

Tele-monitoring in paediatric and young home-ventilated neuromuscular patients - A multicenter case-control study

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INTRODUCTION

Mechanical ventilation has dramatically improved life expectancy in neuromuscular disorders (NMD). Regular monitoring and home-care management are needed to prevent frequent respiratory exacerbations and hospitalisations¹. Few studies have shown that tele-monitoring (TM) in adult NMD patients can reduce hospital admissions secondary to acute respiratory infections^{2,3,4}.

We hypothesized that a TM nationwide study designed for home-ventilated NMD young patients was feasible and effective in preventing hospitalisations for respiratory exacerbations when compared to a standard clinical approach

- Primary outcome were hospital admissions in TM patients compared to controls
- Secondary outcomes were patients/caregivers' satisfaction and caregivers' burden

METHODS

Two-year nationwide case-control multicenter study (Genoa, Alessandria, Catania)

INCLUSION CRITERIA

- Paediatric onset of NMD and established on home mechanical ventilation (invasive/non-invasive) <18 years of age
- Parents proven skills on early detection and management of respiratory exacerbations⁵

EXCLUSION CRITERIA

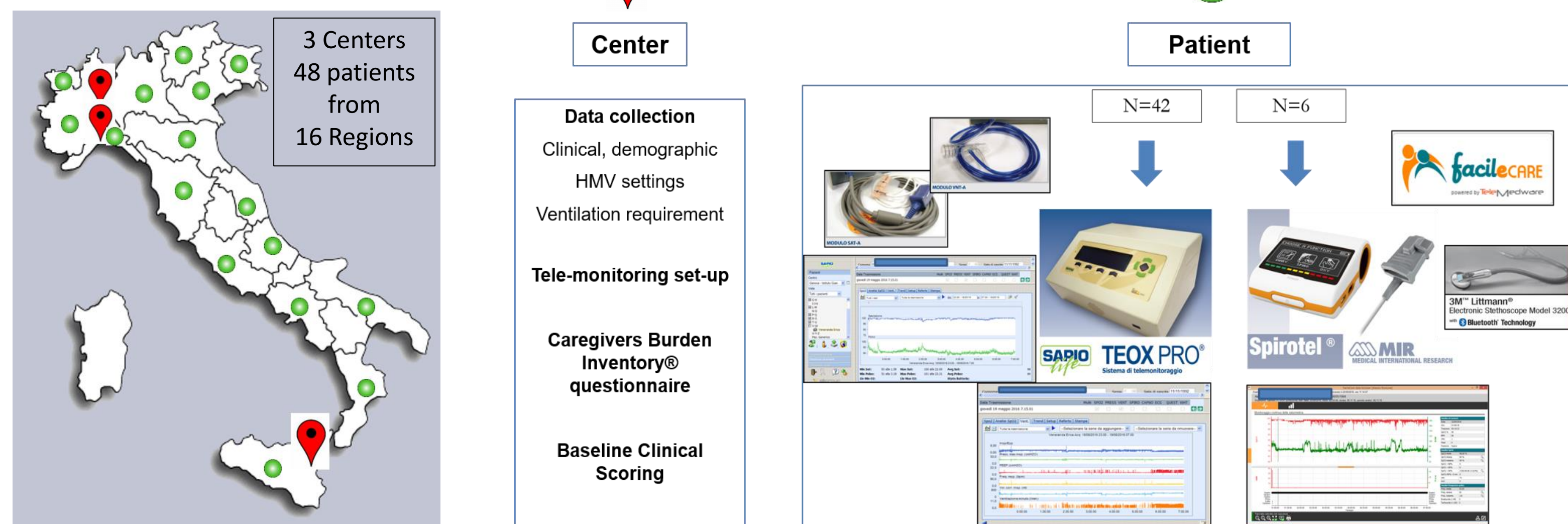
- Patients whose parents/caregivers could not satisfactorily manage home ventilator/cough assistance/suction machine device were excluded

STUDY DESIGN

- Patients' severity was graded according to their ventilator daily requirement in low (<12h/day), moderate (12-20h/day) and high (>20h/day).
- Caregivers' satisfaction was assessed monthly by a three-items questionnaire.
- Caregiver Burden was assessed by a validated questionnaire⁶

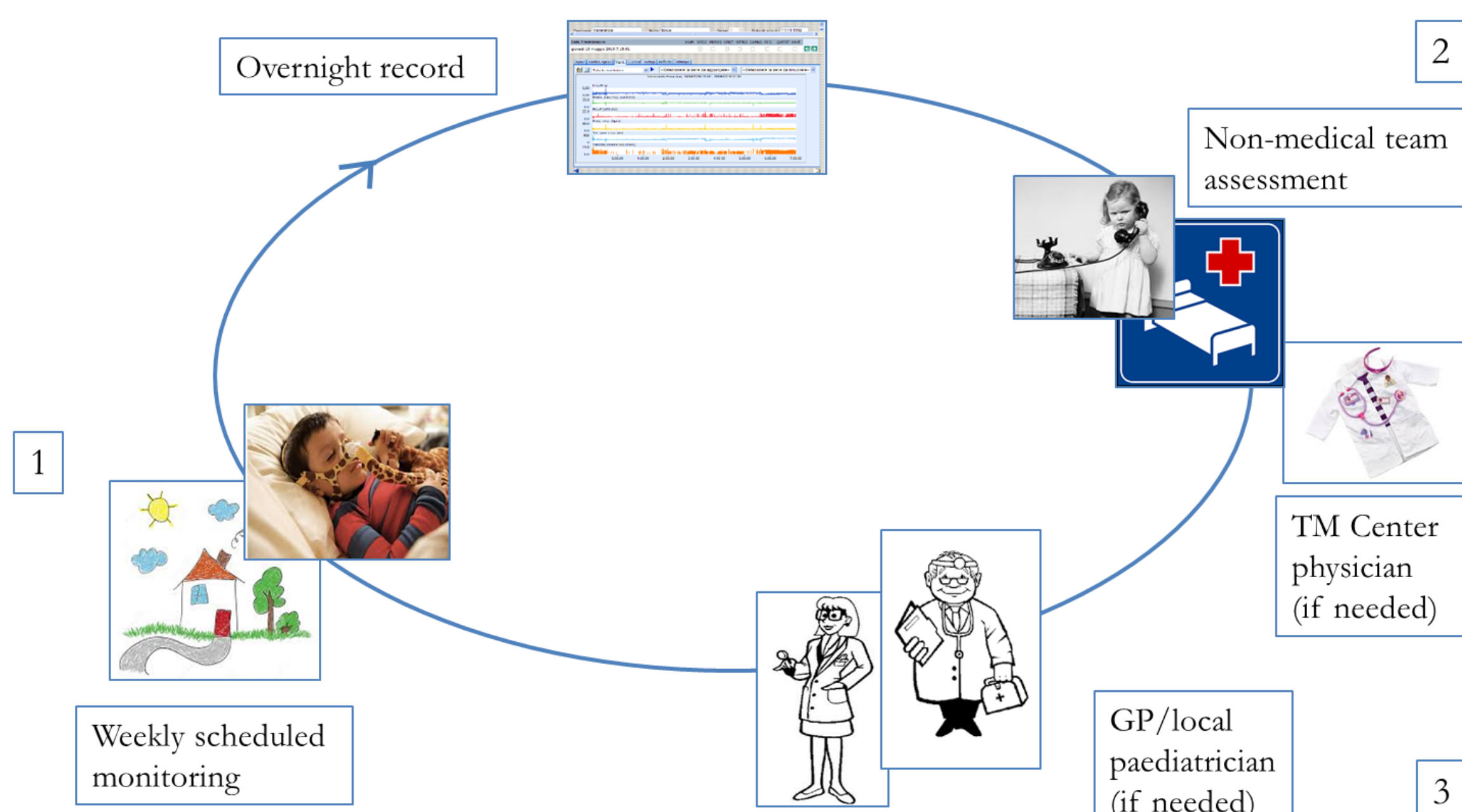
TM patients' hospitalisations over TM study were compared with those of TM patients pre-TM and an age-disease-matched control population.

ENROLMENT AND TM SET-UP



STUDY PROTOCOL

1. Weekly scheduled overnight home monitoring of SaO₂, heart rate and ventilation. Transmission on the following morning to TM Centres
2. TM non-medical team called parents after transmission to assess clinical conditions. At baseline, an "ad hoc" clinical score⁷ was administered. Score variations >3 were considered exacerbations. to each patient.
3. In symptomatic cases, non-scheduled calls were addressed by TM medical team.



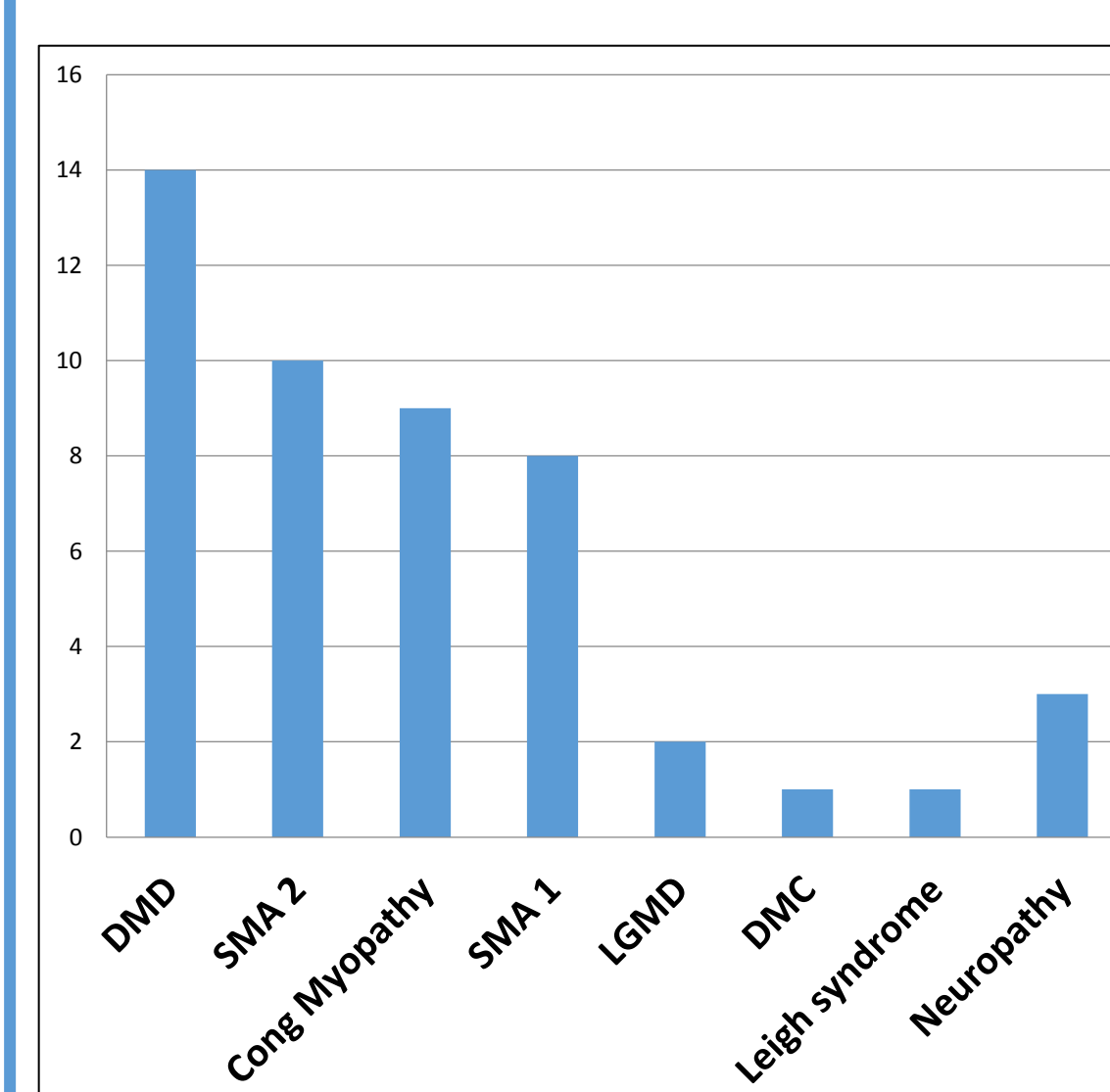
RESULTS

- 48 patients enrolled (mean age 16.3±8.6 years), 30 (62.5%) male
- 41 on non-invasive and 7 on invasive home ventilation
- TM median duration 14.1 (11.4 - 15.6) months

Exacerbations managed at home:

- TM patients: 48/59 (81%) (36 low-, 16 moderate-, 7 high-severity)
- Controls: 32/53 (60%) (24 low-, 12 moderate-, 17 high-severity)

TM PATIENTS AND CONTROLS

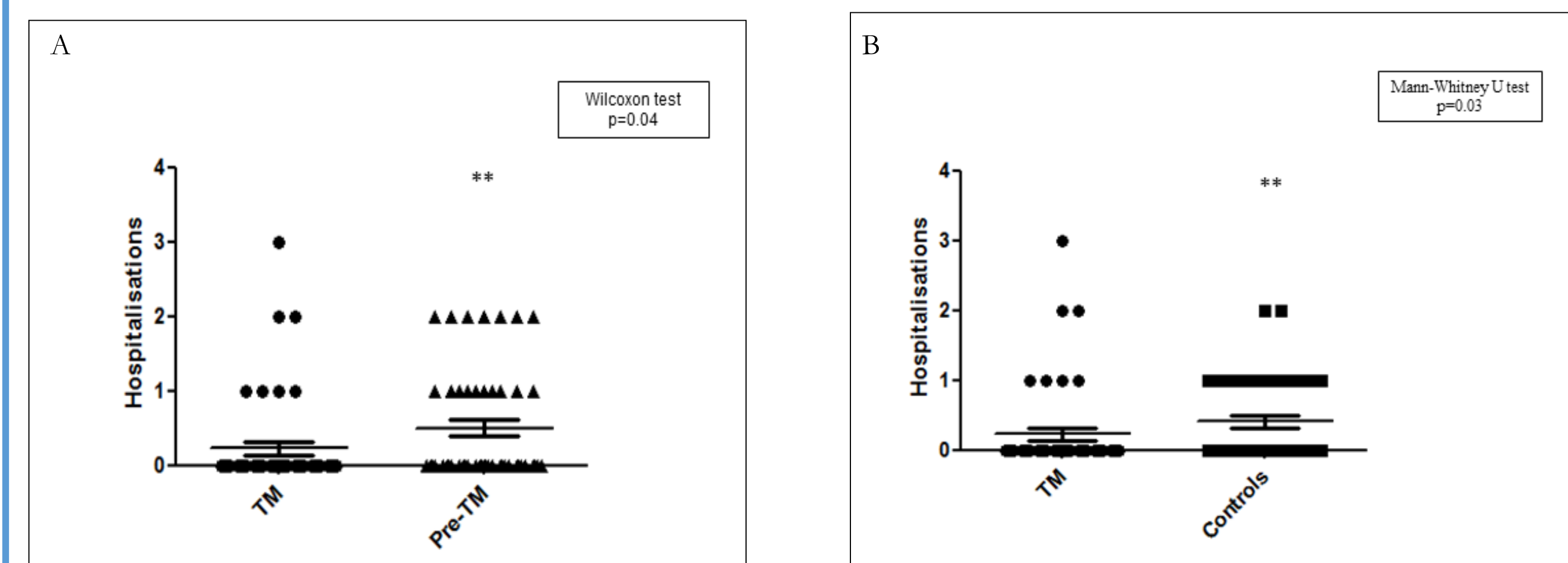


TM patients NMD Diagnosis

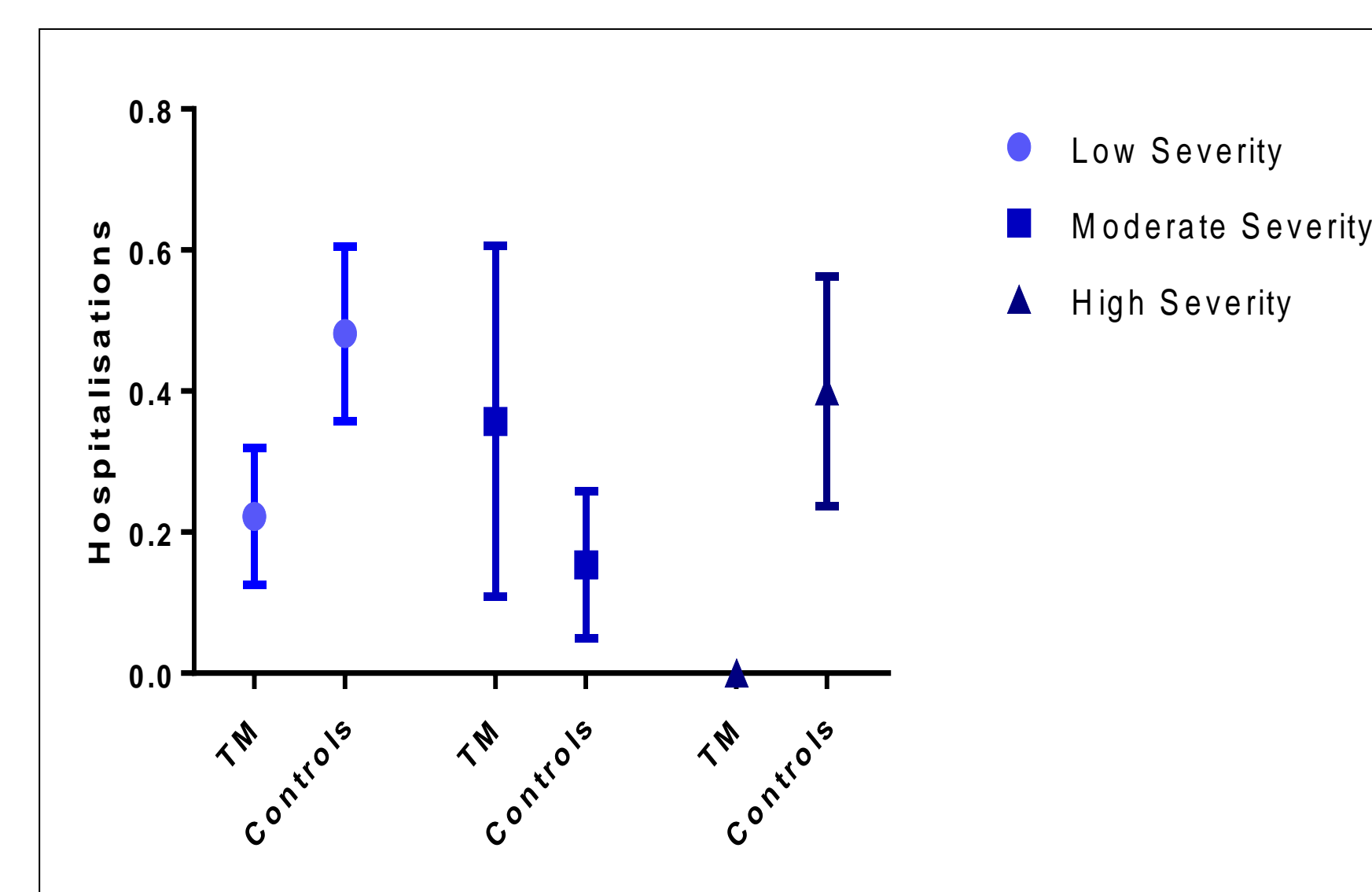
	Cases (N=48)	Controls (N=48)	P
Male (%)	30(62.5%)	36(75.0%)	0.19
Age start TM (y)	16.4(8.9-22.1)	15(9.2-21.5)	0.51
Age start ventilation (y)	12.6(4.5-17.5)	13.9(6.2-17.1)	0.69
Home ventilation (h/day)	10.5(8-16)	8(8-13)	0.24
Severity			0.97
low	26(54.2%)	27(56.2%)	
moderate	13(27.1%)	12(25.0%)	
high	9(18.8%)	9(18.8%)	
Invasive ventilation (%)	7(14.6%)	2(4.2%)	0.16

Clinical characteristics of TM patients and controls

HOSPITAL ADMISSIONS IN TM PATIENTS vs Pre-TM AND vs CONTROLS



Comparison of hospital admissions between TM patients and (A) Patients pre-TM (B) Controls



High-severity TM patients had a significantly lower number of hospitalisations compared to controls. No differences were found in low- and moderate-severity TM patients (Mann-Whitney U test)

PATIENTS' SATISFACTION AND PARENTS' BURDEN

- 5/48 patients complained discomfort due to respiratory flows detector
- Satisfaction was rated as "very good" in 79% caregivers
- No differences in Caregiver Burden Inventory® (p=0.06) were found

CONCLUSIONS

This is the first Tele-monitoring project on young NMD patients on invasive and non-invasive home mechanical ventilation. It has proven effective in reducing number and length of hospital admissions for respiratory exacerbations. Good patient adherence and caregivers' satisfaction were achieved.

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