

# SESSION 2B TRANSLATING EVIDENCE INTO PRACTICE

## C10 PERFORMANCE MEASURES AND ACCOUNTABILITY

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The quality and safety of today's medical care are quite variable and there is growing concern about runaway health care costs. Studies have demonstrated poor adherence to guidelines, indefensible variations in care, high cost and waste. As a result, there is growing distrust of the medical profession and calls for greater accountability by consumers, payers and regulators. A variety of methods are used to achieve accountability including competition, transparency, differential payment, accreditation, regulation and litigation. All of these approaches rely on performance measures even though measuring quality of care is in its infancy. Today's emphasis on information technology to assure accountability has created high societal expectations that can only be met if greater emphasis and resources are applied to measure quality of care.

Common measures of health care quality include: (1) how health care is organized (structure); (2) what is done (process); and (3) what happens to the patient (outcome). Because outcomes are the most difficult to obtain, many systems rely heavily on structure and process measures to hold physicians accountable. Successful approaches require system thinking, a culture of process improvement, and the development of performance data that truly reflect cost-effective patient care. Barriers that have to be overcome include: insufficient evidence, the cost of information technology, a perceived threat to physician autonomy, a traditional silo approach to health care delivery, and competing priorities.

Increasingly, academic medicine must support fundamental research in quality, safety and efficiency. Successful models for quality assessment and improvement will be presented and include creating and implementing data registries, developing and promoting cross department collaboration and fostering a no-blame culture of accountability. Future medical practice must extend beyond the quest for medical innovation to incorporate systems and contexts for using medical discoveries cost-effectively.

## C11 AAN PRACTICE PARAMETER UPDATE: THE CARE OF THE PATIENT WITH AMYOTROPHIC LATERAL SCLEROSIS (AN EVIDENCE-BASED REVIEW)

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*Keywords: evidence-based medicine, management of ALS, practice parameters*

**Background:** The American Academy of Neurology (AAN) issued an evidence-based report on managing patients with amyotrophic lateral sclerosis (ALS) in 1999.

**Objective:** To systematically review evidence bearing on the management of patients with ALS and update the 1999 AAN practice parameter.

**Methods:** The authors completed a systematic literature review from 1998 to 2008. Topics included breaking the news, symptom management, slowing disease progression, nutrition, respiratory management, palliative care, cognitive and behavioral impairment, multidisciplinary clinics, and communication for patients with ALS.

**Results:** The authors identified 10 Class I studies, 13 Class II studies, and 73 Class III studies in ALS. More studies are clearly needed to examine the best tests of respiratory function in ALS, the optimal time for starting PEG, the impact of PEG on quality of life and survival, the effect of vitamins and supplements, symptomatic therapies and palliative care. The following recommendations are made based on the studies analyzed: Riluzole should be offered to slow disease progression (Level A). Percutaneous endoscopic gastrostomy (PEG) should be considered to stabilize weight and to prolong survival (Level B). Noninvasive ventilation (NIV) should be considered to treat respiratory insufficiency in order to lengthen survival (Level B), and may be considered to slow the decline of forced vital capacity (Level C) and improve quality of life (Level C). Early initiation of NIV may increase compliance (Level C), and insufflation/exsufflation may be considered to help clear secretions (Level C). Multidisciplinary clinic referral should be considered to optimize health care delivery and prolong survival (Level B) and may be considered to enhance quality of life (Level C). For the treatment of refractory sialorrhea, botulinum toxin B should be considered (Level B) and low-dose radiation therapy to the salivary glands may be considered (Level C). For treatment of pseudobulbar affect, the combination therapy of dextromethorphan with quinidine should be considered, though side effects are not uncommon and the treatment is currently not approved by the U.S. Food and Drug Administration (Level B). For patients who develop fatigue while taking riluzole, withholding the drug may be considered (Level C). Because many patients with ALS demonstrate cognitive impairment, which in some cases meets criteria for dementia, screening for cognitive and behavioral impairment should be considered in patients with ALS (Level B). Other management strategies all lack strong evidence.

**Discussion:** There are many treatments available for patients with ALS that can alleviate suffering. NIV, PEG, riluzole, and multidisciplinary clinics are the most important and have the best evidence.

**Conclusions:** More high-quality, controlled studies are needed to guide management and to assess outcomes in patients with ALS.

## C12 MEDICATION IN THE LAST DAYS OF LIFE OF MND/ALS – A STUDY FROM SPECIALIST PALLIATIVE CARE PROVIDERS IN THE UK

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Keywords: opioids, palliative care, end of life

**Background:** Specialist palliative care providers (SPC) are often involved in the care of people with ALS/MND in the UK, particularly in the management of symptoms at the end of life. Despite this experience in the use of medication at the end of life, many patients and their families and professionals fear the last days of life with ALS/MND and the use of medication at this time.

**Objectives:** This study aimed to show the medication used in the last 72 hours of life within six specialist palliative care units in the UK and Ireland.

**Methods:** Six SPC units provided details of the last 10 patients who had died under their care. Patient information was collected together with the details of medication used in the last 72 hours before death.

**Results:** 60 patient records were audited –63% male and 37% female with a mean age of 67 years. The mean time from first symptom to death was 32 months. The majority of patients received medication in the last 72 hours of life, primarily:

- Morphine – 23 patients in the last 24 hours, commonly (38%) by subcutaneous infusion with a mean dose of 80mg (oral equivalent) over 24 hours
- Midazolam – 35 patients, commonly by subcutaneous infusion with a mean dose of 31mg/24 hours
- Anticholinergic medication - as glycopyrronium bromide or hyoscine hydrobromide - 35 patients

All patients were reported as dying peacefully, without distress.

**Discussion and Conclusion:** This study showed that medication is commonly given within SPC units for the management of symptoms at the end of life. The doses used are similar to those in other studies and in surveys of cancer patients - for ALS/MND the studies showed a mean oral equivalent dose of morphine of 98mg/24hours (1) and 90mg/24 hours (2), and for cancer patients a mean dose of 166mg/24 hours (3).

The results show that professionals can feel secure in the administration of medication at the end of life and the doses used are not large and similar or less than for other terminal care groups. Patient and families can also be reassured that with good symptom management and the best use of medication dying from ALS/MND is peaceful.

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## C13 FACTORS UNDERLYING END OF LIFE-DECISIONS IN ALS PATIENTS

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Keywords: end-of-life decision, depression, cognitive processes

**Background:** Over the course of the disease, ALS patients have to make decisions with regards to life-sustaining treatment (non-invasive ventilation, NIV; percutaneous endoscopic gastrostomy, PEG; invasive ventilation, IV). Depression and quality of life were found to be independent of the progression of the disease but to be predictors of the wish to die and physician-assisted suicide (PAS). Data on the processes underlying these end-of life decisions are sparse.

**Objectives:** Our investigation aimed to identify factors underlying the end-of-life decision by a longitudinal approach. The course of depression, subjective quality of life, attitudes toward life sustaining treatment and hastened death, as well as the development of the decisional process itself were investigated.

**Methods:** Patients with definite ALS and no cognitive impairment were eligible to participate in the study. The time between interviews was 6 months. Depression, subjective quality of life and attitudes toward hastened death were assessed by standardized instruments. Attitudes and other cognitive factors regarding the end-of-life decision were assessed by the Life Sustaining Treatment Questionnaire (Häcker, 2008, unpublished).

**Results:** T1: The sample consisted of 61 patients. Depression was neither related to demographic or disease related variables (time since diagnosis, bulbar symptoms, pain, ventilatory status) nor associated with the wish to die. Level of depression was related to quality of life ( $r = -0.513$ ), fear of death ( $r = 0.324$ ), and the wish for legalizing PAS ( $r = 0.542$ ). Quality of life was highest in IV-patients and was not associated with disease progression or bulbar symptoms. Low quality of life was related to stronger approval of the legalisation of PAS ( $r = -0.438$ ) and a stronger wish to die. About half of the sample had not made a decision regarding life sustaining treatment yet. Individuals reporting a positive decision toward life sustaining treatment and those who had not made a decision yet, reported a low wish to die. The highest wish to die was found in patients who decided against life sustaining treatment.

T2: Present results suggest that depression, quality of life and the wish to die do not change over time. Only the fear of death decreased significantly.

**Discussion and Conclusion:** Most strikingly, attitudes toward life sustaining/shortening treatment might not be related to the disease itself. Rather, they seem to be mediated by psychological processes that could be subject to intervention. During all stages of the disease, a high quality of life and low levels of depression are possible. The results can contribute to the general debate over the legalisation of PAS. The focus of this debate should lie on the necessity to ensure every possible support to ALS patients to improve their well being towards the end-stage of the disease.

#### **C14 HOW PATIENTS WITH ALS, MAKING ADVANCED DECISIONS, CAN INFLUENCE OUTCOMES IN WHERE THEIR END OF LIFE CARE IS RECEIVED**

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*Keywords: preferred priorities of care (PPC), end of life care, place of death*

**Objectives:** The Preferred Priorities of Care document (PPC) gives the terminally ill patient an opportunity to think, talk about and write down preferences and priorities for end of life care. Our aim was to establish if patients had specified a choice of where their care would be received at their end of life, that this had been achieved and if not what had happened to prevent this.

**Methods:** Comparisons were made between three groups of patients with ALS, those who completed a PPC, those who had had discussions with the MND specialist nurse with regard to their PPC but had not formally recorded their wishes and those who did not wish or had not had the opportunity to complete a PPC. Data recorded included their preferred place of terminal care.

**Results:** Of the 44 people who chose to complete preferred priorities of care, 39 stated they would prefer to die at home. Twenty-five of these achieved their death at home, three in a hospice, nine in hospital, two in nursing homes. Two patients wished to die in a hospice as their second choice and this was achieved. Two chose to die in hospital and one in a nursing home.

Of the 45 patients who did not complete a PPC eighteen died at home, sixteen in hospital, eight in a nursing home and two in a hospice. Fourteen patients had had discussions about PPC but had not made decisions on place of terminal care. Six of these died in hospital, five at home, two in a nursing home and one in a hospice.

The main reasons for not achieving their desired PPC included carers being unable to cope and sudden change in medical condition.

**Discussion:** It is suggested that in the UK between about 80–90% of those with a terminal illness expressed a preference for death at home but 60% die in hospital. The results of our audit suggest that patients have a higher chance of achieving their preferred place of end of life care if their wishes have been recorded on a PPC. Further investigations should be made to establish causes of breakdown in care leading to hospital admission in the last few days or hours of life and how these admissions can be prevented.

#### **C15 CARING FOR THE CAREGIVER PART 1: USING EVIDENCE BASED PRACTICE TO DESIGN INTERVENTIONS TO SUPPORT ALS CAREGIVERS**

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*Keywords: caregiving, quality of life, evidence based practice*

**Background:** Information on how to support caregivers of ALS patients is sparse. An Evidenced Based Practice (EBP) approach was used to identify potential interventions to support caregivers. EBP is the process of systematically searching for the best available evidence to support a clinical decision or clinical intervention.

**Objectives:** To report on the process by which we used EBP to develop a questionnaire which can be used to design interventions to support ALS caregivers.

**Methods:** A multidisciplinary team used EBP to gather and analyze available information on what can be done to support ALS caregivers. Information on caregiving was obtained from three sources: 1) published literature; 2) expert opinions; 3) caregiver focus groups. The information was reviewed for potential intervention development.

**Results:** Published literature: 70 relevant articles were retrieved, 21 of which were applicable to intervention development: Level I (systematic review or multicenter controlled studies) – 5 articles; Level II (single-center controlled studies) – 4 articles; Level III (case-control studies) – 9 articles; Level IV (qualitative reviews or studies) – 3 articles. The study population in the articles included 393 ALS caregivers, 4154 Alzheimer's caregivers, and 2062 other caregivers. The literature revealed the following: early interventions are most effective; high risk-factors and protective functions for caregivers can be identified; interventions should be multifocal; strategies exist to decrease caregiver perceptions of burden; extra supports aid well-being. Expert opinions generated by clinicians from an interdisciplinary ALS clinic supplemented the literature: educate about all aspects of the disease at 3 month intervals; identify sources of stress and coping; identify available support systems; caregiving experiences differ depending on the relationship to the patient; caregivers need encouragement to call the ALS team for assistance. Caregiver focus groups reinforced services that are helpful (hospice; repeating information about services; emotional/social supports from friends/community) and identified areas in which more attention is needed (finding good in-home care; providing information and options about equipment; removing physical signs after the loved one dies). The three sources of information were reviewed by the EBP team, who determined that the design and administration of a Caregiver Assessment Form in ALS clinic would potentially be a useful intervention. The assessment form includes demographics, assessment for caregiver risks (concern with tasks, health and well-being, stress), and protective functions (optimism, confidence, spirituality).

**Discussion and Conclusions:** EBP can be used to foster collaboration between clinicians and researchers to design and construct an instrument for the assessment of ALS caregivers. Such a tool can form the basis for interventions to maximize the quality of life of caregivers of patients with ALS.