

Continuity of care: telemedicine and pulmonary rehabilitation at home may reduce episodes of respiratory failure in patients with neuromuscular disease



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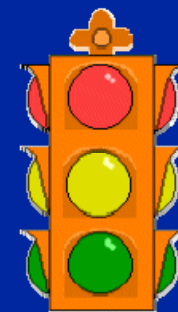
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Background and aim

- **Pulmonary complications are the main cause of morbidity and mortality in neuromuscular patients**
- **Aim of this project was to evaluate the efficacy of a home follow up program combining telemonitoring and chest physiotherapy (CPT) in preventing acute respiratory episodes**

Methods - 1

- **Design:** prospective observational study - 24 months, April 2008-March 2010 – historical control
- **Enrolment criteria:** reduced efficacy of cough, overt or borderline respiratory failure, degree of family support, home to hospital distance
- **Equipment:** pulse oximeter with a modem for transmitting data to a remote control centre, in charge of alerting the GP / home nurses and the Pulmonologist when needed
- **Interventions:** on the basis of patient data and phone consultation, the CPT intervention at home was agreed upon in case of bronchial mucus retention
- **Primary outcomes:** number of emergency room admissions or hospitalization following respiratory exacerbations





Methods - 2

Actors involved:

- Patient and caregiver
- Health-Professional team
 - Hospital Pulmonologist
 - General Practitioner (coordinator)
 - Home care Nurses
 - Chest Physiotherapist
- Service provider
- UILDM (Italian Union Against Muscular Dystrophies)



Settings:

HOSPITAL  HOME


Results

- 0 **13 patients enrolled**, mean age 35.6 ± 16.8 yrs, range 17 - 65 years (3 F/10 M)
- 0 1st year of monitoring, **18 alerts**, average 1.38 ± 1.38 (SD) alert/patient
- 0 2nd year of monitoring, **5 alerts**, average 0.38 ± 0.65 alert/patient
- 0 **Respiratory Therapist's interventions** in 24 months, 241: 34% postural drainage, 17% basic clinical and functional evaluation, 23% use of mechanical cough assistance with an in-exsufflator device and 19% combined treatment, 4% muscular exercises and 2 % training of care-givers

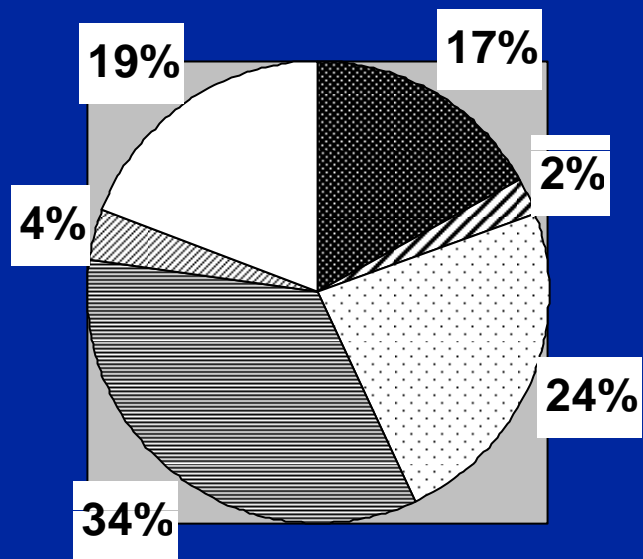
OUTCOMES

- 0 In the first 12 months there were 4 episodes of **hospitalisation**, none in the next 12 months
- 0 In the year prior to the project, there were 7 cases of hospitalisation and 1 case of emergency room admission

Results - patients

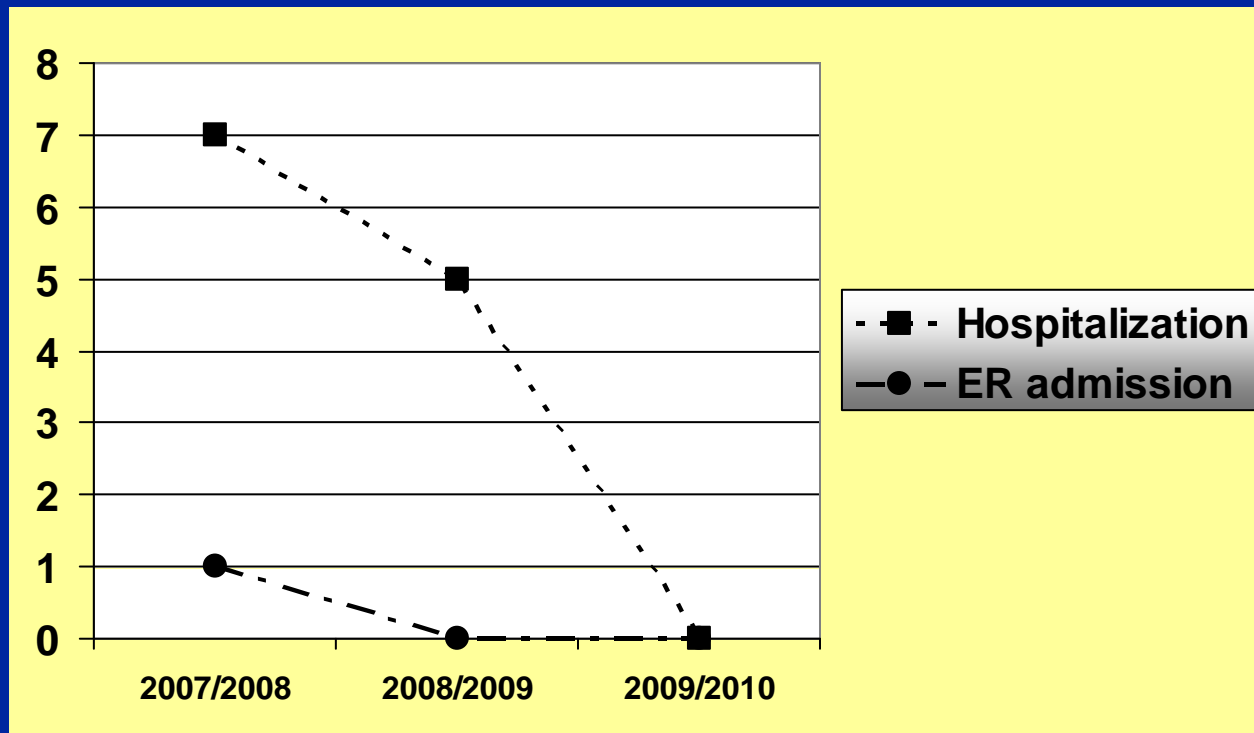
	Year of birth	Diagnosis	Tracheostomy	Mechanical ventilation
I.R.	1943	Chest wall deformity		YES
D.F.	1968	Becker's muscular dystrophy	X	YES
C.A.	1952	Girdle amyotrophy		YES
G.D.	1973	Congenital myopathy	X	YES
F.A.	1988	Congenital Muscular dystrophy		YES
G.F	1994	Type 2 spinal amyotrophy	X	YES
T.L.	1958	Idiopathic myopathy	X	YES
V.G.	1978	Pompe disease		YES
T.A.	1970	Girdle muscular dystrophy		NO
D.V.	1953	Kugelberger-Welander spinal amyotrophy		NO
D.G	1993	Duchenne muscular dystrophy		NO
P.M.	1981	Duchenne muscular dystrophy		YES
C.L.	1982	Duchenne muscular dystrophy	X	YES

RT Interventions by %



- Clinical-functional evaluation
- ▨ Training
- ▤ Mechanical in_exufflation
- ▥ Postural drainage
- ▧ Exercise
- Combined treatments

Hospital admissions in the 12 months prior to the project and during the 24 month observational telemonitoring period



Conclusions

Continuity of care based on close cooperation among patient/care-giver, hospital Pulmonary specialists, General Practitioners, Home nurses, service provider and using telemonitoring and a CPT program at home can reduce hospitalisation and emergency room admissions in patients with neuromuscular disease

Main limitations:

No parallel randomized control group

Small sample