Recognising dying in Motor Neurone Disease: A Scoping Review

Elizabeth Abbey, Maimona Ali, Matthew Cooper, Paul Taylor, Catriona R. Mayland. Department of Oncology and Metabolism, University of Sheffield, School of Health and Related Research, University of Sheffield, Sheffield Teaching Hospitals NHS Foundation Trust 10.1136/spcare-2023-PCC.70

Background Recognising when an individual is dying helps to guide clinical decision making and facilitate communication. Recognising dying, however, remains challenging for healthcare professionals (HCPs). Palliative care research in motor neurone disease (MND) is limited relative to other conditions. Our scoping review aimed to explore the recognition of dying in MND to inform the provision of high-quality end-of-life care.

Methods A scoping review was conducted according to Arksey and O’Malley’s framework and Joanna Briggs Institute guidance. Five databases (Ovid MEDLINE, PubMed, PsycInfo, CINAHL and Scopus) were searched. Citations and grey literature were also searched. Screening and full text review were conducted by two independent reviewers and results thematically organized.

Results From 1067 papers, twelve studies were included. Studies spanned seven countries and included quantitative (n=7), qualitative (n=3), and mixed methods (n=2). Three themes were identified: 1) ‘Symptoms and medical treatment in the last week of life’; 2) ‘Circumstances leading to death’; 3) ‘Challenges of recognising end of life’. Patterns of symptoms and medical management in the last week of life were described. Although variable, a picture of often rapid and unpredictable decline emerged, often over short hours to days. Challenges when recognising dying included preserved functional level late in the illness, and repeated episodes of revival after deterioration. The unique nature of the dying phase of MND was noted, and withdrawal of NIV adds complexity.

Conclusions Overall, few studies examined recognition of dying in MND. Research describes a high symptom burden with an often sudden terminal decline. To meet the needs of these patients, pro-active advance care planning is paramount. Further research should explore the perspectives of HCPs and carers, to explore patterns of the dying process in this condition, how this is recognised, and ensure care is consistent with the needs, priorities, and experiences of stakeholders.