Home ventilation of pediatric patients
- description of a program

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Abstract

Objective: to describe a German program for home ventilatory support, and to analyze the possibility of applying it in Brazil.

Materials and methods: we assessed Dr. von Haunersches Kinderklinik’s Pediatric Intensive Care Unity - Ludwig-Maximilians – Universität - München (Munich, Germany) home ventilatory support program between April 1997 and June 1998.

Results: patients aged between 1 and 21 years - 11 boys and 15 girls - participated in the study. Fifteen out of 26 children presented neuromuscular pathologies, 8 of them had ventilatory problems of central causes, and 3 children presented obstructive pulmonary diseases. Twelve (46.2%) were receiving noninvasive ventilatory assistance, and 19 (73.1%) only needed intermittent ventilatory support.

Conclusion: the program relies on a permanent multidisciplinary staff to treat intercurrent diseases. Patients, at predetermined periods, are re-evaluated as to the evolution of respiratory insufficiency. The adequate system organization provides patients and their families with security, and accounts for the success of the home ventilatory support program. A great deal of organizational efforts should be consolidated before implementing similar programs in Brazil.


Introduction

The advance of Medicine as a whole, especially in pediatrics, has prolonged the life of extremely premature infants and infants with neurological diseases, severe trauma, and congenital abnormalities.1-4 Consequently, the number of pediatric patients who depend on ventilatory support for very long and sometimes indeterminate periods has significantly increased at most tertiary health care centers since the 1980s.5

Children with chronic respiratory insufficiency who need oxygen therapy or prolonged ventilatory support belong to a very heterogeneous population. The major pediatric diseases that trigger chronic respiratory insufficiency can be categorized into three groups: diseases that affect the central nervous system, diseases that affect thoracic respiratory muscles, and intrinsic pulmonary...
diseases. These categories include bronchopulmonary dysplasia, mucoviscidosis, neuromuscular diseases, respiratory control disorders caused by spinal cord injury, and central hypoventilation syndrome, obstructive sleep apnea, some cardiopathies and other congenital diseases.1,2,6

Children with these diseases are usually hospitalized and need to spend long periods in Intensive Care Units, exposed to infection risks and psychoemotional disorders. In an attempt to minimize such problems, the practice of home ventilatory support has been suggested in the last 10 or 15 years. A significant improvement in children’s growth and development has been achieved by restoring children to family life and re-establishing the family unit.3,6

In Brazil, well-structured home ventilatory support programs for children are not available yet. Therefore, the present study describes a German program for home ventilatory support, analyzing the possibility of its application in Brazil.

Materials and Methods

After approval by the Ethics and Research Committee, the study was implemented. The characteristics of the Dr. von Haunersches Kinderklinik’s Pediatric Intensive Care Unit - Ludwig-Maximilians-Universität-München (Munich, Germany) home ventilatory support program were assessed between April, 1997 and June, 1998. During this period, 26 children with chronic respiratory insufficiency participated in the program; 22 of them were on home ventilation and the remaining 4 were submitted to home ventilatory support during the study.

All medical records were examined in order to obtain information such as etiological diagnosis of respiratory insufficiency, ventilation method, time of the day at which ventilation was carried out, duration of ventilatory support, discharge from hospital, recommendation of home ventilation, and duration of home ventilation. The occurrence of previous intercurrent diseases and the results of routine evaluations were analyzed. There was personal contact with all children and their families, as children regularly turned up for hospital evaluations.

All routine evaluations at the hospital are performed on children by the doctors, nurses, and physiotherapists and psychologists. The evaluation at the hospital is determined by patient’s clinical status, and the necessity of evaluating the efficiency of ventilation therapy, the following lab exams are required: blood gas analyses during wakefulness; continuous measurement of oxygen saturation during sleep; measurement of CO₂ concentration during sleep; pulmonary function tests; chest x-ray; electrocardiogram; echocardiogram and respiratory tract endoscopy.

According to the protocol set up by the program, home ventilatory support aimed at providing support, prolonging life, improving quality of life, reducing morbidity, improving the conditions for children’s growth and development, dealing with the psychological aspect of patient-family relationship, and reducing financial costs.

Referrals of children to this program included impossibility of ventilatory support weaning (ventilatory problems of central causes, bronchopulmonary dysplasia, and neuromuscular diseases); attempts to reduce the number of respiratory infections, heart function alterations in obstructive pulmonary diseases and neuromuscular disorders; and stimulation of pulmonary development in children with congenital myopathies.

Home ventilatory support is contra-indicated in the following situations: presence of a psychologically-unstable physical condition (e.g.: FiO₂ > 0.40 requirement); patient and/or family who opt for hospital treatment; families who can not offer their patient security (no protection against fire, risk of power outages, environment with poor sanitary conditions); inappropriate environment (discomfort caused by temperature, poor air quality); lack of financial resources (family members are incapacitated and/or cannot obtain extra-familiar help).

After patients are accepted in the home ventilatory support program, that is, once they fulfill program objectives, obtain referrals for home treatment, and do not present any contra-indications, a list of necessary material and human resources is organized. These resources depend on the severity of respiratory insufficiency presented by each patient and the recommended ventilation method (invasive or noninvasive; continuous or intermittent).

The list of necessary materials, including ventilator, is sent to the family’s, state, or private health insurance company, which contacts suppliers. Patients submitted to continuous ventilatory support or those who can not spend more than 4 hours without ventilation receive 2 ventilators. The approval of human resources is only accepted by means of a justification given by the doctor in charge; the insurance company pays nurses for a maximum daily workload of 12 hours, and the family bears the expenses with any additional hours.

When all the necessary materials are available, the patient is submitted to treatment. Family members are more directly responsible for home treatment. Family members have to dispose of more time when taking care of patients under invasive therapy as they need to get well-acquainted with procedures such as tracheostomy, cannula replacement, and airway aspiration. These patients will only be discharged from hospital when the staff (doctors, nurses, physiotherapists, and psychologists) notice that patients and their families can carry out ventilation therapy with safety and ability, and are able to solve mild intercurrent diseases that might occur.

The frequency of routine evaluations at the hospital is determined at the time of discharge. The evaluations are usually performed every 3 months during the first year, and every 6 months after that, according to age-specific recommendations. Programmed hospitalizations in pediatric ICU last approximately 1 or 2 days. At this time, depending on patient’s clinical status, and the necessity of evaluating the efficiency of ventilation therapy, the following lab exams are required: blood gas analyses during wakefulness; continuous measurement of oxygen saturation during sleep; measurement of CO₂ concentration during sleep; pulmonary function tests; chest x-ray; electrocardiogram; echocardiogram and respiratory tract endoscopy.
The results are analyzed individually and comparatively to previous exams in order to assess the evolutional aspect of the disease, respiratory insufficiency, and ventilation technique and parameters. The anamnesis conducted with a family member or patients themselves is also analyzed together with lab exams. The relevant symptoms that are usually reported include headache, tiredness, physical unwillingsness, insomnia, diurnal sleepiness, nightmares, hyperactivity, and attentional dysfunctions, all of which may be associated with insufficient ventilation.

The assessment of children’s nutritional status and neuropsychomotor development, and specific evaluation of ventilatory support efficiency are simultaneously carried out by specific professionals.

Regular home visits are made between hospitalization intervals. The visits of nurses and physiotherapists occur every week during the periods that are free from any complications, but may be more frequent during infection bouts or any other pathological situation that causes clinical instability. The medical visit occurs once a month, and is arranged by a doctor in charge of the patient’s place of residence (neighborhood). This doctor maintains a permanent exchange of information with the home ventilation program team.

A volume-controlled ventilator (PLV 100 - Lifecare, Aspen, Color., USA) was used for intermittent positive pressure ventilation (IPPV). For negative pressure ventilation, a Pulmo-Wrap-Lifecare International, Inc. ventilator (Lafayette, Color., USA) was used. Face masks, and cuirass devices (Lifecare Europe, GmbH, Seefeld, Germany) were custom-made according to children’s individual necessities.

Results

The home ventilatory support program of Dr. von Haunersches Kinderklinik, Ludwig-Maximilians-Universität-München pediatric intensive care unit dates back to 1989. The program was coordinated by Prof. Dr. Thomas Nicolai and Dr. Karl Reiter, doctors in charge of the pediatric intensive care and bronchoscopy services. Currently, the program consists of 26 patients. During the assessment period, two children with mucoviscidosis died from infectious complications and other 4, also affected by mucoviscidosis, left the program after lung transplantation.

Table 1 shows the characteristics of the population who participated in the program according to their age and gender. Eleven children were males and fifteen were females. Fifteen children (57.7%) were younger than 10 years old, and 10 children (38.5%) were between 10 and 20 years old.

Table 2 shows the distribution of patients according to the time elapsed since home ventilation was suggested. Twenty of the 26 children (76.9%) have been under ventilation therapy for less than 5 years. Four children (15.5%) have been submitted to home therapy for 7 to 9 years, practically since they were introduced to the program.

As far as the diseases that caused chronic respiratory insufficiency are concerned, 15 children (57.7%) presented neuromuscular pathology with altered respiratory muscle function, 8 patients (30.8%) were diagnosed with ventilatory disorders of central cause, and 3 children (11.5%) presented obstructive pulmonary diseases.

12 (46.2%) out of 26 patients were submitted to noninvasive ventilation techniques, 11 children had to use face mask - 10 of whom were under IPPV - and one child was submitted to continuous positive airway pressure (CPAP). The other child under noninvasive therapy was submitted to cuirass negative pressure ventilation. The 14 children who were submitted to the invasive ventilation technique received IPPV by means of tracheostomy.

Table 1 - Distribution of patients under home ventilation therapy according to age and gender

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<tr>
<th>Age (years)</th>
<th>Gender</th>
<th>Total</th>
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<td>03 (11.5%)</td>
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<td>10</td>
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<tr>
<td>Total</td>
<td>11 (42.2%)</td>
<td>15 (57.8%)</td>
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Table 2 - Distribution of patients under home ventilation therapy according to age and gender

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<thead>
<tr>
<th>Ventilatory Support (Years)</th>
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<td>14</td>
<td>3</td>
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(11.5%) (53.8%) (11.5%) (7.7%) (15.5%)
With respect to the duration of ventilation therapy, 7 children (26.9%) were submitted to continuous ventilation, 24 hours a day, and 19 (73.1%) required only intermittent ventilation.

The information obtained through the state health insurance service (“AOK”), which covers most part of the population, reveals that the expenses with a patient under home ventilatory support therapy are basically related to the necessity of 1 or 2 ventilators. The monthly expenses with a patient who requires 1 ventilator, using a continuous inspired oxygen fraction up to 0.40 and with a 12-hour nursing personnel assistance, are approximately R$30,000.00 (US$15,700.00). A patient with the same previously mentioned oxygen requirements and nursing personnel assistance who requires 2 ventilators has a monthly cost of approximately R$44,000.00 (US$23,100.00). The cost for maintaining a child with ventilation and oxygen requirements in an intensive care unit during 30 days is around R$42,000.00 (US$22,100.00). These data suggest that only the expenses with patients under continuous home ventilation therapy, therefore requiring 2 ventilators, would not be reduced if compared to hospital treatment.

**Discussion**

Home treatment is an important alternative for children who require a life-sustaining therapy for a long time. There are no similar programs in Brazil yet; therefore, we decided to evaluate a home ventilation program from abroad, taking maximum advantage of it in order to adapt it to the Brazilian reality. The University of Munich was chosen because it has an expressive population of pediatric patients. The university allowed us access to all information and protocols of the program in addition to offering direct contact with patients and their families, including home visits.

The Task Force on Technology-Dependent Children has recognized that the most important aspect of a proper home care is the adequate management of the situation. This procedure was defined as coordinated care, promoting effective and efficient organization and use of medical, social and educational resources in order to stimulate children’s potential in a more appropriate and less restrictive environment. This workgroup also recognizes that the organization of each technology-dependent situation should be adequate and/or adapted to family environment and also to the community in which patients are involved.7

By comparing our evaluations with an English study that analyzed the evolution of children under home ventilation therapy, carried out in the last decade, we observe a great number of similarities.8 In the English study and also in the Dr. von Haunersches Kinderklinik program, most children with chronic respiratory insufficiency presented neuromuscular diseases (55.9%), followed by congenital central hypoventilation syndrome (14.0%). There was also similarity as to the duration of ventilation therapy during the 24 hours - 24% required continuous ventilation and 76% intermittent ventilation. There were differences, however, in terms of the type of ventilation therapy used - 46% of our children were submitted to noninvasive therapy whereas the use of noninvasive therapy accounted for 64.5% in English children.

The indications and contra-indications concerning the inclusion of patients in the study were similar to most home ventilation protocols. For the adequate selection of patients, we should bear all these indications and contra-indications in mind so that the objectives can be achieved.9-11

The selection of ventilators and other equipment is based on the principle that they have to be portable, durable, and easy to use and handle.11-13 It is important to understand that there is no intention of transferring the intensive care unit to patient’s home.14

The importance of teaching patients and family how to handle ventilation therapy properly is a consensus in the literature.11,15,16 Patients and their families should be provided with comprehensive clarification and preparation in addition to information on the evolution prospects of the core disease. Some diseases remain stable during their course while others progress into respiratory insufficiency and higher ventilation requirements.17

The analyzed protocol includes routine exams. These clinical and laboratory exams are essential for detecting signs of alveolar hypoxia and/or hypoventilation, and for adjusting the ventilatory pattern. In the event of pulmonary hypertension and cor pulmonale signs, the first hypothesis is always inadequate ventilatory support.18

There are differences concerning the expenses with home ventilation therapy among the programs. The necessity of nursing personnel and two ventilators are the main factors that cause a rise in costs.13,19 Some authors state that the importance of humanized care for technologically-dependent patients, and improved quality of life for the family are enough to discourage the comparison between hospital and home treatment costs as an argument for home therapy recommendation and contra-indications.16,20,21

Brazilian social peculiarities and the precarious structure of our health system conspire against the implementation of similar home ventilation programs. The adaptation of the German model to secondary hospitals would perhaps be the first step to bring children and their families close together.

The implementation of home ventilation programs for children becomes an urgent necessity as intensive care is improved. The complexity of these programs demands long
and careful organization so that they can achieve their goal of minimizing the suffering of chronically ill children and of their families as well. This well-organized system provides patients and families with security and accountability for the success of home ventilatory support programs. A great deal of organizational efforts should be consolidated before implementing similar programs in Brazil.

References


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