SESSION 3B TRANSLATING EVIDENCE INTO PRACTICE

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SESSION 3B TRANSLATING EVIDENCE INTO PRACTICE

C20 TREATING MND: DOES THE EVIDENCE LEAD US OR LAG BEHIND US?
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The motor neuron diseases are a heterogeneous and complex spectrum of disorders which implicate a multidisciplinary approach to treatment. The spectrum of signs and symptoms contributing to disability are vast yet the number of established treatments which have been justified by outcomes data are not. Despite this, we continuously introduce novel treatment paradigms into our clinics, built upon our collective experience treating MND patients.

As academics we are oriented to turning our experience into evidence. As clinicians we are oriented to treating our experiences as if they were evidence. The chasm between the two approaches can be significant and complicated given the phenotypic diversity and sense of urgency brought out in patients with MND.

This presentation will first highlight the justification for the existing standards underlying evidence based guidelines in the US and Europe. Furthermore a great variety of treatments which we apply selectively in routine practice will be surveyed and comments will be offered regarding their potential to ever be subjected to formal outcomes testing.

Our individual biases in routine practice are often shaped by experiences which may pertain to selective symptom combinations or specific disease presentations. These can be readily recognized but difficult to capture in a clinical trial. If evidence guidelines are accepted as the best 'standard of care', what role should we prescribe to often more efficacious and numerous non-evidence based interventions that we commonly adopt.

As we draw lines between evidence and experience we struggle with the essence of our purpose in treating MND patients and moving our field forward. The balance between the two may serve as the most significant driving force in identifying novel breakthroughs. Reliance on evidence alone can be as misdirected as a reliance solely on experience. The controversy raised by this dichotomy will be discussed and the perspective of the patient, practitioner and academic physician will be contrasted.

C21 DOES RIGOROUS CONTROL OF EXERCISE INTENSITY AFFECT SURVIVAL AND FUNCTIONAL OUTCOMES IN ALS?
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Keywords: exercise control, oxygen uptake, aerobic work efficiency

Introduction: The uncertainty about exercise in ALS is mainly derived from a paucity of studies, different approaches and lack of rigorous control of exercise intensity, which can be evaluated by gas exchange on cardio-pulmonary exercise stress test protocol (CPET). We aimed to test the efficacy of applying exercise treadmill ramp protocol leveled 20% lower than determined by CPET.

Methods: Prospective, randomized single-blinded controlled-trial. Forty consecutive ALS patients with no other medical condition and able to perform CPET regardless of their FVC, were assigned to group 1 (G1, n = 20) and group 2 (G2, n = 20) as determined by their residential area. Patients in G1 underwent a supervised-exercise program 3 times/week, with non-invasive ventilation (NIV) or Body Weight Supporting System if required. Patients in G2 exercised to fatigue (Borg scale) with no supervision (with or without NIV). All patients performed CPET at admission and during follow-up (3, 6, and 12 months). ALSFRS-R scores and respiratory function tests (RFT) were performed at 3 month-intervals. The main outcomes were: the minute ventilation in L/min-1 (VE); the peak oxygen uptake expressed in L/min-1 (VO2 pk) or in metabolic equivalents (METs), the carbon dioxide output (VCO2); the ratio oxygen uptake/work rate (VO2/WR) as well as ALSFRS-R scores and their respective slopes. Survival analysis was a secondary outcome.

Results: No clinical or laboratory measurement was different between groups at baseline, except for the ratio VO2/WR that was greater in G1 (p = 0.01) that was not found 3 months later. At admission, VO2 pk m ± sd (1.015 L/min ± 0.301; p = 0.9) were under the normal range of the predicted and did not change overtime. VE m ± sd (24.672 L/min ± 11.25; p = 0.7) was low but above the 50% of the predicted value and doubled the initial value in G1 (p = 0.001). The rate of decline of all ALSFRS-R scores at 3, 6 and 12 months was significantly slower for G1. Survival from symptoms onset to...
April 2011 was not different in the two groups but survival from rehabilitation onset was significantly different (longer for G1, 512 days, than for G2, 318 days, \( p = 0.04 \), Kaplan-Meyer estimates with Log-rank test).

**Discussion:** Deconditioning was not observed. Despite the reduced VO\(_2\) pk at admission, no changes in the follow-up were identified. The high ratios VO\(_2\) pk/WR reflected the initial aerobic work inefficiency with diminished breathing reserve. In G1 we observed a significant improvement in the VE and aerobic work inefficiency with diminished breathing reserve. Survival after exercise onset was longer in G1. We conclude that a well-controlled exercise protocol as defined by CPET is beneficial to ALS patients even with low FVC values.

**C22 IMPLEMENTATION OF AMERICAN ACADEMY OF NEUROLOGY (AAN) AMYOTROPIC LATERAL SCLEROSIS (ALS) GUIDELINES AS PERFORMANCE MEASURES IN THE JOINT COMMISSION DISEASE SPECIFIC CERTIFICATION (DSC) PROGRAM AT CAROLINAS NEUROMUSCULAR/ALS-MDA CENTER**

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**References**


**C23 EVIDENCE-BASED GUIDELINES FOR POWER WHEELCHAIR PRESCRIPTION FOR PERSONS WITH ALS/MND**

WARD A, BROOKS BR, BRAVER E, SANJAK M, HOLSTEN S

**References**


**Objective:** Implement and evaluate core performance measures of the ALS DSc profile based on 2009 AANALSPP and collect quantitative patient data for outcomes assessment in a large ALS clinic.

**Methods:** Standardized performance measures: 1) Mini-Mental Status Examination (MMSE); 2) Patient Health Questionnaire (PHQ-2); 3) Patient Health Questionnaire (PHQ-9); 4) Hendrich II Fall Risk Assessment (HIFIRA) and 5) Respiratory Management Assessment (RMA) measured patient status according to 2009 AANALSPP. Monthly and quarterly audits of performance were ascertainment across 689 ± 175 (SD) annual ALS encounters through 2009-2011.

**Results:** Cognitive (93.3 ± 11.7%), psychiatric-screening (PHQ-2) (87.6 ± 21.0%), psychiatric-followup (PHQ-9) (84.4 ± 27.6%), falls (93.5 ± 9.9%) assessments were performed according to practice standards achieving benchmarks with wide confidence limits. Cognitive and psychiatric measures formed the basis of each patient’s assessment that encounter (98.5 ± 5.9%). Falls risk (HIFIRA) used initially to monitor falls was discordant from the number of falls experienced during the inter-clinic interval and was replaced with real-time assessment of falls between last and current clinic visit. Subsequent to this change, number of falls were recorded in each clinic note (89.5 ± 0.7%). Respiratory management assessments identified functional vital capacity (FVC) measurement was high but not universal (95.4 ± 7.2%).

**Conclusion:** Initiating five performance measures in an ALS Clinic requires increased encounter time and increased administrative time. In the first 6 months of implementing and evaluating performance measures in an ALS Clinic, we realized that a standard Falls Risk Assessment scale did not meet the needs of assessing falls risk in ALS patients and corrective measures were taken.
Objective: To survey persons with ALS at 1 month, 6 months and a year after receiving PWC to develop guidelines for what is required for long term effective use, comfort and function of their PWC, and to use these surveys for evidence-based guidelines.

Method: 33-question survey and Psychosocial Scale of Assistive Devices sent at 1 month after getting a new PWC, follow up survey sent at 6 months and 1 year as well. The survey addressed satisfaction, feature use, comfort and function with the PWC.

Results: Based on satisfaction and feature use survey results, we are proposing requirements for what should be ordered on a new PWC for a patient with ALS/MND as well as features which would be helpful but are not required. At 1 month, 38% of users are using tilt, recline and elevating legs features at least 2 times a day, and at 6 months 55% are performing these tasks. For users at 1 month, 88% are still pleased with their choice of cushion, headrest and power features, and this percentage drops only slightly at 6 months.

Discussion: The proposed guidelines include that the PWC should have tilt, recline and power elevating foot platform as power features, upgraded electronics, power features run through the joystick, contoured backrest, pressure relieving and positioning cushion and plush headrest. Other features which are helpful but not required include a seat elevator, alternative drive controls, laterals and thigh guides for positioning support, supportive armrests, and switches for on/off and mode.

Conclusion: Our proposed evidence-based guidelines for PWC users with ALS/MND are currently open for comment and discussion. We feel our multidisciplinary ALS/MDA clinic has a responsibility to develop guidelines and help provide evidence for the long-term needs of these patients and their PWC because of the focused treatment and wheelchair evaluations, which are performed daily at our center.

References

C24 A SYSTEMATIC REVIEW OF ALS SERVICE USERS’ PERCEPTIONS OF SERVICES AND DECISION MAKING IN CARE

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Keywords: care preferences, decision making, health care services

Background: Effective symptom management, physical and psychological support, are components of ALS care. Service users and providers of palliative services can hold different perspectives on the benefits of care. However, few studies have explored the delivery of services from the ALS service user’s perspective.

Objectives: To examine the literature on ALS service users’ perceptions of health care services; to draw attention to factors that may influence preferences for care.

Method: A review of the literature from 1988 to March 2011 was undertaken. Databases used included: Medline, Cinhakl, AMED, PsyInfo, Cochrane Library, Evidence Based Medicine Reviews, Science Citation Index, Social Sciences Citation Index, and Arts and Humanities Citation Index. Search terms used included; ‘amyotrophic lateral sclerosis’ or ‘motor neurone disease’ and/or ‘services’, ‘healthcare’, ‘experiences’, ‘expectations’, ‘satisfaction’, ‘decision-making’, ‘perceptions’, ‘perspectives’ and ‘care preferences’. Separate manual searches of online editions of palliative care journals (including early online where available) were also undertaken using search terms ‘motor neurone disease’ and ‘amyotrophic lateral sclerosis’. A narrative approach was used to synthesise studies (1).

Results: Studies of decision making and preferences for care have focussed primarily on end-of-life intervention. Only few studies report on service users’ decision making in services prior to end-of-life care. According to existing literature, dissatisfaction with services relates to absence of specialised care; limited access to assistive devices; inadequate respite care and emotional support; delays in diagnosis; concerns regarding method of disclosure; and a lack of knowledge about ALS among professionals. Satisfaction with services is confined primarily to the use of assistive devices. Service users also seek autonomy and exert control when making decisions about care. The need to exert control remains stable overtime. However, care preferences change to accommodate to evolving perspectives and support systems.

Discussion: The literature suggests that ALS service users expect dignified care but they have unmet expectations of their care. A combination of personal values, desire to maintain control, perceptions about quality life, social and carer support determine service users’ preferences for and decisions about care. Some service users may resign themselves to the inevitability of ALS. However, the majority seek a broad range of services and some maintain positive perceptions about health.

Conclusion: ALS service users make choices about care that are grounded in how they interpret their own lives and how they judge potential benefits of care. Further research on how service users interact with services and decide about care is recommended. Research on the delivery of services that are sensitive to service users’ preferences for care is warranted.

Reference