

Long-term tracheostomy ventilation in Portugal: Survey based on home care providers



There is a growing number of patients needing long-term tracheostomy ventilation (LTV) worldwide and due to their complexity this poses a huge burden on the health-care system.¹ Better knowledge of the epidemiology is critical to health-care system planning and appropriate resourcing.

In 1996, in Portugal, 21 patients were under LTV at home.² Five years later, data from the EuroVent survey³ confirm the existence of 18 patients under LTV (61% of which were patients with Neuromuscular Disorders-NMD) from a pool of 801 patients under Home Mechanical Ventilation (HMV), showing a prevalence of LTV of 0.17:100,000.

To understand the current situation, all patients being managed by Portuguese home care companies with tracheostomy ventilation were identified. Data collected included age (adult versus pediatric), community care setting, diagnosis, type of tracheostomy tube, ventilatory dependency and use of Mechanical In-Exsufflation (MI-E).

A total of 84 patients were identified on 1/11/18, a 5-fold increase since 2001, with a prevalence of 0.86: 100,000 (pediatric prevalence of: 1.9:100,000 versus adult prevalence of 0.69:100,000).

There was an adult and male preponderance (69% and 60.6% respectively), according to region: 30 adults and 20 children were located in the North (59.5% of total), 3 adults and 2 children in the Center (6% of total) and 16 adults and 13 children in the South (34.5%).

The most common reason for LTV was NMD (44%); diagnosis was unknown for 25%. The majority of patients were being cared for at home (69%) as opposed to in institutional care (31%). There were 7 adults and 7 children institutionalized in the North, 1 child institutionalized in the center, 8 adults and 3 children institutionalized in the south.

Specific diagnoses were: ALS 20 (23.8%) Muscular dystrophies/Myopathies 9 (10.7%) Spinal Muscular Atrophy 5 (5.9%) COPD 4 (4.7%) Spinal cord injury 3 (3.6%), Guillain-Barré Syndrome 3 (3.6%) Cerebral Paralysis 3 (3.6%), Ondine Syndrome 3 (3.6%), Stroke 3 (3.6%) and heterogeneous disorders 10 (11.9%). The majority of cases had a cuffed tracheostomy

tube (55.7%), 63% used MI-E and 66.1% had 24 h ventilator dependency.

Although this survey may have some limitations, it shows there are a significant number of patients on LTV in Portugal, predominantly adults with neuromuscular disorders and high ventilatory dependency and mainly concentrated in the North of Portugal. The existence of a significant number of institutionalized patients makes it important to identify reasons for maintaining the patients in this setting. Moreover there should be an evaluation of the degree of burden on caregivers when patients are treated at home.

Due to the complex care requirements and costs of a homecare package a specific registry should be set up for this patient population and a well defined inter-professional transition plan should be negotiated.

Conflicts of interest

The authors have no conflicts of interest to declare.

References

1. Cox C, Carson S. Medical and economic implications of prolonged mechanical ventilation and expedited post-acute care. *Semin Respir Crit Care Med.* 2012;33:357–61.
2. Winck JC. em representação do Sug-grupo de Ventiloterapia domiciliária da Comissão de Reabilitação Respiratória da SPP. Normas e Recomendações da Ventiloterapia domiciliária. *Rev Port Pneumol.* 1998;IV:447–78.
3. Lloyd-Owen SJ, Donaldson GC, Ambrosino N, Escarabill J, Farre R, Fauroux B, et al. Patterns of home mechanical ventilation use in Europe: results from the Eurovent survey. *Eur Respir J.* 2005;25:1025–31.

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