Service Priorities and Programmes

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Review of patients with neuromuscular disease under Neuro-pulmonary rehabilitation program

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Introduction

Disease prevalence of Neuromuscular diseases is about 1 in 3000. At the late stage, respiratory failure and infection are the most frequent reasons for unplanned hospital admission and mortality. The neuro pulmonary rehabilitation program in the Duchess of Kent Children's Hospital was started since 1997. Physiotherapists are one of the members within this multidisciplinary management team playing an important role in enhancing pulmonary functions, in education of parents and care givers for home chest care, in facilitation of the usage of assisted ventilation, in monitoring of lung function parameters regularly and in maintenance of bronchial hygiene during hospitalization. The average follow up period for this patient group is with an average of 12 years.

Objectives

The patients' clinical and social profiles were reviewed to evaluate how an optimized pulmonary function could enable a better life.

Methodology

42 cases under the program were reviewed in 2012. Their diagnosis, age range, lung function, unplanned hospitalization, education level, employment and social status were analysed

Result

Results: Amongst the 42 cases, There were 9 (21%) female and 33 (79%) male. For their specific diagnosis, 15 (36%) were Duchene muscular dystrophy, 11 (26%) were spinal muscular atrophy, 11 (26%) were muscular dystrophy/ myopathy and 5 (12%) were motor sensory neuropathy. 21 (50%) of them required assisted ventilation during night time. The average age was 25.1 (ranged from 14 to 37) and 37 of them had reached adulthood (age above 17). Amongst these 37 adults under the program, their average forced vital capacity (FVC) was 1502cc at their 17 years of age, 1296cc at 22 years of age and 1222cc at 26 years of age. The average maximal insufflation

capacity (MIC) was 1490cc at 22 years of age and 1450cc at 26 years of age. Amongst all the patients under review (n=42), a total of 6 unplanned hospitalizations for chest exacerbations were reported for the year 2012. Concerning the education level, amongst the 42 cases, 13 patients were either enrolling or have completed university level of education, 4 had obtained high diploma and were on vocational training. 13 patients were employed after graduation. Concerning social status, 35 patients lived with family members, 5 lived in hostel and 2 lived alone with a helper.

Conclusion: Under the neuro-respiratory rehabilitation program, patients with neuro-muscular disease sustain a healthy life span.They are able to live and maintain in the community with satisfactory educational achievement and social integration.