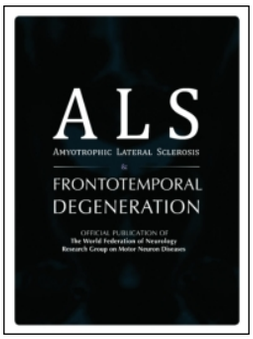

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THEME 7 MULTIDISCIPLINARY CARE AND QUALITY OF LIFE

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THEME 7 MULTIDISCIPLINARY CARE AND QUALITY OF LIFE

P152 COST ANALYSIS OF MULTIDISCIPLINARY ALS CLINICS IN THE VETERANS HEALTH ADMINISTRATION

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Keywords: cost, multidisciplinary clinics, veterans health administration

Background: In a 2003 study regarding multidisciplinary amyotrophic lateral sclerosis (ALS) clinics Traynor and colleagues (1) showed that these clinics increase survival and decrease mortality when compared to general neurology clinics. However, the cost of these clinics has not been extensively studied. The Veterans Health Administration (VHA) is a unique system in that patients receive all their care within a single payer system, allowing for reliable cost analysis.

Objective: To determine if there is a cost difference between multidisciplinary and general ALS clinics within the VHA.

Methods: Staff at the Office of Productivity, Efficiency and Safety (OPES) used the Corporation Data Warehouse to obtain Decision Support System National Data Extract datasets for FY2010. Data merging and analysis were done through scrambled SSN; no patient identifiable information such as name, SSN or addresses were used or revealed. Data was obtained according to patient utilization across different facilities. ALS patients were identified by ICD-9 codes from the inpatient, outpatient and fee files. Multidisciplinary ALS clinics were classified as care offered by a Neurologist or Physiatrist and at least 2 other service lines (PT, nutrition, etc.) at the same visit. All other clinics, including Neuromuscular Clinics, were labeled 'general clinic'. Medical centers with more than 20 ALS patients were identified from a total of 139 facilities within the VHA. 68 medical centers fit this criterion. All 68 medical centers were contacted by phone to obtain information regarding the presence or absence of a multidisciplinary ALS clinic. Nine medical centers were excluded as accurate data could not be obtained and one medical center was excluded due to extremely large unexplained variations in cost. Twelve medical centers were identified as having multidisciplinary ALS clinics. ANOVA testing was done to determine statistical significance.

Results: Total cost of ALS care per patient for FY2010 was $41,186 in general clinics versus $42,089 in multidisciplinary clinics ($p < 0.05$). The average inpatient, outpatient, and fee expenditure costs per patient were $15,063, $19,260, and $6,863 in general clinics versus $15,575, $22,280 and $4,234 in multidisciplinary clinics. Inpatient costs were 37% of the total cost in both clinics. Outpatient costs were 6% higher in the multidisciplinary clinics, which were offset by 6% higher fee basis costs in the general clinics.

Discussion and conclusions: Our study shows that there is no statistically significant difference in the cost of ALS care provided in multidisciplinary versus general clinics in the VHA. Taken in conjunction with previous studies that have shown increased survival and decreased mortality in multidisciplinary clinics, these results strengthen the case for providing patient-care in multidisciplinary ALS clinics.

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P153 VARIATIONS IN COST OF ALS CARE WITHIN THE VETERANS HEALTH ADMINISTRATION

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Keywords: variations, veteran health administration

Background: The Veterans Health Administration (VHA) allows for reliable cost analysis as patients receive all their care within a single payer system. Amyotrophic lateral sclerosis (ALS) is a fully compensable illness within this system making cost studies related to the disease ideal. Although there have been studies evaluating the cost of ALS care, there have not been many looking at variations in costs based on facility location, academic affiliation and physicians in training.

Objectives: To ascertain the cost of ALS care within the VHA for fiscal years 2005–2010. To analyze the cost of care in rural versus non-rural facilities, teaching versus non-teaching facilities and those facilities with neurology residents versus those without neurology residents.

Methods: Staff at the Office of Productivity, Efficiency and Safety (OPES) used the Corporation Data Warehouse to obtain Decision Support System National Data Extract datasets for fiscal years 2005–2010. Data merging and analysis were done through scrambled social security numbers; no patient identifiable information was used or revealed to the investigators. ALS patients were identified by ICD-9 codes from the inpatient, outpatient and fee files (care provided outside the system but paid by VHA). ANOVA testing was done to compare rural versus non-rural facilities, teaching versus non-teaching facilities, and those facilities with and without Neurology residents.

Results: Total cost of ALS care between FY2005-FY2007 ranged from $35,890,466 to $37,389,552. The cost increased to $47,805,567 in FY2008, $81,802,784 in FY2009, and $114,288,333 in FY2010. The number of ALS patients between FY2005 and FY2008 ranged from 1488 to 1599. The number increased to 2304 patients in FY2009 and 2752 patients in FY2010. Total cost per patient increased from

$23,581 in FY2005 to $41,529 in FY2010. The cost per patient in rural versus non-rural ($46,969 versus $40,561), teaching versus non-teaching ($43,370 versus $46,419) and neurology residents versus no neurology residents ($39,509 versus $48,450) only showed statistical significance (p-value < 0.05) in the latter.

Discussion and conclusions: The cost of ALS care has more than tripled in the VHA between fiscal years 2005 and 2010. A large portion of this increase occurred after 2008 when ALS became a compensable illness. The total cost per patient has also increased between 2005 and 2010, which is likely due to increased utilization of services offered by the VHA to veterans as well as increasing costs of providing care. The cost of inpatient, outpatient and fee expenditure care have all increased in a proportional manner. The cost per patient of outpatient care is 20% higher than the cost of inpatient care. There is no statistically significant difference in cost between rural and non-rural facilities as well as teaching versus non-teaching facilities. There is a statistically significant higher cost of ALS care per patient in those facilities with Neurology residents.

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P154 COST ASSESSMENT OF MULTIDISCIPLINARY CLINICS ADHERING TO AAN ALS PRACTICE STANDARDS

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Keywords: multidisciplinary, costs, standards

Background: The multidisciplinary team approach to the treatment and management of amyotrophic lateral sclerosis (ALS) patients is the preferred model of care, with evidence for prolonged survival, improved quality of life, and reduced hospital admissions. (1,2,3,4) There are no published data on costs associated with this model of patient care for U.S. institutions that adhere to the American Academy of Neurology Practice Parameters (AANPP).

Objective: To address these issues, in 2007 five centers providing multidisciplinary care participated in a retrospective review of clinic costs using a self reported data collection tool over a six-month period.

Methods: Each of the five centers self-reported patient volume, staff time, salary and benefit costs; non-clinic staff time; costs of supplies, equipment and overhead including rent, departmental fees and institutional fees at their clinic. All centers met criteria established for ALS Association certified multidisciplinary clinics. Results were presented in a descriptive manner.

Results: A total of 502 patients were seen during the six-month study period, range 35 to 220 patients per center. The total annualized patient visits was 1,645. Non-salary direct and indirect expenses accounted for 3–14% of total expenses at four centers. Annualized staff salaries and benefits were $1,016,405. The annualized mean non-salary direct and indirect cost was $42,000, and mean annualized total expense was $245,000 per center. Mean total expense per clinic day was $5,800 and mean expense per patient per clinic was $772. The mean annual expense per patient was $2,737.

Discussion and conclusions: Results from this pilot study provide an initial estimate of U.S. clinic costs and are useful in identifying the elements of cost of multidisciplinary care conforming to the AANPP.

Investigators decided to expand pilot data and obtain information from a larger number of diverse centers (geography, size, and institution type) so as to garner more reliable and generalizable data. A new and expanded study is employing a prospective approach and also includes an estimate of clinical outcome measures to evaluate practice standards and patient satisfaction. Already underway, this three-month prospective descriptive, multi-center study examines costs associated with care provided at 15 U.S. geographically diverse sites providing multidisciplinary ALS care according to the AANPP. Initial data from the expanded study will be available for presentation at the Symposium.

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P155 HEALTH SERVICE USE BY PEOPLE WITH ALS IN SOUTH EAST ENGLAND

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Keywords: health service use, equipment, symptom severity

Background: Research has begun to provide data on health service and equipment use by people with amyotrophic lateral sclerosis (ALS) in the US, Scotland, Southern Ireland and Spain. Studies have shown that health resource use increases progressively with disease severity and that a wide range of equipment is needed irrespective of disease onset site.

Objectives: As part of a larger prospective, population-based study investigating decision-making about interventions in ALS, our objective was to measure longitudinal health service use by patients in South East England. Here we report our sample's service use at study recruitment (baseline).

Methods: People with ALS were recruited from the South East ALS Register between six and sixty months post-diagnosis. At baseline, participants completed various physical, cognitive and psychological measures. Seventy-five participants also completed a questionnaire about their use of inpatient, outpatient and community services over the preceding three months, and the informal help they received during this time. They were also asked about any equipment obtained and adaptations made to their home. Participants updated this information every three months until death or till the end of the study.

Results: The sample had a mean age of 62.5 years (SD 11.7), and had been diagnosed on average 12.5 months prior to recruitment. Forty-nine were male. The majority had sporadic ALS (71) and non-bulbar onset (65). The mean ALSFRS-R score was 35.3 (SD 7.5). At baseline, very few patients had used inpatient services. Outpatient services were more frequently used, with the majority (56%) seeing a neurologist within the preceding three months and 21% attending a hospice day centre. The most commonly reported community service was the GP (72%). Relatively high numbers accessed occupational therapy (68%) and physiotherapy (63%). Speech therapy (SLT) input was less common (45%). Analysis of ALSFRS-R scores of those using/not using services revealed the largest differences in SLT, personal care and palliative care nursing, with users having greater symptom severity. SLT use differed according to region of onset and ALSFRS-R speech/swallowing scores. Walking aids and manual wheelchairs (51%) were the most commonly used equipment types. Use of the latter was more common in those with lower ALSFRS-R scores. Few patients had major adaptations to their home. The amount of informal help received ranged from none to constant help (mean 20.2 hours/week).

Discussion: This study characterizes current health service use, equipment and informal help received by people with ALS recruited from the South-East ALS Register on average 12.5 months post-diagnosis. Symptom severity was meaningfully related to use of some services, and equipment and amount of informal help required, and service use was related to individual needs. Further publications will plot change in service use over time and examine relationships between service use and intervention uptake.

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P156 IMPORTANCE OF SOCIAL WORK IN DEVELOPING PERFORMANCE MEASURES FOR ASSESSING CARE FOR PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS)

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Keywords: advanced directives, clinic audit, benchmarking

Background: Social work plays a crucial role in the care of patients with amyotrophic lateral sclerosis (ALS). Social work is important in helping patients cope with the rendering of the diagnosis, learn about resources for implementing therapy, dealing with disability, and education and support for the end of life process.

Objective: To identify the role of social work in increasing the proportion of patients who have advanced directives in place and increasing the deployment of appropriate hospice utilization among patients as the disease progresses.

Methods: Social work involvement begins at the first clinic visit when patients who may have ALS are being diagnosed. The initial indepth interview is followed by regular follow up sessions to complete advanced directives between regular clinic followup visits. At the ALS Multidisciplinary Clinic or ALS Ventilator Clinic followup visits social work intervention is optional but nearly universal. Social work involvement is needed for access to care, financial support for treatments and home care, interactions with caregivers, involvement in end of life planning and access to hospice care. Performance measures evaluated for social work contributions to overall ALS care included proportion of patients completing advanced directives and proportion of patients receiving appropriate hospice care at end of life. Statistical analysis was performed with MedCalc Software (Leuven, Belgium).

Results: Surprisingly the proportion of patients completing advanced directives was not 100%. In various groups 72.5 ± 6.4 % of patients completed advanced directives following the first visit. In veterans with ALS who are served at our ALS clinics and who receive care at Department of Veterans Affairs, it was expected that the proportion of patients completing advanced directives would be 100% since that is a major feature of care in that hospital system, however, the proportion of veterans completing advanced directives was similar to the general population. The time from first visit to completion of advanced directives was 9.2 months (95%CI = 4.4–18.6 months). Involvement in hospice care was not universal in our clinics. More patients above 65 years were involved for a larger time than those patients under 65 years.

Conclusions: Social work performance measures identify areas for improvement in ALS care with needs to achieve higher compliance with respect to completing advanced directives and increasing the proportion of younger ALS patients who employ hospice support at the end of life.

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P157 WEEKLY AMYOTROPHIC LATERAL SCLEROSIS (ALS) PATIENT MANAGEMENT CONFERENCE–PIVOTAL ROLE IN PATIENT CARE QUALITY IMPROVEMENT, EDUCATIONAL AND COMMUNITY OUTREACH OF CAROLINAS NEUROMUSCULAR/ALS-MDA CENTER DISEASE-SPECIFIC CARE CERTIFICATION PROCESS

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Keywords: disease-specific certification, benchmarking, multidisciplinary

Background: Crucial to evidence-based guideline management of the care of patients with amyotrophic lateral sclerosis (ALS) is a structure to implement at a per-patient level adherence to these guidelines. Lessons from other diseases, including cancer and cardiovascular disease, indicate that regular review of the diagnosis, initial and follow-up treatment decisions, treatment deployment coupled with acceptance of and compliance with treatment are efficiently managed with a multidisciplinary clinic model. Patient adherence to treatment over the course of disease and changes in recommended treatment is aided by regular review at a per-patient level. The regular audit of patient care has been shown to increase timeliness of proper diagnosis and treatment.

Objective: To describe the structure and function of the Weekly ALS Patient Management Conference at the Carolinas Neuromuscular/ALS-MDA Center in the Department of Neurology at the Carolinas Medical Center in the Carolinas Healthcare System in North Carolina and South Carolina.

Methods: Patients from the Piedmont and western mountain regions of both North Carolina and South Carolina with uncertain, as well as established, diagnoses attend the weekly ALS Intake Clinics for a two-day multidisciplinary clinic evaluation. Each new patient's clinical summary is presented at the Weekly ALS Patient Management Conference by the MD, allowing input from each member of the multidisciplinary clinic team. Treatment plans are formulated and any limitations to initiating these plans are identified by the RN Clinic coordinator/staff. Each week, active patient problems identified by telephone, email or direct contact are reviewed with formulation of potential solutions. Patients with clinical changes that warrant home visits are reviewed by the RN Homecare coordinator. Patients who attend the monthly one-day Ventilator Clinic for patients with tracheostomy and permanent ventilation and who attend the monthly two-day Multidisciplinary Clinic for patients with and without non-invasive ventilation are discussed at the weekly conference prioritized by number of new problems to be addressed. Patient Safety events during clinic, emergency department visits with and without hospitalization, palliative care, hospice and end-of-life referrals and deaths are reviewed. Minutes are kept in rotation by a staff member and circulated by secure email to staff members/allied health/other consultants who participate in the diverse clinic programs but who are not at the weekly conference.

Results: In the period 2010–2011, 170 new patients were reviewed, of whom 12 had diagnoses other than ALS. Ventilator clinic (31) and Multidisciplinary clinic (204) unique patients provided 124 and 816 encounter discussions. Home visits generated 398 discussions and patient problems generated 832 discussions. There were 8 patient clinic fall-related safety discussions. Deaths(62), hospice referrals (56) and hospitalizations (19) were reviewed.

Conclusions: Weekly ALS Patient Management Conference provides mechanism for 1) per-patient diagnosis, treatment plan review, 2) patient clinic review, 3) patient disease milestone review and 4) patient co-morbidity review.

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P158 INTEGRATION OF HOME CARE INTO DISEASE-SPECIFIC CERTIFICATION BY HOME CARE RN COORDINATOR AT CAROLINAS NEUROMUSCULAR/ALS-MDA CENTER: DEVELOPMENT OF BENCHMARKS FOR IMPROVING PATIENT CARE

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Keywords: home care, disease-specific certification, benchmarking

Background: Home care nurse visits are employed to provide care as well as monitor care given at home to patients with ALS. Home care may be divided by who provides the care: caregiver, non-hospice-care or hospice-care (1). The goal of the Carolinas Neuromuscular ALS-MDA Center RN Home Care Coordinator is to facilitate guideline-based care in the home setting for patients with ALS and in nursing homes when patients are cared for in that setting.

Objective: To identify the elements of guideline-based care monitored in the Carolinas Neuromuscular ALS-MDA Center RN Home Care program.

Methods: Home visits occurred per protocol by the Home RN Review of 418 home visits (48% M; 52% F) from 2010–2011 at weekly ALS Patient Review conference to identify criteria for home visits and evaluate adherence to guideline-based care as part of an on-going program to develop performance measures for disease-specific certification of care for patients with ALS

Results: Home visits occurred following gastrostomy, tracheostomy, recent hospitalization or emergency department visit to assess medication and equipment compliance as well as safety review to prevent falls at home. The mean time to first home visit was 8.6 ± 9.4 (standard deviation) months following first clinic visit. Patients received 1–5 visits (mean

3.1 ± 2.8) Patients had lower mean ALSFRS-R scores (18.2 ± 20.3).Some patients who initiated non-invasive ventilation were seen following respiratory therapy home visits when compliance issues were identified. Home visits included monitoring wound care, assistive speech technology, and initiation of home hospice and ALS care education for patients in nursing homes.

Conclusions: Home visits occurred within one year following the first clinic visit. Home visits identifying deviations from guideline-based care were discussed at the Weekly ALS Patient Care Conference to develop potential interventions. Rates of deviation form guideline-based care provide benchmarks for future interventions to improve care at home.

Discussion: Home visits provide a means to enhance compliance to guideline-based care between clinic visits (2, 3).

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P159 CURRENT STATUS OF COORDINATORS FOR PATIENTS WITH INTRACTABLE DISEASES IN JAPAN

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Keywords: intractable disease, co-ordinator

Background: Co-ordinators for patients with intractable diseases (Co) are assigned to manage and supervise circumstance for each patient in most of the prefectures in Japan. They have been acting with multiple health professionals and have been supposed to seek further facilities not only for respite care, but also for long-term services. In addition, Co is involved in a wide range of activities for providing information, running a workshop for health professionals, and doing research. However, there are considerable differences in work content, professional situation and condition for employment among prefectures. Such background may have made Co feel uneasy to maintain and improve expertise of their work.

Objective: To disclose current status of Co including their tasks, skills, intelligence, and behavioral pattern and propose what is needed for Co in Japan.

Methods: Subjects were Co or substitutes in charge of intractable diseases in 47 prefectural governments. We sent a questionnaire for professional situation, cooperation with other health professionals, tasks for education, utilization of a guidebook made by Co, achievement of the activity, work contents and condition for employment.

Results: Fifty five Co were assigned in 39 prefectures (83% of Japanese prefectures) in February 2012. The collection rate was 82% retrieved from Co and 74% from prefectures. Co's professional backgrounds were mostly nurses (39 were qualified nurses, which included public health nurses, and 6 were medical social workers). Condition for employments as Co was full-time in 29 and part-time in 16. Mean Co tenure was 47.5 months. Fourteen (30%) had been working as Co less than 17 months. Thirty one (68%) were assigned as only one Co in each prefecture. Twenty nine (64%) had reported no opportunity of training as a co-ordinator before becoming Co. After becoming it, 42 (93%) had participated in some workshops, and 37 (82%) attend to scientific meetings in a year. Their self-job-evaluations were relatively good about consultation and cooperation with other health professionals, although they estimated lower on finding facilities for long-term service, respite care, or disaster contingency planning. Co and prefectural governments had a similar view on workloads under very low budgets.

Conclusion: Co in Japan have limited opportunity for training and quite a few have a relatively short tenure. Co's activities of finding facilities for long term and respite services are found to be still insufficient in Japan.

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P160 GUIDELINES ON NEUROLOGICAL PALLIATIVE CARE

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Keywords: guidelines, palliative care, neurology

Background: The European Association for Palliative Care and the European Federation of Neurological Societies have collaborated to produce guidelines on the palliative care of neurological disease, including ALS/MND. A taskforce of the EAPC has developed these guidelines and the authors are presenting the results on behalf of taskforce.

Objectives: These guidelines are aimed at encouraging collaborative working between neurology and specialist palliative care services to improve the care of people with ALS/MND

Methods: The guidelines have been developed from a literature search of relevant articles and using a group of experienced clinicians and researchers in both palliative care and neurology to determine areas for the guidelines agree relevant supporting evidence for recommendations and grade the evidence using the GRADE system.

Results: The following areas of recommendations were made and will be presented with supporting evidence: Palliative care should be considered early in the disease trajectory; assessment of care should be by a multidisciplinary

team; patients should have access to a palliative care assessment; communication with patients and families should be open, including setting of goals and therapy options; early advance care planning is recommended; recognition of deterioration over the last weeks and months is relevant for appropriate management; proactive assessment of physical and psycho-social issues reduces the need for crisis intervention; the principles of symptom management should be applied to neurology; diagnosis of the dying phase allows appropriate management and standardised tools, such as the Liverpool care of the dying patients may be helpful; carers needs should be assessed regularly and support provided before and after death; professionals should receive support and supervision; palliative care principles should be provided in the training and education of neurologists; the understanding and management of neurological symptoms should be provided for specialist palliative care professionals.

Discussion: The development of the guidelines has allowed recommendations on practice for the care of people with neurological disease, including ALS/MND. These will be disseminated to both neurology and palliative care clinicians with the aim of improving the care and quality of life of these patients and their families.

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P161 PRELIMINARY EVALUATION OF END-OF-LIFE CARE FOR PATIENTS SUFFERING FROM MOTOR NEURON DISEASE IN DENMARK

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Keywords: palliative and end-of-life care, place of death, support to relatives

Background: In Denmark, 130 patients are diagnosed with MND annually. Of these, 90–95% are referred to the Danish Rehabilitation Centre for Neuromuscular Diseases (RCfM). RCfM is a specialized centre of excellence for Neuromuscular Disorders. RCfM functions as a key player in the co-ordination of a joint care effort among patients, hospitals and local professionals, and assist affected families with guidance throughout the entire course of the disease. In spite of the specialized care, there is still very little knowledge about the terminal phase and end-of-life care for MND patients in Denmark.

Objectives: To examine the following during the terminal phase: Where do MND patients die? Was the time of death expected by the family and relatives? How many patients use PEG tube, non invasive ventilation (NIV) or invasive ventilation (IV)? Is morphine used? How satisfied are the relatives with the support offered?

Methods: Information was gathered through telephone interviews with the closest relatives or the health professionals, who answered questions about the death from a structured questionnaire.

Results: During the period 1 February 2011–31 January 2012, 120 MND patients died at a mean age of 68 years (range 43–97 years). 65% of them were married, 29% were single, and 6% was unknown. 53% of the replies came from relatives, 41% from health professionals and 6% were not available. 38% died in their own home, 30% at a hospital, 17% in a nursing home, 7% at a hospice, and the place of death for 10% was unknown. 49% died in a desired place, 8% in a non-desired place and for the remaining 43% the answer was not available. From the point of view of the relatives, 54% died at the expected time, 28% at an unexpected time and for 12% the answer was not available. At the time of death, 60% had a PEG tube and in terms of respiratory care, 16% died using NIV whereas 13% were on IV. During the terminal phase, morphine was prescribed for palliative treatment in 50% of cases.

Discussion and conclusion: The terminal phase is difficult to handle without professional help and guidance, and it is crucial to have a well-structured care plan. Insecurity and anxiety are common feelings, and even if the patient wants to die at home, he/she only succeeds in some 50% of the cases. In Denmark only few (7%) are in a hospice during the terminal phase. According to their relatives, approximately one third of the patients died unexpectedly.

Among the Danish MND population, two thirds had a PEG tube and almost one third uses respiratory aids such as NIV/IV. Data from the study of satisfaction with end-of-life care among relatives will be presented.

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P162 BREAKING BAD NEWS IN ALS: THE NEED FOR MEDICAL EDUCATION

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Keywords: medical education, breaking bad news, diagnosis delivery

Background: The manner in which physicians break bad news has been identified as an area of discontent for patients with amyotrophic lateral sclerosis (ALS).(1,2) The American Academy of Neurology's Practice Parameter for care of the ALS Patient identified the following research recommendation: "include disclosure techniques in medical curricula and to evaluate their implementation."

Objectives: To explore the need for medical education as it pertains to residents' ability to break bad news when communicating the diagnosis of ALS.

Methods: Residents were videotaped and graded by two ALS neurologists as they broke the bad news of an ALS diagnosis to a patient actor during an objective structured clinical examination (OSCE). OSCEs have been shown to be successful in measuring communication skill. (3) Residents completed a self-assessment checklist before and after they watched their own videotaped performance.

Formation of the checklist was influenced by the existing American Academy of Neurology and European Federation of Neurological Societies guidelines (4,5) and the "SPIKES" protocol(6). The checklist comprised the following subgroups: action, communication, empathy. Ethics approval was acquired through the Health Research Ethics Board at the University of Alberta Hospital. Informed consent was obtained from all participating residents.

Results: Twenty-two residents from the Universities of Alberta, Calgary and Saskatchewan participated in the study.

Residents are defined as physicians in training in a five year post-graduate accredited program in neurology. The examiners found that resident performance on the OSCE was often suboptimal, particularly in the areas of communication and empathy. The mean scores for the subgroups were 62% and 65% respectively. The failure rate for the station was also high; approximately one quarter of residents were unsuccessful. There was good correlation between the two examiners' scores for the grand total score, and the subgroup totals for action and communication. Residents' scores (64%) more closely resembled the examiners' after watching their own videotaped performance for grand total of all subgroup gradings.

Discussion: To our knowledge, this is the first study to evaluate use of a videotaped OSCE as a medical education tool in the specific scenario of delivering the difficult diagnosis of ALS. The examiners' gradings of the residents identified areas in which performance in breaking bad news can be improved. The fact that residents' self-assessment was improved after watching their videotaped performance suggests that this may be a helpful addition to neurological training programs.

Conclusion: There is a need for resident education in breaking bad news when communicating the diagnosis of ALS. The exercise of watching their own videotaped performance appeared to be effective in facilitating more accurate self-assessment by the residents.

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P163 WHAT SHOULD WE SAY AND HOW SHOULD WE SAY IT? - EVIDENCE-BASED COMMUNICATION SKILLS IN MND/ALS

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Keywords: communication, evidence, guidelines

Background: ALS/MND patients and families deserve clinicians with good communication skills. Research on what to say and how to say it is sparse. The Practice Parameter for ALS from the American Academy of Neurology (1, 2) has suggested further research in the following areas related to communication:

- patient/caregiver perceptions of how the diagnosis was disclosed
- effects of disclosure technique on future coping
- the impact of cultural and social factors on disclosure technique.

Objectives: In early 2012, the UK's National Institute for Health and Clinical Excellence (NICE) produced evidence-based recommendations on how to optimise patients' experience of healthcare systems (3). As well as reviewing existing research from different parts of the world, including North America, NICE performed a patient experience scoping study which came up with evidence of relevance to optimal communication. The objective of this paper is to see whether the evidence for the NICE guidelines informs the Practice Parameter research questions.

Methods: The NICE recommendations were studied to see if they shed further light on the Practice Parameter research questions relating to communication issues.

Results: Of the 68 guidelines, 58 (85%) were related to some component of communication. This shows the importance of good communication to patient and family experience.

The following themes were of particular relevance to the questions posed by the Practice Parameter and are examined in more detail in this paper:

- respect and empathy from clinicians
- shared non-judgmental decision-making
- negotiating individualised patient and family care according to their particular health and cultural beliefs

Discussion: While ALS is not amenable to cure, aspects of communication are even more crucial to how patients and their families cope with the disease. The remit and design of the NICE review was to produce guidelines which were generic to all disease states and settings. Whilst it is possible that the nature of ALS and its effects on patients mean that generic guidance is not always relevant, the recommendations were specifically formulated to be applicable to any diagnosis carrying a high disease burden.

Conclusion: Evaluating different aspects of communication in ALS through research remains a challenge, especially in a disease which can affect patients' own communication abilities. However, increasing evidence is combined with previous expert opinion in guiding clinicians in this important area. The other on-going challenge, through education, constant updating and practice, is to make such practice widespread.

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P164 THE ROLE OF DESIRED AND ANTICIPATED HOPES IN COPING WITH THE EFFECTS OF ALS/MND

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Keywords: hope, coping, narratives

Background: Hope is regarded as a fundamental element contributing to enhancement of quality of life for people who are dying (1). Studies have explored hope in ALS/MND (2) but limitations of size or design contribute to ambiguity regarding the nature of hope in ALS/MND.

Objectives: To explore the personal experience of living with ALS/MND as documented in personal illness narratives, written by people diagnosed with the illness and examine the phenomenon of hope as it is experienced and displayed.

Methods: We have previously reported the processes used for locating published and unpublished personal illness narratives about life with ALS/MND. The 161 narratives identified were subject to content and thematic analysis. Data management was aided by Nvivo 7 software.

Results: Narrators revealed the presence of two main types of hope, Desired Hope and Anticipated Hope. The first reflects an 'ideal world' situation with often unrealistic expectations, whereas Anticipated Hope involves 'real world' circumstances with a greater possibility of achievement. People with ALS/MND balance these hopes as a means of coping with their illness. There is also evidence of activities and interactions which sustain hope and those which deplete it. Some narrators demonstrated a third type, Pervading Hope, primarily focused on a cure.

Conclusions: This study has demonstrated the importance of balancing different types of hope in coping with the effects of ALS/MND. There are implications for health professionals who must recognise the benefits to patients in having both Desired and Anticipated Hope. Hope should not be dismissed based on a subjective opinion which associates hope in terminal illness with a cure and as such regards hope in ALS/MND as unrealistic. Hope should be regarded as an important resource for coping with ALS/MND.

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P165 USE OF THE ALS SPECIFIC QUALITY OF LIFE INSTRUMENT-REVISED (ALSSQOL-R) TO EVALUATE QUALITY OF LIFE IN INDIVIDUALS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS): A MULTINATIONAL STUDY

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Keywords: quality of life, multinational, normative data

Background: The ALS-Specific Quality of Life Instrument-Revised (ALSSQOL-R) has been validated in English-speaking patients at 12 American ALS clinics. The QOL experience of individuals in other countries has not been explored with this instrument.

Objectives: 1) To determine whether ALSSQOL-R scores differ in patients with ALS in other countries from those in the United States; 2) To examine the relationship of QOL to function in several countries.

Methods: Three Canadian, 1 Swiss and 1 Israeli ALS Center recruited individuals with definite, probable, probable laboratory-supported, or possible ALS. The ALSSQOL-R was administered to subjects in their native language. The range of possible scores was 0 (worst QOL) to 10 (best QOL). Function was assessed using the ALS Functional Rating Scale-Revised (ALSSFRS-R). Pearson correlations and one-way analysis of variance (ANOVA) were calculated. $P < 0.05$ was taken as significant. The study was approved by the Institutional Review Board or Ethics Committee of each institution.

Results: 385 American, 52 Canadian, 34 Swiss, and 19 Israeli subjects were recruited. Mean ages in years were 60.8 (US), 60.9 (Canada), 60.5 (Switzerland), and 58.26 (Israel). Duration of disease in months ranged from 39.9 (US) to 45.8 (Canada), 47.6 (Switzerland), and 34.7 (Israel). There were no significant differences in disease duration or age in the samples. The US mean ALSFRSR score (33.16, SD 7.86) was not significantly different from the Canadian (31.52, SD 8.60) or Swiss (35.47, SD 7.96) samples but was significantly higher than the Israeli sample (26.79, SD 10.83). The mean ALSSQOL-R of the American sample (6.96, SD 1.27) was significantly higher than the Canadian (5.92, SD 1.10), Swiss (5.07, SD 1.0) and Israeli (5.74, SD 0.98) samples ($p < 0.001$).

The American sample demonstrated a positive correlation of QOL and function ($r = 0.191$, $p < 0.001$). Neither the Canadian, Swiss or Israeli samples demonstrated significant correlations between QOL and function.

Discussion and conclusions: Self-reported QOL in patients with ALS as measured by the ALSSQOL-R and the relationships of QOL to function differed in the 4 countries studied. The ALSSQOL-R was developed and normalized using residents of the United States, and it is unknown whether the construct of QOL, the factors which account for it, and the items within those factors are similar among ALS patients from different countries and cultures. Caution is needed when measuring QOL in groups which differ from those engaged to establish normal values for the instrument being used.

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P166 PATIENT ASSESSMENT OF CLINICALLY MEANINGFUL CHANGES: INSTRUMENT DEVELOPMENT

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Keywords: assessment, clinically meaningful changes, instrument development

Background: While analyses of clinical trial data may demonstrate statistically significant differences, it is not known whether such differences are meaningful to study participants or their caregivers. This study was designed to address this question by developing a methodology to evaluate clinically meaningful changes among participants.

Objectives: To identify the extent to which measures of perceived change and their impact on the patient are related to changes on the ALSFRS-R over a 6-month interval.

Method: Patients with definite or probable ALS, who were able to speak on the telephone, and a family caregiver were enrolled at 5 Network sites and were interviewed at baseline, 3 and 6 months. Measures included the ALSFRS-R

with additional ratings addressing each of the 4 subscale domains: perceived amount of change (10-point scale), direction of change (positive or negative), and its impact (10-point scale) as perceived by the patient. In addition, a 4-item scale of Clinical Global Improvement addressing physical, emotional, social and overall life quality was rated (7-point scale). We report selected findings describing change over 6 months.

Results: 60 patients completed the 6-month study. Mean age was 60, 43% were female, 88% completed some college, and 30% were working part or full time. Mean baseline ALSFRS-R was 33 (SD = 7, range = 9–47).

Mean change over six months on the ALSFRS-R was −5.0, and for the 4 subscales as follows: Bulbar = −0.78, Fine Motor = −1.60, Gross Motor = −1.80 and Respiratory = −0.65. Each of the Change and Impact ratings correlated significantly ($p < 0.05$) with the corresponding ALSFRS-R subscale change scores with the exception of the Respiratory domain which showed the least change in ALSFRS-R subscale score. A 1-point decrease on the ALSFRS-R subscales was associated with increased Impact ratings as follows: Bulbar = 2.9, Fine Motor = 3.8, Gross Motor = 4.5 and Respiratory = 1.9. Backwards stepwise regressions were conducted separately for the 4 ALSFRS domains with the Impact rating as the dependent variable. Independent variables included: change in ALSFRS-R subscale, the patient's rating of Change, and 4 CGI scales. For each domain, the patient's Change rating was the only variable that accounted for a significant portion variance (all p values < 0.001), with the exception of Respiratory, where the CGI-physical scale was also significant ($p < 0.05$).

Discussion: These preliminary analyses suggest that patients' ratings of perceived change and the impact of that change, as it pertains to specific areas affected by ALS, may contribute to our understanding of what is clinically meaningful. Ratings that assess broader life areas were not successful in contributing to this understanding. Patients enrolled in this interview study were able to communicate by telephone and thus are not representative of the total ALS population.

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P167 PERCEPTION OF ALS PATIENTS, DOCTORS AND CAREGIVERS REGARDING CLINICAL MANAGEMENT

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Keywords: quality of life, perception, decisions

Background: Noninvasive positive pressure ventilation (NIPPV) increases survival and improves patient's quality of life. Invasive mechanical ventilation (IMV) can prolong survival in ALS. Percutaneous endoscopic gastrostomy (PEG) improves nutrition but also no improvement in QOL is known. The use of these procedures has often been controversial.

Objectives: To evaluate the point of view of ALS patients, carers and physicians about the use of NIPPV, IMV and PEG.

Methods: 30 ALS patients, 30 caregivers and 30 physicians from four different hospitals were examined with a cross-sectional survey. The survey consists of three groups of questions related to the acceptance or refusal the procedures in different levels.

Results: Patients: mean age: 56.5; 76% were males; mean ALSFRS 31.6; duration of disease 568.6 days (sd 354.4); FVC 72.6. 90% of ALS patients have a carer. All doctors agree to use NIPPV in all patients and situations and 96% of them to use the PEG for nutrition. With regard to NIPPV, 50% of patients agree with the opinion of physicians and caregivers and 26.6% agree regarding PEG. IMV was the most controversial procedure, only in 20% of patients accepted IMV like the caregivers and doctors. Physicians showed very different opinions: from acceptance to the rejection of this procedure.

Conclusion: The perception of the patients, caregivers and doctors in relation to PEG, IMV and NIPPV is very different. Decisions should be taken by all together.

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P168 FAMILY CARER PERSPECTIVES OF HOSPITAL CARE FOLLOWING A DIAGNOSIS OF MND: A SECONDARY ANALYSIS

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Keywords: carer experiences, hospital care, qualitative research

Background: People with MND can experience a number of hospital admissions throughout the course of their illness. These may be planned admissions for specific interventions or emergency hospitalisation as a result of the development of concomitant illness or advancement of their condition.

Objectives: The aim of this study was to explore experiences of hospitalisation following a diagnosis of MND from the perspective of family carers of people diagnosed with the illness.

Methods: The study reports on a secondary analysis of pre-existing data from two previously published qualitative studies conducted separately by the authors in Northwest England. During discussions between the primary researchers, the extent to which experience of hospitalisation was present in the data became apparent. Significant similarities were evident in the datasets which made it viable to pool data and undertake a new and distinctive analysis; this topic was not the primary focus of the previous studies. Only interview transcripts that featured experiences of hospitalisation were included in the secondary analysis; the pooled sample therefore consisted of 10/11 bereaved carers from study 1 and 10/10 bereaved carers together with 3/18 current carers from study 2. The latter study also involved interviews with people with MND, but these data were not included in the secondary analysis as the focus was on carer perspectives.

Results: A number of issues emerged from the analysis. There were distinct differences in standards of care between planned and unplanned admissions and within specialist and general wards. Basic care was lacking at times as was the understanding of how to care for someone with MND. Relatives became educators to overcome deficits in professionals' knowledge. Communication between staff and some patients/relatives was unsatisfactory with patient

preferences disregarded at times. The final memories of loved ones were affected by relatives' experiences of hospital care at that time.

Conclusions: This study has, for the first time, provided insight into the perspectives of carers of people with MND specifically regarding hospital care received subsequent to a diagnosis of MND. There are distinct implications for the delivery of hospital based care, whether it is planned or unplanned.

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P169 ILLNESS BURDEN IN PATIENTS WITH ALS AND THEIR CAREGIVERS: A WEB-BASED SURVEY

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Keywords: quality of life, caregiver burden, patients with ALS

Background: There are compounds in development for the treatment of amyotrophic lateral sclerosis (ALS). In addition to proving a beneficial effect on survival and function, research is needed to quantify economic losses, caregiver burden, and quality of life impact associated with ALS at different stages of the disease. We sought to investigate lost productivity, caregiver burden, and quality of life among patients with ALS (PALS) and caregivers (CALS). This survey is designed to explore relationships between PALS disease severity, functional impairment milestones and the socioeconomic burden on CALS.

Methods: PALS and CALS who participate in PatientsLikeMe, an online data-sharing platform for people with serious illnesses, were invited to take an online survey. Inclusion criteria for participation in the survey were: US residence, activity on PatientsLikeMe in the past 120 days, a self-reported diagnosis of ALS or identification as a CALS who serves as the main provider of help and care to a person with ALS; CALS may be a spouse, parent, child, other relative, friend, or professional caregiver. Both PALS and CALS completed information on demographics, the Health and Work Performance questionnaire (HPQ), and the EuroQoL EQ5D-3L. Additionally, PALS completed the ALSFRS-EX (Extension items) and ALS Assessment Questionnaire (ALSAQ-5). CALS completed the Caregiver Burden Inventory (CBI).

Results: Recruitment is ongoing throughout 2012 but an interim analysis was performed with 31 matched pairs. Both groups were similar in age (mean age, 57 years) with CALS slightly more likely to be female. Mean ALSFRS-R score in PALS was 25.6, although the range of scores was wide. As expected, PALS reported a worse quality of life on the EQ5D-3L VAS than their caregivers (61.3 vs 77.9; $P = 0.002$), though results showed a great deal of variability. More CALS were working for pay than PALS (53% vs 16%; $P < 0.001$). PALS primarily contributed via housework; CALS shouldered a variety of responsibilities in addition to caregiving, including employment, childcare, and housework. Most CALS (87%) reported having had to change work in some way owing to their PALS' illness, with many using vacation days (54%), reduced working hours (46%), or resigning from their job (33%). In terms of caregiver burden, there was a relationship between the negative aspects of caregiving (e.g. burden) and ALSFRS-R (R-squared = 0.338, $P < 0.001$); 52% of CALS were above the threshold for the CBI's cut off of 36 for 'caregiver burnout' warning.

Discussion and conclusions: Preliminary results suggest a high level of burden for CALS across a number of domains (e.g., socioeconomic impairment, personal responsibilities, anxiety, depression, and pain). This project aims to describe the impact that ALS can have on PALS, CALS, and society more broadly, with a secondary goal of identifying specific inflection points in the disease that might trigger significant PALS and CALS burden.

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P170 LONGITUDINAL ASSESSMENT OF CAREGIVERS OF PATIENTS WITH MOTOR NEURON DISEASE

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Keywords: caregiving, quality of life, assessments

Background: As amyotrophic lateral sclerosis (ALS) and primary lateral sclerosis (PLS) progress, caregivers provide increasing physical and emotional supports to patients. The impact over time on caregivers is not clear.

Objectives: To understand the evolution during the ALS/PLS disease trajectory of caregivers' perceptions of their ability to assist patients, and on the caregivers' supports, health, and quality of life (QOL).

Methods: This was a prospective, IRB-approved study in which a questionnaire was sent to caregivers of patients with ALS or PLS prior to each outpatient clinic appointment, usually once every 3 months. Caregivers were asked to assess their level of concern (worry, anxiety, unease) with providing each of 17 caregiving activities. Caregivers also were asked to identify those activities which were supportive to them, and to answer questions about their health and quality of life (QOL).

Results: 239 caregivers were enrolled. The mean age was 58.8 years, 67% were women, and 78.6% were spouses. Factor analysis resulted in two scales which accounted for 43.19% and 13.01% percent of the variance in level of concern with providing caregiving activities. Scale 1 included 9 activities of daily living (ADL) such as assistance with medications, feeding, and mobility; chronbach's alpha = 0.91. Scale 2 included 8 psychosocial activities such as emotional/spiritual support, encouraging the patient to participate in activities, and assisting with insurance issues and community programs; chronbach's alpha = 0.87. Three assessments over 6–8 months were completed by109 caregivers for longitudinal analysis. The mean age was 58.8 years, 66% were women and 78.9% were spouses. Repeated measures analyses of variance found significant increases in concerns over time for both the ADL and Psychosocial Task subscales ($p < 0.004$), with significant effects for the time by gender interaction for both scales ($p < 0.02$), in which the concerns of the women increased and approached the higher levels of the men. There was a significant ($F(1,38) = 5.55$, $p < 0.02$) gender effect for the number of supportive activities engaged in, with women greater than men at each point, although this diminished over time as women gave up some of these activities. There were no significant changes over time in QOL and health measures, but women had somewhat higher

QOL scores at all points, and women's reports of depression began to increase relative to men's at the third time point.

Discussion and conclusions: Caregivers became more concerned about their ability to provide caregiving activities over time, with a decrease of the initial advantage of women over men. Women engaged in more support activities than did men, but this decreased over time. Caregiving in motor neuron disease appears to be a dynamic process. Ongoing monitoring and re-assessment of caregivers is necessary to identify appropriate interventions throughout the disease trajectory.

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P171 PATIENTS' AND CAREGIVERS EXPERIENCE OF MECHANICAL IN-EXSUFFLATION

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Keywords: qualitative research, cough, respiratory therapy

Background: The progression of muscle weakness in amyotrophic lateral sclerosis (ALS) leads to respiratory complications with airway secretion encumberment from ineffective coughing. Mechanical in-exsufflation (MI-E) can be applied to help eliminate secretion for patients with impaired cough. The introduction of technology from the hospital setting into the home leads to increasingly specialized and complex challenges for patients, informal caregivers and community healthcare professionals. How does the use of medical technology influence on the interaction between different actors in the home arena? And how does technology influence patients' experiences of their illness? The complexity of managing a severe disease, such as ALS, will challenge healthcare professionals in offering an optimal treatment for these patients.

Objective: To examine patients with ALS and their caregivers' experiences when using the MI-E to enhance coughing. The study focused on user confidence, and what influence the MI-E had on relationships between the actors, as well as on the patients´ illness perception.

Methods: We did a qualitative study, using semi-structured in-depth interviews with patients with ALS and their caregivers. Eleven interviews were performed with five patients and six caregivers. The material was analyzed using systematic text condensation. Actor-network theory (ANT) was used as a framework to understand the concept of interactions in heterogeneous network when technology is used in medical treatment.

Results: We organized the findings into three themes; 1) Trust and confidence, 2) competency and 3) usage patterns and effect. The findings showed that confidence and user competency were essential aspects for both patients and caregivers in order to be comfortable using the MI-E. The relationships between patient and caregiver affected the experience of using the MI-E. Both patients and caregivers reported that the MI-E had positive and negative impact on their daily life. It was a challenge to achieve good transference of skills in operating the MI-E to every caregiver when there were many caregivers involved. The use of the MI-E differed due to various reasons beyond the effect on eliminating secretion. Using the MI-E, at times, made the disease progression more apparent for the patient.

Discussion and conclusions: These findings show that the complexity of caring increases when a technological device is introduced into the patient's home. By applying a sociological perspective, the diversity in the interaction between humans and technology, beyond the medical intent of the technical device, can be displayed. Healthcare professionals at all levels need to take into account social and individual aspects when introducing the MI-E to patients with ALS. Further research is needed to improve the knowledge of how interactions in a network impact on patients and caregivers' perception of purpose and confidence when medical technology is introduced.

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P172 PHYSIOTHERAPY AND EXERCISE TO PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS)

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Keywords: physiotherapy, exercise therapy, clinical guideline

Background: Physiotherapists in Denmark have an important role in guidance regarding respiration, exercise and assistive devices to patients with amyotrophic lateral sclerosis (ALS). There is no current consensus among physiotherapists in Denmark about which treatments to use and when to use them. In the literature very few papers describe treatment given by physiotherapists to patients with ALS.

The aim of this study is to investigate which treatments are used, the evidence for these treatments and whether it is possible to create consensus on a clinical guideline in Denmark built on clinical experience and evidence.

The study started on 1 January 2012 with expected completion in December 2012.

Objectives: 13 hospitals in Denmark diagnose and treat patients with ALS. They all have an ALS-team with at least one physiotherapist. All 13 teams are included in this study. The populations in the area of the 13 hospitals are comparable.

Methods: The study consists of three steps:

Step one: 16 team-physiotherapists have received and answered a semi-structured questionnaire about their treatment strategies for patients with ALS.
Step two: A systematic search for literature in the databases Medline, Cinahl, Cochrane and Pedro was made. Publications of evidence level Ia and Ib were read systematically and critically.
Step three: All team-physiotherapists were invited to a workshop with focus on discussion of evidence and treatment strategies.

Results: The aim of this study is to reach consensus about the physiotherapy treatments for patients with ALS in the hospitals in Denmark and to publish a national clinical guideline.

Step one: 16 out of 19 physiotherapists answered the questionnaire. All physiotherapists give instructions to patients in exercises and respiratory aid and support, but the instructions were different in each of the 13 hospitals.

Step two: 7 papers about exercises and 14 papers about respiratory support and exercise were included for critical reading. There was good evidence for non-invasive ventilation (NIV) but no guidelines for exercises were found.
Step three: 12 hospitals were represented by physiotherapists at the workshop. Agreement was reached on a clinical guideline.

Knowledge from clinical practice and evidence from the literature will result in a national clinical guideline. The guideline will include optimal time for respiratory aid and support, guidance on respiratory support, training instructions and cough-support.

Discussion and conclusion: We have found good clinical practice points for training in our literature study but no strong evidence. Several studies recommend NIV as a respiratory support also in the early stage of ALS. In the future, physiotherapists in Denmark will focus on earlier use of NIV, regular tests of lung function and recommendations on exercise.

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P173 AQUATIC PHYSICAL THERAPY PROGRAM FOR AMYOTROPHIC LATERAL SCLEROSIS (ALS) PATIENTS

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Keywords: aquatic physical therapy, function, pain

Background: Despite a recognized need for a physical therapy (PT) program to care for people with motor neuron disease (MND), access to PT is often delayed. The aim of aquatic PT in patients with ALS is to maintain the patients' health related to functionality, and quality of life (QoL) as well as minimizing their fatigue.

Objectives: To verify the beneficial effects of an aquatic PT program for ALS patients as applies to increased strength and function; as well as minimizing pain and fatigue, and overall QoL improvements.

Method: A prospective study of patients with sporadic ALS ($n = 4$) was conducted. Patients were submitted to a 12 week program consisting of 24 sessions of aquatic PT in a heated 33°C pool, twice a week, for 45 minutes each session. Standardized assessments were used to evaluate patients before and after the 12 week treatment period by the following scales: ALSFRS-R, Manual Measurement Test for strength, Fatigue Severity Scale and Visual Analogic scale for pain.

Results: Evaluation of the patient questionnaires revealed that muscle groups were able to maintain their strength, as well as most ALSFRS-R items (33.5 ± 2.5 before and 30.25 ± 5.1 after), and QoL. All patients stated that they had decreases in both pain and fatigue.

Conclusion: Recognizing ALS as a progressive and incurable disease, a program of aquatic PT designed specifically for this group of patients produced exemplary results. Aquatic PT both delayed the evolution of the disease and helped maintain muscle strength, physical function and QoL as well as decreased pain and fatigue.

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P174 A SURVEY OF HEALTH CARE PROFESSIONALS' VIEWS ON EXERCISE AS A TREATMENT FOR PERSONS DIAGNOSED WITH AMYOTROPHIC LATERAL SCLEROSIS

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Keywords: survey, exercise, therapy

Background: Few published studies exist that examine the effects of exercise on persons with amyotrophic lateral sclerosis (ALS). Available studies have not shown adverse effects of exercise, but they also have not shown conclusive long-term benefits. (1,2) As there is no standard of care, health care providers must decide on their own whether exercise should be prescribed to this population.

Objectives: The purpose of this study is to clarify what exercises, if any, health care professionals in the United States (US) are prescribing to persons diagnosed with ALS and determine what research and experience-based views professionals working regularly with persons diagnosed with ALS hold.

Methods: A survey of 12 questions regarding ALS and exercise and 3 questions requesting demographic information was developed. A link to this survey was sent to ALS Association Chapters and Muscular Dystrophy Association ALS Clinics in the continental US. A letter sent with the link asked all physical therapists, occupational therapists, neurologists and physiatrists associated with the center to fill out the survey. Survey Monkey collected data.

Results: After incomplete responses were omitted, 109 responses were used to compute results. Thirty-nine percent of respondents said they only recommend active exercise to persons with ALS if exercise was part of the person's lifestyle pre-diagnosis. Thirty-six percent of respondents said they recommend active exercise to all persons with ALS, but 92% clarified this statement with comments such as "depending on fatigue level". The other 24.7% of respondents do not recommend active exercise to any persons diagnosed with ALS. Only 20% of respondents think exercise maintains strength while less than 5% think exercise improves strength in persons with ALS. Contrary to prior published research examining exercise and ALS, many respondents reported that, in their experience, exercise by persons with ALS could have adverse effects, such as falls, fatigue and rapid strength loss. Only 32% of respondents listed previously published literature when asked about articles they refer to regarding ALS and exercise.

Discussion: There is some variation in exercise prescription among healthcare professionals who have experience with persons diagnosed with ALS. Many professionals believe that exercise prescription should be done on a case-by-case basis for persons with ALS as both positive and

negative effects can result. Experience has not shown conclusively that exercise is beneficial for maintaining or increasing strength in persons with ALS.

Conclusion: Further research is needed to standardize prescription of exercise in persons with ALS. Development of an algorithm, taking variables such as lifestyle and fatigue into consideration, rather than a general prescription may be most effective.

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P175 CLINICAL FEATURES OF FATIGUE IN PATIENTS WITH MND

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Keywords: fatigue, sleepiness, psychological distress

Background: Fatigue is a persistent and disabling symptom for MND patients. Research studies evaluating the relationship of fatigue and other disease factors, including depression and functional status, have provided conflicting information.

Objective: To clarify the relationship between fatigue and other features of MND in a large cross-sectional study using a disease-specific measurement tool for fatigue in MND.

Method : A pack containing the Neurological Fatigue Index for Motor Neurone Disease (NFI-MND) summary scale, the Hospital Anxiety and Depression Scale (HADS), the Amyotrophic Lateral Sclerosis Functional Rating Scale – revised (ALSFRS-R), the Epworth Sleepiness Scale (ESS) and questions regarding sleep, disease presentation and other demographic factors, was mailed to patients at five neurology care centres in the UK.

Results: Data from 298 respondents (54.7% response) were analysed. Fatigue was positively correlated with daytime sleep ($r = 0.13$, $p < 0.0001$) and sleepiness ($r = 0.40$, $p < 0.0001$). There was a strong relationship between fatigue and psychological distress (anxiety and depression) ($r = 0.57$, $p < 0.0001$). Fatigue was not correlated with age or disease duration. Levels of fatigue were significantly higher if patients experienced respiratory symptoms ($t = -3.49$ $p = 0.001$). Patients with limb symptoms experienced higher levels of fatigue than those with bulbar presentation only ($t = -6.29$, $p < 0.0001$). Fatigue correlated mildly with functional status ($r = -0.18$, $p = 0.031$). Patients that slept for 30 minutes during the day and seven hours at night reported the lowest levels of fatigue.

Conclusion: Relationships were apparent between fatigue, daytime sleep, sleepiness, psychological distress and functional status. Knowledge of these relationships may be used to inform further work to develop interventions for patients suffering from fatigue.

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P176 PAIN IN MOTOR NEURON DISEASE (MND) – A PILOT STUDY

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Keywords: symptom, pain, Brief Pain Index – Short Form

Background: Pain can occur in almost 70% of patients with MND and is often a frequent symptom in the later stages of the disease. Although effective clinical management of MND requires different aspects of pain to be identified and possibly treated, the character of the pain is insufficiently studied.

Objectives: The aim of this pilot study was to describe the character of pain in MND in a limited Swedish population, specifically the location and severity of pain, the interference in daily life, and possible sex differences regarding the experience of pain.

Methods: The study was conducted at the Department of Neurology, MND-unit, Uppsala University Hospital, Uppsala, Sweden. Data were collected from personal files through the Brief Pain Inventory- Short Form. Thirty-six participants (mean age 61.5 years, 56 % men) fulfilled the requirements: the average time from diagnose was 2 years.

Results: 72% of the patients experienced pain, primarily in the legs (23%) and shoulders (23%). Pain intensity ranged from $Md = 0$ (minimum pain) to $Md = 7$ (worst pain), with an average pain sensation of $Md = 3$. For a variety of daily activities, pain had the greatest influence on"general activities, the ability to walk and sleep". There was no significant difference in the average estimate of pain between men and women ($p = 0.402$).

Conclusion: A majority of the patients experienced pain, despite an early stage of the disease. This highlighted the need for including clinical assessment methods for adequately determining the character and consequence of pain.

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P177 A CLASSIFICATION SYSTEM TO ASSESS THE DEGREE OF DISABILITY IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

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Keywords: functional scale, disability, factor analysis

Background: Establishing the degree of disability in patients with amyotrophic lateral sclerosis (ALS) is useful for defining treatment plans and rehabilitation guidelines in these patients.

Objectives: To propose a disability classification system for patients with ALS based on the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R).

Methods: A sample of consecutive patients with possible, probable and definite case definition of ALS according to clinical and electrophysiologic criteria was assessed. In every patient, age, gender, initial topographic presentation, time from onset of symptoms to the moment of assessment, level of clinical certainty and total score of the ALSFRS-R Spanish version were determined. A principal component factor analysis of the ALSFRS-R was carried out to establish the different domains of the scale and to choose its most useful variables. With the chosen variables, groups of disability were defined. Correlation between these groups of disability and the ALSFRS-R total score, rate of progression of the disease (DFS) and muscle strength median (according to the Medical Research Council) was assessed.

Results: Eighty-one patients (male 61%) were assessed. Initial topographic presentation was 16 (20%), 35 (43%) and 30 (37%) for bulbar, cervical and lumbar segments, respectively. Clinical certainty was 15 (19%) possible, 22 (27%) probable and 44 (54%) definite. Factor analysis of the ALSFRS-R showed three domains that accounted for 72% of variance: 1) activities related to bulbar functions, 2) activities related with upper limb dexterity and 3) activities related to gross motor function. One activity was selected from each of these three domains according to its weight within the domain. Swallowing, cutting food and handling utensils and walking were selected from domains one, two and three, respectively. These three activities were dichotomized as dependent (ALSFRS-R score of 0, 1 and 2) or independent (ALSFRS-R score of 3 and 4). Afterwards, four groups of disability were defined: dependent in the three activities (12 patients, 15%), independent in one activity (9 patients, 11%), independent in two activities (28 patients, 35%) and independent in three activities (32 patients, 39%). These four groups of disability were statistically correlated to the level of clinical certainty ($p = 0.003$, $r = 0.32$), rate of progression of the disease ($p = 0.003$, $r = 0.32$) and muscle strength ($p = 0.000$, $r = 0.5$).

Conclusion: This four-group classification system of disability based on three selected activities from the ALSFRS-R discriminates functionality of patients with ALS, is easy to use in everyday practice and has an association with the level of clinical certainty, DFS and muscular strength.

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P178 EXPLORING THE APPLICATION OF SENSECAM TO INDIVIDUALS WITH MND

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Keywords: occupational therapy, adaptations, technology

Introduction: Motor neuron disease is a disease which rapidly erodes people's ability to participate in everyday occupations. It is the occupational therapists (OT) role as a part of the multidisciplinary team management of the MND patient, to assess and explore to optimum management of the patient's difficulties in everyday life. The specialist OT at the Barts and the London MND Centre is able to provide assessment and intervention recommendations but this does not allow for full, timely and appropriate assessment of an individual's occupational environment in order to support their continued engagement in important life roles. Opportunities exist to consider how innovative technology may be of best use in providing health services to individuals living with MND. SenseCam is a small, wearable digital camera which captures an electronic record of a wearer's day. The device takes photographic images automatically, without user intervention, whilst it is worn on a lanyard around the user's neck.

Objectives: The aim of this project was to evaluate the occupational therapy service provided for individuals living with MND to ensure that it met service-user needs. As part of this intervention, the SenseCam was utilised as an alternative means of obtaining detailed information about a person's environment/s and how they perform a range of functional activities.

Methods: The project involved the appointment of a full-time occupational therapist for a 12-month project to provide occupational therapy services in the Barts and the London MND Centre. Service-users were given the opportunity to use the SenseCam as a component of their occupational therapy intervention. Evaluation was conducted across a range of methods including clinical effectiveness, activity analysis of the SenseCam images and service-user feedback.

Results: Service-users utilised the camera for varying amounts of time and in varying environments. Activity analysis of the digital images revealed beneficial use of the SenseCam in relation to the following areas of occupational therapy assessment and intervention: postural management; environmental assessment; risk identification and management; fatigue management and ergonomics; carer and family education; and management of disease progression.

Discussion: Preliminary analysis of service-user feedback has supported the extension of the occupational therapy service, which has been enabled by the use of the SenseCam as a therapeutic adjunct. Additionally, the SenseCam images have been useful in informing timely and appropriate involvement of the multi-disciplinary team, and supporting early recognition and management of functional difficulties.

Conclusion: The SenseCam utilisation has been demonstrated to have notable potential in supporting comprehensive occupational therapy assessment and intervention for individuals with MND.

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P179 A VIRTUAL TELEVISION REMOTE VIA COMPUTER FOR INDIVIDUALS WITH ALS/MND

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Keywords: environmental control, assistive technology, television access

Background: For many individuals living with amyotrophic lateral sclerosis (ALS), maintaining independence is an important goal. This includes independence as it relates to controlling devices in the environment. One activity that can become quite difficult is the use of a standard remote control for the television

due to the strength and dexterity required to press buttons. While there are switch adapted controlling systems available, these systems are restricted by expense and limitations in their functionality. We have set out to design a flexible, low-cost controller that can be plugged into any Microsoft computer. We are using television control as proof of concept.

Objectives: The objective is to design a low-cost virtual remote device (NIXBOX) capable of television control and expandable to other infrared (IR) remotes to enhance the independence of individuals living with ALS/MND.

Materials and methods: This system is designed for the user to control their television with a switch via a virtual remote on the computer screen. It utilizes two types of software and hardware. The software used is Arduino and LabVIEW. Arduino receives, processes and sends IR signals. LabVIEW controls the graphical user interface (GUI), signal storage and user customization. The two types of hardware are an Arduino microcontroller and electrical components (3.5mm audio jack, 38kHz IR detector, 940nm High-Output IR LED, Green LED, 10kOhm Resistor, two 330Ohm Resistors). There are three steps necessary to complete the task of controlling the television. In the first step, the virtual remote learns the remote control's IR signals for each button. Next, the virtual remote stores the signal data onto the computer. The final step allows the GUI to control the television through the computer by transmission of IR signals. The basic television remote is displayed as a virtual remote on the monitor. It is designed in row-column form for scanning compatibility using any type of switch. Each button on the virtual remote is linked to a unique signal that is sent to the television. This device connects to the computer via USB. Combining the hardware and software technologies, environmental control is possible.

Results: We have built a prototype NIXBOX that is being demonstrated and tested for user feasibility.

Discussion and conclusions: We have designed an inexpensive, versatile, computer-based IR controller that has been used as a television remote for proof of concept. The system is designed to work with any IR remote and has capabilities of further implementation for other environment controls. This device is easy to set-up and it can accommodate to changing levels of function. This system will be accessible to people living with ALS/MND for increasing their independence and at a relatively low cost.

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P180 MULTIDISCIPLINARY QUALITY CARE AFTER THE POWER WHEELCHAIR DELIVERY: CHANGES REQUIRED OVER TIME

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Keywords: wheelchair, rehabilitation, durable medical equipment

Background: Rapid progression of ALS/MND means the power wheelchair must be flexible for long-term needs for comfort and function. No current articles exist on what types of changes are required and how often the changes must occur after a client receives a power wheelchair.

Objectives: To report the types and frequency of changes required after receiving power wheelchairs and to develop guidelines for what is required for long term effective use, comfort and function of their power wheelchairs as the disease progresses.

Methods: Chart review was completed to compile records of power wheelchair repairs and changes in type and frequency. All power wheelchairs were ordered originally with experienced therapy evaluators and vendors to have the maximum long-term flexibility.

Results: From 2010 to present day, 92 ALS patients received power wheelchairs out of 145 seen through the multidisciplinary clinic. The average patient with a wheelchair received 5.75 (SD 1.3) changes to their wheelchair in this 2-year time period, and 4.0 (SD 2.4) repairs in the same period. Some of the changes made include a pressure relieving cushion, headrest lateral or forward supports, more supportive armrests, thigh guides, and alternative drive controls including switches. Clients were re-evaluated for necessary changes at every clinic visit by experienced therapy and vendor staff. Repairs were generally minor, and completed at the clinic visit as well.

Discussion: Most insurances in the US will pay for medically necessary changes to be made to the chair once it is purchased. Patients require skilled assistance to help them make these changes to maintain full control over the chair as well as comfort and function over time, and this requires not only knowledgeable clinic staff, but also an experienced vendor.

Conclusion: We feel our multidisciplinary ALS/MND clinic has a responsibility to help provide evidence for the long-term needs of ALS/MND patients and their power wheelchairs because of the full time experienced therapy staff, as well as competent dedicated vendors. Our patients desire to use and control their wheelchairs fully, with whatever means they may.

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P181 UPPER EXTREMITY ORTHOSES IN ALS/MND

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Background: Occupational Therapists often provide custom and pre fabricated Orthoses for support and bracing of weak and ineffective joints or muscles of the upper extremity in the management of ALS/MND. The purpose of the orthosis is to decrease the effects of muscle imbalance to provide greater ease in performance of activities of daily living (ADLs), prevent joint contracture, and to relieve pain.

Objectives: The objective of this study is to perform a systematic review of the literature as well as to draw on experiences in the ALS clinic to determine which upper extremity orthotic devices are useful for pts with ALS/MND.

Methods: A systematic review of the literature available on Medline, EMBASE, Google Scholar, PubMed, and Cinahl was performed; 32 articles were appraised by one author according to a standard format. Observational, qualitative, and quantitative studies were included. In addition, the author

drew on her own experience over the past 25 years with ALS/MND patients.

Results: No randomized controlled trials or controlled clinical trials were identified. A summary of descriptive and qualitative studies that relate to upper extremity orthoses as well as results in the author's experience will be discussed.

Discussion and conclusions: Although there were no randomized controlled trials, five upper extremity orthoses are discussed. These will be described with photographs and case descriptions in this poster. The orthoses can be categorized as volar and dorsal wrist, proximal interphalangeal (PIP) finger extension, night resting, thumb opposition, and orthoses designed for a specific function. Further research is needed into appropriate study designs for the use of upper extremity orthoses and the best manner of assessing outcomes with this intervention. Case experience (Level 5 Evidence: "Expert Opinion") reveals functional advantage to use of the above stated orthoses.

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P182 FALLS IN COMMUNITY DWELLING AMBULATORY INDIVIDUALS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS) AND PRIMARY LATERAL SCLEROSIS (PLS)

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Keywords: falls, balance, injury

Background: Falls in ALS and PLS have not been well studied, but may lead to a reduction in activities, increased dependence on others, or more severe health consequences.

Objectives: To determine the prevalence, characteristics, and consequences of falls in a sample of people with ALS or PLS and compare characteristics of fallers and non-fallers.

Methods: We conducted a prospective study of ALS and PLS outpatient's attending our ALS clinic. Eligible subjects were able to stand without assistance, and had an ALSFRS-R walking score of two or greater. All maintained a daily falls calendar and reported falls by telephone. In-person assessments were performed every 3 months with the Berg Balance Scale (BBS), Timed Up and Go (TUG), Activities Specific Balance Confidence (ABC) Scale, ALSFRS-R (total score, and fine and gross motor sub-scores), quality of life, manual muscle testing, and the upper motor neuron score. Pearson correlations ($p < 0.05$) and stepwise regression were employed for analysis. The Penn State Hershey Medical Center Institutional Review Board approved the study.

Results: Fifty seven patients were enrolled - 52 ALS and 5 PLS (65% men). Mean duration of disease at first study evaluation was 61 months for PLS and 29 months for ALS. Over 14 months, 136 falls were reported in 33 subjects (66%). While a greater percentage of women than men fell (60 vs. 56%), overall men had more falls (71%) than the women (29%) with 16 of the 18 subjects that had 3 or more falls being male. 62 of the falls (45%) resulted in injuries, seven of which were severe (fractures), 13 moderate (laceration or sprain), and 42 minor (bruise or abrasion not requiring medical attention or alteration in function). 28 participants (49%) reported a past history of falls at study entry, while 12 participants experienced their first reported fall during the study. Thus, a prior history of falls is indicative of increased risk for a second or repeated fall. A significant correlation was found between falling and the ABC, ALSFRS-R total, and ALSFRS-R gross motor sub-scores ($p < 0.05$). By stepwise regression, the ALSFRS-R gross motor sub-score ($R^2 = 0.24$, $p = 0.01$) was most predictive of future falls. Follow-up regression analysis found that the change in ALSFRS-R gross motor score between the baseline and second visits was a significant ($R^2 = 0.20$, $p < 0.05$) predictor of increased risk for falling before the next clinic visit.

Discussion and conclusions: Patients with ALS and PLS are likely to experience one or more falls, injuring themselves nearly half of the time. A decline in gross motor sub-score on the ALSFRS-R, and self-confidence using the ABC may provide clinicians opportunities for timely falls prevention intervention.

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P183 ADAPTATION AND SERVICEABILITY OF THE MAXIMUM INSUFFLATION CAPACITY (MIC) TRAINING TO THE PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

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Keywords: maximum insufflation capacity training, respiratory physiotherapy, peak cough flows.

Background: Maximum insufflations capacity (MIC) is the maximum volume of air stacked in the patients' lungs beyond spontaneous vital capacity. It has been suggested that MIC training is useful for patients with muscular dystrophy in maintaining the elasticity of lung and chest-wall range of motion.

Objectives: To investigate adaptation and serviceability of the MIC training for patients with ALS.

Methods: The method of MIC involved patients inhaling 3 to 5 times continuously through the Bag Valve Mask (BVM) until their mean airway pressure reached 40 to 50 cm H_2O, then, following air stacking, to exhale in one breath. Subjective difficulties of performing MIC was assessed using a Visual Analogue Scale (VAS). Speech and swallowing scores were assessed using the ALSFRS-R (3–4 scores; non-bulbar, 0–2 scores; bulbar) and Video fluorgraphic examination (VF) in order to examine MIC training serviceability. The patients who were thought to have adapted to MIC training had further examinations of Volume Capacity (VC) and Peak Cough Flows (PCFs) 5 times each before, during and after their operations. At the end, we present two case studies of patients we succeeded in assessing long term.

Results: Eight patients were included in the multidisciplinary study. As an entry criterion, they were diagnosed clinically probable ALS (6 patients) and clinically possible ALS (2 patients), according to the revised El Escorial, and

participated in physiotherapy sessions with prospective study during April 2010 to May 2011.Their mean age (y.o), ALSFRS-R, number of lapsed years from onset (years), % predicted vital capacity (%) were 55 ± 3.4, 32.1 ± 7.1 (44–22), 2.1 ± 2.8 (0.9–3.8), 50.6 ± 18.1 (29.1–80.1), respectively.

We found MIC training was suitable for non-bulbar type ALS, with over 5 VAS, and over 3 on the ALSFRS-R for speech and swallowing, and no sign of miss-swallowing at VF.

MIC training also showed a significant increase in VC and PCFs, not during training alone, but also in its post-operation results compared with its pre-operation results. On during operation, the results of VC and PCFs reached 172.8 ± 41.1% and 189.2 ± 84.4% respectively, and on post-operation the results of VC and PCFs reached 118.2 ± 23.1% and 110.8% respectively in comparison to being as 100% on pre-operation results of VC and PCFs. Moreover, the two patients who performed MIC training over a longer term showed excellent potential exists to not only maintain and improve MIC but also keep up and increase PCFs even though their VC had been dropping from 74% to 48% for year, and 74% to 61% for 6 months respectively.

Discussion and conclusions: This study showed MIC training has a benefical effect on non-bulbar ALS patients to keep up their chest compliance and mobility as one aspect of their respiratory physiotherapy.

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P184 USABILITY OF BIOSIGNAL COMMUNICATION DEVICES FOR PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS) USING TRACHEOSTOMY VENTILATION

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Keywords: biosignal-based communication devices, brain-machine interface, communication stage

Background: Research on ALS patients using communication methods through brain-machine interfaces (BMI) and other systems using biosignals has been limited. Few studies have examined biosignal devices in the severely disabled.

Objective: The purpose of this study was to examine the usability of biosignal-based communication devices for ALS patients, focusing on the relationship between responses of patients and appropriate levels of output signals.

Methods: Subjects were six ALS patients (four males and two females) undergoing tracheostomy positive pressure ventilation (TPPV). Their mean duration of the disorder or post-diagnosis survival = 11.3 years, and a mean duration of TPPV use = 8.0 years. Study details: Responses by the patients, their ability to communicate, and results of the trial use of the following devices: 1) biosignal-based MCTOS (a bio-switch system produced by Technos in Japan); 2) Kokorogatari (equipment designed to express "yes" or "no" using cerebral blood flow in the brain, when thinking deeply; developed by Hitachi in Japan), and 3) Neurocommunicator (an EEG-based BMI system developed by AIST). The subjects were classified into five stages (Stages I to V) according to the level of communication ability. The researchers evaluated use of the three types of communication devices.

Results: Three patients at "Stage I" were able to communicate using sentences. They could convey thoughts and feelings by means of a word board and other communication devices. Stage III included one patient with the ability to express "yes" or "no" by eye movement. One patient was a "Stage IV" and was sometimes able to express "yes" or "no" through eye movement. Stage V consisted of one patient who was unable to communicate due to total paralysis. Three patients at Stage I were able to use all equipment. The Stage I patients indicated that the Kokorogatari, "cannot express anything, but 'yes' or 'no,' and is too slow. "Accuracy of Kokorogatari for the patients on stages IV and V was 70 to 100% at the chance level of 50%. Accuracy of Neurocommunicator for those on the stage I and III was 50 to 100% at the chance level of 12.5%.The accuracy of these systems might be dependent on the noise interference and/or the consciousness level of the patients.

Discussion and conclusion: Stage IV and V groups were able to respond using the Kokorogatari. This suggested that biosignal-based communication methods served as a means of conveying thoughts and feelings by totally paralyzed patients using TPPV. Further studies should examine the time required for patients to adapt to equipment and changes in their responses over time, since the appropriate timing for introducing devices and frequency of their use vary depending on the patient. We recommend early initiation of the devices in tracheostomy patients and to follow the patients' progress.

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P185 OPINIONS AND BEHAVIORS OF JAPANESE AND AMERICAN ALS CAREGIVERS REGARDING TRACHEOSTOMY WITH INVASIVE VENTILATION (TIV)

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Keywords: tracheostomy, patient decision-making

Background: International studies have found widely disparate rates of TIV between countries, between areas within countries, and even in the same hospital. When TIV is initiated, it is often done emergently without advance directives. Many contributory factors have been suggested, including contextual, patient and family influences.

Methods: We conducted national surveys of American and Japanese patients and caregivers, selected because American patients have among the lowest, and Japanese the highest rates of TIV. Here we present selected findings from the caregiver survey. Two groups of patients were included: recently diagnosed, and patients with respiratory problems. During routine

clinic visits, patients accompanied by a family member were asked whether they knew about TIV, and if so, were invited to participate. Five geographically distributed clinics in the USA and five in Japan participated in enrollment of patients for this study; data collection in Japan is ongoing.

Results: 129 American patient/caregiver dyads and 44 Japanese dyads completed questionnaires so far. Caregivers were similar demographically: mean age in each group was 56, 66–71% were female, about 60% had completed at least some college, close to half were working part-time or full-time.

Japanese caregivers were more likely than Americans to know patients with TIV (34% vs. 5%). Only 12% of Japanese caregivers reported having sufficient information about ALS management vs. 69% of Americans, and fewer Japanese reported excellent personal health status (16% vs. 61% of Americans).

When asked whether they had decided in favor of the patient's getting TIV, 35% of American caregivers vs. 51% of Japanese were definitely or probably in favor, 47% of Americans and 5% of Japanese were undecided, and 19% of Americans vs. 44% of Japanese were probably or definitely not in favor ($p < 0.0001$). Not only do the two groups differ, but the distributions do as well: Japanese caregivers had definite opinions, pro or con, while most Americans were undecided.

In the American sample, the most common reasons for favoring TIV included confidence in the patient's ability to maintain quality of life (83%), and the fact that the patient would live longer (61%). Only 34% were confident of family support for TIV. Too few Japanese caregivers responded to these items to meaningfully evaluate.

Reasons NOT to choose TIV were answered by only 21 American caregivers and even fewer Japanese. Most cited inevitable progression of disease and God's will as the main reasons.

Discussion: What stands out is the difference between caregiver groups regarding preference for TIV. It is surprising that so many Japanese caregivers are not in favor of TIV, given the substantially higher TIV rates in Japan to date. The modest Japanese sample size must be considered when evaluating these findings.

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P186 OPINIONS AND BEHAVIORS OF JAPANESE AND AMERICAN PATIENTS REGARDING TRACHEOSTOMY WITH INVASIVE VENTILATION (TIV)

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Keywords: tracheostomy, patient decision-making

Background: International studies report widely disparate rates of TIV between countries, between areas within countries, and even in the same hospital. When TIV is initiated, it is often done emergently without advance directives.

Objectives: We conducted surveys of American and Japanese patients and caregivers, selected because American patients have among the lowest, and Japanese the highest rates of TIV. Here we present selected findings from the patient survey.

Sample: Two groups of patients were included: recently diagnosed patients and those with respiratory impairment, defined as scores < 8 on the Respiratory subscale of the ALSFRS.

Methods: Eligible patients accompanied by a family caregiver were approached during routine clinic visits, asked whether they knew about TIV, and if so, were invited to participate in the surveys which were given to them to complete during the clinic visit. Five geographically distributed clinics in the USA and five in Japan participated in enrollment of patients for this study.

Results: 129 American and 44 Japanese patient/caregiver dyads participated to date. Mean age in both groups was about 63, nearly 50% were female. 75% of American patients and 48% of Japanese completed at least some college, and about one-fifth of both samples was employed. 75% of American patients and 50% of Japanese lived with their spouse.

Advance planning was limited in the American sample; 38% had signed DNR orders, and 59% had advance directives. This question was not included in the Japanese survey. American patients used many more sources of information about ALS and its management than Japanese, who largely relied on their neurologists and, to a lesser extent, clinic staff.

Significantly more Japanese patients knew a patient with TIV (23% vs. 5%, $p = .002$). When asked whether they had decided to get TIV, 18% of Americans and 17% of Japanese were definitely or probably in favor, 54% of Americans and 29% of Japanese were undecided, and 28% of American and 55% of Japanese were probably or definitely against having TIV ($p = .0037$). Most common reasons endorsed by American patients for wanting TIV included confidence in being able to maintain quality of life (81%), confidence in family support (72%), and respect for the value of life (55%). Too few Japanese responded to analyse meaningfully.

Reasons NOT to choose TIV included the belief that the disease would progress anyway (85%), they will be too disabled by then (82%), fear of losing all ability to communicate (50%), and belief that the outcome is God's will (50%).

Discussion: While approximately similar demographically, national differences were found regarding preference for TIV: while about one in five were in favor, more than half of American patients were undecided while more than half of Japanese patients were probably or definitely opposed to having TIV.

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P187 HEALTHCARE PROFESSIONALS' VIEWS ABOUT THE PROVISION OF GASTROSTOMY AND NON-INVASIVE VENTILATION IN AMYOTROPHIC LATERAL SCLEROSIS (ALS)

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Keywords: healthcare professionals, gastrostomy, non-invasive ventilation

Background: Prognosis following diagnosis of ALS is poor, with survival limited to ~3–5 years from diagnosis. Current interventions tend to be limited to slowing disease progression. Bulbar symptoms commonly result in dysphagia, weight loss and respiratory muscle weakness, for which gastrostomy and non-invasive ventilation may be options. It is generally felt that despite the provision of guidelines about when gastrostomy or non-invasive ventilation (NIV) might be made available to patients, fewer patients avail themselves of these interventions than might benefit from them. It is unclear whether the availability of interventions may depend to some extent on the attitudes of healthcare professionals (HCPs) who are in a position to discuss these interventions with patients.

Objectives: To quantify the views of healthcare professionals with respect to the provision of gastrostomy and NIV for people with ALS in England, Wales and N. Ireland.

Methods: We conducted an online survey of the views of healthcare professionals about the provision of gastrostomy and NIV in ALS. Emails inviting professionals to participate were sent to: 33 Neurologists; 18 MND specialist care centres; the Association for Palliative Medicine; and the South-East MND network. There were two versions of the questionnaire, one about gastrostomy and one about NIV. Participants were asked to complete the version concerning the intervention about which they felt they had most experience. If they felt knowledgeable about both interventions, they could complete both versions.

Results: Of the 1298 healthcare professionals who received the questionnaire, 166 completed at least one questionnaire giving a response rate of 12.8%. Chi square analyses found significant differences between medical and non-medical professionals' views on: whether HCPs adhered to policy and legal constraints when it came to making gastrostomy available for people with ALS; in their impressions of patients' and carers' understanding of the effects on gastrostomy and NIV on symptoms and quality of life; and the challenge faced by HCPs when subsequently caring for patients who have refused gastrostomy. However, HCPs with more than 10 years' experience did not find this challenging.

Discussion and conclusions: Despite our low response rate, it is possible that different types of HCPs hold dissimilar views on the provision of gastrostomy and NIV. This may impact on the clinical provision of these interventions and patients' and carers' experiences. Clinical experience may also be a relevant factor when providing care for people who refuse palliative interventions. There appears to be a need for more widely available guidelines regarding the provision of gastrostomy, along with advice on the best way to impart information to patients and carers regarding gastrostomy and NIV, to allow for a potentially more consistent approach to the care of people with ALS.

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Reference

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