

**Satisfaction Surveys: What Our ALS Patients Can Teach Us**

*Tami Kendra-Romito and Peggy Allred, PT, DPT*

**Author(s):** Tami Kendra-Romito, Richard Lewis, MD, Abirami Muthukumaran, MD, Robert H. Baloh, MD, PhD, and Peggy Allred, PT, DPT
**Background:** General surveys rarely query for specific ideas or suggestions to enhance the clinical experience. We surveyed both our ALS patients and team providers to ensure we are meeting their needs as a program. Two individual surveys were developed with open-ended questions focusing on overall program satisfaction and suggestions for improvement. Patient survey results showed 30 (100%) stated there were benefits of attending the clinic, 17 (57%) had suggestions for improvement and 16 (53%) shared ideas for additional services. The provider survey focused on gathering opinions regarding program structure and flow. Only the allied healthcare team members were surveyed; 16/17 (92%) team members responded. Results allowed us to make quick and meaningful changes to improve patient and provider satisfaction. Serial surveying of patients and providers is highly beneficial for a large multidisciplinary ALS program to improve communication, follow-up and promote provider job satisfaction.

Patient surveys are used almost daily in the hospital and outpatient settings to monitor patient satisfaction and calculate HCAHPS scores. These surveys rarely query for specific ideas or suggestions to enhance the clinical experience. We felt it was important to survey our ALS patients and providers to ensure we are meeting their needs as the program experienced 389% growth in 3 years with little change in staffing. Two surveys, one for patients and one for providers, were developed with open-ended questions focusing on overall program satisfaction and suggestions for improvement. Patient surveys were distributed at the clinic visit. The survey was comprised of 3 questions: “What do you see as the benefits of the ALS Clinic?”, “What would you change about the clinic?”, and “What additional services would you like?” Surveys were provided to 112 patients with a 27% return rate. Results showed 30 (100%) stated there were benefits of attending the clinic, 17 (57%) had suggestions for improvement and 16 (53%) shared ideas for additional services. The provider survey focused on gathering opinions regarding program structure and flow. Only the allied healthcare team members were surveyed. 16/17 (92%) team members responded. Responses were evaluated for commonalities and ranked by most common/similar to least common. Overall the responses from both groups were overwhelmingly positive with many of the suggestions for improvement being fairly benign.

“Fantastic team”, “helpfulness” and the “ability to see many providers in one setting” were common program benefits expressed by the majority of the patients. In contrast, suggestions such as “having a clinic closer to home”, “having access to a shuttle bus” and “neck massages”, while not feasible, did help to remind us that patient participation in the multidisciplinary clinic can be taxing. There was general consensus from the providers regarding the positive aspects of their clinical experience. Descriptors such as “organized”, “caring”, and “collaborative” were listed frequently. Provider concerns included limited number of EMR stations, difficulty tracking room utilization and communication opportunities. Both groups expressed the need for “someone to vent to” and “help with psychological aspects of disease”. The survey results allowed us to make quick and meaningful changes to improve patient and provider satisfaction.

Some of these changes included adding more EMR stations, better triage of patient needs, implementing a team tracking system and setting up quarterly team meetings. Partnering with neuropsychologists and the Chaplaincy program allowed us to address the shared concerns for
supportive care. Serial surveying of patients and providers is highly beneficial for a large multidisciplinary ALS program to improve communication, follow-up with team recommendations and promote provider job satisfaction. We believe targeted surveys are important for positive growth of a neuromuscular specialty clinic and will continue to survey both patients and providers annually as a mechanism for process and performance improvement.

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Poster 121

Use of the ALS CBS to Identify Cognitive Impairment in PALS
Heather Clark, PhD, and Julie Stierwalt, PhD, CCC-SLP

Objectives: Amyotrophic lateral sclerosis (ALS) is a progressive motor neuron disease affecting voluntary muscles, with gradual loss of movement and motor function. While traditional descriptions of ALS allude to evidence of cognitive decline, such impairments are reported as occurring in only a small percentage of individuals with the diagnosis (“Amyotrophic Lateral Sclerosis (ALS) Fact Sheet” 2016). Contrary to this claim are reports of high incidence of cognitive impairment in people with ALS (PALS). Over a decade ago, one study reported an incidence of 51% demonstrating some degree of cognitive impairment (Ringholz et al., 2005); similar rates were reported in a study published this year (Murphy et al., 2016). The incidence of frontotemporal dementia in ALS may also be higher than initially estimated (Ringholz et al., 2005; Woolley & Strong, 2015).

Growing evidence of cognitive impairment in ALS motivated the development of standard methods to identify cognitive decline in PALS. The ALS Cognitive Behavioral Screen (ALS CBS; Woolley et al., 2010) was developed with the goal of identifying cognitive and behavioral changes associated with decline in executive function. The screening tool is comprised of two sections, a cognitive scale with tasks adapted from standard testing, and a behavioral scale/checklist to monitor behavior and personality changes. Initial examination revealed performance on the ALS CBS differentiated PALS without cognitive impairment, with cognitive impairment, and with FTD (Woolley et al., 2010).

Having adopted the ALS CBS for cognitive screening in our multidisciplinary ALS clinic, we examined the distribution of scores obtained from 50 PALS in order to characterize the incidence of cognitive impairment using the guidelines offered in the original standardization report (Woolley et al., 2010).

Materials and Methods: The cohort of PALS studied included 32 men and 18 women with a mean age of 63.2 years. The ALS CBS was administered by a certified speech-language pathologist during each participant’s regularly-scheduled multidisciplinary ALS Clinic visit.

Outcomes and Results: No difference in performance was observed between men and women on either the cognitive or behavioral screens. The average performance of both men and women fell in the range of cognitive impairment. There was a trend for men to score lower on the behavioral screen compared to women, with the mean score for men falling in the impaired range.
Overall, 72% of PALS scored in the impaired range on the cognitive scale, with 6% falling in the range of frontotemporal dementia (FTD). On the behavioral scale, 30% of PALS scored in the impaired range, with 22% scoring in the range of FTD. Nine PALS (18%) scored in the impaired range on both scales, with only one PALS scoring in the range of FTD on both scales. Performance on the ALS CBS was not strongly correlated with age, ALSFRS, or months post-diagnosis. Moreover, performance on the cognitive scale was not strongly correlated with performance on the behavioral scale. Education data was not available at the time of this writing, but will be reported in the final poster.

**Discussions and Conclusions:** Similar to the reflections offered by Woolley et al., (2010), we observed that PALS scoring in the range of FTD on the cognitive scale were symptomatic, either by their own report or by the report of their care-providers. Most PALS scoring in the impaired range did not complain of changes in cognition. Higher agreement between scores in the impaired range on the behavioral scale and family concerns about changes in behavior are not surprising given that the behavioral scale is a checklist completed by the care provider.

The relatively high number of PALS scoring in the impaired range on the cognitive scale, as well as the relatively small differences in performance between healthy controls and PALS identified as impaired in the original validation study leads us to question whether the normal range of performance may actually be broader than was reported based on the performance of 15 healthy controls. In our future research, we propose to administer the ALS CBS to spouses and adult children of PALS, as well as to neurologically healthy individuals from the community at large. Richer normative data will allow for more confident interpretation of cognitive scores that are above the range of FTD.

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**Program for Pairing Graduate Students with PALS to Provide AAC Support**

*Jane Luethke, RN*

**Author(s):** Jane Luethke, RN, and Jillian H. McCarthy, PhD, CCC-SLP

**Objective:** Utilize graduate SLP(speech language pathology) students as ALSA volunteers to provide home or clinic based support to AAC (alternative augmentative communication) users who are otherwise not eligible for professional support due to hospice status, immobility, insufficient vendor support or other issues.

**Materials and Methods:** Provide a program whereby graduate students from, the University of Tennessee SLP program who have been trained in AAC and are familiar with ALS become chapter volunteers and are matched with PALS (persons with ALS) who need assistance with AAC devices. These devices may be items owned by the PALS or they may be chapter loaner devices.

The first step in the program is for the care services coordinator to identify the clients who are in need of AAC support. Clients who desire assistance then complete the chapter’s volunteer request form.
which includes their contact information, release, and information about emergency procedures for the individual client.

The SLP students are graduate students who have completed the AAC course through the University of Tennessee Augmentative-Alternative Communication, Language, and Literacy Lab. They are trained in the use of eye gaze and device troubleshooting. They have the capability of providing SLP evaluations through the University and also receive HIPAA training.

The students are certified as ALSA volunteers by completing the requirements for the Tennessee ALSA Volunteer program. This process includes a background check and the completion of a volunteer agreement and confidentiality agreement. The volunteers are required to read information regarding the role of a volunteer as well as publications that give them an overview of the ALS. At this time the required reading includes the publications ALS and the ALS Association and Basic Home Care for ALS Patients. The students are also encouraged to read the Living with ALS Manuals. Once the students have read the material the SLP instructor tests the students over the assigned reading.

Once an ALS Client has requested a volunteer and the student has been cleared through the volunteer process the care services coordinator notifies the assistant professor who is director of the AAC Language Lab. The professor identifies a willing student and the student or the professor contact the PALS and arrange for a home visit or for the person to come to the AAC Lab on campus. Once the contact is made the professor or student provides a summary of the visit to the care services coordinator. The coordinator also contacts the PALS after the visit. If both reports are satisfactory the students and PALS arrange for further visits as needed and continue to report back to the care services coordinator periodically.

**Outcomes and Results:** To date seven ALS clients have been assisted through this program. Services provided have included assistance with setting up devices and calibration, helping with Facebook and Skype and troubleshooting a variety of issues. One PALS received assistance with voice banking and four were assisted with training and set up of loaner devices. Five of the PALS who were assisted continued to use their devices on a regular basis. One did not use the loaner device and returned it to the chapter. One is voice banking and does not have a device at this time. All of the follow up reports from both the PALS and the students have been positive.

The SLP students are receiving a valuable educational experience by reading the assigned materials and working one-on-one with ALS clients. One unexpected benefit came when one of the PALS wrote and delivered a lecture about his experiences with ALS and communication to the SLP class using his AAC device. Another positive outcome has been the ability to store some chapter devices at the school to be readily available to PALS.

One challenge to the program is the distance the students are willing to travel. Most are willing to travel only 30-45 minutes from campus which restricts the access to the program unless the PALS is willing to travel. Students who live in farther reaching areas of the state have indicated a willingness to volunteer near their hometown which may eventually allow for more access. Another challenge is working around
school schedules and holidays coupled with the rapid demise of some ALS patients. Four requests for services were left unfulfilled due to the death or progression of the patient.

**Discussions and Conclusions:** This program has provided a fruitful partnership between the ALS Association and the University of Tennessee in providing instruction and support in the use of AAC. PALS whom otherwise would not have had access to assistance with their AAC devices have received services and been assisted to better use their devices. Students who might never have encountered an ALS client in their training are receiving hands-on experience with ALS while providing useful assistance to PALS.

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**Friday, November 4, 2016**
**1:15 pm – 2:15 pm**
**Poster 123**

**The Role of Occupational Therapy in the Management of ALS**

*Jana LaMarca, OTD, OTR/L, ATP, Maria Lim OTR/L, ATP, and Erica Law, MA, OTR/L*

**Background:** A multidisciplinary treatment model for patients with amyotrophic lateral sclerosis (ALS) has been found beneficial in prolonging good health outcomes (Van den Berg et al, 2005), Traynor et al, 2003). Occupational therapists have a large and unique role as a member of the multidisciplinary team care of patients with ALS (Mayadev et al, 2008), (Arbesman, M & Sheard, K., 2014). Occupational therapists work with patients with ALS in both primary care and rehabilitation settings to triage and address changes in function, equipment needs or malfunctions, psychosocial needs for both patient and caregiver, and other barriers that impact participation in activities, environments or systems (AOTA, 2014), (Muir, 2012). Occupational therapists can also help by providing functional home evaluations (McCluskey, Lewis, Sharanan, 2007) to identify safe and effective solutions for patients and caregivers, wheelchair evaluations and prescriptions (Trail et al, 2001), (Ward et al, 2010) and home exercise programs which can delay declines in strength (Dal Bello-Haas, V. et al, 2003). At the VA Long Beach Health Care System, the Occupational Therapists have also developed an Occupational Therapy group for patients and caregivers to share experiences, gain valuable knowledge, and offer a role as mentors and supporters of each other to improve quality of life (Foley, G, 2004).

**Objectives:**

1. Participants will be able to identify the role and value of occupational therapy in end of life care
2. Participants will be able to identify 3 benefits of complex equipment evaluation and prescription for patients with ALS
3. Participants will be able to identify 3 steps in how to develop and foster an ALS Support Group for patients and caregivers

**Materials and Methods:** An Occupational Therapy support group for patients with ALS and caregivers has been created by the authors. The group meets monthly and is patient-driven. At the conclusion of each session, participants are encouraged to fill out anonymous feedback forms. These forms are
structured with a four-question Likert Scale and a place to add comments in order to provide in-depth feedback and offer suggestions.

**Outcomes and Results:** This is a work that is still in progress. However, thus far, the quality improvement survey results show that patients find the support group intervention to be very valuable and that they are highly satisfied with the content delivered.

**Discussions and Conclusions:** Although this quality improvement project is a work in progress, initial findings from the support group intervention are rated positively. An occupational therapy support group has shown to be a valuable tool in the management of ALS.

**References:**

Physical Therapy Home Visits to Facilitate Continued Mobilization for Patients with Amyotrophic Lateral Sclerosis in the Advanced Stages

Melissa Ramirez, PT, DPT, NCS

**Objectives:** To recognize the clinical challenges in the advanced stages of Amyotrophic Lateral Sclerosis (ALS) and to apply physical therapy (PT) interventions in the home that will assist caregivers in maximizing the patient’s mobility.

**Materials and Methods:** This poster will review three individual scenarios, where patients in the advanced stages of ALS were unable to tolerate transportation to and from the clinic. The PT in the ALS clinic performed home visits in each scenario to optimize wheelchair seating and positioning, home modifications for wheelchair accessibility and family and caregiver transfer training.

**Outcomes and Results:** As per caregiver report, patients and families were able to increase the amount of time the patient was able to tolerate upright. Discomfort due to constriction and respiratory compromise limited tolerance for upright. At times more than one visit was required to improve patient’s comfort.

**Discussions and Conclusions:** The PT in the ALS clinic serves as a resource to patients and families throughout the stages of ALS. Conducting home visits is a valuable tool for providing continuous clinical education and for promoting continued mobility.
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