Home mechanical ventilation in Sweden, with reference to Danish experiences

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The Swedish Society of Chest Medicine has started a national register of patients on home mechanical ventilation, to establish reliable national prevalence data and to accurately document patient and treatment characteristics to enable a scientific evaluation of this treatment.

In this first collection of retrospective register data, covering patients on home mechanical ventilation at the register start on 1 January 1996, we found 541 patients, corresponding to 6.1/100,000 inhabitants, using home mechanical ventilation. Non-invasive ventilation, night-time ventilation and volume controlled ventilation dominated.

We found four diagnosis categories of approximately equal size, namely post-polio, chest wall deformities, neuromuscular diseases and ‘other diseases’. The age distribution was bimodal, with one small peak in the 20–29 year group and a large peak in the 60–69 year group. A survey of Danish patients on home mechanical ventilation showed that they were considerably younger and that almost half of them suffered from neuromuscular diseases. Further work will be done to follow the situation in Sweden and in Denmark to elucidate the obvious differences in the selection of patients for home mechanical ventilation.

Introduction

Increasing numbers of patients on home mechanical ventilation are reported from many centres (1). The French organization ANTADIR reported a prevalence of 10/100,000 inhabitants (2) in 1991, rising to 14/100,000 4–5 years later (Leger, personal communication). Data from other countries usually show lower prevalence figures, but may be highly unreliable, since few countries have national organizations for collection and analysis of data on patients on home mechanical ventilation. Reviewers often have difficulties in finding comparable data from different countries (3), and national data often report a mixture of patients on long-term oxygen and home mechanical ventilation (4).

The Swedish Society of Chest Medicine has started a national register of patients on home mechanical ventilation, collecting data both retrospectively and prospectively since 1 January 1996. The introduction of the register was facilitated by the fact that the Society has run the Swedish national oxygen register successfully for almost 10 yr (5).

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The primary aims of the register are to establish reliable national prevalence data on home mechanical ventilation and, for the retrospective part, to obtain some basic medical and technical data. Secondary aims for the prospective part (to be presented later) are to accurately document patient and treatment characteristics and pulmonary function data to enable a scientific evaluation of this kind of treatment, to facilitate quality control and to collect information on adverse experiences during home mechanical ventilation.

The definitions of the variables collected in the Swedish register were elaborated in close Swedish–Danish cooperation. Both countries have publicly financed healthcare systems and had a very similar cultural and socioeconomic structure, which makes national comparisons of special interest. Early data from Denmark and Sweden have been briefly reported in the Nordic Medical Journal (Nordisk Medicin) (6,7). Since interesting national differences were demonstrated in those reports, the authors of the Danish report have kindly agreed to co-author the Discussion part of the present analysis of Swedish data.

In this first report, we present retrospective cross-sectional data for those patients who already were on home mechanical ventilation on 1 January 1996. These data will be discussed in relation to the situation in Denmark.
Methods

From previous national inquiries and appeals in the Swedish Medical Journal, we had a good general view of the clinics and responsible physicians engaged in home mechanical ventilation in Sweden. Information about the new register was given during the autumn of 1995. Registration forms and patient information leaflets were sent to all chest clinics and other clinics known to manage patients on home mechanical ventilation at the end of 1995. Two reminder letters were sent during the spring of 1996, and we were also in personal contact with some clinics.

The following data were registered for those patients who were already on home mechanical ventilation on 1 January 1996: Age, sex, primary and secondary diagnoses, starting year of home mechanical ventilation, type of ventilator, type of connection, hours of ventilator use per day and concomitant oxygen therapy.

The Swedish register has been approved by the Swedish Data Inspection Board and the study has been approved by the Medical Ethics Committee at the University of Lund. All patients are given written information on the register and are specifically asked by their physicians if they accept registration.

Results

In Sweden (population 8.9 million), 541 patients (262 males), corresponding to 6.1/100 000 inhabitants, were reported to use home mechanical ventilation on 1 January 1996. A total of 45 clinics reported patients to the Swedish register. The 10 largest clinics accounted for more than 2/3 of the patients and 20 clinics reported less than three patients.

The prevalence in our 26 health care regions varied between 1.2 and 20/100 000 inhabitants. The age distribution for the patients is bimodal, which contrasts to the Danish unimodal distribution, as illustrated in Fig. 1. The major diagnosis groups are given in Fig. 2. The average duration of therapy was 4.7 yr, and 9% of the patients had had their ventilator therapy for more than 10 yr. Chest physicians cared for 70% of the patients and 20% were cared for by anaesthesiologists (mainly from one centre).

Technical data for the therapy are given in Table 1. Non-invasive ventilation predominates and the therapy is generally limited to night-time only. Volume controlled ventilators were used by 75% of the patients, the fraction of patients on pressure controlled ventilators has however increased considerably in the prospective part of the register, not reported in detail in this paper. Only 25% had supplemental oxygen.

Discussion

The total prevalence of home mechanical ventilation in Sweden on 1 January 1996, was slightly higher than that in Denmark (6.1 vs. 5.5–5.6/100 000). From a previous survey of this mode of therapy in the other Nordic countries (8), we know that the prevalence in Norway and Finland is lower than that of Denmark. Comparative figures from other countries are difficult to obtain, but contemporary prevalence data amounting to 14/100 000 have been reported, for example in France.

In Sweden, we estimate that there has been a doubling of the number of patients during a 6-yr period preceding the start of the register. A similar trend has also been reported from Minnesota (1) and the doubling time in Denmark may have been even shorter. Preliminary data from the years following
Some of the large differences in the number of patients on home mechanical ventilation in different countries may be explained by different national systems for the provision of healthcare, rather than by actual differences in the prevalence of the underlying diseases. In Sweden, as well as in Denmark, patients have, at least nowadays, free access to ventilatory devices regardless of insurances, personal financial prerequisites etc. We have, however, shown that there may be large differences, even if the healthcare systems are homogenous or very similar. One likely explanation for this is that the indications for home mechanical ventilation are not well defined, which (for good or for bad) may make room for more individual decision making. In a review of ventilator use by muscular dystrophy association patients (9), Bach points out that there are tremendous differences in the utilization of home mechanical ventilation between different clinics.

The sleep apnoea syndrome poses a problem of classification, since some patients with this syndrome use pressure-controlled ventilators (e.g. BiPAP Respironics Inc., U.S.A.) due to intolerance of nasal CPAP, while other patients use ventilators to control overt hypoventilation. Only the latter category is included in the Swedish register. Misclassification of sleep apnoea patients may, at most, account for 10% of the county-specific variation in prevalence of home mechanical ventilation.

Analysis of clinical patient data from the Swedish counties with the highest prevalence rates (15–20/100000) does not reveal any strikingly different features when compared to data the country as a whole. Thus, there are no indications of over-prescription in these counties. Preliminary analysis of more recent data from the register indicate a net annual increase of approx 10%, with no difference between counties with high and with low prevalence rates.

We therefore conclude that the prevalence of home mechanical ventilation will probably continue to rise in most regions, a steady-state has, to our knowledge, not yet been reached in any country or region. There is a lot of work to be done in low-prevalence regions to catch up with the development in the high-prevalence regions, both nationally and internationally.

References


