

# Home mechanical ventilation patients: a retrospective survey to identify level of burden in real life

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**ABSTRACT:** *Home mechanical ventilation patients: a retrospective survey to identify level of burden in real life. M. Vitacca, J. Escarrabill, G. Galavotti, A. Vianello, E. Prats, R. Scala, A. Peratoner, E. Guffanti, L. Maggi, L. Barbano, B. Balbi.*

**Background and Aim.** Home care for patients under home mechanical ventilation (HMV) may cause dramatic physical and economic burden in addition to the burden of time on family/caregivers and health care service (HCS) with difficult resource allocation decision-making.

**Our aims were:** 1. To identify conditions causing major care burden in managing HMV patients according to family and payer's perspectives related to characteristics of the disease, dependency and accessibility; and 2. To find, if any, differences among diseases.

**Methods.** A questionnaire was sent to eight pulmonary centres to identify factors connected with the greater care burden. Retrospective data of 792 patients still alive and in HMV was reviewed.

**Results.** Compared to neuromuscular disorders (NM)

and chest wall deformities, the COPD group have presented a statistically greater number of hospitalisations/yr ( $1.37 \pm 0.77$ ), greater length of stay ( $13 \pm 10$  days), higher number of outpatient visits/yr ( $2.55 \pm 1.73$ ) or emergency room accesses/yr ( $0.74 \pm 1.08$ ). Patients with NM diseases need more home care. The prevalence of one, two and three among five selected burden criteria (needs of MV > 12 hrs/day, tracheotomy, high dependency, distance from hospital, frequent hospitalisations) was respectively 19%, 30% and 33% of the cases; the NM was the group most represented.

**Conclusions.** In HMV patients: 1. underlying disease, level of their dependency, hours spent under MV, presence of tracheotomy, home distance from hospital, hospital accesses are the causes of major care burden; and 2. as a novelty we have demonstrated that more than fifty percent of them present two or three contemporaneous criteria selected as care burden, being NM and COPD patients the most representative group necessitating of family's and HCS's care respectively.

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## Introduction

Home care for respiratory patients is a complex array of services delivered in an uncontrolled setting in which patients and families are integral members of the health care team [1]. Complexity, lack of direct control, acute exacerbations and chronic condition of patient health problems, are all likely contribute to the difficulty in organising home care assistance [1].

Among various home care programmes, mechanical ventilation at home (HMV) shows a great prevalence in European countries [2]. Although neuromuscular, chest wall and lung diseases were the main diagnosis for which HMV was equally prescribed, a wide variability in the type of underlying diseases merged among the enrolled centres [2]. Moreover, the follow-up of HMV patients is heterogeneous among Europe. Follow-ups have

been strictly recommended to be structured and are to be integrated with technology for patients on HMV [3-7] since traditional, nurse-based home follow-up programmes, if they exist, have limitations relating to the number of patients that can be included, costs and logistic problems such as distance and time needed to reach the patients at their homes. Unfortunately, the European survey [6] on HMV lacks information on actual and most efficient forms of follow-up, on details of patients and families' burden or information on health care services (HCS) economic burden sustained for home environments and hospitalisations. Home health agencies, nurses, chest physicians, and other providers, can contribute to a societal discussion on reframing the goals of home care to include those that are both desirable and achievable [1]. A recent ATS statement [1] has stressed the necessity to provide home care focusing on a patient-cen-

tered perspective and patient and family satisfaction: reduction of complications resulting from hospitalisation, maintaining an acceptable quality of life, and enabling a comfortable and dignified death have been proposed as major end point [1]. At the same time costs are increasing and reimbursement structures are vital items for home care services [1]. According to recent recommendations to facilitate European planning guidelines, to promote further epidemiological research [2] to ensure equality of provision and access [2], to exchange information on quality control between the different partners involved in home mechanical ventilation [6] we have conducted a retrospective survey with the following purposes:

1. To identify, among patients on HMV, the issues and conditions which cause the major care burden according to patient/families and payer's perspectives related to the main characteristics of the disease, dependency and accessibility.
2. To find, if any, differences among diseases.

### Methods

The investigative multicentre protocol was approved by the Institutional Ethics Committee (S. Maugeri Foundation, Gussago, Italy). In the first part of the study, a questionnaire was proposed by the main author (M.V.) to doctors of eight hospitals while illustrating the aims of the study (seven Italian hospitals: Chest divisions of Fondazione S. Maugeri IRCCS Lumezzane and Veruno, Ospedale Poma Mantova, Ospedale Civile Padova, Ospedale S. Donato Arezzo, Ospedale Civile Udine, Spedali Riuniti Bergamo, Rehabilitation centre of Casatenovo, and one Spanish: Chest Division, Hospital Universitari de Bellvitge, L'Hospitalet, Barcelona). Three out of eight units were devoted to the rehabilitation of sick patients including subjects coming from ICUs and admitted to a weaning centre for prolonged attempts of MV liberation. In these units common protocols for pulmonary rehabilitation programmes are used. The other five units were acute respiratory departments of large hospitals devoted to care all kind of respiratory diseases. All units have been particularly involved in home mechanical ventilation (HMV) programmes (educational or follow up) for 10 years. Appendix 1 shows the list of items resulted by the doctors' interviews as the major causes of care burden in patients under HMV for family and HCS related to the main characteristics of the disease, dependency and accessibility and the % of centres which have proposed the single items. Among all the reviewed items proposed, a final list of five criteria (high dependency, tracheotomy, necessity of more than 12 hrs of MV, distance from hospital more than 30 km, presence of frequent hospitalisations due to respiratory deterioration or side effects of MV) was finally identified by a steering committee composed by the two principal investigators (M.V. and J.E.) with two nurses and one respiratory therapist expert in this field. The five criteria were chosen because

they had been described by all the centres as strong criteria for care burden (see appendix 1). The contemporary presence of 5, 4, 3, 2 or 1 criteria was considered by the steering committee as extremely compromised (5 criteria), highly compromised (4 criteria), seriously compromised (3 criteria), moderately compromised (2 criteria) and compromised (1 criterion).

In the second part of the study, each referent doctors of the eight specialised centres was then invited to review retrospectively one year of their database concerning all of their patients followed on HMV who were still alive on the 30th March 2006 according to the following data:

Anthropometrics data, duration of MV, diagnosis, time under MV, number of tracheotomized patients, level of patients' dependency, distance from hospital, hospitalisations, length of hospital stay, number of outpatients visits, ER accesses, nurse home visits, home relapses and urgent phone calls to sanitary staff.

All of the centres were confident about the number of patients who were still alive at the time of the revision because these patients are usually followed by a strict dedicated outpatient programmed for HMV users. A discharge plan according to recent statement on Home Care for Patients with Respiratory Disorders [1] was used by all 8 centres. All of the centres have similar electronic database with clinical records for each patient. According to the European survey [2] exclusion criteria were patients presenting obstructed sleep apnea with home CPAP use because they are a selected population with different follow up problems and diagnosis of cancer, pulmonary fibrosis and central neurological disease because samples size with end of life necessities. Three main diagnosis groups were collected: 1. neuromuscular (Duchene syndrome, Becker's disease, Cingular disease, congenital dystrophy, rigidoid rachides syndrome, amyotrophic lateral sclerosis) 2. COPD and 3. chest wall disease.

Nurse home visits have been scheduled by local home care programmes according to individual necessities with scheduled and on demand appointments. The categories of topics addressed included review of symptoms and medications; education about disease, symptoms, about ventilation tracheotomy care and medications; smoking cessation; education for an action plan for worsening symptoms; contact with primary care physician. Criteria for urgent phone call to the respiratory centre were sudden worsening of symptoms to review the action plan in this case. The functional follow up planning included outpatient blood gas analysis every 4 months or more frequent if necessary and lung function tests when possible and requested by care staff.

All data relating to centres, and therefore users, was coded and kept strictly confidential. Data was summarised for each centre using non-parametric statistics and were presented as median, standard deviation or percentage. Differences in hospitalisations, length of stay, outpatients and home care visits between COPD and not COPD

patients were conducted with the unpaired Student *T*-test for non-parametric data ( $p < 0.05$  was considered significant)

## Results

Table 1 shows the anthropometrics characteristics of reviewed patients, neuromuscular disease being the largest cause of HMV (48%). A great variability was found among centres for prevalence of neuromuscular patients (from 16% to 100%), of chest wall disease (from 0% to 45%) and of COPD (from 0% to 68%). All of the patients were under HMV for at least two years NM group being the more time consuming. Table 2 summarises the number of patients according to patient centered burden criteria. 251 patients (32%) were described as ventilator-dependent for more than 12 hours being the NM group of patients (56%) with the higher incidence. 158 patients (20%) presented tracheotomy and were ven-

tilated invasively being NM patients (54%) the more frequently tracheotomised. 354 (45%) patients presented severe immobility with high home dependency being, also in this case, the NM group (61%) who were the most represented. 283 (36%) lived more than 30 km away from the referral hospital: in particular NM (50%) were described as more needing of transfers to hospital. 80% of patients were admitted to a home visit programme (96% NM, 85 % COPD and 70 % CWD); table 3 shows the mean number of home nurse visits according to diagnosis. 85% of patients needed a home visit of the primary doctor after an urgent call. Table 3 shows the number of phone calls requested by the patients to the respiratory centre. As shown in table 3, in the year preceding the study, the reviewed patients had been admitted into hospital  $0.91 \pm 0.46$  times/y with a mean stay of  $7.5 \pm 4$ ; when compared to non-COPD patients, the COPD group was the most frequently hospitalised ( $1.37 \pm 0.77$  times/yr  $p < 0.001$ ) with the higher stay ( $13 \pm 10$  days  $p < 0.001$ ). The whole group necessitated of  $2.8 \pm 1.9$  outpatient visits/y being the COPD group the higher ( $2.55 \pm 1.73$  visits/yr  $p < 0.03$ ) consumer of outpatient hospital visits. Emergency room accesses were necessary  $0.48 \pm 0.58$  times/yr while a mean of  $2.77 \pm 0.32$  urgent telephone calls/yr were requested by patients or family to referral pulmonologist or nurse. In addition, COPD patients utilised ER access more frequently ( $p < 0.001$ ) than other groups. Table 3 shows NM patients received double ( $p < 0.001$ ) the number of visits when compared to other patients ( $8.27 \pm 18.8$  home visits/yr). When doctors checked for the number of COPD with at least one hospitalisation or two severe home relapses in the previous year they found that 93% of the COPD group met these criteria. The figure shows the distribution of patients according to common presence of one or more among five burden criteria proposed by authors. The majority of patients were defined as seriously compromised, moderately compromised and compromised in the 19%, 30% and 33% of the cases according to presence of 3, 2 and 1 criterion

Table 1. - Anthropometrics characteristics of reviewed patients

Patients, n°	792
Age, y	$67 \pm 11$
Males, n°	563
Diseases:	
COPD*, n (%)	289 (36)
Neuromuscular, n (%)	375 (48)
CWD, n (%)	128 (16)
Duration of HMV, y	$3 \pm 2$
Range, y	2-6

COPD = chronic obstructive pulmonary diseases; \* including overlap syndrome; CWD = chest wall disease; HMV = home mechanical ventilation.

Table 2. - Data from the patient's and family's perspective

	Neuromuscular N°	CWD N°	COPD N°	Total N°
Home ventilated pts, n	375	128	289	792
Duration of HMV, y	$5 \pm 4$	$4 \pm 3$	$3 \pm 2$	$4 \pm 2$
Age, y	$50 \pm 12$	$77 \pm 6$	$73 \pm 5$	$67 \pm 11$
Pts necessitating > 12 h MV, n (%)	141 (38)	16 (13)	94 (33)	251 (32)
Pts with tracheotomy, n (%)	86 (23)	12 (9)	60 (21)	158 (20)
Pts with mobility dependency*, n (%)	216 (58)	55 (43)	83 (29)	354 (45)
Pts who lives more than 30 km from Hospital, n (%)	142 (38)	58 (45)	83 (29)	283 (36)

\* For explanation of dependency see ref 12; MV = mechanical ventilation.

Table 3. - Data from HCS's perspective

	Neuromuscular		CWD		COPD		Total	
	n°	SD	n°	SD	n°	SD	n°	SD
Home ventilated pts,	375	/	128	/	289	/	792	/
Hospitalisations/y	0.54	0.39	0.78	0.47	1.37§	0.77	0.91	0.46
Length of stay/pt/y, days	5.08	5.27	3.76	1.60	13.14§	9.6	7.5	4.0
Out- patients visits/y	1.61	0.94	2.20	1.37	2.55#	1.73	2.82	1.84
Emergency Room Accesses/y	0.17	0.26	0.23	0.35	0.74§	1.08	0.48	0.58
Home visits/y	8.27^	18.8	4.53	10	4.53 +	8.7	5.2	10.6
Urgent phone calls/y	2.20	0.38	1	1.41	2.5	3.5	2.77	0.32
Unstable* COPD						270**	270**	

HCS: health care system; \* instability was defined as uncontrolled clinical status of chronic respiratory failure with at least one hospitalisation or two home relapses necessitating antibiotics and steroids.

\*\* This group was the 34% of the whole sample and the 93% of the all COPD patients.

§ compared to NM and CWD p < 0.001, # p < 0.03, + < 0.01, ^ compared to CWD and COPD p < 0.001.

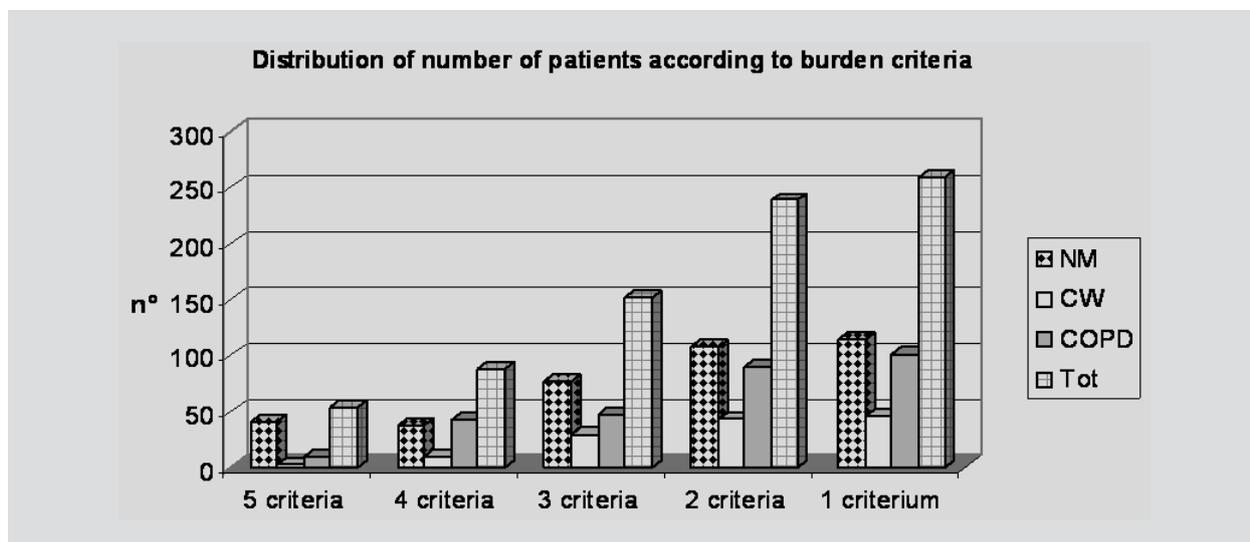


Fig. 1. - Distribution of patients according to frequency of burden criteria.

The criteria were: High dependency, tracheotomy, necessity of more than 12 hrs of MV, distance from Hospital more than 30 km, presence of frequent hospitalisations. According to the concomitant presence of one or more criteria the patients were divided in:

- extremely compromised: 5 criteria,
- highly compromised: 4 criteria,
- seriously compromised: 3 criteria,
- moderately compromised: 2 criteria,
- compromised: 1 criterion.

respectively. Only 11 and 7 % of patients were defined extremely compromised and highly compromised presenting 4 and 5 criteria respectively. In any subgroup of severity's classes NM patients were prevalent.

### Discussion

The present survey has shown that for patients submitted to home mechanical ventilation:

1. underlying disease, level of their dependency, hours spent under MV, presence of tracheotomy, home distance from hospital, hospital accesses are the causes of major care burden;
2. as novelty we have demonstrated that more than 50% of them present two or three contemporaneous criteria selected as care burden, being NM and COPD patients the most representative group necessitating the family's and HCS' care respectively.

As it has been shown in the Eurovent survey [6] that there is a great variability among centres regarding both the severity of the patients, neuromuscular, chest wall and lung diseases being the main diagnosis in which HMV is equally prescribed. To improve quality control of home ventilators and patients' necessities, recommendations have been addressed on the mandatory request of some form of follow up [3-7]. It is in fact well known that this group of patients may cause a dramatic physical, timely and economic burden [1, 3] to caregivers and families [8] for the severity of disease [1, 3], due to the presence of a neuromuscular disorder [3, 7], presence of tracheotomy and or time spent under MV [3, 7, 9], level of dependency [8], travels necessities [3, 8], instability and hospitalisations needed [1, 8]. On the other hand it is also well known that this group of patients request enormous resources from the health care service (HCS) [1, 3] with difficult resource allocation decision-making. It seems reasonable that more severe patients will need more close follow-up. Unfortunately, the European survey [6] on HMV lacks of information on actual and most efficient forms of follow-up, on details of patient compliance and time spent under MV, the number of tracheotomised patients, families' burden for travels, visits, direct assistance and costs necessities. In addition the survey [6] does not give any information on HCS economic burden sustained for home environments and hospitalizations.

The present survey has tried to focus on the most important items recognised by experts as time or costs consuming for families and HCS to propose future follow-up programmes in HMV patients underlining the importance of collecting common data and the possibility of transferring these results to others to have more information through European HCSs. The present data has confirmed that NM and COPD patients are the most prevalent home ventilator users. Among patients with HMV, neuromuscular disorders have been described as highly time consuming for caregivers in particular for tracheotomy and ventilation care [3, 9]. The present survey has also confirmed that neuromuscular patients are subjects, who spent high time under MV, use prevalently invasive MV, necessitate of robust tracheotomy's care, are prevalently bedridden and live far from hospital causing great burdens for their families. In NM diseases the burden is highest for the family than for the health system, especially in terms of hospital admissions. In general, patients with NM diseases other than amyotrophic lateral sclerosis or other rapidly progressive NM diseases, remains more or less stable from the clinical point of view. The key element in these cases is, probably home care (in a face to face way or through telemedicine support) [10, 11]. Time spent by caregivers to provide assistance for patients with poor activities of daily life has been described as enormous [8]; at the same time the additional time required for caregivers to provide transportation to physician visits are usually not included in the costs analysis [8]. Discharge from hospital to home it is a key point in the care

of patients with NM diseases and HMV. Continuity of care and the role of the healthcare as co-coordinator are crucially important; issues such as supervision of the home equipment or planning of the visits for education or continued training may improve the quality of life patients and the security for caregivers [11]. The present survey has confirmed that among patients under HMV, COPD represents the major burden for HCS: they are more frequently hospitalised, present the higher hospital stay, frequency of emergency room (ER) accesses, necessity of visits, urgent phone calls to hospital. The majority of them present also a high frequency of home relapses necessitating of antibiotics or steroids.

### *Limitation of the study*

Although an evident limitation of the present survey is that it is retrospective, not full representative of the total European and or Italian situation, based on a subjective consensus of health care personnel we believe that a doctors' survey is of interest as it shows the points of view of different experts in the area of home mechanical ventilation.

### *Practical implications*

We are confident of the urgent necessity to propose strict follow up programmes with the following expected results: reduction in either healthcare utilisation as prevention in hospitalisations and GP urgent calls for exacerbations, home visits by nurses and costs for acute episodes of relapse and emergencies. In absence of outcomes as the survival, the data related to the severity of the illness (tracheotomy and ventilation > 12 hours), the accessibility (distance to the hospital and disability) and the consumption of health resources, they can facilitate the description of the needs of the patients with HMV. The present survey adds information to facilitate national health planning to focus on recommendations of follow-up application in the future: among a large population of candidates it is in fact reasonable to invest more home care assistance in subgroups of severely dependent patients with more health care requests.

In conclusion, the present survey has shown that for patients submitted under HMV:

1. underlying disease, level of their dependency, hours spent under MV, presence of tracheotomy, distance from home to hospital and hospital accesses are the causes of major care burden;
2. as novelty we have demonstrated that more than 50% of them present two or three contemporaneous criteria selected as care burden, being NM and COPD patients the most representative group necessitating of family's and HCS's care respectively.

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### Appendix 1

Question sent to doctors of the eight hospitals involved in the study:

*"According to your experience of patients under HMV, describe all the issues and conditions you think as being the greater causes of caregiver's burden (time consuming, direct and indirect costs, care difficulties) and HCS's burden (care resources utilisation)".*

Items/conditions collected by doctors' answer

Items/conditions	n° and % of centers which have indicated the single item
<b>Criteria and conditions according to patient and family's perspective:</b>	
1. neuromuscular disease	5 out 8 (63%)
2. time spent under mechanical ventilation more than 12 h/day	8 out 8 (100%)
3. presence of tracheotomy and invasive mechanical ventilation	8 out 8 (100%)
4. level of dependency*	8 out 8 (100%)
5. distance from hospital (more than 30 km) and transfers necessity	8 out 8 (100%)
<b>Criteria and conditions according to health care system (HCS)'s perspective:</b>	
6. frequency of hospitalizations	8 out 8 (100%)
7. length of stay during hospitalizations	5 out 8 (63%)
8. frequency of emergency room (ER) accesses	5 out 8 (63%)
9. necessity of home visits	6 out 8 (75%)
10. frequency of urgent phone calls to hospital	4 out 8 (50%)
11. frequency of out-patients visits	6 out 8 (75%)
12. frequency of home relapses necessitating of antibiotics or steroids at least 2/year	7 out 8 (88%)

\* Level of dependency was measured according to the pre-morbidity lifestyle score (PLS > 2; from 0 = no limitation to 4 = bedridden) [12].