

Advance care plans in progressive neurological conditions: quality of life measure, end of life measure or both?

Millett-Spicer C¹, Nelms L², Head J², Willis D²

1. Keele Medical School, 2. Severn Hospice, Shrewsbury
With thanks to Bowen J (neurologist, SaTH), Thompson S (care of the elderly physician, SaTH), Haywood M (Parkinsons disease specialist nurse, SaTH)

Background

Progressive neurological conditions (PNC) are associated with high symptom burden and complex psychosocial needs. These needs are well recognised in patients with motor neurone disease (MND), but less so in patients with other PNC despite their similarities. Progressive communication difficulties and cognitive impairment make it critical to have early discussion of their wishes for future care.

As a result of service development through COVID-19, a community based Speciality Doctor was recruited to write Advance Care Plans (ACP) for patients with non-MND PNC. Patients deemed to be in the last 12-18 months of life were referred to the service via neurology and elderly care consultants. This cohort study aims to explore palliative care needs of patients with PNC and whether neuropalliative ACP service might improve end of life care.

Methods

Patients referred to the service between October 2020 and June 2021 were included in the study. Advance care plans were written or reviewed in all patients. The ACP included a holistic document, anticipatory symptom management, Advance Decisions to Refuse Treatment and ReSPECT documentation. Further actions required as a result of ACP were recorded as were the number of patients who died and whether they had stayed in their preferred place of care.

Results

The doctor visited 38 patients during the study period; the majority of whom had Parkinson’s disease (60%) as per Figure 1.

33 (87%) patients had no ReSPECT form in place which was subsequently completed by the doctor. 27 (71%) patients required a more comprehensive ACP which took an average of 3.3 hour-long visits to achieve.

The process of ACP identified a number of unmet needs including symptom control requiring medication changes or onward referral to other disciplines - Figure 2.

12 patients died within the study period. All had just in case medications prescribed, an ACP in place and died in their preferred place of death.

Conclusions

This study confirms that patients with PNC have complex, unmet palliative care needs requiring multidisciplinary team input and early ACP discussion. Palliative care involvement improved symptom burden and end of life care for these patients.

Further analysis of hospital admissions has been undertaken. Ongoing qualitative work focusing on views of service users including patients, GPs and carers regarding ACP discussions will inform and improve future service delivery.

References

Boersma I, Miyasaki J, Kutner J, Kluger B. Palliative care and neurology: time for a paradigm shift. *Neurology*. 2014 Aug 5;83(6):561-7
Motor neurone disease: assessment and management. National Institute For Health and Care Excellence guideline [NG42]. July 2019. Accessed 08/02/2022



University of
Chester

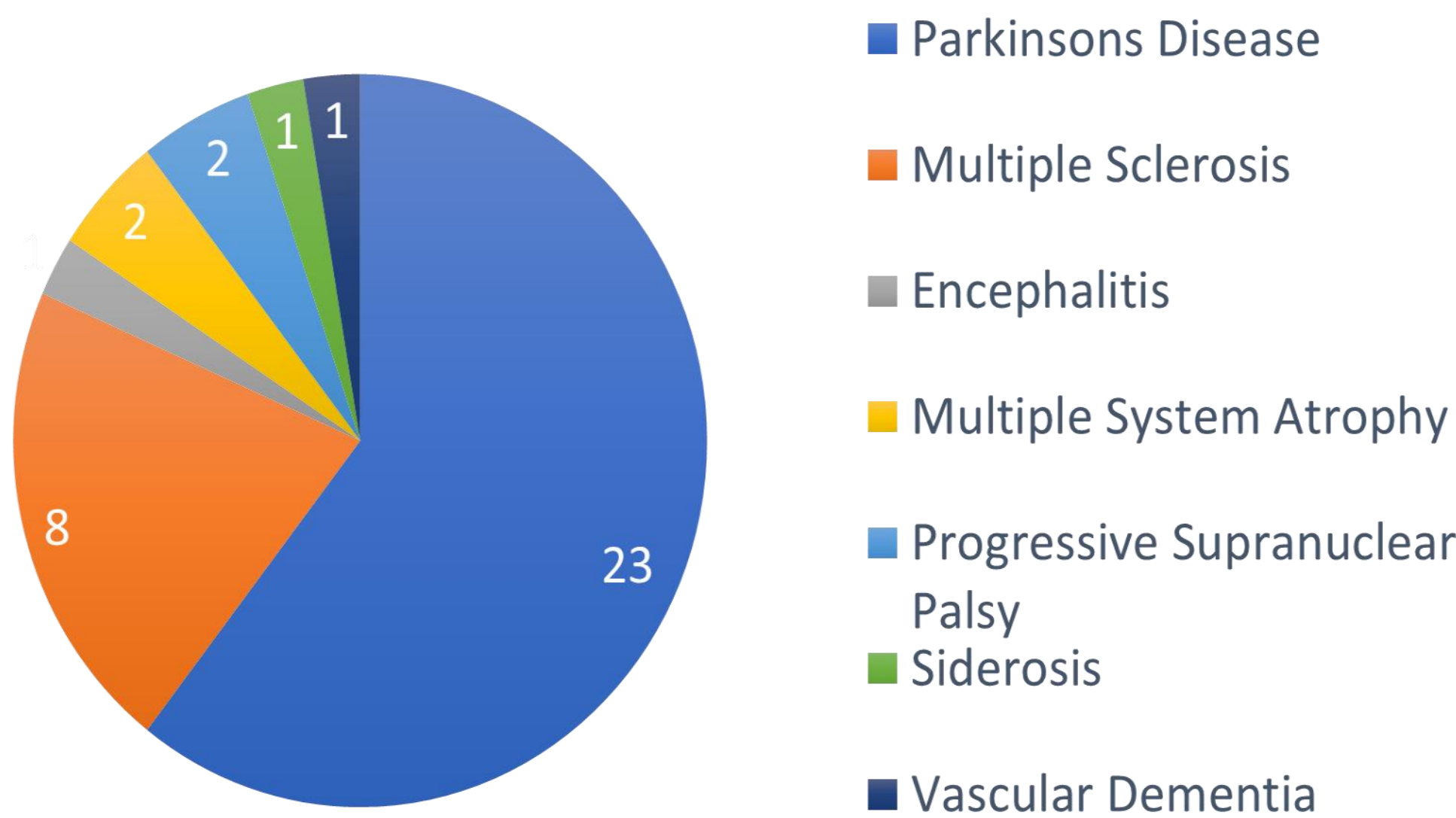


Figure 1: Patient diagnosis

Doctor action	Total (%)
Medication changes	27 (71%)
Onward referral to:	
•SALT	10 (26%)
•Social worker	12 (32%)
•Physiotherapy	11 (28%)
•CHC	7 (18%)

Figure 2: breakdown of actions from ACP appointment