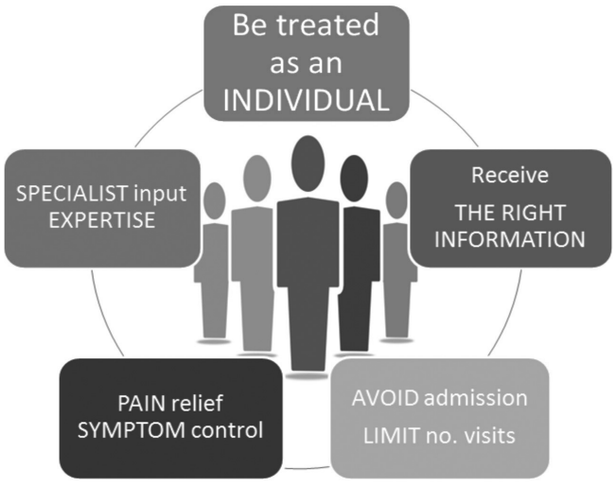
Results 18 patients were surveyed (4 after ascitic procedures), 9 had emotional mapping. The mean overall service rating was 4/5. The graph above represents both responses to the question 'What is important to you?' and themes that emerged from emotional mapping.

More detailed insight was gained from the discussion with one patient's relative, this was triangulated with the other data to give a clearer picture of what was most important to patients. Similar themes were combined to form 5 final patient-centred outcomes that were important to patients (see Figure 1 attached). E.g. 'Be treated as an INDIVIDUAL' encompassed good interpersonal relationships and personal choice, and 'Receive the RIGHT INFORMATION' for consent, medical care and managing waiting.



Abstract P189 Figure 1

Discussion These five outcomes were developed for a specific service. The data has come from a relatively small number of patients from a specific cohort, but they seem credible, and may be more widely applicable. The next step is to measure the service against these outcomes before and after the. A new patient survey has been designed to measure these outcomes. It will be administered before and after the start of the new service.

Home non-invasive ventilation

P190 DEVELOPMENT OF A RESPIRATORY QUESTION SET FOR REMOTE MONITORING IN MOTOR NEURONE DISEASE (MND)

[1]HJ Ashcroft, [1]H Ando, [1]B Chakrabarti, [2]R Halhead, [2]P Levene, [1]RM Angus. *[1]Aintree Hospital Trust, Liverpool, UK; [2]DOCOBO Ltd, Bookham, UK*

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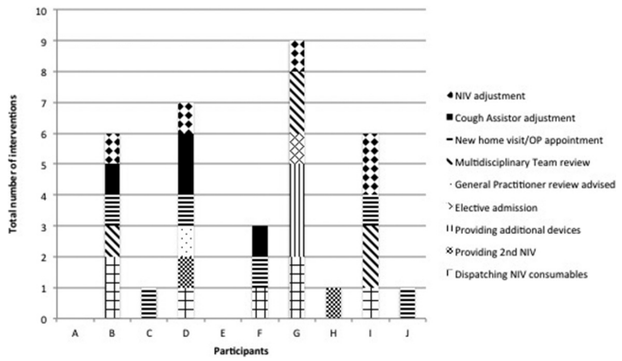
Background Benefits of tele-monitoring (TM) of home non-invasive ventilation (NIV) in MND have been reported. Question sets for other respiratory conditions may not be transferrable. This work sought to develop questions transmitted via tablet device (Docobo Careportal®) allowing patients to inform clinicians of respiratory status, illness progression and NIV issues.
Methods Modified Delphi methodology was used involving 4 stages: initial expert panel with clinicians (EP1), trial of questions and feedback sessions (FS) with patients, second panel with professionals (EP2). 21 questions were developed at EP1 and trialled with 9 patients (male = 7; mean = 58 years; mean illness duration = 52 months) for 8 weeks. FS were conducted after the trial to examine face validity, clarity and relevance. Each question was deemed clear if at least there was 80% agreement.18 questions were retained, 3 modified, 2 deleted and 5 added. EP2 repeated the process, the resulting final question set contained 26 items of which 17 generate a notification. Patients completed questions weekly, appropriateness of alerts was checked by phone call; the panel specified some notifications to be of greater clinical importance requiring intervention or further observation. It was possible to review reported issues against overnight oximetry and patient ventilation interaction data.
Results For 12 weeks, 10 patients using NIV male = 7; mean (SD) age = 62 (8) years; median illness duration = 16.5 months, completed the final question set weekly. 210 alerts (geometric mean 15.3, IQ range 11–24.) were generated for; sleep quality, alertness, tiredness, NIV compliance, secretion clearance difficulty, increased secretions, and increased dyspnoea. 34 interventions resulted as described in the bar chart: the median number of interventions per patient was 2 (range = 0–9).
Discussion To date the questions appear valid with no misunderstanding revealed. Appropriate and timely treatment adjustment and clinical review was facilitated. Prompt interventions may reduce psychological distress for patients and caregivers. This patient group are normally followed up three-monthly under the current NICE guidance; this question validation work suggests value in more frequent contact. Tele-monitoring, including symptom monitoring with a validated question set, may offer an alternative approach to following these complex patients.



Abstract P190 Figure 1 Bar chart showing total number and type of interventions per participant

P191 SURVIVAL IN PATIENTS WITH CHRONIC TYPE 2 RESPIRATORY FAILURE: A COMPARISON OF OBESITY HYPOVENTILATION SYNDROME, COPD AND OVERLAP SYNDROME

A Jothieswaran, M Mascareno, S Bokhari, N Chaudhry, TW Felton, AM Bentley. *University Hospital of South Manchester, Manchester, UK*

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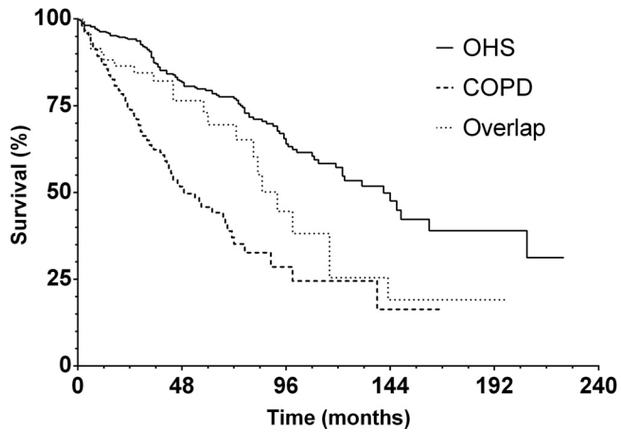
Introduction and objectives Home non-invasive ventilation (NIV) is established for the treatment for patients with obesity-related type 2 respiratory failure. Long-term outcomes for the use of NIV in patients with chronic hypercapnic COPD and "overlap syndrome" are less certain. Our objective was to

compare the long-term survival of patients with obesity hypoventilation syndrome (OHS), COPD and overlap syndrome who were established on NIV.

Methods All patients with a diagnosis of COPD, OHS and overlap syndrome were identified retrospectively from a patient database. Overlap syndrome was defined as COPD and either OHS or obstructive sleep apnoea resulting in chronic type 2 respiratory failure. The diagnosis was defined at the time NIV was established from medical assessment and respiratory physiology. All patient data was anonymised. A Kaplan-Meier survival analysis was performed. Median survival was estimated for each of the three groups. Survival was compared using Mantel-Cox test, Gehan-Breslow-Wilcoxon test and Log-rank test.

Results In total 463 patients were established on NIV. NIV was initiated on 158 patients with COPD (51% female, 49% male, mean age at set up 66 years), 269 patients with OHS (46% female, 54% male, mean age 62 years) and 36 patients with overlap syndrome (48% female, 52% male, mean age 66 years). The Kaplan-Meier survival curves for the three groups are shown. A clinically and statistically significant difference in survival was observed between the three groups ($p < 0.0001$). Patients with COPD had the worst long term survival compared with patients with OHS and the overlap syndrome. The median survival was 49 months for patients with COPD, 92 months for patients with overlap syndrome and 141 for patients with OHS.

Conclusion Evidence for domiciliary NIV in patients with OHS is well established. There is emerging evidence to support with use of NIV in patients with chronic hypercapnic COPD and low body mass index. Patients with overlap syndrome are a heterogeneous group representing a spectrum from predominately COPD to predominately OHS. Further studies are required to establish if patients with overlap syndrome benefit from NIV and to identify potentially modifiable risk factors associated with a poor outcome.



Abstract P191 Figure 1 Showing the survival for patients with obesity hypoventilation syndrome (OHS), COPD and overlap syndrome

P192 CLINICAL EFFECTIVENESS OF NON-INVASIVE VENTILATION IN PATIENTS WITH MOTOR NEURON DISEASE

D Freeman, A Jothieswaran, M Mascareno, N Chaudhry, S Bokhari, TW Felton, AM Bentley. *University Hospital of South Manchester, Manchester, UK*

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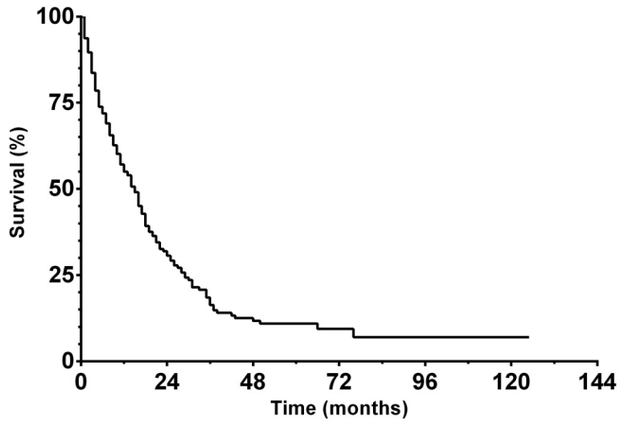
Introduction and objectives The use of long term non-invasive ventilation (NIV) for type II respiratory failure caused by Motor Neuron Disease (MND) is well recognised. In patients with MND and good bulbar function, NIV has been shown to improve survival and quality of life.[1] NIV use in patients with MND has increased since the publication of the National institute of Clinical Health Excellence guidelines in July 2010. Our objective was to identify the clinical effectiveness of NIV in all patients with MND referred to a large tertiary referral teaching hospital service.

Methods All patients with MND established on NIV were identified retrospectively from a clinical database. Patients were excluded from the analysis if there was another diagnosis as the main indication for establishing NIV. All patient data was anonymised. A Kaplan-Meier survival analysis was performed and the median survival was estimated.

Results 222 patients with MND established on NIV were identified. The median age was 64 years (range 19–90 years). One hundred and forty patients (63%) were male and 82 (37%) female. The median survival was 436 days on NIV. The Kaplan-Meier survival curve is shown below.

Conclusion A median survival of 436 days compares favourably with the median survival of 219 days identified in patients with MND receiving NIV in the trial by Bourke *et al*. Our patient cohort included patients with both limb onset and bulbar onset forms of the disease. The impact on survival may, in part, be due to NIV but overall improvements in medical care, supporting adequate nutrition and assisted cough techniques in a specialist centre will have contributed.



Abstract P192 Figure 1 Showing the survival of patients with motor neurone disease receiving NIV

REFERENCE

1 Bourke SC, *et al*. Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. *Lancet Neurol*. 2006;**5**:140–7

P193 HOW SAFE IS DOMICILIARY CHANGE OF TRACHEOSTOMY TUBE IN VENTILATOR DEPENDENT PATIENTS?

JM Palmer. *Plymouth Hospitals NHS Trust, Plymouth, UK*

10.1136/thoraxjnl-2015-207770.330

Introduction Tracheostomy ventilation (T-HMV) is indicated in a small group of patients with chronic ventilatory failure. These