CORRESPONDENCE

Chronic respiratory care for neuromuscular diseases in adults

To the Editors:

We read with interest the article describing noninvasive ventilation (NIV) alternatives to tracheostomy ventilation (TIV) [1]. We agree that NIV cannot be used indiscriminately, particularly for amyotrophic lateral sclerosis patients with severe bulbar involvement, and that nocturnal use can be beneficial [1]. However, up to continuous NIV can also be a viable alternative to TIV as has been demonstrated for over 500 patients with Duchenne muscular dystrophy, spinal muscular atrophy, polio, amyotrophic lateral sclerosis and other neuromuscular diseases, in many cases for 20 to >50 yrs of continuous ventilatory support [2, 3]. In the section “NIV versus tracheostomy,” AMBROSINO *et al.* [1] stated that “tracheostomy ventilation may be preferred [...] when the patient is ventilator dependent for most of the day”, but upon review of their references, we found no mention of the clear preference for NIV by continuously NIV dependent neuromuscular disease populations [4]. Of 168 patients who used NIV and TIV continuously, both for ≥ 1 month, all who were decannulated to NIV preferred it for safety, speech, swallowing, cosmesis, sleep and, especially, overall, as did the majority of those who underwent tracheotomy after using NIV [4]. Since AMBROSINO *et al.* [1] do not employ the most convenient, cosmetic and effective methods for daytime NIV, that is, ventilatory support *via* 15 mm angled mouthpieces (not widely available in Europe) kept near the mouth for the patient to grab three or four times a minute or exsufflation belts [2], rather than be hooked up to ventilators *via* nasal interfaces all day, their counselling is biased towards tracheotomy, as ours is to remain noninvasive. Thus, it is not surprising that their patients might consider tracheotomy preferable because they are told that it is inevitable. In yet another study, 157 intubated patients who failed extubations and spontaneous breathing attempts were told that survival was impossible without tracheotomy but refused it and remained intubated up to 76 days until they had the resources to be transferred to our unit for extubation without tracheotomy [5]. Their extraordinary determination to refuse tracheotomy when given a noninvasive alternative speaks for itself [5].

A.J. Hon and J.R. Bach

University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark, NJ, USA.

Correspondence: A.J. Hon and J.R. Bach, University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark, NJ, USA 07103. E-mail: honaj@umdnj.edu

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From the authors:

We would like to thank A.J. Hon and J.R. Bach for their interest in our article [1] and for their useful suggestions concerning management of these patients. We apologise that we neglected to cite the reference quoted in the paper [2].

They seem to suspect that we are fans of tracheostomy ventilation (TIV), always and in any way. We want to assure them that this is not the case. We made the best effort to review chronic respiratory care techniques on the basis of the present evidence. Nevertheless, the topic of noninvasive ventilation (NIV) *versus* TIV is actually a matter of experience rather than of evidence-based medicine. A.J. Hon and J.R. Bach support their conclusions about NIV *versus* TIV with studies performed exclusively by their own group [2–5]; no randomised controlled studies are cited. We appreciate and acknowledge their results in the acute setting but we wonder how these results apply to long-term (usually non-professionally managed) home therapy. We also wonder why, after almost two decades, no other group claims the superiority of one modality over another. Reproducibility of results is important for diffusion of techniques. Indeed, there is no agreement either on time of tracheostomy or on the possible impact of tracheostomy on survival: clinical protocols for tracheostomy are far from being standardised [6]. This is confirmed by an Italian survey on 719 patients from 32 Italian respiratory intermediate care units, which reports that a substantial proportion of patients maintained tracheostomy despite the fact that they did not require mechanical ventilation, with no agreement on indications and systems for closing tracheostomy [7]. This suggests the need to evaluate the choice of interface for patients on an individual basis.

The time for ideologies is over...

N. Ambrosino, N. Carpenè and M. Gheradi

Pulmonary Division, Cardio-Thoracic Dept, Azienda Ospedaliera, Universitaria Pisana, Pisa, Italy.

Correspondence: N. Ambrosino, Pulmonary Division, Cardio-Thoracic Dept, Azienda Ospedaliera, Universitaria Pisana, via Paradisa 2, Cisanello, Pisa, 56124, Italy. E-mail: n.ambrosino@aopisa.toscana.it

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Exercise capacity in chronic respiratory diseases

To the Editors:

We read with great interest the paper by SWALLOW *et al.* [1], comparing skeletal muscle function in chronic obstructive pulmonary disease (COPD) patients and patients with idiopathic scoliosis. In our opinion, the reported muscular weakness in patients with a chronic noninflammatory respiratory disease may have important implications in rehabilitation and prevention of chronic respiratory diseases.

Pulmonary rehabilitation is defined as an “evidence-based, multidisciplinary, comprehensive intervention for patients with chronic respiratory diseases...” [2], but most of the scientific literature is about COPD patients, with less attention devoted to other chronic respiratory diseases. In COPD patients, the cause of skeletal muscle limitation is a subject of debate; whether the reduction of physical activity is because of the respiratory symptoms or the so-called systemic effects of the disease [2]. If, as suggested by SWALLOW *et al.* [1], the common determinant of muscular impairment in COPD and scoliosis is the deconditioning caused by the disease, there is a basis for pulmonary rehabilitation in the majority of patients with chronic pulmonary disease, regardless of the cause. Recently, good results have been reported in the rehabilitation of patients with non-COPD respiratory diseases, such as interstitial lung diseases including idiopathic pulmonary fibrosis [3]. Furthermore, rehabilitation is possible in patients previously excluded by this kind of treatment, such as those with pulmonary hypertension [4].

Another interesting topic is the prevention of loss of exercise capacity in pulmonary patients. Recently, we described the case of a 70-yr-old COPD patient who, having exercised regularly since a young age, maintained a good physical performance (peak oxygen uptake 130% of predicted) despite a significant pulmonary function limitation (forced expiratory volume in 1 s 60% pred) [5]. GARCIA-AYMERICH *et al.* [6]

reported a reduced pulmonary function decline and reduced risk of COPD in smokers practising regular physical activity. The study by WATZ *et al.* [7] showed a reduction of physical activity across the Global Initiative for Chronic Obstructive Lung Disease (GOLD) stages in COPD patients. There is a significant body of evidence about the beneficial anti-inflammatory effect of exercise [8]. It is generally accepted that the amount of exercise required to prevent the loss of exercise capacity is less than that required to improve physical performance. If this is the case, in the future, much attention must be devoted to early diagnosis of chronic respiratory diseases to prevent the decline of exercise capacity, which is a major determinant of the quality of life of such patients, by a regular physical activity.

G. Fiorenzano, C. Santoriello, V. Musella and M. Polverino
Fisiopatologia Respiratoria, Ospedale di Cava de' Tirreni, ASL Salerno, Italy.

Correspondence: G. Fiorenzano, Fisiopatologia Respiratoria, via Santoriello, 2, 84013 Cava de' Tirreni, Italy. E-mail: gxfiore@tiscali.it

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