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Title: How well do questionnaires capture symptomatic relief and well-being over time with NIV in motor neurone disease?

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Body: Benefits of non-invasive ventilation (NIV) in motor neurone disease (MND/ALS) have been explored using quantitative health measurements with little examination of subjective experience. This study explored whether current quantitative tools commonly used in MND adequately capture the effects of NIV. 6 patients (all male, mean age= 67) from an original cohort of 35 were available for the present study having survived a year on NIV. Both questionnaires and semi-structured interviews were completed at 3 occasions: pre-NIV (Point A), 4-6months (Point B) and 10-12months post-NIV (Point C). The scales used were ALSFRS-R (physical functioning), ALSAQ-40 (ALS specific health status), MNDRS (dyspnoea), BDI (depression), BHS (hopelessness), HADS (depression and anxiety), and ESS (sleepiness). During the interviews, experience of NIV, physical changes and their impact on daily life were explored. All interviews were assessed using thematic analysis. Quantitative scores were compared using analysis of variance. Changes were seen from points A to C in ALSFRS-R 33 v 27 (p=0.021), ALSAQ subscale for communication 46 v 29 (p=0.018), BHS 3.67 v 1.80 (p=0.03) and ESS 9.50 v 2.8 (p=0.046). The scores of ALSFRS-R denote worsening functional status, while the other scales indicate improvement. Qualitatively, 4 symptoms were discerned as problematic and were improved by NIV: energy level, quality of night sleep, daytime sleepiness and breathlessness. The results show the multidimensional range of symptoms that relate to hypoventilation in MND and how the routinely employed scales may fail to capture significant symptomatology or the impact of NIV on such symptoms.