

Enhancing care for people with Advanced Multiple Sclerosis using a Neuropalliative Hub Model

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Introduction

People with advanced Multiple Sclerosis (pwAMS) have accumulated physical, psycho-social, existential and spiritual needs.

Such patients meet the criteria for palliative interventions according to the World Health Organisation^{1,2}, however most people with MS do not get the support they need for their palliative care needs under current healthcare provision³.

The MS Hub service:

- Multidisciplinary team (MDT) meeting: integrating community teams with secondary care
- Neuropalliative clinic: person-centred focusing on quality of life, addressing multimorbidity, polypharmacy and advance care planning (ACP).

We describe the pilot experience of this novel service.

Design and Method

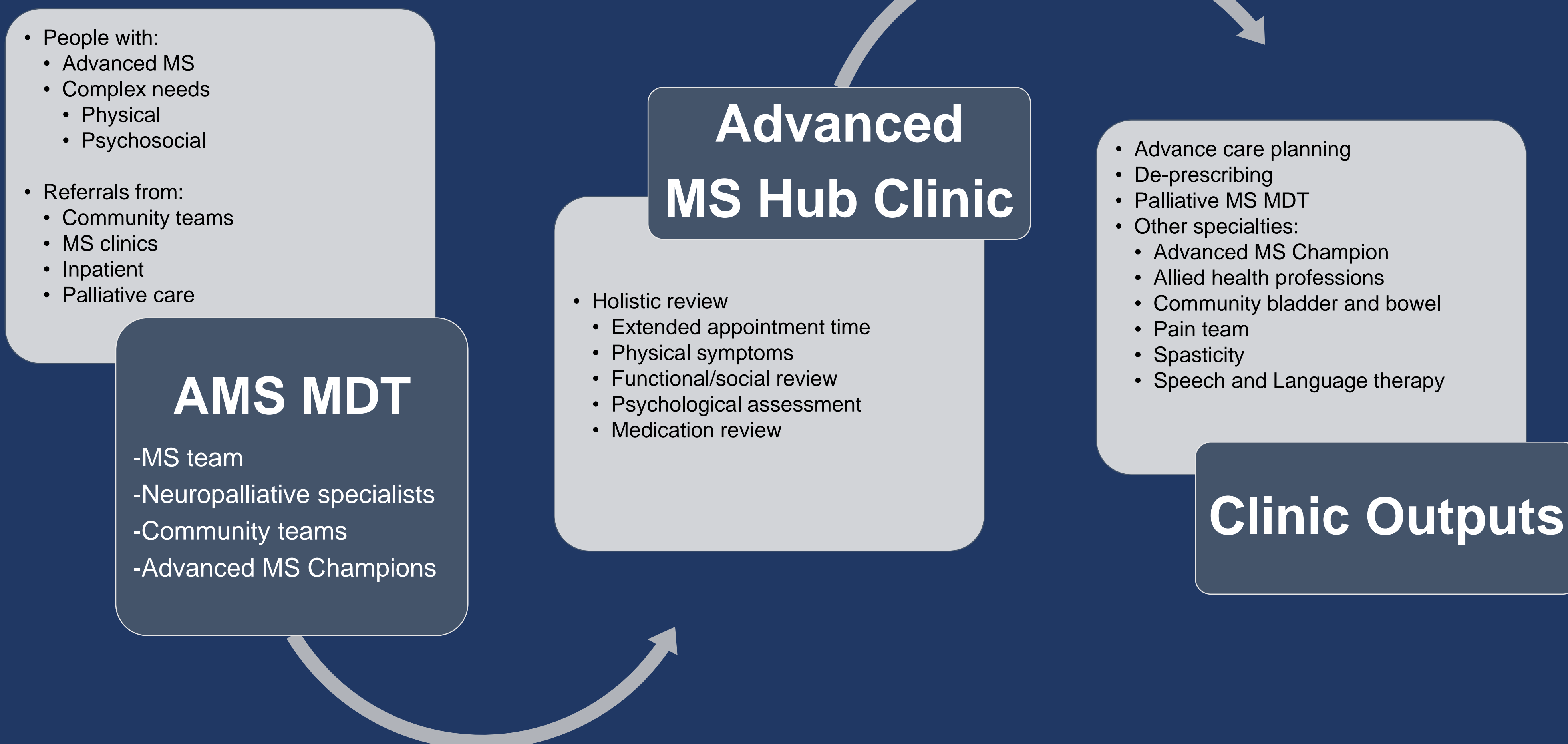
- Descriptive statistics were used to characterise:
 - Referral characteristics
 - Demographics
 - Unmet palliative care needs
 - Service outputs

MS Hub clinic patients (n=23):

- Mean age 60 years
- High disability (EDSS 8)
- 23% had cognitive impairment
- Most (87%) living in their own home
- Combined 175 hospital bed days in the previous year.

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Service Model



Results

- First 12 months:
 - MDT: 44 meetings, 152 patient discussions, 78 patients
 - Clinic: 23 patient reviews
- Referrals received:
 - Community (38%) and secondary care (52%)
- Demographics:
 - Mean age: 58 (range 28-80), median EDSS: 8, mean number of comorbidities: 6.2 (2 to 11) and mean number of medications: 7.4
- **Unmet needs were identified in the following areas: care/equipment (56%), mobility/spasticity (38%), neuropsychiatric (23%), pain (18%), advance care planning (22%) and bladder/bowel symptoms (21%)**
- Clinic interventions included: formal ACP (78%), bladder and bowel interventions (52%), spasticity interventions (30%), Referral to allied professions (OT, SLT, PT, SW) (83%) and specialist palliative care (13%).

Conclusions

People with MS referred to our advanced MS Hub service have multidimensional suffering which affect multiple aspects of personhood⁴.

We have demonstrated the palliative care needs of this population and propose an integrated primary palliative care service to address suffering. Our service builds on opportunities for collaboration between community and secondary care teams to provide clear and compassionate communication, manage symptoms and provide advance care planning for this vulnerable group in a sustainable manner.

Timely reviews and focussed advance care planning discussions may alleviate worry for patients and families and reduce unnecessary utilisation of healthcare services.

Future developments will utilise patient feedback and focus on collaboration with specialist palliative care services and Advanced MS Champions as well as evaluating impacts on health outcomes.

References:

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3. The Forgotten Many: A 2020 Vision for Secondary Progressive Multiple Sclerosis [Online]. Available: [The-Forgotten-Many-A-2020-Vision-for-Secondary-Progressive-Multiple-Sclerosis-JUNE20-15062020.pdf](https://www.wilmingtonhealthcare.com/wp-content/uploads/2020/06/The-Forgotten-Many-A-2020-Vision-for-Secondary-Progressive-Multiple-Sclerosis-JUNE20-15062020.pdf) (wilmingtonhealthcare.com)
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