EDITORIAL

Health Case Support for Home Machanical Ventilation: Networking Versus Centralization

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Home mechanical ventilation has become fully established in Spain over the last 15 years, but its origin was different from that of other European countries.[1] The poliomyelitis epidemic that devastated most western countries in the 1950s condemned a small number of patients to indefinite hospital stays owing to their dependence on mechanical ventilation. Gradually patients, physicians, and society at large became convinced that patients could live with a ventilator at home.[2] Such was the origin of home mechanical ventilation in Europe.

Spain was also hit by poliomyelitis, but in difficult years when fear prevailed and rights were few. Patients received scant social support during the epidemic and there was little interest in alleviating the sequelae.[3] Many patients died and some few, after hospital stays of several years' duration, were transported home along with their iron lungs and for decades received ventilation with no clinical support. Such a situation prevented the training of support teams with experience in long-term treatment of tracheostomized patients, and ventilation among children was carried out only in hospitals. In the early 1980s, Spain had no experienced ventilation teams like those of other countries, where teams that had been treating such patients became leaders in the new, noninvasive ventilation techniques.[4,5]

The first reports of home mechanical ventilation in Spain were of isolated cases.[6,7] In 1987 poncho-wrap ventilation was introduced at the Hospital Universitario de Bellvitge (L'Hospitalet, Barcelona); subsequently the same technique was used for a tracheostomized patient who had spent 6 years in a pediatric intensive care unit.[8] Shortly thereafter noninvasive ventilation was begun at the same hospital[9] and at the Hospital San Pedro de Alcántara in Caceres.[10]

In the early 1990s few Spanish hospitals provided ventilation. Information on variation in indications, regardless of the number of patients treated, was gathered in a brief questionnaire at 7 of the leading hospitals that had begun to oversee home ventilation.[11] Differences between hospitals was marked regarding the percentage of ventilated patients with chronic obstructive pulmonary disease or with hypoventilation–obesity syndrome. Since 1995, the number of health care facilities providing ventilation has been on the rise,[12] and 2 basic problems have emerged: the great variation between facilities and the high percentage of facilities that provide ventilation only for very few patients. In 1998, 77% of centers treated fewer than 50 patients.

In 2001 the mean prevalence of home mechanical ventilation in Catalan patients with neuromuscular diseases was 2.5 per 100 000 inhabitants; however, the rate ranged from 4.2 per 100 000 inhabitants in Barcelona to 0.3 per 100 000 in Lleida. The explanation for such variation may perhaps be found more in the skeptical attitude of professionals toward home ventilation than in the prevalence of the diseases.[14]

In Spain there are no registries of patients using home mechanical ventilation. Apart from the problem of the costs of maintaining records, there was no consensus on criteria to define borderline cases, such as patients with sleep alterations who use double pressure devices: from the administrative viewpoint such patients are sometimes considered users of ventilation, but from the technical viewpoint they are suffering sleep apnea. Indirect data (from sources such as the Spanish Ministry of Health's open competition to award contracts to home mechanical ventilation suppliers) have indicated that over 5000 patients in Spain were using this treatment in 2005.

In 1994 most European patients on home ventilation were using volumetric ventilators.[15] In 1998 a study by De Lucas et al[12] reported that only 50% were, and at present almost all indications are for pressure cycled ventilators. There is also a tendency to replace volumetric ventilators with pressure ventilators in Switzerland.[16]

An important issue is the variation in application of home ventilation in different geographic areas and in different hospitals in the same city. The VentiQuali study reported such a variation among 4 university hospitals in Barcelona.[17] The number of patients, diagnoses, severity (patients with neuromuscular diseases and patients requiring full-night and partial day ventilation), and the types of ventilators and masks used were significantly different between the 4 hospitals.

Home ventilation requires experienced teams and the number of patients treated is a very important factor. Díaz Lobato and Mayorales-Alises[18] define an expert team as that which monitors more than 100 patients and receives at least 10 new cases annually.

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At present the situation in Spain is similar to that of other European countries. The Eurovent study,[19] which analyzed more than 27 000 European patients on home ventilation, reported on the variation in prevalence, types of patients, and the problem of the number of ventilated patients each center was responsible for. As in Spain, more than half of the centers in Europe initiated their prescription of ventilation at home during the 1990s. Even countries like Sweden, known for strict regulation, have a commensurate increase in number of patients and variation between regions.[20] From 1996 to 2004 prevalence of home mechanical ventilation in Sweden increased from 6.2 to 22.4 cases per 100 000.

The increase in number of patients with home mechanical ventilation has overloaded prescribing centers and prompted them to consider providing patients with easier access to prescription by enabling smaller hospitals to offer this treatment option. The diffusion of information on ventilation techniques has motivated more and more teams from medium and small hospitals to start programs.

There is no empirical evidence that helps in the choice between a large hospital and a small one; or between a nearby hospital with few home ventilation patients and a less experienced team, and a distant one with a large number of patients and a highly skilled team. In fact, a stable situation (an equilibrium between new prescriptions and deaths) seems unlikely in the near future, owing clearly to the increase in numbers of patients with hypoventilation–obesity syndrome. It therefore seems evident that the total number of patients with ventilators at home will continue to increase. One alternative is to have large referral centers with high levels of expertise, even though many patients may have difficult access to such centers. Some centers have decided to opt for this alternative, and not without reason.

For example, although decentralization of therapy improves accessibility, it presents a learning curve problem. The introduction of a new procedure such as home mechanical ventilation implies a learning curve for the team, just as happens with the introduction of a new surgical procedure.[21] The learning period usually inconveniences patients to some extent—eg, prolonging hospital stays or increasing the number of checks—but what is unacceptable is increased risk owing to lack of expertise when a patient could be referred to a highly skilled center. On initiating a new therapy, the negative impact of the learning curve can be minimized through training, protocols, and direct help from experts.

The quest for a balance between accessibility and expertise cannot be based on disinterested good will. Some authors firmly defend the referral hospital plan, championing expertise over accessibility. This leads to the need to accumulate activity and implies more resources. It is rather like a "container" policy: since the team must remain highly skilled, the best strategy is to accumulate (fill up the "container"). With such a policy, the system lacks permeability and transfer of knowledge is superficial. No one can imitate an expert team. This "container" concept is based on a hierarchical plan with the referral hospital at the top.

An alternative is to create nonhierarchical networks, with no referral center at the top. Every element of such a network assumes a unique role, determined by patient needs: during stable periods the nearby hospital with less technology provides the care, with appropriate support from the center with more technology or more expertise. However, if unusual problems or decisions that require highly specialized interventions develop, the brunt of the decision-making process falls to expertise rather than to accessibility. Furthermore, such circumstances can change over time, favoring some needs over others. The system operates through protocols agreed on by all, not imposed, and adapted to patient needs. Networks are composed of flexible links which, however, require periodic contacts and exchange of information (eg, common data bases).

The concept of networks applied to home mechanical ventilation may seem vague about both the evaluation of the impact of such networks and their capacity for detecting problems. Therefore this manner of delivering ventilation should be analyzed from the standpoint of outcomes rather than the description of cases. After all, it is not excessively complicated to evaluate patient survival, consumption of health resources (hospitalizations, visits, emergency care, etc), and quality of life. Each hospital in the network assumes responsibility for obtaining optimal outcomes for all patients (not only "theirs").

A model based on networks is more flexible than one based on "containers." A network distributes care responsibility better, without renouncing the expertise of certain centers with a higher volume of activity or more experience. Furthermore, networks are safer. Everything can be lost when containers leak (eg, owing to small changes in care teams or simply to the leave taking of a single professional).

Networks facilitate access to a critical mass of know-how—in other words, more shared expertise (number of cases, adverse events, evaluation of results), comparison of protocols, greater interaction among all professionals involved in the care of complex patients and, especially, sharing and increasing the speed of transmission of innovations.[22] Clearly, the divide between networks and containers is the divide between interrelationship and isolation. Networks stand for the optimization of emerging knowledge through interactivity[23]: the final result is better than the sum of the individual parts.

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