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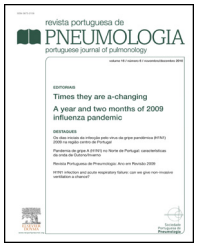

ORIGINAL ARTICLE

Pilot study for home monitoring of cough capacity in amyotrophic lateral sclerosis: A case series☆

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KEYWORDS
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Abstract
Background: Cough capacity derangement is associated with a high risk of pulmonary complications in amyotrophic lateral sclerosis patients when cough assistance is not routinely performed at home. The primary aim of this study was to evaluate the feasibility of a long-term home based daily self-monitoring cough capacity.
Methods: Eighteen subjects were enrolled in a 9-month study at home. Changes in peak cough expiratory flow, oxygen saturation, respiratory discomfort and incidence of respiratory deterioration events were evaluated. In subjects presenting respiratory deterioration events, decline in the abovementioned respiratory variables was evaluated (#NCT00613899).
Results: During an average follow-up of 125 ± 102 days, a total of 1175 measures were performed on 12 subjects. Mean compliance to proposed evaluations was 37 ± 32% which worsened over time. Peak cough expiratory flow decreased by 15.08 ± 32.43 L/min monthly. Five subjects reported 6 episodes of respiratory deterioration events, after a mean period of 136 ± 108 days. They had poor respiratory function and more years of disease. There was no difference in peak cough expiratory flow and its decline whether subjects presented respiratory deterioration events or not. In 4 subjects the respiratory discomfort score significantly worsened after respiratory deterioration events from 3.0 ± 1.41 to 4.25 ± 1.71.
Conclusion: Daily self-monitoring of peak cough expiratory flow, oxygen saturation and respiratory discomfort seems difficult to obtain because of poor adherence to measures; this protocol does not seem to add anything to current practice of advising on clinical derangements. Confirmatory larger studies are necessary.

☆ The study was performed at Fondazione Salvatore Maugeri IRCCS Lumezzane (BS) Italy.
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PALAVRAS-CHAVE
Doenças neuromusculares;
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Serviços de cuidados domiciliários;
Tosse;
Monitorização doméstica;
Infecções das vias respiratórias

Estudo-piloto de monitorização domiciliária da capacidade de tosse na esclerose lateral amiotrófica: série de casos

Resumo
Antecedentes: A disfunção na capacidade de tosse está associada a um elevado risco de complicações pulmonares nos doentes com esclerose lateral amiotrófica, quando a sua monitorização não é realizada rotineiramente no domicílio. O objetivo principal deste estudo foi avaliar a viabilidade de uma automonitorização domiciliária diária da capacidade da tosse, a longo prazo.
Métodos: Dezoito doentes foram incluídos num estudo com duração de 9 meses, realizado no domicílio. Foram avaliadas as alterações do débito expiratório máximo da tosse, a saturação de oxigénio, o desconforto respiratório e a incidência de eventos de deterioração respiratória. Em doentes que apresentavam eventos de deterioração respiratória, foi avaliada a diminuição nas variáveis respiratórias supracitadas (#NCT00613899).
Resultados: Durante um acompanhamento médio de 125 ± 102 dias, foram realizadas um total de 1.175 medições em 12 doentes. A média de cumprimento para as avaliações propostas foi de 37 ± 32%, e piorou ao longo do tempo. O débito expiratório máximo da tosse diminuíu em 15,08 ± 32,43 L/min mensalmente. Cinco doentes relataram 6 episódios de eventos de deterioração respiratória, após um período médio de 136 ± 108 dias. Tinham uma função respiratória mais alterada e mais anos de doença. Não existia diferença no débito expiratório máximo da tosse e na sua diminuição, quer os sujeitos apresentassem eventos de deterioração respiratória ou não. Em 4 doentes o resultado de desconforto respiratório piorou significativamente após os eventos de deterioração respiratória, de 3,0 ± 1,41 para 4,25 ± 1,71.
Conclusão: A auto monitorização diária diária do débito expiratório máximo da tosse, da saturação de oxigénio e do desconforto respiratório parecem difíceis de obter devido à fraca adesão a sua determinação; este protocolo parece nada acrescentar à prática atual de aconselhamento sobre os distúrbios clínicos. É no entanto necessária a confirmação deste resultado em estudos posteriores com amostras de maior dimensão.

Introduction

Deterioration of respiratory function is a critical factor in amyotrophic lateral sclerosis (ALS).[1] Respiratory tract infections (RTIs) are the principal causes of morbidity and mortality.[2] Low level of peak cough expiratory flow (PCEF) is associated with a high risk for pulmonary complications during RTIs,[3–5] for hospisalization,[6] and is also considered an indicator for spontaneous cough effectiveness during an acute RTI.[6–8] PCEF reflects the capacity to expulse debris from the airways (cough efficacy) and values less than 160 L/min are associated with extubation failure.[9]

After RTIs, subjects with neuromuscular diseases have a slow recovery of clinical, functional and oxygenation parameters.[3]

Studies have also demonstrated the importance of using specific cough assistance techniques[9–13] in order to avoid rehospitalisation.[4,11,14–18]

Although easily evaluable, PCEF is not routinely done at home in subjects with ALS.

The primary aim of this study was to evaluate, in subjects with non-bulbar ALS, the feasibility of a long-term (9 months), home-based, comprehensive protocol involving daily self-monitoring for cough capacity. Changes in objective (PCEF and S_{pO_2}) and subjective (respiratory discomfort [RD]) respiratory variables, occurrence of respiratory deterioration events (RDEs) and influence of baseline PCEF and its decline during time on RDEs were evaluated as secondary outcomes.

Methods

Subjects

Subjects with diagnosis of ALS according to the El Escorial criteria,[19] admitted to the Rehabilitation Respiratory Division of Fondazione S. Maugeri – Lumezzane (BS), were considered for this study. Inclusion criteria were: (1) ALS functional rating scale (ALS-FRS-R) score < 35, (2) non-bulbar impairment at first presentation defined by clinical presentation and a PCF/PEF (peak espiratory flow) ratio > 1, (3) PCEF < 450 L/m, (4) NIV prescription at home. Criteria for starting NIV were daytime hypercapnia, sleep-related hypoxemia, and decrease of vital capacity below 50% predicted.[20] Exclusion criteria were refusal, tracheostomy, no caregiver availability, dementia, bulbar patients. The study was approved by the Technical and Scientific Committee of our Institute. All subjects gave informed consent.

Measures

At baseline the following tests or evaluations were carried out: (a) anthropometric characteristics, (b) ALS-FRS-R score, (c) respiratory function (FEV_1, FVC, FEV_1/FVC, VC, MIP, MEP) according to Quanier predictive indices,[21] (d) arterial blood gases (ABG), (e) mechanical ventilation use,[22] (f) PCEF measured at rest using a peak flow meter