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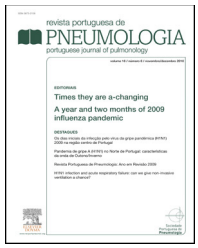

ORIGINAL ARTICLE

Place of death in patients with amyotrophic lateral sclerosis

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KEYWORDS
Amyotrophic lateral sclerosis;
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Abstract Amyotrophic lateral sclerosis (ALS) is a degenerative neurological disorder that affects motor neurons. Involvement of respiratory muscles causes the failure of the ventilator pump with more or less significant bulbar troubles. ALS course is highly variable but, in most cases, this disease entails a very significant burden for patients and caregivers, especially in the end-of-life period.

In order to analyze the characteristics of ALS patients who die at home (DH) and in hospital (DHosp) and to study the variability of clinical practice, a retrospective medical records analysis was performed ($n = 77$ from five hospitals). Variables: time elapsed since the onset of symptoms and the beginning of ventilation, characteristics of ventilation (device, mask and hours/day), and support devices and procedures.

Results: In all, 14% of patients were ventilated by tracheotomy. From the analysis, 57% of patients were of DH. Mean time since the onset of symptoms was 35.93 ± 25.89 months, significantly shorter in patients who DHosp (29.28 ± 19.69 months) than DH (41.12 ± 29.04) ($p = 0.044$). The percentage of patients with facial ventilation is higher in DHosp (11.4% vs 39.4%, $p < 0.005$).

DH or not is related to a set of elements in which health resources, physician attitudes and support resources in the community play a role in the decision-making process. There is great variability between countries and between hospitals in the same country.

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Given the variability of circumstances in each territory, the place of death in ALS might not be the most important element; more important are the conditions under which the process unfolds.
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PALAVRAS-CHAVE
Esclerose lateral amiotrófica;
Local do óbito;
Hospital;
Ventilação mecânica caseira;
Traqueotomia

Local do óbito em doentes com esclerose lateral amiotrófica

Resumo A esclerose lateral amiotrófica (ELA) é uma perturbação neurológica degenerativa que afeta os neurónios motores. O envolvimento dos músculos respiratórios causa a falha da bomba ventilatória, com problemas bulbares mais ou menos significativos. A evolução da ELA é bastante variável, mas, na maioria dos casos, esta doença implica um peso muito significativo para doentes e prestadores de cuidados, em particular no período terminal.

Para analisar as características dos doentes com ELA que morrem em casa (DH) e no hospital (DHosp), para além da avaliação da variabilidade das práticas clínicas, foi realizada uma análise retrospetiva dos registos médicos (n=77 de 5 hospitais). Variáveis: tempo decorrido desde o aparecimento dos sintomas e o início da ventilação, características da ventilação (dispositivo, máscara e horas/dia) e dispositivos e procedimentos de apoio.

Resultados: Catorze por cento dos doentes foram tratados por traqueotomia. Cinquenta e sete por cento dos doentes morreu em casa (DH). O tempo médio desde o aparecimento dos sintomas foi de 35,93 ± 25,89 meses, significativamente inferior em doentes que morrem no hospital (DHosp) (29,28 ± 19,69 meses) comparativamente com os que morrem em casa (DH) (41,12 ± 29,04) (p=0,044). A percentagem de doentes com ventilação facial foi superior nos DHosp (11,4% vs 39.4%, p<0,005).

DH ou não, está relacionado a um conjunto de factores em que os recursos de saúde, as atitudes dos médicos e o apoio na comunicação desempenham um papel importante na tomada de decisão. Existe uma grande variabilidade entre países e entre hospitais no mesmo país. Dada a variabilidade de circunstâncias em cada território, o local do óbito na ELA poderá não ser o elemento mais importante, sendo provavelmente mais relevantes as condições em que o processo se desenrola.
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Introduction

Amyotrophic lateral sclerosis (ALS) is a degenerative neurological disorder that affects motor neurons, causing progressive and irregular loss of muscle strength. ALS progressively affects ventilatory pump with more or less significant bulbar involvement. The course of the disease is highly variable, and although lung function has prognostic value,[1] it has no predictive value since the loss of respiratory muscle function can occur abruptly.

This disease entails a very significant burden for caregivers,[2] both from the perspective of care and from the economic and emotional aspects. In recent years there has been a change of attitude toward tackling the disease. Initially the clinicians' position was more pessimistic about the treatment, citing the poor short-term prognosis. However, the introduction of noninvasive ventilation, percutaneous gastrostomy and mechanical aids for cough augmentation[3] improved the quality of life of patients and, possibly, even their survival. One of the challenges facing most health systems is to respond to the needs of these complex patients in the final stages of life.

Previous studies have shown the main issues for patients and caregivers for coping with the disease, especially during the end-of-life period: overall, ALS patients were aware of their prognosis and disease severity, having been kept well informed by their doctors. Caregivers reported control of symptoms in their relatives but the relief of the respiratory symptoms was not easily achieved despite the use of drugs and sedatives. Family burden and hospitalization access were high. Deaths were equally distributed between home and hospital, and NIV use and diagnosis influenced familial reporting.[4]

The aim of this study was to analyze the characteristics of ALS patients who die at home and in hospital and to study the degree of variability of clinical practice. Moreover, it aimed at identifying the elements that can improve care in the final stages of life in order to design care projects capable of responding to patients' real needs.

Methods

This retrospective study was conducted in five hospitals from the north of Italy and Catalonia (Spain) by analyzing medical records of ALS patients treated at the hospital and who died of the disease. Four hospitals were public hospitals with beds dedicated to acute care and fifth was a private center (Fondazione S. Maugeri IRCCS) involved in rehabilitation/long-term needs and research for chronic

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