

A retrospective case review of patients with neurodegenerative conditions presenting to Severn Hospice

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Introduction & background

Neurodegenerative conditions are complex and heterogeneous, hence the difficulty in standard setting. The EOLC Strategy 2008 estimated that there are 10 million patients living with neurodegenerative conditions in the UK, with Parkinson's Disease (PD) being the most prevalent [1].

This review aimed to identify patients with life-limiting neurodegenerative conditions referred to Severn Hospice over a 12 month period during 2017, and to gather data relating to reason for referral, key symptoms & whether advance care planning (ACP) had been addressed.

Method

- Patient referrals over the whole of 2017 searched
- Referrals related to neurodegenerative life limiting conditions identified, excluding Motor Neurone Disease (a comprehensive service exists already)
- Data collated, anonymised & analysed

Patient demographics

| Female | Male | Total |
|------------|-----------|-------|
| 24 (53.3%) | 21(46.7%) | 45 |

Figure 1
Table demonstrating sex distribution of patients included in the review.

Patients with neurodegenerative conditions referred to Severn Hospice in 2017

- Parkinson's Disease (PD)
- Multiple Sclerosis (MS)
- Progressive Supranuclear Palsy (PSP)
- Multiple System Atrophy (MSA)
- Huntington's Disease (HD)
- Corticobasal Degeneration (CBD)

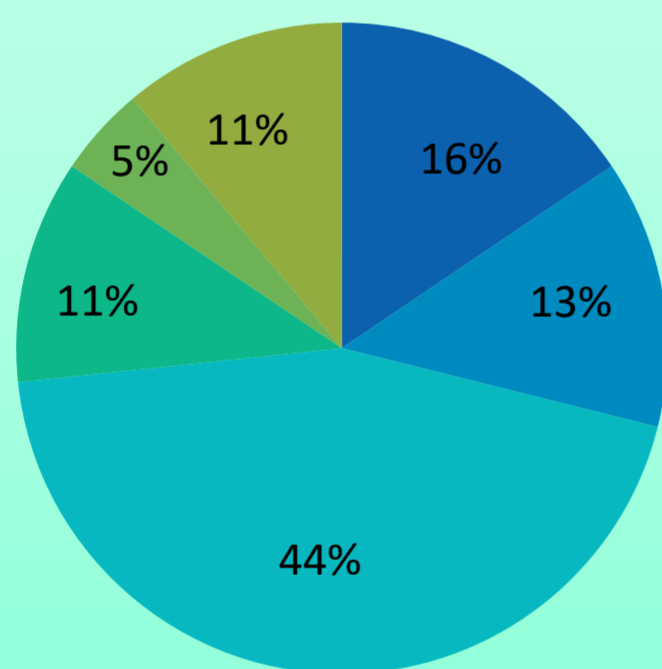


Figure 2
Over a 12 month period 45 patients with neurodegenerative conditions were referred to Severn Hospice. The greatest number of patients had been diagnosed with PSP (44%) and the second most common presentation was PD (16%).

Current challenges & barriers

The NCPC framework for neurological conditions identified some of the complexities making service design so challenging [2]. These included:

- Long duration of illness & slow deterioration
- Unpredictable trajectories
- Complex MDT care needs
- Many patients dying with, not from, their condition
- Widely variable disorders, with a range of symptoms

This raises the question – when should palliative services be involved in care, and does a lack of involvement at an early stage lead to poorer outcomes for patients?

DNACPR in place at time of referral

- DNACPR
- No DNACPR

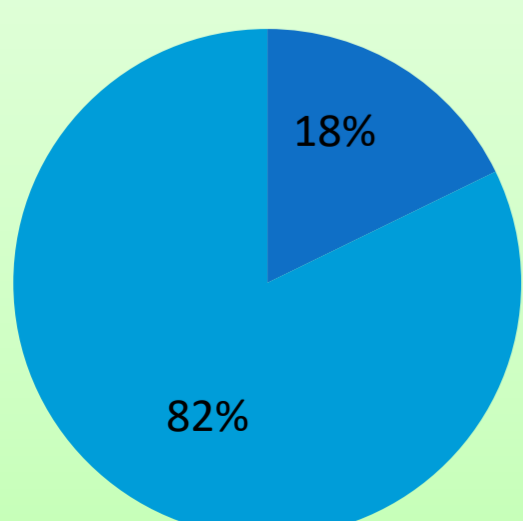


Figure 3
The majority of patients seen did not have a DNACPR prior to referral.

Advance Care Plan (ACP)

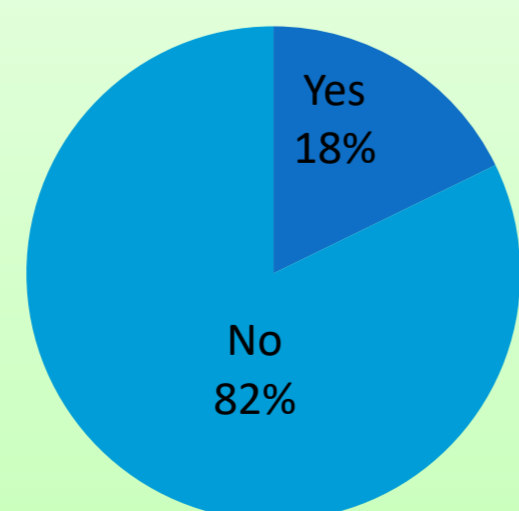


Figure 4
Prior to palliative care involvement most patients had no ACP.

Average no of years between diagnosis & referral to palliative care services

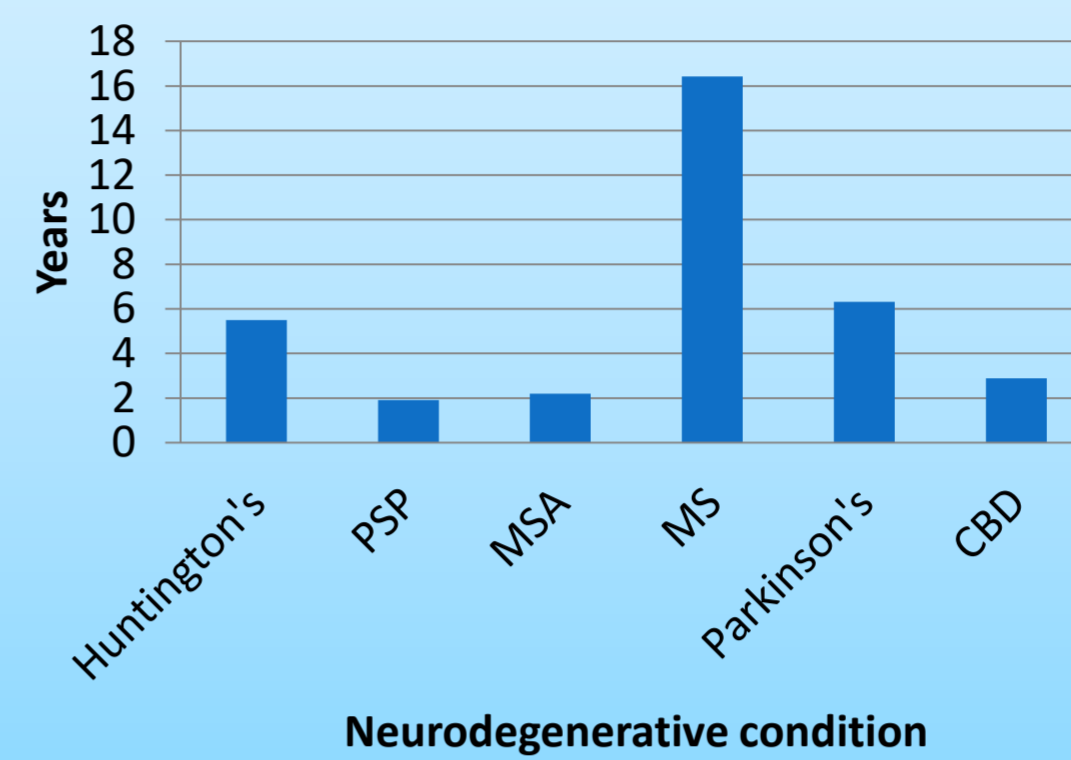


Figure 5
Disease trajectories greatly differ across neurodegenerative conditions. MS had the longest period (~16 years) between diagnosis & referral to palliative care. Evidence suggests if referral is too early this can be psychologically distressing for patients [3].

Calculations based on mean average.

When should patients be referred to palliative care services?

Trigger factors have been identified which could prompt referral to palliative care in the absence of joined-up care [4][5][6] including:

- Rapid physical decline
- Cognitive decline
- Complex symptoms
- Risk of aspiration
- Infections

Referrals & symptoms

Figure 6
Physical deterioration was the most common known reason for referral.

Reason for referral to Palliative Care services

- EOLC
- Future planning
- Unknown
- Symptom management
- Deterioration

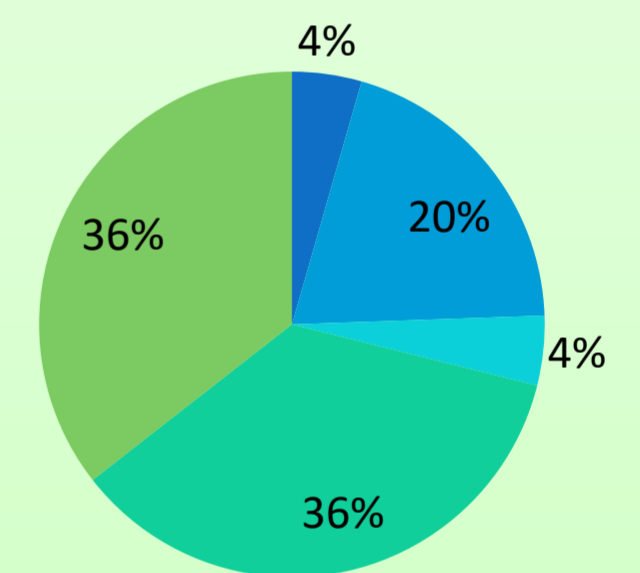
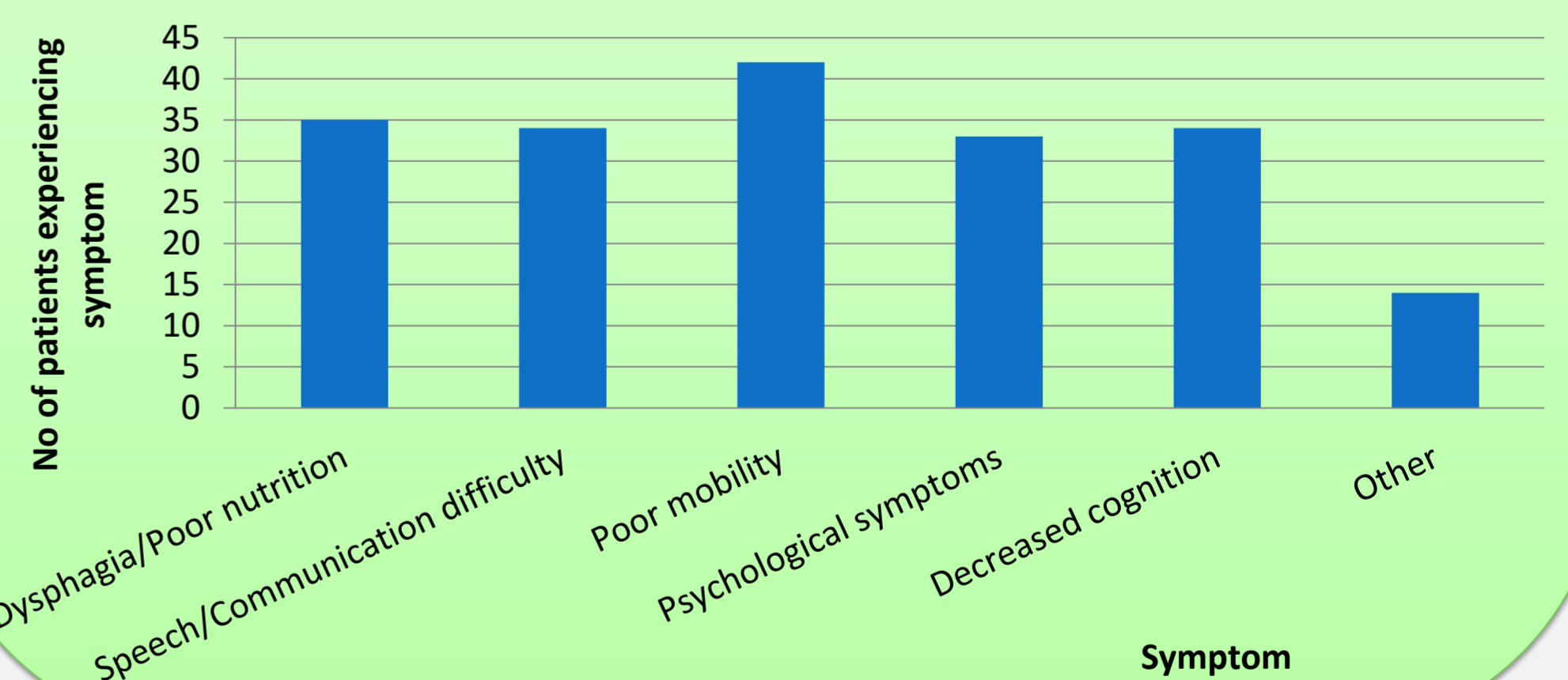


Figure 7
This review found that patients referred had experienced symptoms classed as triggers to referral by the SPICCT tool [5] Other symptoms included pain, incontinence & hypersalivation.

Most common symptoms experienced by patients referred to Palliative Care services



Conclusions & recommendations

- Criteria for referral [4][6] corresponds with symptoms experienced by this patient group. Further evidence should be collated to support use of SPICCT tool & its adoption more widely.
- Further education & training for all healthcare professionals, particularly in relation to ACP and DNACPR and when they should be put in place.
- Earlier palliative care involvement prior to deterioration to build relationships with patients & families and to allow earlier symptom control.

References

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- [3] van Vliet et al. How integrated are neurology and palliative care services? BMC Neurology (2016) 16:63 DOI 10.1186/s12883-016-0583-6 (Accessed 23 July 2018)
- [4] Hussain et al. Palliative care triggers in progressive neurodegenerative conditions: An evaluation using a multi-centre retrospective case record review and principal component analysis. Palliative Med (2018) 32(4):716-725. doi: 10.1177/0269216318755884 (Accessed 23 July 2018)
- [5] University of Edinburgh. The Supportive and Palliative Care Indicators Tool (SPICCT) (2017). Available at: <https://www.spicct.org.uk/download/the-supportive-and-palliative-care-indicators-tool-2/?wpdmdl=867&refresh=5b71787da30681534163069> (Accessed 23 July 2018)
- [6] Marie Curie. Triggers for palliative care: Improving access to care for people with diseases other than cancer (2015). Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf> (Accessed 24 July 2018)