



Service Priorities and Programmes Electronic Presentations

Convention ID: 991

Submitting author: Ms wong kit man

Post title: Advanced Practice Nurse, Pamela Youde Nethersole Eastern Hospital,
NULL

Evaluation of a nurse-led clinic for patient with Neuromuscular Disorders

KM Wong, MC Chow, PH Chiu, HY Lo, CN Lee, HY Cho, KYL So

Department of Medicine, Pamela Youde Nethersole Eastern Hospital

Keywords:

nurse-led clinic

neuromuscular disorders

survey

Introduction

In the past, many patients with Neuromuscular Disorders (NMD) and their families were forced to make hurried decision on tracheostomy and mechanical ventilation at the verge of death, without knowing or time to consider the long term implications of such commitment. Indeed, many of them regret their decision. In retrospect, this could be avoided by advanced end-of-life care planning. Therefore, since 2012, the respiratory team has joint-hand with the neurology team to set up a comprehensive management protocol for NMD patients. Upon diagnosis of NMD, these patients and their family would be referred to a dedicated Respiratory Nurse-led Clinic. A respiratory nurse specialist will interview the patient and family in the nurse clinic. Structured education on disease course of NMD, implications of progressive respiratory failure and various options of respiratory support would be offered. Particular focus would be put on practical aspects and implications of assisted ventilation, impact on quality of life and their subsequent care. These patients would be followed up every 3 to 12 months subsequently depending on disease progress. Ventilation support would then be provided according to patients' wishes.

Objectives

To evaluate the satisfaction of patient and their families toward a nurse-led clinic.

Methodology

A survey was carried out after the NMD patients have attended the nurse-led clinic.

Result

Results: 16 patients were recruited in 2012 - 2015. Evaluation results from the 16 patients are as follows: 1. Average age 62.1 years old. 2. 12 patients (75%) are male and 4 patients (25%) are female. 3. Nurse-led clinic attendance rate 96.4% (53/55 nurse clinic appointments). 4. 15 patients opted not for tracheostomy and only 1 patient decided for tracheostomy. Results from the questionnaire: Question 1: Adequate content and explanation provided (9.5 /10) Question 2: Make me understand my future care plan (9.8125 /10) Question 3: Have opportunity in participating my future care plan (9.8125 /10) Question 4: Illness

monitoring (8.8125 /10) Question 5: Attending nurse's attitude (9.8125 /10)
Question 6: Feedback on question (9.5625 /10) Conclusions: The traditional care path for NMD patients is associated with poor anticipation, lack of planning and suboptimal patient engagement. Our nurse-led clinic helps to improve the knowledge level, psychological aspect and physical care of NMD patients and their families. This service receives lots of favorable responses from these patients and families.