

## Causes of Death in Neuromuscular Disease Patients: 15-Year Experience in a Tertiary Care Hospital

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**Abstract :** Background□Cardiopulmonary complications seem to cause high morbidity and mortality in patients with neuromuscular diseases (NMD) but so far there is no domestic data reported in Taiwan. We, therefore attempted to analyze the factors to cause the death in NMD patients from our cohort. Methods□From 1998 to 2013, we retrospectively collected the information of the NMD patients treated and followed up in Kaohsiung Medical University Hospital. Forty-two patients with NMD who expired during these fifteen years were enrolled. The medical records of these patients were reviewed and the causes of death and the associated affecting factors were analyzed. Results□Eighteen patients with NMD (mean age=13.3, SD=12.4) with complete medical record and detailed information were finally included in this study, including spinal muscular atrophy (SMA) (n=9, 7/9: type 1), Duchenne muscular dystrophy (n=6), congenital muscular dystrophy (n=1), carnitine acyl-carnitine translocase (CACT) deficiency (n=1) and spinal muscular atrophy with respiratory distress (SMARD)(n=1). The place of death was in ICU (n=11, 61%), emergency room (n=3, 16.6%) or home (n=4, 22.2%). For SMA type 1 patients, most of them (71.4%, 5/7) died in emergency room or home and the other two expired during an ICU admission. The causes of death included acute respiratory failure due to pneumonia (n=13, 72.2 %), ventilator failure or dislocation (n=2, 11.1%), suffocation/choking (n=2, 11.1%), and heart failure with hypertrophic cardiomyopathy (n=1, 5.55%). Among the 15 patients died of respiratory failure or choking, 73.3% of the patients (n=11) received no ventilator care at home. 80% of the patients (n=12) received no cough assist at home. The patient died of cardiomyopathy received no medications for heart failure until the last admission. Conclusion: Respiratory failure and choking are the leading causes of death in NMD patients. Appropriate respiratory support and airway clearance play the critical role to reduce the mortality.

**Keywords :** neuromuscular disease, cause of death, tertiary care hospital, medical sciences

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