

Hospitalisation Burden Following Tracheostomy in Amyotrophic Lateral Sclerosis: the population-based DISCOVERY study

Karin Ersson¹, Magnus Ekström², Össur Emilsson¹, Ludger Grote³, Mirjam Ljunggren¹, Josefin Sundh⁴, Andreas Palm¹

¹ Uppsala universitet, ² Lunds universitet, ³ Göteborgs universitet, ⁴ Örebro universitet

Background: Invasive ventilation (IV) via tracheostomy represents a major life-sustaining intervention in amyotrophic lateral sclerosis (ALS), yet hospitalisation patterns following its initiation remain poorly characterised.

Objective: To describe hospitalisation burden during the three months following initiation of IV via tracheostomy in people with ALS (pwALS).

Methods: Population-based data from the Swedevox registry and the Swedish National Patient Registry were used to identify pwALS initiating IV. Participants were classified according to the context of IV initiation: acute, elective, or transition from non-invasive ventilation (NIV). Multivariable linear regression models examined associations between hospital length of stay (days) and age, sex, initiation context, marital status, and educational level.

Results: A total of 103 pwALS were included (47 acute, 11 elective, and 45 NIV-to-IV transitions). Mean age was 58.3 years (± 11.5), and 42% were women. Participants in the transition group were younger than those in the other groups ($p = 0.025$). During the three months following the tracheostomy, mean hospital stay was 55.4 days (± 32.8): 58.5 (± 35.7) for acute, 53.4 (± 35.4) for elective, and 52.6 8 (± 29.2) for transitions, with no significant group differences. In linear regression analyses, no covariates were significantly associated with hospital length of stay.

Conclusions: pwALS experience a substantial hospitalisation burden of approximately two months following tracheostomy, irrespective of the clinical context of IV initiation. These findings highlight the need for proactive care planning and coordinated multidisciplinary management in advanced ALS.