Reckoning Dying in Motor Neurone Disease: A Scoping Review

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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, proactive 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.

Needs Assessment of End-of-Life Care in the Emergency Department

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Background Improving end-of-life care (EOLC) in Emergency Departments (ED) is a top research priority for the Royal College of Emergency Medicine. Our hospital palliative care team created a Senior Clinical Nurse Specialist (CNS) role to facilitate quality improvement and address this priority. This project scoped the current workflow to identify needs and barriers to excellent EOLC in the ED.

Methods Retrospective review over ten months of patients’ notes who received palliative care input, in ED. Baseline data on recognition of dying, and care documents were reviewed. Further research is needed, including evaluating patient acceptability.
was established, and processes identified, followed by eight weeks fieldwork. This included observation and consultation with ED and a Palliative CNS.

**Results** 150 patients received palliative care input whilst in ED. 33% (49) died within three days of admission to ED. Of these, 18% (9) died in ED and 59% (29) were admitted into hospital.

Relationships have been built between Palliative Care and ED staff to enable a collaborative approach to driving improvement in these areas.

From the fieldwork, the points identified for improvement include: Rapid Discharge Pathway (RDP) being difficult to use; potentially patients at risk of dying in ED rather than preferred place of death; syringe driver training; access to equipment; lack of space for chairs, pillows and quietness to provide support at end-of-life for patients and families.

ED team’s knowledge on symptom management in EOLC is being explored. The process of patient flow in ED was identified, so patients ‘to come in’ (TCI) was acknowledged as a group to explore further for earlier palliative care interventions and support.

**Conclusions** Palliative care patients in ED are at risk of dying in ED or shortly after. Future work needed focusing on priorities identified eg streamlining the RDP. Training and renovation of ED environment. An in-reach service may help to identify a higher proportion of patients with palliative care needs.

**REFERENCE**

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**53 CASE REPORT: HIP FRACTURE AT THE END OF LIFE – GUIDING PATIENTS’ CHOICE OF OPERATIVE OR NON-OPERATIVE PALLIATION**

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We are presenting this case as a late abstract owing to the time of presentation and the learning that arose from it.

A 70-year-old man with T4b N3 M0 poorly differentiated squamous cell carcinoma of the oesophagus was referred to the Community Palliative Care Team. His preferred place of care and death were home and he requested not to receive CPR, although open to hospital admission for reversible causes. His condition deteriorated with intermittent delirium and agitation, making home care challenging. He was admitted to the local Cancer Centre as no beds were available in the local Hospice inpatient unit and suffered a witnessed fall on a Sunday. Examination revealed a shortened and externally rotated left leg and inability to weight bear. Pelvic XR demonstrated a left displaced intracapsular hip fracture. The patient was discussed with the on-call Orthopaedic Registrar who advised that the patient would be discussed in the regular trauma meeting on Monday and should remain in the Cancer Centre. On Tuesday, in order to avoid admission to the local Major Trauma Centre, the patient was visited in the Cancer Centre by the Consultant Orthogeriatrician. After consultation with the patient and his family, it was agreed that he did not need surgery and that his hip fracture could be managed conservatively with bed-rest and analgesia. The patient was transferred to the Hospice on Tuesday and felt to be in the last days of life 24-hours later. The patient’s pain was managed effectively with a continued subcutaneous infusion with Morphine and Midazolam. The patient continued to steadily deteriorate and peacefully died on Saturday.

**Discussion** Orthogeriatricians now lead the acute peri-operative care and rehabilitation of hip fracture patients in every acute trauma unit in the UK. This case demonstrates how early discussion of complex patients with an Orthogeriatrician can help the patient, oncology and palliative care teams to make the right choice of available operative and non-operative options, and avoid inappropriate hospital transfers.

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**54 END OF LIFE CARE PARASOL SERVICE**

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**Aim** To develop an End of Life Service that provided direct clinical support and education to health professionals to improve End of Life Care within Swansea Bay University Health Board.

**Method** Project started with obtaining retrospective baseline information from four general wards in acute hospital. Retrospective data collection incorporated the five priorities of care, pre-project survey from ward-based health professionals. Real-time data collected over 12 weeks to compare to baseline.

**Analysis** Collected data during a 12-week period identifying a need for direct clinical support and education to improve End of Life Care. Resource folders with core End of Life information provided to each ward. Contact details for staff to contact if advice or support required. Drop-in sessions held on each ward for staff to promote awareness of All Wales Care Decision Guidance. Supported staff with recognising dying, clinical assessment, communication and administering of anticipatory medications. Staff survey repeated.

**Results** Over the 12-week period, the data showed:-
- Recognising dying and documented effectively increased by 15% demonstrating timelier acknowledgement of when someone was dying.
- Documented evidence of communication to those important to the patient increased by 18%.
- Use of All Wales Care Decision Guidance to guide and support care in the last days of life increased by 34%.

**Conclusion** End of Life Care identified as a Quality Priority for the Health Board. Action plan developed by steering group of health professionals from diverse clinical areas. Development of End of Life Care Parasol Service with X2 full-time bands 7 CNS and X1 full-time Health Care Support Worker band 4. Implementation of End of Life Champion programme. Development of End of Life Care Parasol framework, the PARASOL framework was developed and underpins the five priorities of care and is an underlying framework for a Champion programme and service.