ORIGINAL ARTICLES

Home Ventilatory Assistance in Chilean Children: 12 Years' Experience

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OBJECTIVE: Home ventilatory support systems are a treatment option for patients with severe chronic respiratory failure. The objective of the present study was to characterize the children admitted to a home ventilatory assistance program.

PATIENTS AND METHOD: The home ventilation program was created by our hospital to coordinate professional and technological support for chronic ventilator-dependent children. We revised and updated information on patient characteristics, type of assisted ventilation, respiratory morbidity, and equipment failures between 1993 and 2004.

RESULTS: Follow-up of 35 children (18 male) was carried out by our hospital staff. Median age upon admission to the program was 12 months (range, 5 months to 14 years). Median length of time in the program was 21 months and we were able to wean 40% of patients from ventilators. Six patients died. The main indications for assisted ventilation were neuromuscular disease (12 cases), airway alteration (11 cases), cardiopulmonary disease (7 cases), and hypoventilation syndrome (5 cases). The types of assisted ventilation used were continuous positive airway pressure (in 17 cases), bilevel positive pressure (in 8 cases), and synchronized intermittent mandatory ventilation (in 10 cases). Invasive ventilation via a tracheostomy was used in 26 cases. The use of noninvasive ventilation increased in the last 4 years. Respiratory morbidity (pneumonia and bacterial tracheitis) was the most frequent cause of hospitalization and the annual rate of such episodes was 1.6 per child. The annual rate of hospitalization due to equipment failures was 0.1 per child.

CONCLUSION: The program provides safe and necessary home ventilatory assistance for children with severe chronic respiratory failure. The professional support that home hospitalization offers had a positive effect on outcome in these children. It is important to take our experience into account in creating a Chilean national home ventilatory assistance program.

Key words: *Mechanical ventilation. Assisted ventilation. Invasive ventilation. Chronic respiratory failure. Children.*

Asistencia ventilatoria domiciliaria en niños chilenos: 12 años de experiencia

OBJETIVO: Los sistemas de apoyo ventilatorio domiciliario son una alternativa para el tratamiento de los pacientes con insuficiencia respiratoria crónica grave. El objetivo del presente estudio ha sido caracterizar a los niños ingresados en el Servicio de Asistencia Ventilatoria en Domicilio (SAVED).

PACIENTES Y MÉTODO: El SAVED es un programa de nuestro hospital que coordina el apoyo profesional y tecnológico para niños con dependencia de asistencia ventilatoria (AV) crónica. Se revisaron y actualizaron datos demográficos, tipo de AV, morbilidad respiratoria y fallos de equipo entre 1993 y 2004.

RESULTADOS: Se realizó seguimiento en nuestro centro a 35 niños (varones: 18). La mediana de edad al entrar en el programa fue de 12 meses (rango: 5 meses a 14 años). El tiempo de permanencia fue de 21 meses y la retirada del soporte se logró en el 40% del total. Fallecieron 6 pacientes. Las principales indicaciones de AV fueron: enfermedad neuromuscular en 12 casos, alteración de la vía aérea en 11, enfermedad cardiopulmonar en 7 y síndrome de hipoventilación en 5. Los tipos de AV utilizados fueron presión positiva continua de la vía aérea en 17 casos, presión positiva en 2 niveles (BiPAP) en 8 y ventilación mecánica intermitente sincronizada en 10. Se administró ventilación invasiva a 26 pacientes a través de traqueotomía. En los últimos 4 años se produjo un aumento de la utilización de la ventilación no invasiva. La morbilidad respiratoria (neumonía y traqueítis bacteriana) fue la causa más frecuente de hospitalización y alcanzó 1,6 evento/niño/año. Los fallos de sistema fueron causa de hospitalización en 0,1 evento/niño/año.

CONCLUSIÓN: El SAVED es un programa seguro y necesario para niños con insuficiencia respiratoria crónica de carácter grave. El apoyo profesional que proporciona la hospitalización domiciliaria ha beneficiado la evolución de estos niños. Es importante considerar esta experiencia para la formación de un programa nacional de AV domiciliaria.

Palabras clave: *Ventilación mecánica. Ventilación no invasiva. Ventilación invasiva. Insuficiencia respiratoria crónica. Niños.*

Introduction

Advances in neonatal and pediatric intensive care have resulted in increased survival of extremely complex patients, many of whom require ventilatory assistance in order to remain alive.[1-4] The vast majority

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of such patients require special care and remain hospitalized for prolonged periods before they are able to return home.[5] This means high costs for prolonged hospitalizations and blocking beds in intensive care units. We must also consider the negative effect of hospitalization on the child's integral development[6] and the risk of exposure to nosocomial infections.

With a view to sending chronic ventilator-dependent children home as quickly as possible our hospital developed a home ventilatory assistance program whose main objective was to coordinate multidisciplinary professional and technological support for chronically ill children in order to allow them to rejoin their families for a more complete recovery encompassing psychological and social well-being. In a previous publication, in which we reported our experience with the first 15 children sent home on this program, we showed the favorable results of long-term ventilation for the treatment of patients with severe chronic respiratory failure.[7] In that study the considerable savings in hospitalization costs were clearly apparent. Recent technological progress has led to the development of new equipment for noninvasive ventilatory assistance and this has changed the indications for ventilatory support despite limited clinical experience in children.[8-10]

Our main objective in this study was to characterize the population of children admitted to the home ventilatory assistance program according to diagnosis and type of support in order to provide the necessary information for the creation of a Chilean national home ventilatory assistance program.

Patients and Method

Patients

We carried out a retrospective study of all the patients referred to our program from the Pediatric Service of the Hospital Clínico de la Pontificia Universidad Católica de Chile. The study period was from January 1993 to June 2004. We contacted all the patients and updated their records with information from their home and hospital medical charts. For our hospital's patients in the program we had complete medical records, which we systematically revised to record clinical characteristics. The underlying disease was considered to be the one that had caused the chronic respiratory failure that led to respirator dependence. We classified the following as underlying diseases: airway abnormality, neuromuscular disease, hypoventilation syndrome, and cardiopulmonary disease. All other conditions were considered to be associated diseases or syndromes. We identified the type and mode of home ventilator assistance, its duration, and the way the patient was weaned from the system. For patients requiring invasive ventilation, time until hospital discharge was calculated as the time from the date of the tracheotomy until the day the patient was sent home. Time until discharge did not exceed 1 month in any case for those requiring noninvasive ventilation (NIV), and so was not considered in the calculations. Time in the program was defined as the time from hospital discharge to either the withdrawal of ventilatory assistance, the end of the study (June 2004), or the death of the patient, whichever occurred first. Episodes of respiratory morbidity, incidents associated with airway manipulation, and equipment failures during the study period were recorded retrospectively.

Staff

The program coordinates professional support for each patient. Each child entering the program is assigned a doctor to supervise home care. In our series, this was a pediatric pneumologist. In addition, clinical supervision by a nurse, a physical therapist, a respiratory therapist, and a nurse's aide was included, all in accordance with each patient's needs. For the professional support offered during the first years of the program (1993-2000), we took into account those aspects of care that could be covered by the family, and during that period parents were the principal caretakers. Due to modifications in the Chilean health care law in the year 2000, an additional insurance for costly diseases was created in order to "professionalize" home care for the child with special needs. This had a clear effect on home support in providing for basic needs for each patient.[7]

Parents were given a questionnaire focusing on psychomotor development and home neurorehabilitation. Speech therapy, occupational psychotherapy, and physical therapy were also included. Use of trained professional support, hours of nurse's aide assistance, and professional visits to the home were also recorded. Only those patients admitted to the program after the year 2000 were included in this analysis.

Statistical Analysis

The statistical analysis for discontinuous data was performed with the χ^2 test when necessary. A P value less than .05 was considered significant.

Results

Thirty-five children were admitted to the home ventilatory assistance program between January 1993 and June 2004. During this period 6 other children received home ventilation, but they were followed in another hospital due to the particular health insurance the patients had. The data for these children were not considered in the present study. Distribution by sex was 18 boys and 17 girls. The underlying diseases were neuromuscular disease (12 cases), airway abnormality (11 cases), cardiopulmonary disease (7 cases), and hypoventilation syndrome (5 cases). Underlying and associated diseases and syndromes are shown in Table 1. Invasive ventilation via tracheostomy was prescribed for 26 children. Of these, 16 used continuous positive airway pressure (CPAP) and 10 required synchronized intermittent mandatory ventilation. Distribution of patients according to the type of ventilation used is shown in the Figure. Mean age at which tracheotomy was performed was 9 months (median, 4 months; range, 1 month to 6 years). NIV was delivered through a nasal or nasal-oral mask in the other 9 children, 8 of whom used bilevel positive airway pressure (BiPAP) and only 1, CPAP. Only 1 child received intermittent ventilatory

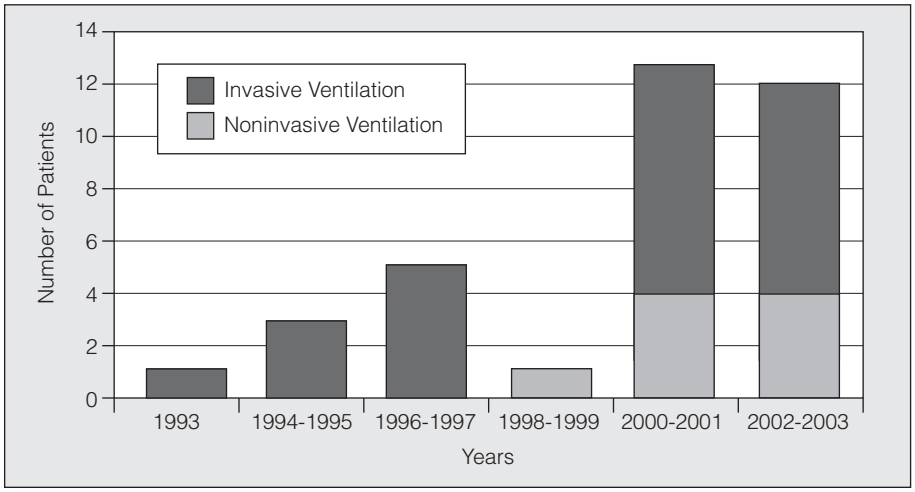

Figure. Number of patients admitted to the home ventilatory assistance program during the study period. An increase in the use of noninvasive ventilation can be observed after 1999.

assistance delivered through a face mask at home. All the others used a nasal or oral-nasal mask.

The median age upon admission to the program was 12 months (range, 5 months to 14 years). Median length of time in the program was 21 months. The patient who required ventilatory assistance for the longest period had been in the program from the very beginning. Complete weaning from ventilatory support was achieved in 14 (40%) of the 35 children, and 15 continued to depend on the system. Ventilation was withdrawn in the majority of patients with airway abnormalities, in clear contrast to patients with neuromuscular diseases (8 out of 11 compared to 2 out of 12; $P<.05$). There were no differences in the statistical analysis when groups were compared according to the type of ventilation used (Table 2). During the study period, 6 children died while in the program. In 4 patients, cause of death was respiratory failure due to progression of the underlying disease. One patient with pneumonia died at home and another died in hospital due to sepsis secondary to peritonitis from a ruptured appendix.

TABLE 1
Underlying and Associated Diseases

Underlying Disease	No.	Associated Diseases
Neuromuscular disease	12	
Nonspecific congenital myopathy	2	
Nemaline myopathy	2	
Spinal atrophy types 1 and 2	4	
Diaphragmatic paralysis	3	Congenital heart disease
Congenital myasthenia gravis	1	
Airway abnormalities	11	
Tracheomalacia/bronchomalacia	10	CHARGE syndrome VACTERL syndrome Pierre Robin syndrome Apert syndrome Arnold-Chiari syndrome Dandy-Walker syndrome Fraser syndrome Prematurity
Subglottic stenosis	1	
Cardiopulmonary diseases	7	
Chronic lung lesions	3	Omphalocele
Chest malformation	1	Chronic lung lesion
Imperfect osteogenesis type 3	1	Chronic lung lesion
Pulmonary fibrosis	1	
Congenital heart disease	1	Down syndrome
Hypoventilation	5	
Obstructive sleep apnea	3	Nonspecific myopathy Prader-Willi syndrome
Central hypoventilation	1	Haddad syndrome
	1	Ondine syndrome

Of the patients who continued to require ventilatory assistance, ventilatory mode was changed in 8 cases. Six patients who had needed continuous ventilation managed to change to nighttime support only (synchronized intermittent mandatory ventilation in 4 cases, invasive CPAP in 1 case, and BiPAP in 1 case). One child progressed from invasive ventilation (CPAP) to NIV (BiPAP) and only 1 child worsened, requiring a change from nighttime BiPAP to 24-hour BiPAP. Acute respiratory infections were the main cause of morbidity in the study population, and the annual rate of lower respiratory tract infections (pneumonia and bacterial tracheitis) was as high as 2.6 episodes per child. The annual rate of hospitalization for such infections was 1.6 episodes per child. Of the 26 children with tracheostomies, 21 developed granulomas in some segment of the airway. This led to hospitalization because of the need for procedures such as fiberoptic bronchoscopy, resection of the granuloma, or change of the tracheostomy tube, or because of complications such as hemoptysis and hypoxia due to airway obstruction (Table 3).

Problems related to the ventilation equipment were most frequently due to failures in the electrical system requiring replacement with an emergency system (in 13 patients). In 2 patients pulmonary aspiration of distilled water from the humidification system due to errors on the part of caretakers was recorded. The overall annual rate of equipment-related incidents was 0.5 episodes per child. Of these, only 0.1 episodes per child per year resulted in hospitalization. At least 1 episode of

TABLE 2
Characteristics of Patients According to Type of Ventilation Used*

	Invasive Ventilation	Noninvasive Ventilation	Total
Sex, M/F	15/11	3/6	18/17
Underlying disease			
Neuromuscular	8	4	12
Airway	11	0	11
Cardiopulmonary	5	2	7
Hypoventilation	2	3	5
Ventilation mode			
CPAP	16	1	17
SIMV	10	–	10
BiPAP	–	8	8
Age upon admission to HVP, median (range)	12 (3 months to 6 years)	12 (5 months to 14 years)	12 (3 months to 14 years)
Time spent in HVP, median (range)	21 (2 months to 11 years)	21 (1-31 months)	21 (1 month to 1 year)
Discharged from HVP	12	2†	14
Remained in HVP	11	4†	15
Died in HVP	3	3†	6
Total	26	9	35

*M indicates male; F, female; CPAP, continuous positive airway pressure; SIMV, synchronized intermittent mandatory ventilation; BiPAP, bilevel positive airway pressure; HVP, home ventilation program.
†*P* value not significant

accidental decannulation at home occurred in 8 of the children with invasive ventilation (0.4 episodes per child annually). This was resolved by the timely replacement of the tube in 7 of them. One patient suffered a severe hypoxic cerebral lesion due to the direct caretakers' failure to deal with the episode in time. Tolerance of NIV was generally acceptable, although mask use was temporarily interrupted in 2 patients due to poor tolerance. A high percentage of the children showed some delay in psychomotor development, which was normal in only 3 patients. In a considerable number of the children there was an underlying cause for this developmental delay. Twenty-one patients received physical therapy at home, 12 patients received occupational psychotherapy, and 15 patients received speech therapy (Table 3). The majority of the children with more comprehensive programs were sent home after the year 2000. Of the 35 children, 24 had the supervision of a nurse's aide. The majority of these patients (18 out of 24) had been admitted to the program after the year 2000.

Discussion

This study represents the largest clinical series reported in the literature of South America to date and confirms previous reports from developed countries concerning the increase in the number of children with severe chronic respiratory failure who are ventilator-dependent. Our experience confirms the usefulness of multidisciplinary support for highly complex patients. Morbidity was low and accidents due to equipment failures and accidental decannulation had no serious consequences in the vast majority of cases. Prognosis for weaning from ventilatory assistance was best for those patients with airway abnormalities; those with neuromuscular diseases remained in the program longer. Finally, the study showed a growing trend towards the use of NIV, especially in patients with neuromuscular diseases.

The number of children requiring home ventilatory assistance has increased throughout the world.[11] This tendency is a clear reflection of the success pediatric and neonatal intensive care units have had in increasing survival in children with complex diseases that would previously have resulted in death. Home ventilatory assistance as an alternative to hospital stays for such children was analyzed in 2 recent studies from Chile.[7,12] We now have a better understanding of the needs of each

TABLE 3
Morbidity, Emergencies, and Treatment According to Type of Ventilation Used*

	IV	NVI	Total
Morbidity			
Acute respiratory infection			
Episodes/child	5.7	4.5	5.4
Episodes/child/y	2.4	3.7	2.6
Hospitalization			
Episodes/child	3.3	3.2	3.3
Episodes/child/y	1.3	2.6	1.6
Airway granuloma	21	–	
Emergencies			
Decannulation			
Episodes/child	0.9	–	
Episodes/child/y	0.4	–	
Equipment failures			
Episodes/child/	1.1	1	1.1
Episodes/child/y	0.4	0.8	0.5
Hospitalization			
Episodes/child	0.3	0	0.2
Episodes/child/y	0.1	0	0.1
Neurorehabilitation			
Physical therapy	16	5	21
Occupational psychotherapy	10	2	12
Speech therapy	13	2	15
Gastrostomy	15	4	19
Total	26	9	35

*IV indicates invasive ventilation: NIV, noninvasive ventilation.

patient with chronic respiratory failure and of the benefits that ventilatory assistance can provide in each particular case. In recent years, several reports have mentioned NIV as a treatment that should be considered early on in patients with respiratory pump failure in order to prevent muscle fatigue. In a series of patients with Duchenne muscular dystrophy[13] there was great improvement in the chances of survival once ventilation was initiated in 1990. The success of NIV was also confirmed when improvements were shown in ventilatory function (tidal volume), in sleep disorders, and in respiratory regulation thanks to the respiratory muscle rest NIV provides throughout the night.[14-16] Our series showed a clear increase in the use of NIV as a method of ventilatory assistance over the last several years. This is largely due to the ease with which the system can be used in various diseases and to the flexibility it offers in intermittent ventilatory support, mainly at night. The efficacy and tolerability of NIV is as high as 80% in children using nasal CPAP.[10,17,18] Massa et al[18] observed better results in children over 5 years, especially if parents were strongly motivated. The success rate in our series was similar. In fact, in those patients in whom ventilation was temporarily removed, emphasizing the importance of using the system was all that was needed to allow ventilatory support to be resumed. A very important factor in the question of mask tolerance is the limited availability of masks in different sizes. Our successful experience with the use of a face mask in 1 child seems, at least, to offer a promising alternative.

The most frequent cause of chronic respiratory failure requiring ventilatory assistance in our series was neuromuscular diseases. This is consistent with other published reports.[19,20] Patients with such diseases would probably benefit the most from NIV. In our experience, however, this was also the group that required ventilator assistance for the longest time. Airway abnormalities made up the second most common group of diseases in our series. In this category, there were numerous patients with genetic syndromes and combinations of several malformations, the presence of which should alert us to look for respiratory manifestations. Patients in this category had the best prognosis for weaning from ventilatory assistance. In our series, 8 out of the 11 children with airway abnormalities were weaned from ventilatory assistance, 1 child was able to reduce ventilatory support, and only 2 died. Possible treatment alternatives, such as the use of airway stents, exist for patients in this category, although experience with such treatments is still limited. The group with cardiopulmonary disease had the worst prognosis and the highest mortality rate. This category included complex diseases with severe lung lesions that predispose to multiple exacerbations due to acute respiratory infections and progression of the lesion to irreversibility.

Initiation of ventilatory assistance was not elective for any of the patients in our series. This is not surprising if we consider that the types of diseases that led to admission to the program were of rapid progression, and thus there was no time to anticipate the need for ventilatory assistance. In a study on invasive mechanical ventilation,[20] treatment was elective in only 21% of patients; in the rest, it was initiated due to exacerbation, and the need for mechanical ventilation was in no case foreseen. There may be a tendency to underestimate how poor the quality of life of a child with hypoventilation is and to believe that quality of life is worsened by ventilatory assistance.

The median age of admission to and median length of time in the program were the same for both the NIV and invasive ventilation groups. The annual rate of respiratory morbidity (defined as episodes of pneumonia and bacterial tracheitis requiring hospitalization) was 1.3 episodes per child in patients with invasive ventilation and 2.6 episodes per child in those with NIV. This apparent contradiction can be explained by the presence of a professional in the homes of those patients with invasive ventilation. This allowed for better supervision and early treatment. Bacterial contamination of NIV systems has been reported to be as high as 15%, a percentage that is proportional to the care and cleaning of the equipment.[21] However, it is important to consider the possibility of bias due to the absence of adequate records for the population of patients with NIV. Such error is inherent to any retrospective study.

Overall mortality in our series was about 26%. However, only 6 children (17%) died while in the program. Cause of death was progression of the underlying disease in 4 children, and only 2 had potentially avoidable complications. It is noteworthy that there were no emergency events that resulted in death, in contrast to the experience of Gilgoff and colleagues,[22] in whose series 2 patients died at home as a result of the disconnection of the ventilator and 2 others died suddenly of unknown causes. A considerable part of the success we achieved may have been due to the advances in our program resulting from the professionalization of home care. Emergencies due to decannulation occurred in 50% of the children, but only 1 child suffered severe cerebral hypoxia with a permanent lesion.

In summary, the ventilatory assistance program is a safe and necessary program for children with chronic respiratory failure. The professional support offered by home hospitalization has a positive effect on outcome in such children. However, such a program is not exempt from accidents or problems related to equipment use. It is important to take our experience into account in creating a Chilean national home ventilatory assistance program.

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