Home mechanical ventilation in Sweden—inequalities within a homogenous health care system

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Received 20 January 2003; accepted 18 August 2003

Summary

We examined local differences in prescription pattern of home mechanical ventilation (HMV) within the homogenous health care system in Sweden. We used 6 years prospective data from the national HMV Register covering the entire Swedish HMV patient population (more than 1000 patients). The treatment prevalence of HMV in Sweden, January 1, 1996 was 6.2/100,000 and January 1, 2002 10.5/100,000 with a steady increase each year in all counties. The differences between leading and non-leading counties showed a tendency to diminish due to an increasing prescription rate in the non-leading counties. During the 6 years, the proportion of Pickwickian patients increased significantly in the country as a whole, but remained considerably and significantly higher in the leading counties, in spite of similar and temporally stable prescription criteria. Even if the evident dissimilarities in treatment prevalence may be levelling out, it will most probably do so at a level as high as or higher than today’s top level of more than 20/100,000 since we found that HMV therapy was well founded also in the counties with the highest prescription rates and that the prescription rate of the non-leading counties was approaching the level of the leading counties.

KEYWORDS

Home care; Respiratory failure; Pickwickian syndrome; Assisted ventilation; Home mechanical ventilation; Epidemiology

Introduction

Whereas the criteria, e.g. long-term oxygen therapy in chronic hypoxaemic COPD are well established, the criteria for initiating home mechanical ventilation (HMV) are less well defined. There is a great diversity in the causes of chronic hypoventilation and there is little scientific evidence concerning when to start HMV. Prescription habits may therefore vary considerably between countries with different health care systems, as has been shown in a recent EU survey (JA Wedzicha, personal communication).

In a previous retrospective cross-sectional report, we demonstrated considerable inequalities within Sweden in spite of the generally homogenous health care system in our country. In this prospective longitudinal analysis, we focus on the clinical background of temporal changes and geographic inequalities in the prescription of HMV. More specifically, the Pickwickian group was chosen for detailed analysis, since this clearly was the most rapidly growing disease category and had the most variable prescription rates.

Methods

We have previously reported how the Swedish HMV Register is organized. The register is owned by the
Swedish Society of Chest Medicine and is financially supported by the National Board of Health and Welfare. In brief, it collects and works up reports for all patients from all clinics in Sweden (8.9 million inhabitants) prescribing ventilators for home use. Annual follow up forms are requested from the register with reminders sent within 6 months. Since all Swedish citizens have a unique person identification number, no patient still living in Sweden can be lost from follow up.

The register forms for those patients who started HMV before January 1, 1996 contain data on, i.e. age, sex, primary and secondary diagnoses (pre-defined groups). For patients starting therapy after that date, we also have data on blood gases (spontaneous breathing, room air), vital capacity, height and weight.

We use the term "treatment prevalence" for the number of patients (per 100,000 inhabitants) using a ventilator at a given occasion. The differences in treatment prevalence for patients of various disease categories were assessed by chi-square test. We use the term "prescription rate" for the annual number (per 100,000 inhabitants) of new ventilator users. Differences in prescription rates between groups of counties are analysed with \( t \)-test and changes over time with regression analysis. Values are expressed as mean and standard deviation (SD).

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

The treatment prevalence of HMV in Sweden was 6.2/100,000 on January 1, 1996 and 10.5/100,000 on January 1, 2002 with a steady increase each year (Fig. 1). The annual mortality is low (7–8%) and the fraction of patients discontinuing ventilation is typically less than 2%.

There are evident dissimilarities in treatment prevalence between the 26 counties in Sweden. The highest treatment prevalence January 1, 1996 was 14/100,000 and has increased to 22/100,000 6 years later, whereas the lowest treatment prevalence in the same period has increased from 1 to 4/100,000. The same four counties (from now on designated "leading counties", comprising 15% of the Swedish population), have retained their top position, with a large gap to the non-leading counties as shown in Fig. 2. The initial large difference in prescription rate between the leading and the non-leading counties has, however, decreased and did not reach statistical significance in 2001 (Fig. 3). This equalization is primarily caused by a highly significant increase \( (r = 0.3, P < 0.001) \) in the prescription rate among the non-leading counties.

The percentual diagnosis distribution of patients alive on ventilator January 1, 1996 is compared to January 1, 2002 in Fig. 4. The increased proportion with Pickwickian syndrome is statistically highly significant \( (P < 0.001) \). The age distribution has a bimodal pattern, and has not changed with time (Fig. 5).

The percentual diagnosis distribution in leading vs. non-leading counties is shown in Fig. 6. The difference for the Pickwickian syndrome is statistically highly significant \( (P < 0.001) \). When expressed as number of patients per 100,000 inhabitants, the figures for Pickwickian syndrome differed with a factor of 3.4. The latter difference

Figure 1 Annual number of new and active users of HMV in Sweden.

Figure 2 Cumulated prescriptions (per 100,000 inhabitants, not corrected for deceased patients or "quitters") of HMV in the four leading counties (———) vs. the 22 non-leading counties ( . . . . ). Error bars denote range (max–min).
does, however, not alone account for the large geographic variations in total prescription rate.

The Pickwickian patients (65% males) were on average 60 years old (SD 11) and had a BMI of 40 (SD 11). Among these patients 24% had an additional diagnosis of COPD, and in this subgroup BMI was 35 (SD 6), which is statistically significantly lower compared to the whole group. Data on apnoea/hypopnoea index are not available in the register.

Initial blood gases in the Pickwickian patients were the same for each year during the 6-year period, and did not differ between leading and non-leading counties (Table 1). Initial vital capacity was significantly lower in 2001 than 1996 but did not differ between leading and non-leading counties. We have analysed blood gas data and vital capacity for the other diagnosis groups as well, but found no temporal or geographic differences.

Discussion

An increased number of patients on HMV has been demonstrated in other centres and countries.\(^3\)\(^-\)\(^5\) The present data indicate that, although there is a slightly increasing recruitment of new patients, the main reason for the increasing prevalence may be a low mortality, i.e. a steady state has not been reached. Treatment is seldom discontinued due to the patient’s request and even more rarely on the physician’s initiative. Swedish physicians obviously see little reason to switch from mechanical ventilation to CPAP in Pickwickian patients.

It is difficult to estimate at what level the demand for HMV may be fully met. Our present data indicate that today’s top levels of 22/100,000...
are medically justified, since we could show that counties with high prescription rates had as strict indications as other counties. We made a deeper analysis of the Pickwickian patients due to their particular feature of an increase in quantity that was higher than any other patient group and showing the greatest geographic differences. This may have several explanations. Enhanced awareness of the symptoms of sleep-related respiratory disturbances and increased body weight in the general population are factors that may contribute. Widening of the indications seems not to be the case, as shown by our continuous analysis of the initial blood gas data. On the other hand, when the Pickwickian patients had an additional diagnosis of COPD they initiated ventilation with a lower BMI than the whole group. An obvious explanation for this is the synergistic respiratory effect of the two conditions. Unfortunately, the register does not include sufficient lung function data to evaluate this argument.

The steady increase in the proportion of Pickwickian patients and the fact that the leading counties were leading also for this disease category indicate that the health care system must be prepared to meet increasing demands for care of this heavy patient group.

It is noteworthy that the Swedish treatment prevalence of HMV for patients with primary lung diseases is considerably lower than that in many other European countries (JA Wedzicha, personal communication). Lower prevalence of smoking-related respiratory insufficiency could theoretically partly account for this difference. Reluctance of Swedish chest physicians to initiate ventilator treatment in COPD patients due to expected high mortality and low patient compliance is another and probably more plausible explanation. Should a paradigm shift in this field occur, it may result in a radical increase in the total number of patients on HMV.

Dissimilarities in treatment prevalence between nations with different health care systems is to be expected, irrespective of actual differences in the prevalence of underlying diseases. Furthermore, from a global point of view, an international specification of a medically justified treatment prevalence is likely to be controversial, as this prevalence is influenced not only by economy, but by local cultural and political factors as well. The novel finding in our study is that large differences may appear within a homogenous health care system, even if indications for treatment seem to be uniform. We wish to point out that the four counties with the highest prescription rates have no particular demographic properties in common. One is entirely urban (Gothenburg), whereas two are extremely sparsely populated (in the very north of Sweden). Major economic differences between Swedish counties are actively counteracted by the state, with a method sometimes called “Robin Hood-taxation”, allocating money from the rich to the poor counties. The most plausible explanation for the differences in prescription rate rests on the individual physicians. We believe that dedicated clinicians in the four leading counties started early to identify the target population that could gain benefit from HMV. However, the non-leading counties seem to be catching up, since their prescription rate increases significantly, whereas the leading counties may have reached a more stable activity (Fig. 3).

A register-based study may be severely biased in case of under-reporting. The register receives reports from 35 clinics, of whom eight are responsible for two-thirds of the entire registered population. We cannot claim total coverage of all small centres in Sweden, but their numerical contribution to our data would be negligible. Loss of data from the bigger centres may be a more significant problem. Therefore, we annually send out individualized reports to each clinic with a request for completion of data if necessary. Telephone calls have also been used to ensure completeness of data. It is estimated that the register covers at least 95% of the target population. It is extremely rare (approximately 1%) for patients to refuse participation in the register. The diagnosis groups are predefined in the register forms. The Pickwickian group is defined

| Table 1 Lung function and blood gas data (room air, spontaneous breathing) (mean and SD) for Pickwickian patients divided according to leading vs. non-leading prescription counties and divided for year of prescription. |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|
|                                | Leading counties, | Non-leading counties, | All counties, | All counties, |
|                                | all years         | all years         | 1996           | 2001           |
| Vital capacity (l)             | 2.4 ± 0.9         | 2.3 ± 1.0         | 2.9 ± 1.0      | 2.3 ± 0.9*     |
| PO2 (kPa)                      | 7.4 ± 1.3         | 7.6 ± 1.6         | 7.3 ± 1.9      | 7.8 ± 1.4      |
| PCO2 (kPa)                     | 7.1 ± 1.2         | 7.0 ± 1.3         | 7.8 ± 1.6      | 7.0 ± 1.3      |

*P-values typically 0.5 = NS for all comparisons, except for the difference in VC between 1996 and 2001 where the difference is significant (P < 0.05).
as obstructive sleep apnoea syndrome (OSAS) patients with chronic hypoventilation. The register specifically excludes sleep apnoea/hypopnoea patients using BilevelPAP only because they do not tolerate conventional CPAP. Blood gas data confirm that the material is not influenced by such patients. However, weight data from the register suggest that some patients with pure obesity-hypoventilation syndrome not fulfilling criteria for OSAS may have been classified as “other diagnosis” in the register.

In conclusion, we have found a medically justified continuing increase in the number of patients on HMV and an increasing proportion of Pickwickian patients. The evident dissimilarities in local prescription rates are not explained by different therapeutic criteria between the clinics, but rather with differences in levels of ambition and/or problem recognition. There are reasons to believe that future treatment prevalence on a national base may exceed today’s local top level at 22/100,000 inhabitants.

Acknowledgements

The author’s workplace (Lund, Sweden) is situated in one of the non-leading counties.

The Swedish HMV Register is primarily funded by The Swedish National Board of Health and Welfare. Additional financial support was given by Breas Medical Sweden. There are no other financial relations between the authors and the industry.

We cordially thank Asst. Prof. Kerstin Ström for her valuable help in reading the manuscript.

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