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Long-term non-invasive ventilation in muscular dystrophy.

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Abstract

Long-term non-invasive ventilation (NIV) was introduced in the 1980s, initially mainly for patients with poliomyelitis, muscular dystrophy (MD) or scoliosis. The obesity-hypoventilation syndrome has since become the commonest reason for referral to most centres providing home-NIV. Patients with MD are numerically a much smaller part of the workload, but as their disease progresses the need for ventilatory support changes and they require regular comprehensive assessment of their condition. We have examined the trend in MD use of home-NIV in our unit over the last 25 years. The number of new referrals appears to be stabilizing at around 20-25 over a 5-year period, equivalent to approximately 0.5 per 100,000 of population per year. The mean age at commencement of home-NIV is now 37.5 years, with 5-year survival rates of 70-75%. Ten-year survival rates are just over 40%. The distance of usual place of residence from our unit is fairly stable, currently at a mean of 27 km. Excellent survival rates mean that patients with MD, while numerically small, are likely to remain an important part of the workload of centres providing home-NIV. Our data should prove useful in the planning of future services for this group of patients.

KEYWORDS: Non-invasive ventilation; muscular dystrophy; respiratory failure; respiratory muscles; ventilation

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