SUPPORTING MND PATIENTS USING NIV: EXPERIENCES OF PROFESSIONAL CAREGIVERS

Background Regular administration of positive pressure non-invasive ventilation (NIV), typically at night to ameliorate nocturnal hypoventilation, extends survival without halting disease progression (1). Many people with MND need practical support to benefit from NIV treatment beyond that which can be provided by family caregivers. There is a paucity of research describing formal care support in MND in general, and very little knowledge of the work of professionals supporting NIV treatment in any context.

Objectives To understand how professional caregivers support NIV treatment in MND.

Methods A qualitative approach was used to facilitate exploration and description of formal support of NIV treatment by a variety of health and social care professionals who, as a part of their job, provide support for MND patients using NIV. The semi-structured interview schedule included knowledge of MND symptoms, familiarity with NIV treatment, practical support, expectations, and a critical assessment of NIV treatment and their ability to support NIV treatment. The analysis was essentially explanation building, towards seeing common patterns, and ultimately providing recommendations.

Results Seventeen professionals consented, including GPs, community and respiratory physiotherapists, speech and language therapists (SLTs), community nurses and nursing home/care agency staff. GPs, community physiotherapists and SLTs reported very few cases in their practices but had knowledge of NIV treatment, in contrast to community nurses and nursing home/care agency staff, who typically have neither knowledge nor experience until faced with a patient using NIV. Practical support provided by professionals included advice, titrating pressure, assistance for those unable to use the equipment independently, and psychological support.

Discussion Attitudes and expectations of NIV differed, with some professionals being concerned about symptom relief, some about functional improvements (such as improved speech), and some with operational issues (such as mask comfort), without considering the worth of NIV as a treatment. Some professionals who are responsible for the daily care of patients using NIV report no education about NIV in advance of meeting such patients, and so typically learn about NIV treatment ‘on-the-job’.

Conclusions Professional carers were very disparate in their attitudes and their background training in MND and NIV. There is a need to examine training requirements for nursing

home/care agency staff. Furthermore, professionals showed no consensus on the benefits of NIV but were fulfilling their professional duties to administer and sustain it without knowledge or involvement in the decision to commence it.

Reference

Bourke S, Tomlinson M, Williams T *et al* Lancet Neurology 2006; 5:140-7.

Acknowledgements This research was funded by the Motor Neurone Disease Association, UK. We also thank participants for their time in supporting the research.

Keywords

NIV treatment

Carers

Training