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Respiratory Management of Patients with ALS in Northern New England

Katie Davisson, Ariel Gallant-Bernstien, Mai Hoang, David Longstroth, Bryan Mason, Colleen Moran, Omar Ozgur, Abigail Woodhead, With Dr. Rup Tandan of the University of Vermont College of Medicine and Christine Broderick of Northern New England ALS Association.

Background

• Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive neurodegenerative disease caused by the degeneration of brain and spinal cord motor neurons, leading to steady loss of voluntary muscle function and early death from respiratory failure.
• The incidence of ALS is 1-2/100,000 population, the prevalence is 5-6/100,000 and approximately 30,000 people are living with ALS in the United States.
• Currently there is no cure for ALS; treatment is focused on symptomatic care and improving the quality of life.
• Most ALS patients in the United States are treated either at multidisciplinary ALS centers/clinics in academic institutions or by community-based physicians / neurology practices.
• It is unclear how outcomes in patients with ALS are different among those followed in multidisciplinary clinics (MDC) versus community based physicians / neurology practices (CP).
• The goal of this project was to compare the type of respiratory education and care received by patients with ALS from Northern New England at MDC's (Fletcher Allen and Dartmouth Medical Center) versus CP.

Methods

• An anonymous, self-administered questionnaire focused on respiratory care management was mailed asking patients about the setting in which they received the majority of care in the previous 12 months.
• The survey was distributed by the ALS Association's Northern New England Chapter to patients in Maine, New Hampshire, and Vermont, 50% of total number of patients in the region.
• Survey responses were entered into a database and analyzed with specific attention paid to the setting of care, counseling received, respiratory testing, use of non-invasive ventilation and frequency of adverse respiratory events.
• Patient data were sorted into two groups; those that had been seen one or more times at the MDC versus those that had never been seen at the clinic but were followed by CP's. Fisher's Exact test was used (alpha = 0.05, 2 tailed) to compare the proportions of "yes" responses from the two groups.

Results

• 120 surveys were mailed of which 64 were returned; 46 were usable, 9 were unusable due to incomplete information, and 9 were returned as undeliverable.
• 27 patients had attended a multidisciplinary ALS clinic at least once in the last 12 months, and 19 had never attended a multidisciplinary clinic and were followed by community-based physicians.
• Comparison showed that the following data were not statistically significant:
  • 52% of MDC patients versus 74% of CP patients reported respiratory counseling.
  • 96% of MDC patients versus 71% CP patients reported having respiratory function checked in the last 12 months (p=0.06).
  • 100% of MDC patients were using noninvasive ventilation, versus 63.6% of CP patients.
  • Of those who had never been to a multidisciplinary clinic, the incidence of pneumonia was 18% (versus 20% of those who had):
    • ER visits for pneumonia was 9% (versus 10%);
    • Use of antibiotics for chest infection was 18% (versus 30%);
    • Admission to the hospital for pneumonia was 18% (versus 10%).
• 57% of patients who attended a MDC in the last 12 months received respiratory assistance and all were using non-invasive ventilation.
  • 58% of those who received care by a CP were on respiratory support - 63.6% via non-invasive ventilation and 36.4% via tracheostomy.

Conclusions

• ALS patients who were treated by CP's were counseled about respiratory function as frequently as patients seen in MDC, but they did not undergo respiratory function testing as often.
• Greater use of invasive ventilation by patients followed by CP's suggests that in patients with advanced disease the ability to travel and attend multidisciplinary clinics is limited.
• Since the survey sample size was small and few patients developed respiratory events to obtain meaningful comparisons between groups, further investigation is warranted.

References