



Service Priorities and Programmes Electronic Presentations

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Motor Neuron Diseases (MNDs) patient journey: Neuropalliative Approach

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Introduction

Motor neuron disease (MND) is a life-limiting progressive neurological disorder that destroys essential voluntary muscle activity with no definitive diagnostic test and curative treatment. Other than physical symptoms, psychological, social and spiritual needs cannot be ignored. Neurology nurse specialist has unique and significant role within multi-disciplinary team in providing holistic care throughout the journey.

Objectives

1) To review the impact of symptoms to quality of life in MND patients 2) To enhance the quality of care by collaboration among different professionals in interdisciplinary approach in providing holistic care to MND patients through their life journey

Methodology

A retrospective case study was conducted on 14 male and 6 female, (aged 40 to 73), diagnosed with MND and treated in Caritas Medical Centre (CMC) from July 2010 to June 2015.

Result

Results: First symptoms were muscle weakness (n=11, 55%), slurring (n=4, 20%), dysphagia (n=3, 15%), shortness of breath (n=1, 5%) and poor cognition (n=1, 5%). Major burdens were walking (n=20, 100%), swallowing (n=13, 65%), breathing (n=11, 55%), speaking (n=10, 50%) and impaired cognitive functions (n=1, 5%). 5 (25%) followed up in Joint Care Clinic, 9 (45%) cared at home by palliative nurse, 5 (25%) received in-patient care and required invasive ventilator support. Symptoms onset to consulting neurologist were 0 to 29 months, neurology and palliative nurses were 0 to 50 months. Symptoms onset to confirming diagnosis were 5 to 40 months. Diagnosed to certify death were 2 to 35 months (mean 10 months) with 11 patients alive at time of study. The findings indicated the involvement of neurology nurse and palliative care specialists in early phases was limited. Psychosocial and spiritual burdens were also significantly affecting patient's quality of life and end-of-life. Conclusions: Collaboration among different professionals in interdisciplinary

approach is deemed crucial in providing comprehensive and holistic care to walk with MND patients through their life journey. A one-stop interdisciplinary Neuropalliative Joint Care MND Clinic in CMC has proven beneficial in attending neurology, palliative care and allied health professionals in one single session which saving patient's energy in transportation and consultations in holistic approach.