

The Evolution of Home Mechanical Ventilation in Poland Between 2000 and 2010

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BACKGROUND: Home mechanical ventilation (HMV) is a routine method of treatment for patients with chronic ventilatory failure. Over the last 20 y, a marked development in HMV has been noted in terms of its prevalence and the changing proportion of patients with various indications. However, data on HMV come exclusively from the developed countries of Europe and North America. Nowadays, we can see the emergence of HMV in less developed countries. This study aimed to describe the development of HMV in Poland. **METHODS:** Data from the largest HMV centers were retrospectively evaluated with regard to cause of respiratory failure, ventilation technique, and characteristics of the HMV-implementing institution. **RESULTS:** The number of subjects treated with HMV increased from 8 in 2000 to 928 in 2010. Neuromuscular diseases remained the main indication. However, their relative contribution decreased from 100 to 51% in favor of pulmonary diseases (an increase from 0 to 21%) and hypoventilation syndromes (0% in 2000 and 11% in 2010). The majority of the HMV population treated between 2000 between 2008 was ventilated by tracheostomy; however, since 2007, the percentage of subjects on noninvasive ventilation significantly increased and was equal to the number of tracheostomized subjects. HMV was initiated mainly in ICUs. However, their role systematically diminished, and an increasing number of subjects were recruited in respiratory departments. **CONCLUSIONS:** The prescription pattern of HMV in Poland has evolved, and there is a clear shift from neuromuscular to respiratory diseases. The prevalence of ventilation via tracheostomy still remains very high in comparison with other European countries. The Polish experience could be useful for countries with emerging HMV care systems. *Key words:* chronic respiratory failure; epidemiology; home mechanical ventilation; noninvasive ventilation; invasive ventilation. [Respir Care 0;0(0):1–•. © 0 Daedalus Enterprises]

Introduction

Home mechanical ventilation (HMV) is a well-established method of treatment for patients with chronic ven-

tilatory failure. The worldwide development of HMV began in the 1980s.¹ The main method of ventilation at that time was volume cycled ventilation via tracheostomy.^{2,3} Negative-pressure ventilation was an alternative method.⁴ Although more physiologic, this method had some major

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disadvantages and was too cumbersome to be widely used. The first beneficiaries of HMV were patients with primary impairment of the ventilatory pump due to neuromuscular diseases and restrictive chest-wall disorders.⁵⁻⁷

Technological developments of ventilators and interfaces in the 1990s allowed a wider application of noninvasive ventilation (NIV), and thus, ventilatory support became more acceptable for the patient and easier for the physician. In adults, ventilation via tracheostomy was almost completely replaced by NIV.¹ This method improves quality of life and helps to avoid some complications related to an invasive approach.⁸ The advantages of NIV and concomitant advances in the diagnosis of sleep medicine resulted in broad institution of HMV not only after an acute episode, but also mainly electively in the course of disease. At the same time, some epidemiological factors significantly affected the HMV population. Aging of the population,⁹ rising prevalence of obesity,^{10,11} and COPD (www.goldcopd.com. Accessed April 24, 2013) resulted in an increased number of patients with chronic respiratory failure. A substantial increase in the number of patients treated with HMV was noted in the 1990s.¹²⁻¹⁴ In 2001, the prevalence of HMV was estimated as 6 patients/100,000,¹ and this number further increased to 16–20 patients/100,000 in 2009.¹⁵ This increase was associated with a distinct shift in underlying diseases from neuromuscular and restrictive lung diseases to obesity hypoventilation syndrome¹⁶ and end-stage COPD.^{14,17}

Almost all data on HMV published to date come from well-developed areas around the world: United States,⁵ Western European countries,^{1,2,12,14,15} Australia and New Zealand,¹⁶ and Hong Kong.¹⁸ Data about HMV in other countries are scarce. The largest pan-European survey of HMV was published in 2005, providing data from 13 countries. Poland was the only country from the former Eastern Bloc and reported only 40 patients (with half of them being ventilated for < 1 y), which gave a prevalence of 0.1 patient/100,000.¹ Almost all of these patients had neuromuscular diseases and were tracheostomized. Data from

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QUICK LOOK

Current knowledge

Home mechanical ventilation (HMV) is a routine method of treatment for patients with chronic ventilatory failure. In the last 2 decades, HMV use has increased significantly, with the largest increase seen in noninvasive ventilation for neuromuscular disease. The use of HMV in less developed countries appears to be increasing.

What this paper contributes to our knowledge

The prescription pattern of HMV in Poland has evolved with a shift from support of patients with neuromuscular disease to primary respiratory diseases. The prevalence of ventilation via tracheostomy remains high in comparison with other European countries.

Poland were considered as representative of other countries from Central and Eastern Europe.¹⁹ More recent data from 2008/2009 showed that the prevalence of HMV in Poland was 2.2 patients/100,000, with a marked number of patients with neuromuscular diseases (80%) and a dominant technique of invasive ventilation (60%).²⁰

The aim of the study was to analyze data on HMV in one of the developing European countries. We intended to describe the trends in HMV in Poland over the last decade, focusing on the causes of chronic respiratory failure, ventilation technique, and type of institution where ventilatory support was initiated.

Methods

Definitions

HMV was defined as volume or pressure cycled support ventilation delivered by positive pressure via a tracheostomy or a noninvasive interface. Subjects treated only with CPAP were not considered as HMV. As far as we know, in Poland, there are no patients treated with negative-pressure ventilation.

The HMV subject was defined as a patient who had been treated with temporal or continuous mechanical ventilation for at least 6 h/d and stayed at home under family care. Patients from chronic care institutions were not included in the survey. According to our knowledge, institutionalized patients comprise a very low proportion of patients ventilated outside hospitals as a result of the low number of such centers in Poland.

The site of HMV initiation was defined as an in-patient or out-patient setting where subjects stayed when the need for prolonged ventilation was established as appropriate,

followed by titration of ventilator settings, choosing the most adequate interface, and training the subject and caregivers. Because no commonly accepted guidelines on weaning from mechanical ventilation and indications for HMV were available, the decision on initiation of HMV was always left to the discretion of the treating physician.

Center Identification

We arbitrarily selected institutions that managed at least 40 patients and had at least a 5-y experience with HMV. The selected institutions provided treatment for the vast majority (~90%) of all patients ventilated at home in Poland. HMV provided by all centers was funded by Public National Health Funds. Uniform rules for HMV care for all patients were established by the Ministry of Health and were described in a previous publication.²⁰ We distinguished regional centers, which provided HMV in only one administrative province (voivodeship), and multiregional centers, which provided HMV in more than one voivodeship.

Study Design

In September 2011, a questionnaire designed specifically for the purpose of the study was sent to the heads of the eligible institutions. Every center was asked to provide medical data of their HMV subjects, covering the period between 2000 and 2010. All completed surveys were returned by May 2012.

The study protocol was approved by the institutional review board. Because no interventions were performed and no individual data were analyzed, the need for informed consent was waived.

Survey Content

The first part of the questionnaire included general questions about center details: location, area of activity (uniregional or multiregional), and year of initiating HMV. The second part consisted of 4 sections containing questions about the number of subjects treated with HMV in each consecutive year between 2000 and 2010. The first section concerned the overall number of treated subjects, divided into 5 disease categories: 1) neuromuscular diseases, 2) lung diseases (COPD, bronchiectasis, cystic fibrosis, interstitial diseases), 3) chest-wall diseases (scoliosis, thoracoplasty, ankylosing spondylitis, post-tuberculosis sequelae), 4) hypoventilation syndromes (due to obesity, central congenital hypoventilation syndrome, central sleep apnea), and 5) other diseases that were not included in the first 4 groups. The second section was devoted to the technique of ventilation (invasive and noninvasive) and included queries about the number of new cases and the

Table 1. Characteristics of the HMV Centers in Poland

Center	Area of Activity/ No. of Provinces	Year of Start of HMV	Subjects (n)		
			Invasive Ventilation	NIV	Total
1	Regional/1	1999	3	71	74
2	Regional/1	1999	26	44	70
3	Multiregional/3	2000	81	5	86
4	Multiregional/11	2003	205	185	390
5	Multiregional/4	2003	78	82	160
6	Regional/1	2004	63	20	83
7	Regional/1	2004	22	25	47
8	Multiregional/7	2004	NA	NA	423
9	Multiregional/5	2006	88	76	162
Total subjects, n			566	508	1,495

HMV = home mechanical ventilation
NIV = noninvasive ventilation
NA = data not available

overall number of subjects treated with NIV or tracheostomy. The third section gathered data on the age of the treated subjects (adults and children), and the questions in the last section referred to the site where ventilation was initiated: ICU, respiratory department, neurology department, general medicine department, home, or other.

Results

HMV Centers

Nine HMV centers fulfilled the eligibility criteria, and all returned a completed questionnaire. However, quality assessment revealed numerous missing data in one questionnaire. These data could not be completed as a consequence of the lack of data in the center's records. The missing data concerned the first section (diagnosis; only new subjects every year were reported instead of all subjects treated every year) and the entire second section (technique of ventilation). Therefore, those data were not included in the results shown for prevalence and diagnostic groups. Two centers started HMV in 1999, one in 2000, two in 2003, three in 2004, and one in 2006. The mean center experience was 9 ± 3 y (range of 6–13 y). One center was dedicated specifically to children, two centers were dedicated solely to adults, and other centers treated subjects irrespective of age. Five centers (56%) were multiregional. Details of the data from the individual centers are presented in Table 1.

Subjects

All centers reported data regarding 1,495 subjects treated between 2000 and 2010. In 2000, there were only 8 sub-

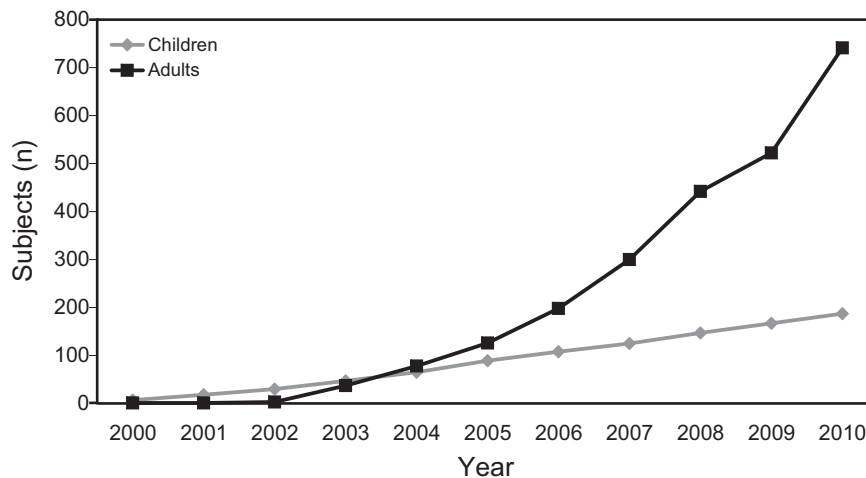


Fig. 1. The number of adults and children treated with home mechanical ventilation in Poland in the surveyed centers.

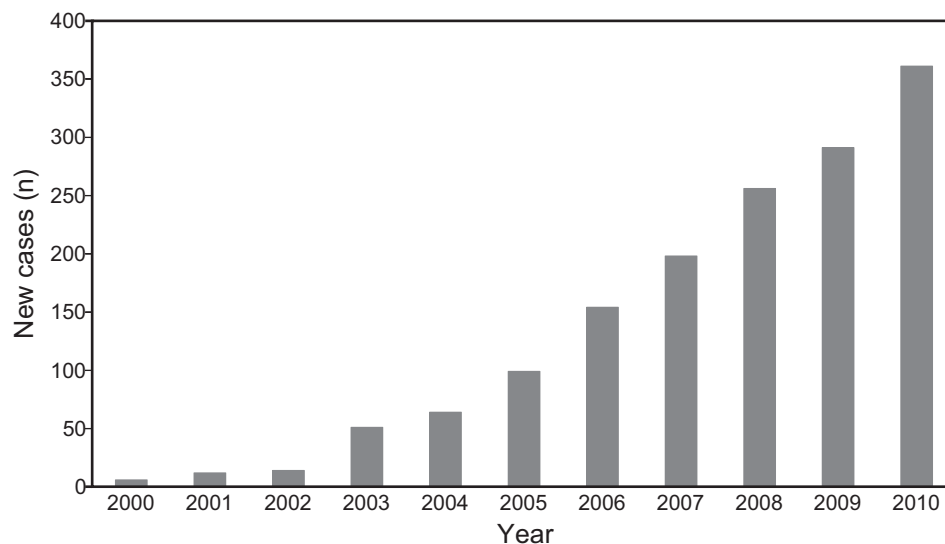


Fig. 2. Number of new cases of subjects treated with home mechanical ventilation in Poland in the surveyed centers.

jects (7 children), and in 2010, there were 928 subjects (187 children, 20%). Between 2000 and 2002, children formed the vast majority of HMV subjects (88–95%). Since 2003, the percentage of children progressively decreased as a result of rapid growth of the population of treated adults, and in 2010, children accounted only for 20% of the total number of HMV subjects (Fig. 1).

The number of new cases stabilized at a level of ~10 subjects/y between 2000 and 2002. Thereafter, it increased to 50 subjects/y in the following 2 y. Since 2005, the number of new subjects increased systematically by ~50 subjects/y. The largest progress was noted in the last year of the study and reached an increase of 70 subjects compared with the previous year. The trend in the number of new cases is shown in Figure 2.

Because the collected data include the majority (~90%) of all treated patients in Poland, we estimated the approximate prevalence of HMV use. In 2010, it reached almost 2.5 subjects/100,000 of the general population. The change in prevalence over time is shown in Figure 3.

The majority of subjects on HMV in Poland suffered from neuromuscular diseases. This preponderance persisted over the whole study period. However, it gradually decreased from almost 100% between 2000 and 2002 to 51% in 2010. The decreasing contribution of neuromuscular diseases was a consequence of the increase in the number of subjects with pulmonary diseases and, to a lesser extent, with hypoventilation syndromes. The first subjects with a diagnosis of respiratory failure due to pulmonary conditions appeared in 2004, and the number of subjects rapidly

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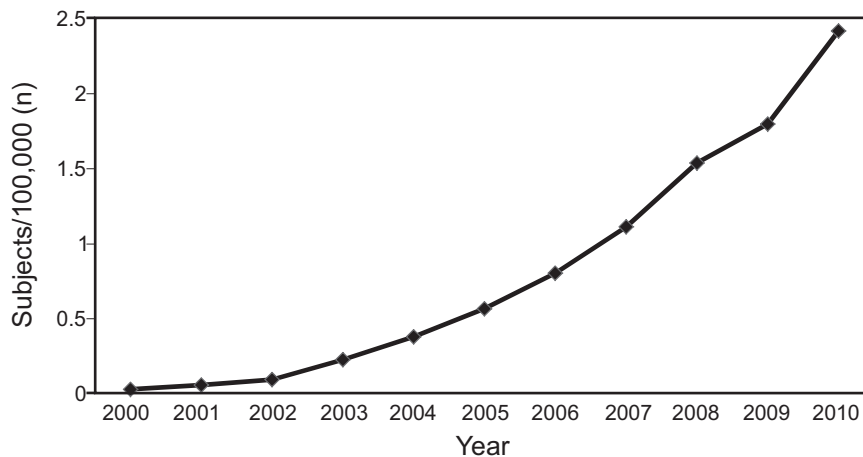


Fig. 3. The prevalence of home mechanical ventilation in Poland in the consecutive years based on data from surveyed centers. Note that results are slightly understated (see explanation in text).

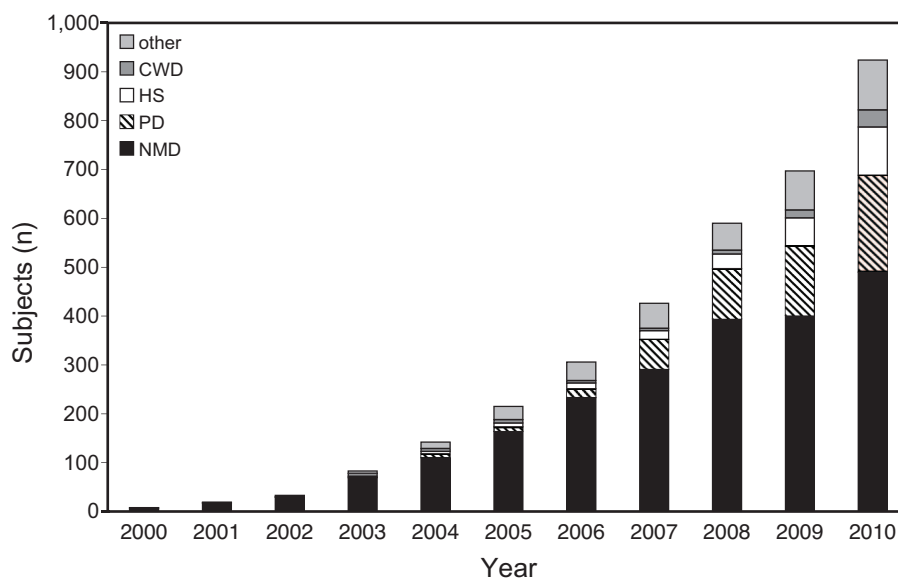


Fig. 4. Number of subjects on home mechanical ventilation in Poland according to diagnostic group, with data from 8 centers. CWD = chest-wall diseases; HS = hypoventilation syndromes; PD = pulmonary diseases; NMD = neuromuscular diseases.

increased beginning in 2007. In 2010, they accounted for almost 25% of all HMV cases. Hypoventilation syndromes were the third main diagnostic group. The percentage remained at a level of 4% until 2008, when it started to increase, reaching 11% in 2010. The proportion of chest-wall diseases remained very low at ~3% and did not change during the last decade. The increase in the number of HMV subjects within the diagnostic groups is shown in Figure 4.

Technique of Ventilation

In 2000 and 2001, ventilation via tracheostomy was exclusively used. The first subjects on NIV were treated in

2002. The number of subjects on NIV reached one third in 2004 and then leveled off for the following 5 y, followed by a rapid increase until 2010, when the proportions of subjects treated with NIV and tracheostomy equalized. Since 2008, the number of new cases treated noninvasively surpassed the number of new cases treated with invasive ventilation (see Fig. 5), and in 2010, the total number of subjects in both groups was virtually the same.

Setting of HMV Initiation

In 60% of all treated subjects, ventilation was started in the ICU setting. Between 2000 and 2002, all HMV sub-

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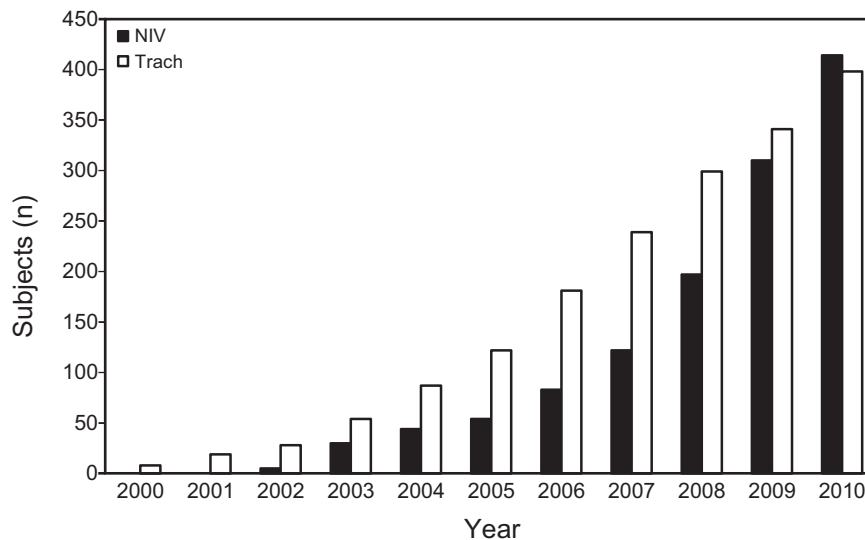


Fig. 5. Number of subjects on home mechanical ventilation in Poland according to the technique of ventilation, with data from 8 centers. NIV = noninvasive ventilation; Trach = invasive ventilation via tracheostomy.

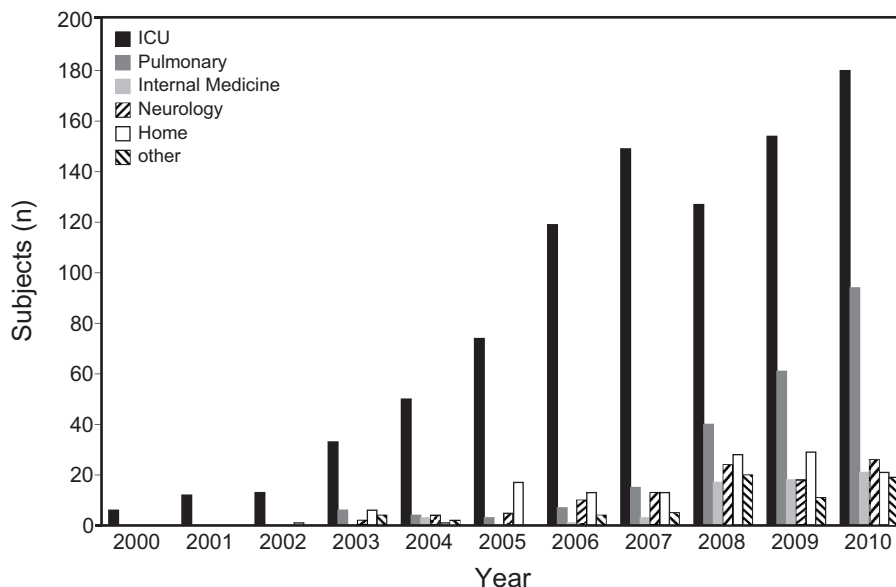


Fig. 6. Number of subjects using home mechanical ventilation according to the site of initiation.

jects came from the ICU. In 2003, the first subjects were received treatment in other settings, mostly pulmonary departments or at home. Since 2007, the number of HMV cases initiated in pulmonary departments gradually increased. In 2010, 46% of new subjects started HMV in the ICU and 35% in pulmonary departments. Over the entire decade, initiation of HMV in neurology and general medicine departments and at home remained relatively stable at $6 \pm 3\%$, $4 \pm 3\%$, and $9 \pm 5\%$, respectively. Details concerning the site of HMV initiation are presented in Figure 6.

Discussion

To our knowledge, this is the first HMV survey coming from an Eastern and a Central European country. We managed to obtain data from all large centers working in this field for a mean period of 9 ± 3 y. A total of 1,495 subjects were analyzed. We demonstrated a > 100 -fold increase in the number of HMV subjects over 11 y, from 8 subjects treated in 2000 to 928 subjects in 2010. Such a striking result has not been reported in any previous survey. The French Register showed a 10-fold increase from

180 subjects in 1988 to 1,800 subjects in 1998.¹³ Analysis of data from the Swedish National Register²¹ and Swiss Regional Register¹⁴ indicated a similar net annual increase of ~10%. A similar 10-fold increase was noted in the northern Netherlands but over a longer time period (1980–2004).²² The most significant increase in HMV use in developed countries took place in the 1990s. In the first decade of the 21st century, the increase was still preserved, but was much slower, reaching an annual 2–3-fold increase.¹⁵

In Poland, HMV was occasionally used in the 1990s. At that time, it was not funded by public resources. Only a few patients, mainly children, were ventilated with devices donated by charity foundations or foreign countries or, very rarely, purchased by families.²³ In 2000–2003, a pilot pediatric program enabling sponsorship of the devices for children was introduced by the Ministry of Health.²⁴ The cornerstone of the development of HMV use in Poland was the establishment of regulations of HMV patient care by the Ministry of Health in 2004. Simultaneously, the National Health Fund started to reimburse for HMV from the public health budget. Since then, we observed a rapid increase in the number of patients and new health centers dedicated to HMV.

The most striking difference between the pattern of HMV use in Poland and more developed countries is the type of ventilation. In the latter, subjects treated with invasive ventilation are a diminishing minority. According to data gathered in early 1990s in a single-center register in California, tracheostomized subjects accounted for 76% of HMV cases,²⁵ whereas the Swedish National Register documented 25% of tracheostomized cases before 1996²¹ and only 6% in the following 10 y.²⁶ A pan-European survey (Eurovent) presenting data from 2001 to 2002 revealed only 13% of tracheostomized subjects.¹ The most recent survey from Australia and New Zealand estimated the proportion of tracheostomized subjects as 3%.¹⁶ The frequent use of invasive ventilation in Poland could be partly explained by the high number of neuromuscular patients. The Eurovent study showed that as many as 24% of subjects with neuromuscular diseases were tracheostomized, whereas only 8% of subjects with lung diseases and 5% of those with thoracic deformations were tracheostomized.¹ However, in some countries, including The Netherlands, the percentage of neuromuscular patients is as high as 59%, and invasive ventilation is used only in 18% of all patients (personal communication, 2012, Mike Kampelmacher MD, Medical University of Utrecht, Utrecht, The Netherlands).

Notwithstanding, the high percentage of invasive ventilation use in Poland cannot be explained only by the high number of patients with neuromuscular diseases. Apparently, the main reason is the timing of HMV initiation. According to regulations of the Ministry of Health, every

patient had to be qualified exclusively by a specialist in intensive care medicine. The main idea of creating the HMV system in Poland was to release beds in ICUs, which were continually occupied by chronically ventilated patients. This system was not available for stable patients who had symptoms of hypoventilation and had not experienced an acute episode. Laub and Midgren²⁶ reported that subjects who had started HMV in an acute setting were more likely to be ventilated via tracheostomy than subjects qualified electively. Moreover, the long-term retrospective observational study performed by Duiverman et al²² suggested a worse prognosis for subjects in whom HMV was implemented on an acute basis. In Poland, a rapid decrease in the proportion of tracheostomized subjects began in 2007 due to the increased number of HMV cases initiated in respiratory departments.

In contrast to Western European surveys, the Polish study demonstrated a notable predominance of subjects with neuromuscular diseases. Despite a 2-fold decrease in the proportion of subjects with neuromuscular diseases versus subjects with pulmonary diseases and hypoventilation syndromes, neuromuscular diseases were still the most frequent indication for HMV in 2010.

Pan-European data demonstrated that subjects with neuromuscular diseases accounted for one third of all HMV subjects in 2001¹ and 20–25% in 2009.²⁷ In some countries (Denmark and The Netherlands), the number of chronically ventilated subjects with neuromuscular diseases was relatively high. In The Netherlands, these subjects accounted for 51–63% HMV cases depending on the center (personal communication, 2012, Mike Kampelmacher MD, Medical University of Utrecht, Utrecht, The Netherlands).

The need for ventilatory support in patients with neuromuscular disorders is rather obvious; lack of mechanical ventilation translates easily to a very poor prognosis. This may, at least to some extent, explain the relatively high proportion of these patients among subjects treated with HMV in various countries, particularly in those with lower medical care expenses. Indications for HMV and its impact on prognosis in pulmonary disorders, such as COPD^{17,28} or cystic fibrosis,²⁹ are a matter of ongoing discussion.

The very low proportion of subjects with chest-wall disorders in our register (~3% throughout the entire decade) is an unexpected finding. Poland had a relatively high incidence of tuberculosis in the second half of the 20th century³⁰; one would expect that this may have resulted in numerous post-tuberculosis complications deforming the thoracic cage. We believe that most of the patients with chest-wall disorders in Poland are managed in long-term oxygen therapy (LTOT) centers and treated with oxygen alone. This shows the need for further development of HMV, as studies in this population clearly in-

dicating a significantly better prognosis in the group treated with HMV compared with LTOT.^{31,32}

The low percentage of subjects with hypoventilation syndromes, mainly obesity hypoventilation syndrome, is another marked difference between the pattern of HMV indications in Poland and other countries. In our survey, the number of hypoventilation syndrome cases remained below 5% until 2007, when they started to steadily increase, reaching 11% in 2010. This is comparable with data from the Dutch Register showing that subjects with hypoventilation syndromes accounted for 4% of HMV cases (personal communication, 2012, Mike Kampelmacher MD, Medical University of Utrecht, Utrecht, The Netherlands). This is in contrast to reports from other European countries. In Switzerland, this subgroup was dominant since the end of the 1990s and accounted for one third of all treated subjects between 1990 and 1999.¹⁴ A similar percentage was found in more recent surveys from Scandinavia,²⁶ France,²⁷ and Australia and New Zealand.¹⁶ In all studies, obesity hypoventilation syndrome was the leading cause of respiratory failure. In Poland, patients with obesity hypoventilation syndrome are treated mainly with CPAP only or with CPAP and LTOT when applicable.³³ However, since 2007, an increasing number of patients with hypoventilation syndromes are being treated with HMV, which could be a result of a growing awareness of chest physicians and greater access to sleep laboratories.³⁴

Depending on the nature of the underlying disease and its course, patients with chronic respiratory failure may require different treatment modalities (HMV, LTOT, CPAP). It seems that optimal management could be offered by institutions that have experience with these methods. In Poland, centers dedicated to the treatment of respiratory failure usually focus on a single method, and this may limit access to adequate treatment. In France, the management of patients with chronic respiratory failure is provided by centers that offer complex care and is supervised by a national organization.² This is a good future direction for countries that are developing their model of care for such patients and enables optimal treatment of chronic respiratory failure.

Beginning in 2007, the number of subjects with pulmonary diseases treated with HVM has increased rapidly, and in 2010, it reached 21%. This may be attributed to the growing awareness of chest physicians regarding the need for such therapy or to the development of NIV. Comparison of the evolution of this population in Poland with that in other countries is difficult due to lack of data. In the Eurovent study, the proportions of subjects with pulmonary pathologies treated with HMV ranged from 10 to 50%.¹

On the whole, the percentage of patients with pulmonary disorders (mainly COPD) in Poland and developed countries in Europe does not differ significantly. In a sur-

vey by Veale et al,²⁷ this group accounted for 24%. However, outside Europe, the reported data differ significantly. In Australia and New Zealand, lung pathologies account for 13% of HMV cases,¹⁶ whereas in Hong Kong, the percentage is 49%, with lung pathology being the most frequent indication for HMV in this region.¹⁸

Children constitute a large group of patients treated with HMV in Poland. Until introduction of national funding in 2004, the number of children on HMV was higher than that of adults. Within the following years, their proportion systematically decreased due to a rapidly growing number of included adults. In 2010, children accounted for 20% of HMV cases. Most European surveys did not include children.^{1,26} Midgren et al²¹ reported interesting differences in age distribution of HMV subjects in Sweden and Denmark in the mid-1990s. Subjects < 20 y of age composed almost half of the Danish HMV population and ~10% of the Swedish HMV population. Differences in age were accompanied by differences in the pattern of indications and the system of organization of HMV care. The Danish model focused on young subjects with neuromuscular diseases, and HMV was managed by anesthesiologists. According to data from The Netherlands, subjects < 20 y of age accounted for 11% of the population treated with HMV (personal communication, 2012, Mike Kampelmacher MD, Medical University of Utrecht, Utrecht, The Netherlands).

Conclusions

In summary, the development of HMV in Poland was delayed in comparison with that of more developed countries. Within the first years, it differed from common European practice, mainly due to a very high proportion of tracheostomized patients and very few patients with pulmonary disorders and hypoventilation syndromes. The main concerns of the Polish system are the lack of centers offering complex treatment of patients with chronic respiratory failure and the small contribution of pulmonologists to the process of HMV use. We believe that the Polish experience not only broadens the knowledge of HMV care systems, but also may give useful information to those countries that are planning to institute HMV.

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