

such conversations should occur with all dying people and those close to them.

**Aim** To explore doctors' views and experiences of communicating and making decisions about assisted hydration at the end of life.

**Design** Semi-structured qualitative interview study with framework analysis.

**Setting/participants** Sixteen UK-based Geriatrics and Palliative Medicine doctors were recruited from a range of hospitals, hospices and community services, before and during the Covid-19 pandemic.

**Results** Participants reported clinical, practical and ethical challenges associated with this topic. The hospital setting provides several barriers to high-quality communication about assisted hydration at the end of life, which may contribute to the low incidence of documented assisted hydration-related conversations. Workplace culture in some hospices may make truly individualised decision-making about this topic more difficult. Exclusion of patients from decision-making about assisted hydration appears to be common practice.

**Conclusions** Proactive, routine discussion with dying people about issues relating to hydration is indicated in all cases. There is room for debate regarding the limits of shared decision-making and the benefits of routine discussion of assisted hydration with all dying people. Clinicians have to navigate multiple barriers as they strive to provide individualised care.

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#### EXPLORING NON-INVASIVE VENTILATION DECISION-MAKING BY PATIENTS WITH MOTOR NEURONE DISEASE: AN INTEGRATIVE SYNTHESIS WITH THEMATIC ANALYSIS

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**Background** Motor neurone disease (MND) is a fatal neurodegenerative disease characterised by a loss of upper and/or lower motor neurones, consequential progressive respiratory muscle weakness, and eventual death from respiratory failure. Non-invasive ventilation (NIV) is the standard treatment for hypoventilation in these patients; however, literature suggests that patients with MND are often not involved in, and do not fully understand the process of decision-making regarding NIV treatment.

**Aim** To explore the process of NIV decision-making by patients with MND through a systematic review of the quantitative and qualitative evidence available.

**Methods** Quantitative and qualitative studies were identified through a search of six databases, and bibliography screening and citation searching of identified and other relevant background articles. Papers were shortlisted based upon pre-established eligibility criteria, data was extracted, and its quality assessed against standardised criteria. The findings were synthesised through thematic analysis of the qualitative data, and the integration of relevant quantitative findings.

**Results** Four qualitative and three quantitative studies were included. Participants included patients with MND, their caregivers and healthcare professionals (HCPs). The quality of the papers was low to moderate; however, none were excluded on this basis. Three superordinate themes were identified in the literature: the process of decision-making, factors influencing acceptance of NIV, and factors influencing

rejection of NIV. One paper found that an education session significantly improved patients' knowledge ( $t = 5.9$ ,  $p \leq .001$ ), and helped > 90% of them to make a decision regarding ventilation.

**Conclusion** Numerous factors – particularly those within the control of HCPs – influence the decision-making process and the decisions patients with MND make; and education helps them make an informed NIV decision which aligns with their values and wishes. However, high-quality evidence is lacking and no established decision-aids for this population currently exist, therefore, further research is needed to develop an appropriate patient-centred aid.

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#### THE UNCERTAINTY GAP: A SYSTEMATIC REVIEW & THEMATIC SYNTHESIS EXPLORING MULTI-PERSPECTIVE EXPERIENCES OF UNCERTAINTY IN ADVANCED MULTIMORBIDITY

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**Background** Multimorbidity in older adults is the norm, typically resulting in a complex illness trajectory pervaded by uncertainty. We aimed to identify and synthesise evidence of the uncertainties experienced by older people with advanced multimorbidity, their informal caregivers, and health and social care professionals. We focused on differences in experience between groups.

**Methods** Systematic review and thematic synthesis of published and grey literature from nine databases. Inclusion criteria: people over 65 with advanced multimorbidity (defined as the presence of two life-limiting conditions, or one life-limiting condition with comorbidities/functional impairment/acute healthcare use); informal carers/healthcare professionals caring for this group; qualitative research with exploration of uncertainty. We used Gough's Weight of Evidence to assess quality. We extracted the results section of included articles and conducted thematic synthesis, using an existing taxonomy to classify the sources, issues, and loci of uncertainty.

**Results** From 4427 search results, we included 43 articles from 11 countries. 22 focused on patient experiences of uncertainty ( $n = 460$  participants), 14 carer experience ( $n=185$ ), and 19 health professional experience ( $n = 490$ ). Patients experience uncertainty due to unpredictable and constantly changing health. They may be uncertain about the cause of symptoms, how to access care, or how to balance multiple problems, particularly if provided with ambiguous information. As a result, many disengage from care planning and focus on day-to-day life. Carer uncertainties tend to link to more practical concerns: 'what do I do now?' Conversely, healthcare professional uncertainties arise as they attempt to disentangle complex combinations of illness; they also experience uncertainty about care processes when multiple professionals are involved.

**Conclusion** The differing experiences of patients, professionals and carers point to an 'uncertainty experience gap' in advanced multimorbidity. Communication interventions to address uncertainty may help to focus care-planning conversations and facilitate delivery of person centred care.