Palliative care and advance care planning in Myotonic dystrophy type 1

Audet E [1], Turner C [2], Hewamadduma C [3], Maidment L [4], Lilleker J [5], Kelly P [5], Nikolenko N [2], Marchant J [6], Willis D [1,7], Willis T [7,8]

1) Severn Hospice
2) National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust
3) Sheffield Institute for Translational Neurosciences (SITRAN), University of Sheffield
4) Academic Neuromuscular Unit, Sheffield Teaching Hospitals NHS foundation Trust
5) Salford Royal Care Organisation, Northern Care Alliance NHS Group
6) The University of Manchester
7) Chester University Medical School
8) Robert Jones and Agnes Hunt Hospital

BACKGROUND

The creation of an 'emergency care plan' is recommended for all patients with complex neuromuscular disorders. These provide concise, relevant and rapidly accessible clinical recommendations for emergency use, including 'escalation plans', and ceilings of care whilst considering and engaging the patient's views and wishes. In contrast, 'advance care plans' (ACPs) focus more specifically on symptom control and 'end of life' decisions and are usually produced with involvement of the palliative care team. Such discussions may be more difficult to have with patients due to their complexity.

A 'traffic light' system relevant to patients with neuromuscular disease, the 'Oswestry model', has been created and subsequently adapted for DM1. This categorises patients as red, amber, or green, according to the likely palliative care needs at each stage of disease. Use of this tool has been piloted in four geographically varied neuromuscular centres in the UK, highlighting the need for identifying patients for discussion around ACP and 'symptom control' clinic. Those categorised as 'amber' in the traffic light system requires consideration for discussion' and those who were 'red' prompt referral to a palliative care clinic.

We report on the last five years of deaths from four neuromuscular centres in the UK.

AIMS/OBJECTIVES

To understand whether the 'Oswestry Traffic Light model (DM1) adapted' successfully highlights patients with DM1 nearing the end of their life, who may then benefit from palliative care and advance care planning.

To see whether this method of categorisation leads to more palliative care input and advance care planning for patients flagged as 'amber' or 'red'.

METHODOLOGY

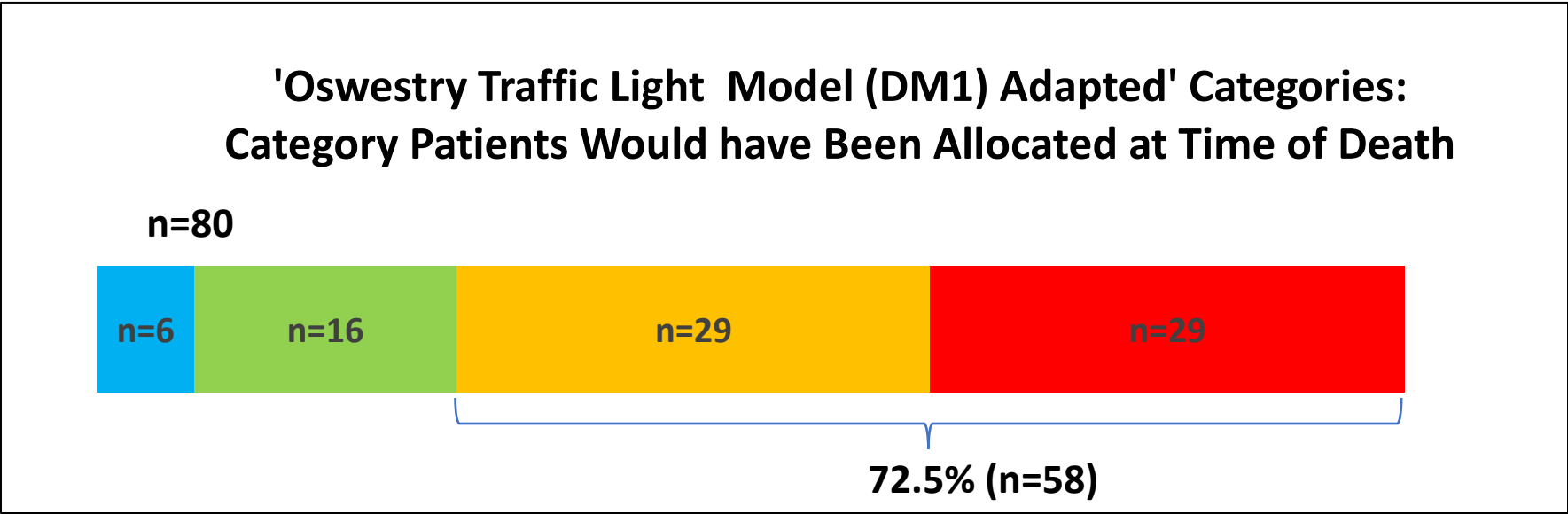Table 1   Oswestry traffic light model (DM1) adapted

- DM1 Deaths from the last 5 years at four neuromuscular centres have been reviewed.
- Three centres retrospectively applied the 'Oswestry Traffic Light model (DM1) adapted' to patients with DM1 who had died (2020-2025).
- The fourth centre: Robert Jones and Agnes Hunt (RJAH) Orthopaedic Centre, had prospectively used the 'Oswestry Traffic Light model (DM1) adapted' for their patients with DM1 over the last 5 years, allowing insight into whether the tool can successfully prompt action and appropriate support.

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RESULTS

81 deaths occurred across the 4 centres over 5 years, 1 data set was excluded due to lack of information to be able to apply the traffic light model.

'Oswestry Traffic Light Model (DM1) Adapted' Categories: Category Patients Would have Been Allocated at Time of Death

n=80

n=6   n=16   n=29   n=29

72.5% (n=58)

The traffic light system successfully identified over 70% of the DM1 patients as approaching the latter stages of their life. Had the model been prospectively applied, 58 patients meeting amber or red categorisation could have been identified, prompting more advance care planning and palliative care referrals allowing better support and patient-centred care towards the end of life.

The Traffic Light System prospectively piloted at RJAH, Oswestry, had allowed allocation of these 11 patients to the traffic light categories prior to death; of these patients; 5 allocated to 'amber' were known to Palliative Care at the time of their death, 2 had documented ACP discussions – one in the 'green' category and one in the 'amber'. Average age of death in 'amber' 59.8 years.
None of the patients who died in the Manchester (n=32) or Sheffield (n=4) cohorts had any documented evidence of ACPs or palliative care input – despite some of these patients' deaths being identified as expected. The London cohort (n=33) had evidence of 4 ACPs in plave, 3 of these were in the 'red' category and 1 in the 'amber'; it was unknown whether any of this cohort were known to palliative care.

Average Age at death ranged from 56.7- 59.8 years. Data was limited about cause of death. However, it was observed that of the unexpected 'Green group' deaths there were recurrent features of frailty and poor self care with reports of falls, poor nutritional status, evidence of poor personal care and poor compliance. Future work will explore whether this could be another sign of poor prognosis leading to additional key indicators to influence traffic light allocation.

CONCLUSIONS

Palliative care involvement and advanced care planning is an important but often overlooked facet of the management of patients with complex neuromuscular disorders. Our results suggest that tools such as the 'Oswestry model' can be used to structure care, to prompt advance care planning and to facilitate access to appropriate palliative care services.

Further work is needed to understand whether there are adaptations needed to the 'Oswestry Traffic Light model (DM1) adapted' to more accurately stratify patients into categories that better represent their prognosis.

Future work will continue to look at the impact of the prospective use of this model for people living with DM1 to inform the ongoing development of services and support.

REFERENCES

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