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Choosing the place of death: Empowering motor neurone disease/amyotrophic lateral sclerosis patients in end-of-life care decision making

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Motor neurone disease/amyotrophic lateral sclerosis (MND/ALS) is a fatal neurodegenerative disease that requires special attention at the end-of-life, particularly because disability is relentlessly progressive and death generally occurs in a predictable fashion.^{1,2} In the absence of a cure, palliative care and advance care planning (ACP) are key management strategies.^{1,2} The quality of care provided throughout the illness profoundly influences the end-of-life care (EOLC).^{1–3} The ‘End of Life Care Strategy’ aims at promoting excellence in EOLC.³ The central aspect of this strategy concerns patients’ preference for place of death. There is little in the literature about enabling MND/ALS patients to make choices about their EOLC, particularly relating to the preferred place of death (PPD).

Honouring patient’s choice for PPD is important, and this can be achieved through ACP.^{2,3} The Preferred Priorities for Care (PPC) document is a patient-held dynamic record that can be used as an ACP tool to promote discussion and documentation of wishes, preferences and priorities for care in relation to end-of-life issues.^{3,4} The Preston MND care and research centre serving a population of 1.6 million in North West England offers PPC document to all MND/ALS patients.

We reviewed the case notes of patients who died in 2012 and 2013 to investigate whether completion of PPC document affected actual place of death or hospital use towards end-of-life. There were a total of 99 deaths, of which 33 (33.3%) occurred in hospital. PPC document was completed by 52 patients (52.5%); 29 (55.8%) identified home as a PPD and the rest identified hospice/home ($n=11$; 21.2%), hospice ($n=10$; 19.2%) or nursing home ($n=2$; 3.8%). None identified hospital as a PPD. The majority of patients completing the document (completers) died at home ($n=18$; 34.6%) or hospice ($n=16$; 30.8%); 12 (23.1%) died in hospital and 6 (11.5%) died at nursing home. PPC document was not completed in 47 cases (47.4%). Majority of those who did not complete

(non-completers) the document died in hospital ($n=21$; 44.7%), while 16 (34%) died at home, 6 (12.8%) at nursing home, 3 (6.4%) at hospice and 1 (2.1%) while on holiday (Figure 1). A chi-squared test demonstrates statistically significant difference between whether patients completed the document and where they died ($\chi^2(16)=71.06$, $p<0.001$). Odds ratios indicate that non-completers were 1.96 times more likely to die in hospital. In contrast, completers were 4.84 times more likely to die in a hospice.

The main reason for admission in both groups was respiratory failure/shortness of breath (12 non-completers; 6 completers); 4 non-completers and none of the completers were admitted with general deterioration. Other causes for admission included falls, breakdown of care and other medical reasons. The major reason for non-completion of PPC document was reluctance or refusal by the patient to discuss EOLC issues (51%). Other reasons included late diagnosis, inability to make wishes known due to cognitive impairment and unexpected deterioration.

Majority of people would prefer to die at home, but unfortunately, this is not the reality they experience.³ Healthcare towards end-of-life places a major resource burden on the health service.^{3,5} A retrospective study of 1600 hospitalisations in patients with MND/ALS demonstrated prolonged and expensive admissions, a high in hospital mortality rate and few routine discharges.⁵ Most of our patients who completed the PPC document were

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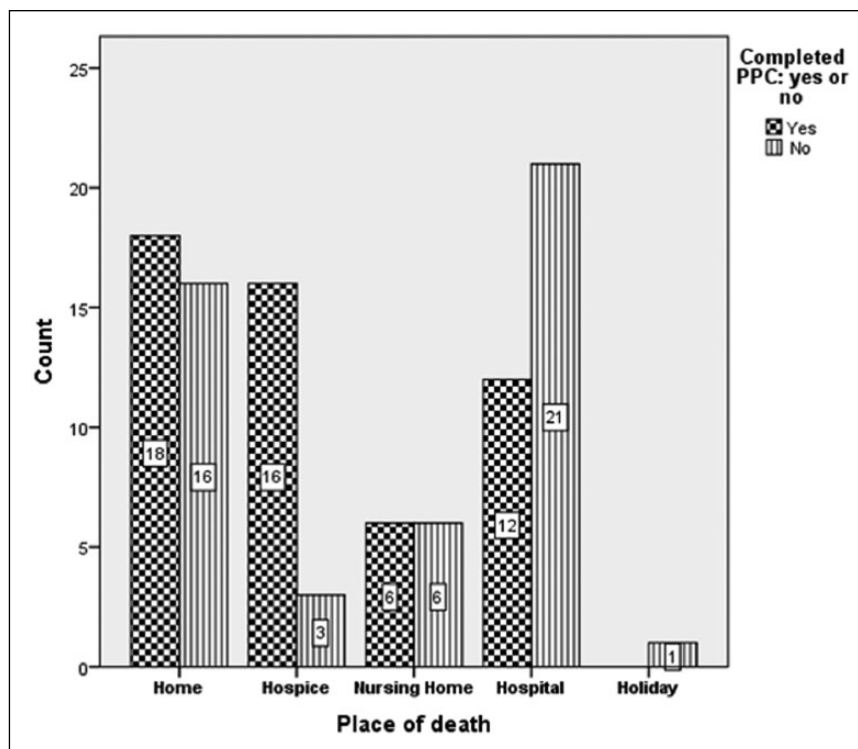


Figure 1. Actual place of death of patients who completed the PPC document ($n=52$) as compared to those that did not ($n=47$).

able to achieve their PPD. Completion of document was associated with significantly reduced hospital deaths and increased hospice deaths: 44.7% of non-completers died in hospital. This value is strikingly similar to MND/ALS deaths in hospitals (45.1%) in England.⁶ A significant proportion of these patients could potentially be cared at home, if their care preferences are known. The PPC document thus facilitates multi-agency collaborative working including involvement of specialist palliative care team and enables MND/ALS patients to die in their PPD. ACP has also been shown to yield positive experiences in caregivers of patients with MND/ALS and reduce grief related symptoms in the bereavement phase.² Patients/relatives feel empowered by participating in decisions about EOLC, and shared decision making is valued at the end-of-life.¹⁻³

We demonstrate that the use of PPC document empowers patients to gain control over their EOLC when dealing with an uncontrollable cruel illness, enables delivery of personalised care and reduces hospital admissions. EOLC should be discussed early and throughout the disease trajectory as an integral part of holistic care in MND/ALS. The PPC document is commonly used in the field of oncology but not in MND/ALS. Our study supports the view that PPC document should also be offered to MND/ALS patients as a standard of care.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Ethics

The study was approved by the clinical governance and audit department, Lancashire Teaching Hospitals NHS Foundation Trust.

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