



## Original Article

## Home Mechanical Ventilation: Dependency and Burden of Care in the Home

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## ABSTRACT

**Background:** While home mechanical ventilation (HMV) prolongs survival in selected groups of patients, its use is associated with progressive dependency in basic activities, and many users will require informal care in their homes. The workload assumed by the informal caregivers can have financial, physical, and psychological repercussions. Our objective was to study dependent patients on HMV, and to describe the impact of the situation on their caregivers.

**Patients and methods:** In November 2007, we undertook a descriptive cross-sectional study of patients in stable condition who had been receiving HMV for at least 6 months. Using the Katz index, we identified dependent patients (class C and higher). In this group we studied social and economic variables, comorbidity, and need for care. The Zarit interview was used to evaluate the caregiver burden.

**Results:** Of the 66 patients enrolled, 20 (30%) were dependent. The mean (SD) age in this group was 60 (12) years and 46% were women. These patients had been on HMV for a mean of 45 months, and 40% were using ventilatory support for over 12 hours per day. Care was provided by women in the majority of cases (77%), and 58% were sole caregivers. The mean age of these carers was 51 years, and 70% of them also worked outside the home. In 7 cases (35%), the caregiver scored over 40 on the Zarit index.

**Conclusions:** One third of the patients required informal care in order to remain in their homes. Most of the caregivers were women, and one third were overburdened or were at risk of becoming so. Changes involving both physicians and the health authorities are needed to provide satisfactory care to this group of patients.

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### Ventilación mecánica domiciliar: dependencia y carga de cuidados en el domicilio

## RESUMEN

## Palabras clave:

Ventilación mecánica domiciliar

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**Introducción:** La ventilación mecánica domiciliar (VMD) aumenta la supervivencia en grupos seleccionados de pacientes, pero se asocia a dependencia progresiva para las actividades básicas y muchos pacientes necesitarán cuidadores informales en su domicilio. Éstos asumen una carga de trabajo que puede tener repercusiones económicas, físicas y/o psíquicas. Nuestro objetivo ha sido estudiar a pacientes con VMD y dependencia, y describir el impacto sobre sus cuidadores.

**Pacientes y métodos:** En noviembre de 2007 estudiamos de forma descriptiva y transversal a pacientes con un mínimo de 6 meses en VMD, en situación estable. Se identificó a los dependientes aplicando el índice de Katz (índice C y superiores). En este grupo se estudiaron variables socioeconómicas, de comorbilidad y de necesidad de cuidados. Para establecer la sobrecarga del cuidador se aplicó el índice de Zarit.

**Resultados:** De los 66 pacientes incluidos, 20 (30%) mostraban dependencia (edad media  $\pm$  desviación estándar: 60  $\pm$  12 años; 46% mujeres), llevaban una media de 45 meses en VMD y el 40% recibía ventilación durante más de 12 h al día. En los cuidadores, el 58% era cuidador único, la mayoría eran mujeres (77%), la edad media era de 51 años y un 70% trabajaba además fuera del domicilio. El índice de Zarit en 7 casos (35%) era superior a 40.

**Conclusiones:** En nuestra serie, una tercera parte de los pacientes precisan cuidadores informales para poder permanecer en su entorno. El cuidador es mayoritariamente del sexo femenino, y un tercio tiene sobrecarga real o corre el riesgo de presentarla. Para adecuar la asistencia a este colectivo harán falta cambios que impliquen a los médicos y a la Administración sanitaria.

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## Introduction

Two therapies play a particularly important role in the long-term management of chronic respiratory insufficiency—supplemental oxygen therapy and home mechanical ventilation (HMV). HMV prolongs survival in selected groups of patients and its use is often associated with progressive dependency in the basic activities of daily living and a growing need for care in the home. The care of dependent patients with restricted mobility is provided by competent informal caregivers, usually close family members. The provision of care may give rise to considerable changes in the family structure that will affect its members and particularly the primary caregiver, who is the person with the greatest workload. This responsibility can have financial, physical, and psychological repercussions<sup>1</sup> even to the extent that some authors consider that these caregivers are themselves potential patients.<sup>2</sup> Caregiver strain has been studied in groups of older patients and in patients with chronic diseases.<sup>2,3</sup> Moreover, the presence of chronic respiratory disease is associated with a particularly heavy workload in terms of the time the informal caregiver spends caring for the patient.<sup>4</sup>

Starting with a group of all the patients on HMV being treated in our department, our objective was to select the subgroup of dependent patients who had limited mobility and required help to perform the basic activities of daily living, and to describe the workload involved in the care of such patients as well as the possible impact of this burden on their caregivers. We used specific indicators to measure this burden.

## Patients and Methods

Our Respiratory Medicine Department is in a tertiary level hospital that serves a reference population of some 300 000 inhabitants. Between January 1999 and December 2007, the department treated 192 patients with HMV. In November 2007, we undertook a descriptive cross-sectional study of patients in stable condition who had been on HMV for at least 6 months. The following 3 types of data were obtained for each patient:

1. Personal details.
2. Information on comorbidity and the patient's disease process: the primary diagnosis that led to the use of HMV, time on HMV (in months), hours per day on ventilation, comorbidity score as per the Charlson index, and the presence of a tracheostomy or a gastrostomy (for tube feeding).
3. The information required to assess the patient's need for care and the degree of involvement of the caregiver: dependency measured by the Katz index, the patient's ability to attend physician visits alone, annual number of visits to the hospital (scheduled

consultations with specialists), use of multiple medications (more than 3 drugs a day), distance to the hospital (greater or less than 25 km), whether the patient was homebound (unable to leave home without the assistance of another person), caregiver's perceived need for help (response when asked "Do you think you need more help to sustain your role as a caregiver?"), use of social services or private assistance paid by the patient, monthly income (more or less than €600, a figure close to the poverty threshold in Spain).

In each case, we identified the primary carer (whether a sole caregiver or several individuals) and assessed their risk of becoming overburdened. This was done using the Zarit Burden Interview<sup>5</sup> in a face-to-face meeting with the caregiver alone. The object of the interview was explained and informed consent was obtained. The cases selected for analysis were those in which the patient was most dependent and therefore required the assistance of a caregiver (Katz level C or higher). Quantitative variables were expressed as means (SD) and qualitative data as percentages. Differences between variables were analyzed by comparing mean values using the Student *t* test for quantitative variables and the  $\chi^2$  test for qualitative variables.

The study was approved by the hospital's ethics committee.

## Results

In November 2007, our department treated 66 patients who had been on HMV for more than 6 months. Of these, 10 had neuromuscular disorders, 27 obesity-hypoventilation syndrome, 11 chest wall deformities, and 18 chronic obstructive pulmonary disease (COPD) and multifactorial hypoventilation. All these patients were using positive-pressure ventilation systems and nasal prongs. The mean age of the group was 61 (13) years and 52% were men. The 20 (30%) patients assessed as Katz level C or higher constituted the subgroup of highly dependent patients (9 with neuromuscular disorders, 4 with chest wall deformities, 4 with obesity-hypoventilation syndrome, and 3 with multifactorial disorders). Table 1 lists the general characteristics and therapeutic needs of this subgroup of dependent patients as compared to the less dependent individuals (Katz index level A or B). Table 2 shows the data relating to disability and need for assistance within this subgroup. In most cases (77%) care was provided by women, and in 12 cases (58%) by sole caregivers. The mean age of the group of caregivers was 51 (17) years, and 70% also worked outside the home. The mean score on the Zarit Index for this group of caregivers was 24 (17); however, in 7 cases (35%), the score was over 40, and in 3 (6%) it exceeded 55. The areas of the questionnaire that scored highest were those relating to personal relationships. With respect to the caregiver's own perception of their need for help, 16 (80%) gave an affirmative answer to the question:

**Table 1**  
Patient Characteristics<sup>a</sup>

	Katz Index A or B (n=46)	Katz Index C (n=20)	P
Mean age, y	62 (12)	60 (12)	NS
Women	24 (52%)	9 (46%)	NS
Charlson index	3.1 (1.7)	4.1 (1.3)	NS
≥12 h de HMV/day	7 (16%)	8 (40%)	.008
Months on home ventilation	40 (20)	45 (36)	NS
No. of scheduled visits to outpatient clinic per year	3.7 (1.9)	4.3 (1.6)	NS
Tracheostomy	0	1 (5%)	–
Gastrostomy tube feeding	0	5 (25%)	.005
Oxygen therapy	12 (27%)	6 (30%)	NS
Multiple medications	33 (72%)	14 (73%)	NS

Abbreviations: HMV, home mechanical ventilation; NS, not significant.

<sup>a</sup>Data are expressed as mean (SD) or absolute number (%).

**Table 2**  
Situation Regarding Disability and Need for Assistance

	No.	%
Distance to hospital >25 km	4	20
Homebound	7	35
Able to visit doctor alone	0	0
In receipt of assistance from social services	2	10
Contracting private care	2	10
Income close to the poverty threshold	4	20

“Do you feel that you need more help if you are to sustain your task as a caregiver?”

## Discussion

Almost one third of the patients with HMV in this study required the assistance of an informal caregiver to remain in their homes. The majority of the caregivers were women, and in many cases they also worked outside the home (70%). In one third of cases the caregiver was at risk for strain or already clearly overburdened. Assistance received from outside the family (whether public or private) was scant, and the majority of caregivers recognized that they needed more help to enable them to continue to provide the care necessary.

The mean age of the group was very similar to that of the case series studied by Tsara et al<sup>1</sup> and slightly lower than that of the patients studied by Vitacca et al.<sup>6</sup> Comorbidity as measured by the Charlson index was high, even compared to the level found in a recent study of patients with COPD,<sup>7</sup> which reported a mean comorbidity score of 3.8 in an older group than our study population.

Comparison is difficult because all of the studies contributing information on dependency in patients on HMV used different indicators to define this parameter. The proportion of dependent patients does, however, appear to vary between studies. In a multicenter study, Vitacca et al<sup>6</sup> found that 45% of patients had very limited mobility while only 7 (14%) of the 50 patients on HMV studied by Tsara et al<sup>1</sup> appeared to require the assistance of a caregiver. The proportion of dependent patients in our case series (30%) fell between that observed in those 2 studies. Caregivers in the cases we studied spent a high number of hours on care. All the patients required the assistance of another person to attend routine medical appointments, which were scheduled 4 or 5 times a year (compared to between 2 and 3 per year in the study by Vitacca et al<sup>6</sup>). The burden is even greater in the case of sole caregivers (58%) because they cannot delegate any responsibilities, and in the 70% of carers who also work outside the home. Another facet of the caregiver's task is that they have to become competent in managing complex treatments that require both time and attention (management of multiple medications, tracheostomy care, oxygen therapy, and ventilation systems as well as tube feeding and gastrostomy care). Vitacca et al<sup>6</sup> highlighted the following as factors that increase the burden on informal caregivers: the use of daily mechanical ventilation (>12 h), the level of dependence of the patients, and the distance between the patient's home and the hospital. The price sometimes paid by the patient is confinement to the home (one third of the patients in our study) for various reasons, including their level of disability, architectural barriers, transport problems, and not having the assistance of another person.

We used the Katz index to identify the dependent patients. This tool evaluates the 6 basic functions hierarchically depending on whether the patient is unable to perform the activity without assistance or only requires supervision of the function.<sup>8</sup> The Katz index, which is the scale most often used in geriatric and palliative

medicine,<sup>9</sup> is capable of predicting death, the need for institutionalization in the short and long term, and active life expectancy.<sup>10</sup> It is a very effective tool for classifying patients with high levels of dependency, but its effectiveness is lower in patients who are less dependent and when it is used to investigate tasks that involve only the use of the arms<sup>11</sup>; this bias may perhaps have led us to underestimate the need for assistance in some of our patients.

Typically, caregivers in these cases are women<sup>1,12</sup>; in our study 77% of the carers were women as compared to only 46% of the patients. This finding supports the hypothesis that in many cases the primary caregiver will not be the patient's partner but rather other female relatives.<sup>12</sup>

A singular feature of our study was that we focused on a group of more highly dependent patients by using the Katz index to select the individuals in need of the assistance of a caregiver because of their level of disability. We then used the Zarit interview to assess caregiver burden. The Zarit scale is a multidimensional tool that measures caregiver burden in terms of stress, negative feelings, and the difficulties associated with the care of a dependent patient. It is designed to assess both physical and emotional health as well as social and financial issues. This tool is used to identify informal caregivers at risk for developing emotional problems or measurable adverse health consequences.<sup>5,13</sup> Although no definitive threshold has been established for diagnosing strain in caregivers, most authors situate it around 40 on this scale.<sup>14</sup> Applying this threshold, we find that one-third of the caregivers in our study were either at risk for strain or clearly overburdened, and when we investigate the responses by domain, we find that all those interviewed reported marked impairment of their personal relationships and social life, a finding consistent with the results reported in other similar studies.<sup>1</sup>

Some studies have investigated the burden of informal caregivers caring for patients with respiratory diseases, although without explicitly determining the degree of the patients' dependence. When Rossi et al<sup>15</sup> used a specifically designed questionnaire to investigate a group of informal carers of tracheostomized patients, one of the problems detected was the restrictions the situation imposed on their personal lives. Pinto et al,<sup>16</sup> who studied strain in a group of individuals taking care of 42 patients with COPD, observed that the following 2 factors predicted greater perceived strain in informal caregivers: a bad personal relationship between the caregiver and the patient; and the presence of physical and emotional problems in either patient or caregiver. In a study of 21 caregivers of patients with amyotrophic lateral sclerosis, Mustfa et al<sup>17</sup> found the presence of muscle weakness to be one of the factors with the most negative impact on quality of life. Langa et al<sup>4</sup> found decreased physical health among informal caregivers of patients with chronic respiratory disease and showed that patients with activity limitations generated the highest number of hours of care. Booth et al,<sup>18</sup> using a specific interview to study patients with COPD or lung cancer, found that the presence of dyspnea had a negative impact on their caregivers. While the authors of these 3 studies did not expressly measure dependency, they did assess dyspnea, physical limitation, and muscle weakness, all indirect indicators of this variable. The findings of these studies reinforce the importance of explicitly assessing indicators of dependency because limitations in the mobility and activity of these patients generate the highest care workload.<sup>1,4</sup>

The financial repercussion of the provision of care is another factor that must be taken into account in any assessment of the strain and burden on informal caregivers.<sup>1</sup> In our study, 20% of the patients and families had incomes close to the poverty line, and the informal caregivers' perceived need for additional assistance was very high (80%). However, while the determination of perceived health status has been shown to be a very powerful variable in health

surveys, the closed form of question used in our study may have given rise to a bias in the responses obtained. It appears, therefore, that our health system is facing a problem of equitable distribution since in the population of patients on HMV there is a clearly defined subgroup of highly dependent patients with needs that are not currently being met. In spite of the provisions of the new Spanish Dependency Act (*Ley de Dependencia*), only 2 patients in our setting are receiving partial support from official bodies.

Information on the real situation with respect to strain among caregivers of patients on HMV on a national scale, or at least within a single autonomous community, would provide valuable information that could be of use in the assignation of resources. The chief limitation of the present study was its local scope. Another limitation was the absence of certain variables that may be relevant to our understanding of the problems faced by these patients and their caregivers. However, we did use innovative indicators that may open up new perspectives for future research.

Finally, this study also forms part of the broader framework of the problem of dependency in general, a problem that affects not only respiratory patients but also other specialty areas, the process of aging itself, and society as a whole. According to the Spanish government's White Book on Dependency (published in 2005 by the Ministry of Labor and Social Affairs), social services coverage in Spain of the older population in a dependent situation was under 10%. In respiratory medicine it may perhaps be necessary to identify the patients with needs in order to promote changes that will improve the assistance available, including the following measures: increasing the provision of aid and services to these patients; minimizing the need for travel for routine physician visits; decentralizing care<sup>19</sup>; and formulating coordination plans together with primary care physicians and the other parties involved in the provision of care and assistance to these patients.<sup>20</sup>

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