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POSTER ABSTRACT

Review of best practices of integrated care for people living with Motor Neurone Disease

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Introduction: Motor neurone disease is a life limiting progressive neurological condition that requires a team-based approach to care. Person-centred care (PCC), integrated care and access to specialised motor neurone disease (MND) multidisciplinary clinics (MDC) are optimal approaches to the delivery of quality service for people living with MND (plwMND) for improved quality of life, health outcomes and care experiences. These MND MDCs models of care vary in design, implementation, and are predominantly specialist hospital based. Therefore, not all MND services are delivered consistently highlighting a need to explore the evidence on current practices that contribute to more effective, efficient person-centred integrated care practices across the continuum.

Aim: This rapid review explores best practices of integrated care for people living with motor neurone disease, and their families and carers.

Methods: A search was undertaken of six databases, Medline (Ovid), Embase (Ovid), CINAHL, Cochrane, Joanna Briggs Institute and Google Scholar. The 1469 retrieved abstracts were screened for eligibility against the inclusion criteria, and full text review was conducted on 149 studies. Data were extracted from 58 studies and a quality assessment conducted on final 45 included studies. The following information was gathered from the included studies to inform the review.

1.What is 'best practice' in the management/care of plwMND

2.What models of (integrated) care have been developed to support plwMND

3.What are the common elements of integrated care approaches that have been implemented in MND?

4.What impacts, outcomes, or effects of integrated care approaches have been reported for plwMND?

Results: The initial review analysis indicated specialised MND multidisciplinary clinics (MDC) as 'best practice' in the optimal management of MND, but revealed no standardised approaches in design and implementation, the multidisciplinary workforce, and degree of integration and partnerships between hospitals and the community. MND MDC are predominantly hospital based, but the inclusion of either outreach community teams, hub and spoke approaches, and/or a hybrid design, (care delivered in person and /or by telehealth), improved integration, knowledge sharing and coordination across services. The timing of introduction and delivery of palliative care services differs but there is greater focus on integration into MND MDC, or earlier referrals to dedicated palliative care service and/or specific palliative care training of neurologist/multidisciplinary team, to optimise symptom management, decision-making and end of life care. Additional features that enable integration, improve care satisfaction and equity are one or a mix of 1) telehealth, 2) care coordination, 3) case management, 4) partnerships with MND associations, and/or 5) MND helpline.

Conclusion: This review highlights a range of practices of integrated care that are not universal and predominantly practiced in high income countries. Adapting delivery of model of care to stage and duration of MND, and differing expectations, needs and priorities of plwMND and caregivers, is a common theme throughout. There has been greater uptake in telehealth and technology to support the equitable delivery of integrated approaches to care, with rapid development in this area during COVID 19 pandemic.