The End of Life: An Overview of Issues and a Project to Optimise Care in Huntington's Disease Patients

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Introduction

Mill Lodge is a 13-bed inpatient neuropsychiatric ward in Leicestershire, UK. The service primarily functions for patients with Huntington's Disease (HD), an autosomal dominant neuropsychiatric disorder. It manifests with progressive signs and symptoms within a clinical triad, comprising choreic motor disturbance, cognitive decline, and psychiatric disorder.

The over-arching service in Leicester comprises the inpatient ward; a community division, extending to Northamptonshire and Rutland; and a research arm. Due to both a paucity of appropriate community placements and the complex needs of this unique patient group, some are inpatients for long durations, and End of Life (EoL) care is necessitated. On average in the inpatient setting, this occurs approximately 1-2 times per year and is co-ordinated with the help of GP colleagues and the local district nurses.

As such, inpatient psychiatric staff are deeply involved in this complex area of care, and it can create high degrees of discomfort in the group.

Aims

This project therefore aims to optimise End of Life (EOL) care at Mill Lodge using a QI framework.

This was achieved through an initial primary aim of understanding both inpatient and external staff attitudes and confidence around providing EoL care at Mill Lodge.

From here, a number of further aims were added, broadly including:

- The identification of specific areas of EoL care that staff felt could be improved
- To subsequently introduce a series of initiatives to optimise EoL care for our patients.

Specifically, this included projects to enhance collaboration with external stakeholders; understand and streamline pharmacy processes; the optimisation of internal resources for staff, such as psychology-led debriefing; and seek relative feedback on EoL care they had experienced.

Method

The first stage of intervention included the planning and delivery of an educational event on EoL care specific to HD, achieved with our regional palliative care colleagues.

As well as our inpatient nursing and medical staff and the palliative care teams, local GPs, district nursing (DN) colleagues, speech and language therapists and psychologists attended.

The meeting allowed an open forum where we were able to identify barriers and facilitators to optimal care from all aspects of the assembled MDT.

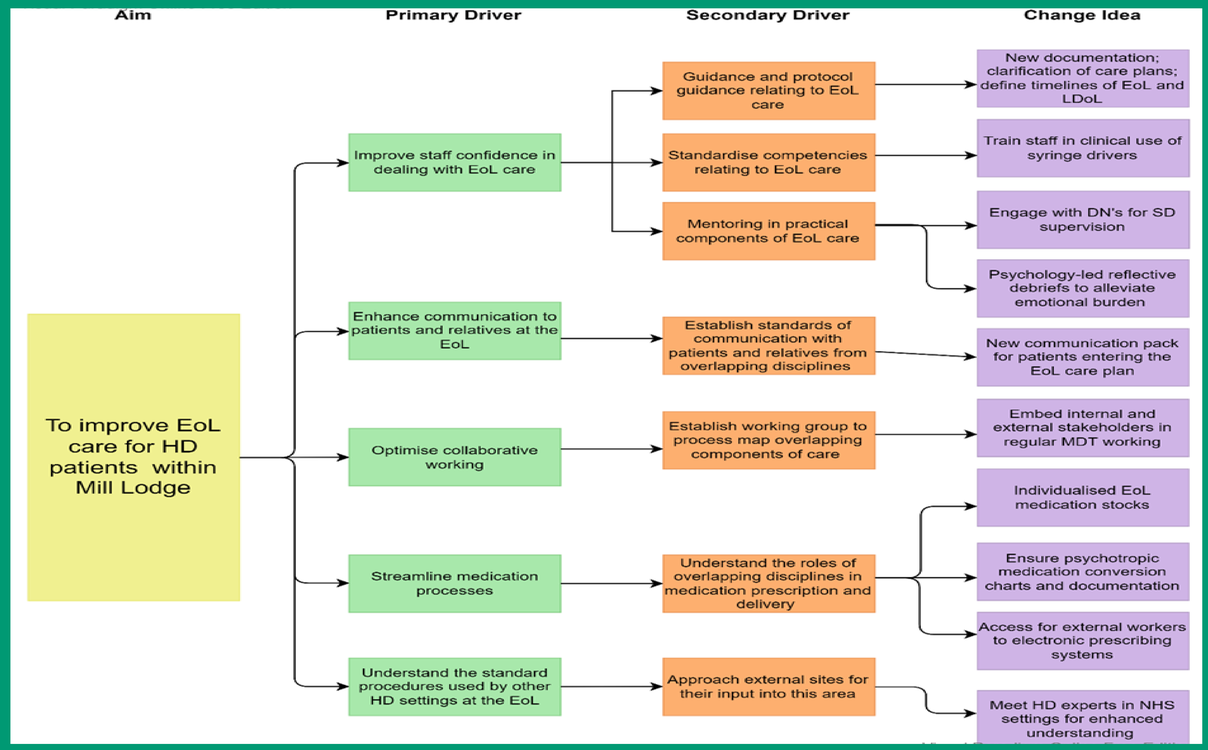
We also commenced involvement with the local QI team to develop the project, and a driver diagram to establish change was completed; this is **provided below.**

Results

Initial interactions revealed that staff confidence in dealing with EoL care was low. This was consistent across inpatient staff and the involved external teams. Issues with care-planning; medications; communication barriers; and when to refer for specialist help were key reasons for this.

Specifically, staff commented on the use of overlapping systems for the prescription, administration and safeguarding of EoL medications. Prescription was provided by GPs from a protocol written by internal medical staff. The electronic system used on the ward was unavailable to external staff, who duplicated this work on paper, increasing the chance for errors. This was compounded by the doses of EoL medications required for patients unable to orally accept medications that controlled their involuntary movements. At times when staff and relatives wanted to ensure comfort, the slow up-titration of EoL medications frequently saw movements escalate, with an associated perception of discomfort for the patient. The available equipment – in particular, syringe drivers (SD) – were sometimes unavailable in the numbers required, adding a barrier to optimal care. The inpatient nursing team were not comfortable with SD administration, whilst the DN's felt they could be trained in this to help their workload, for which they could provide oversight and mentoring.

A range of interventions were commenced to enhance collaborative working between the overlapping teams; optimise medication administration; and to enhance communication between staff, patients and their carers.



Conclusion

Staff without specialist knowledge require support. The efforts made to improve collaboration with external colleagues broke down barriers that were preventing optimal care and allowed all parties to express their opinions. This allowed us to transparently appraise our current processes and optimise guidance within this complex area.

The journey of optimisation continues, with practical educational interventions planned, such as syringe-driver training, and efforts to improve shared documentation. Collaborative working between different disciplines continues, with, for example, psychology-led reflective debriefing. Liaison with external specialist HD teams is beginning.

Optimal, collaborative EoL care from a confident team is possible and a crucial part of care for this unique patient group.

Acknowledgements

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