

Title: Telemonitoring to optimise care in motor neurone disease: a pilot study

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Background Advances in telemedicine may benefit patients with motor neurone disease/ amyotrophic lateral sclerosis (MND/ALS). *Aims* This study aimed to improve care through telemonitoring utilising standardised symptom monitoring, clinical measurements and assessment non-invasive ventilation (NIV) parameters. It was hypothesized that telemonitoring allows proactive intervention allowing symptom management and optimized ventilation indicated by adequate nocturnal SpO₂ levels and minute ventilation (MV).

Methods 13 ventilated patients (mean age=62yrs; median illness duration=14m; median NIV usage= 8m) were recruited. Previously developed questions monitored symptoms and NIV-related issues, generating alerts and interventions where required. Nocturnal pulse oximetry and the patient-ventilator interaction (PVI) data were collected weekly. A revised ALS functional rating scale (ALSFRS-R) was completed three-monthly. Given the sample size, Friedman's ANOVA and Spearman's correlation coefficient were used for analysis at the baseline, at 3 month, and at 6 month.

Results In total, 137 alerts led to 62 interventions (direct review 13, treatment adjustment 14, equipment provision 20, referral 15). Inspiratory positive airway pressure levels were increased median 16.8 and 21.9cmsH₂O (Wk1 and 22), NIV adherence also increased over time (both $p<.01$). No change was observed with nocturnal SpO₂ levels. ALSFRS-R scores showed illness deteriorations. No consistent correlations were found between the variables.

Conclusions This pilot study found telemonitoring to be beneficial in maintaining ventilation MND despite the illness deterioration.