

Survey of children supported by long-term mechanical ventilation in Switzerland

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Summary

Objective: The aim of the present study was to identify the number of children, from birth to 16 years of age, on long-term mechanical ventilation in Switzerland, and to establish their current location, underlying diagnoses and ventilatory needs.

Methods: Postal questionnaires were sent to all chest physicians (pulmonologists), intensive care specialists, neurologists, national health care organisations, rehabilitation services and ventilator suppliers known or thought to be involved in paediatric long-term ventilation in Switzerland.

Results: Detailed information was obtained on 32 children from 7 centers. Underlying disorders included congenital central hypoventilation syndrome (CCHS, 41%), neuromuscular disorders (41%), spinal cord injury (6%), craniofacial anomalies (6%) and others (6%). 10 children received positive pressure ventilation by tracheostomy and 19 children by nasal mask. Two children were ventilated by phrenic nerve pacing and one child with the help of a pneumatic belt. Children with CCHS

were almost equally divided into nasal mask and tracheostomy users. Ventilation for 16-24 hours a day was necessary in 5 children, exclusively during sleep in 24 children and only episodically in 3 children. All but 2 children were cared for at home. The majority of families received home care support. The most common reasons for readmission into hospital were regular follow-up examinations and respiratory tract infections. The children were mainly admitted to paediatric intensive care units.

Conclusions: There are few ventilator-supported children in Switzerland and most of them are cared for at home. Nevertheless, there is a need to establish a system for continuing data collection in this particular patient population to assess outcome and quality of home care support and to follow incidence trends.

Keywords: congenital central hypoventilation syndrome; home ventilation; neuromuscular disorders; non-invasive ventilation; tracheostomy; phrenic nerve pacing

Introduction

Owing to medical and technological advances, increased survival after intensive care and because of changes in society's expectations regarding long term disability, the numbers of children dependent on long term ventilator support are increasing. Home care has long been recognised as providing the best environment for the care and further development of these children [1-3]. Over the last two decades, much progress has been made in bringing home care into practice. This includes improvements in the variety of technological equipment for providing home respiratory support, as well as development of guidelines to enable a smooth transition from hospital to home [4-6], as well as improvements in home care support [7].

The use of home ventilation in Switzerland is

well documented for adult patients in registers maintained by the Swiss Lung Association, which is responsible for the organisation and supervision of this treatment in most adult patients [8, 9]. In contrast, however, there is virtually no data or information available on ventilator-supported children in Switzerland whose health care costs are usually covered by the National Disability Insurance. The aim of our survey was to characterise the present status (number, location, underlying diagnoses and medico-technical management) of long-term ventilation of children in Switzerland. Such information is essential for the assessment of needs and to enable further improvements in medical and social support for these children and their families.

Subjects and methods

Our objective was to identify all children aged 0 to 16 years resident in Switzerland who require long-term ventilatory support at home or in an institution. All children with long-term ventilatory support were included regardless of the number of hours each day spent on the ventilator or whether ventilatory support was used only episodically, e.g. only during respiratory infections.

Initial contact was made by telephone or mail with all senior respiratory physicians and intensive care specialists of all Swiss children's hospitals, the clinical directors of the Swiss Paraplegic Centre in Nottwil and the Rehabilitation Centre for Children and Adolescents in Affoltern, asking them to identify the number of children in their care dependent on long term ventilatory support. In addition, all adult respiratory physicians involved in home ventilation were contacted through the working group on home ventilation of the Swiss Association for Tuberculosis and Lung Diseases. Finally, we also contacted the "*Schweizerische Gesellschaft für Muskelkranke*" and the Swiss Disability Insurance for help with our survey. All non-responders to mail were subsequently contacted by telephone to confirm that they had no such children in their care. Those clinicians taking care of any children with chronic respiratory insufficiency were sent questionnaires for each child. We also sent questionnaires to the sales representatives of the various ventilator suppliers with a request to forward them

to the parents of their paediatric clients. The questionnaires were distributed and returned during the second half of the year 2000. In addition, we traced one child living in Switzerland through the WebPages of the Congenital Central Hypoventilation Syndrome network in the United States.

The specific information requested on each child in our anonymous questionnaire included:

- Initials and date of birth
- Diagnosis / symptoms necessitating ventilatory support
- Age at onset of mechanical ventilation and onset of home care
- Method of ventilatory support
- Type of ventilatory device
- Concurrent use of additional technological equipment (e.g., oxygen therapy, pulse oximetry, humidifiers, etc.)
- Duration and/or frequency of the daily ventilatory support
- Frequency, reasons and duration of hospitalisations in the preceding year
- Location of hospitalised children dependent on home ventilation (e.g., intensive care unit, general ward)
- Type of support at home
- Professionals involved in the ventilatory management of the patient

Results

The 32 children requiring long-term ventilatory support identified by our survey are listed according to age range in Table 1. Data on all but one child were disclosed by hospital based physicians from the following centers: University children's hospitals from Zurich (n = 9), Basel (n = 10), Genève (n = 4), Lausanne (n = 2) and Bern (n = 2); and from the Kantonsspital Zürich (n = 1) and St. Gallen (n = 3). All additional enquiries did not produce any further results.

The main diagnostic categories responsible for the need of ventilatory support of children in Switzerland (table 2) were congenital central hypoventilation syndrome (CCHS) and neuromus-

cular disorders. Much less frequent were craniofacial syndromes, anomalies of the upper airways and spinal cord injury. Four children were affected by more than one disorder or multiple anomalies contributing to chronic hypoventilation such as the combined occurrence of craniofacial anomalies, severe kyphoscoliosis and tracheomalacia. These children were listed in the category judged to be most in need of ventilator support.

All but three children received intermittent positive pressure ventilation (table 3), applied via tracheostomy in roughly one third and via a mask device in two thirds of cases. There were two children with CCHS who relied on a diaphragmatic pacer at night; one of them also had a tracheostomy. One child with acquired hypoventilation was supported with a pneumatic belt at night. All but two patients with neuromuscular disorders were ventilated by a nasal mask. Children with CCHS were almost equally divided into nasal mask and tracheostomy users.

Table 1

Number of children on home ventilation in Switzerland in 2000 according to age.

| Age interval | no. of children |
|----------------|-----------------|
| <12 months | 1 |
| 1 to 5 years | 7 |
| 6 to 10 years | 17 |
| 11 to 16 years | 7 |

Table 2

Main diagnostic categories of children requiring home ventilation in Switzerland.

| Disorder | no. of children |
|---|-----------------|
| Congenital central hypoventilation syndrome | 13 (41%) |
| Neuromuscular disease | 13 (41%) |
| Spinal cord injury* | 2 (6%) |
| Craniofacial syndrome / upper airway malformations** | 2 (6%) |
| Other | |
| Severe burns | 1 (3%) |
| Multiple problems (lung hypoplasia, diaphragmatic paralysis and tracheomalacia) | 1 (3%) |

* Myelitis, after surgery for kyphoscoliosis

** Obstructive sleep apnoea included

Table 3

Number of children supported by long-term ventilation according to type of ventilatory support and underlying aetiology.

| Type of ventilatory support | CCHS | NMD | spinal cord injury | craniofacial syndrome | other | all |
|-------------------------------|------|-----|--------------------|-----------------------|-------|-----|
| Positive pressure ventilation | | | | | | 29 |
| Tracheostomy | 6 | 2 | | 1 | 1 | 10 |
| Non-invasive mask | 5 | 10 | 2 | 1 | 1 | 19 |
| Diaphragmatic pacing | 2 | | | | | 2 |
| Pneumatic belt | | 1 | | | | 1 |

CCHS, congenital central hypoventilation syndrome

NMD, neuromuscular disorder

The degree of ventilatory support varied widely in this group of children (table 4). Three children required ventilatory assistance 24 hours a day. Two children had ventilator support during sleep, as well as intermittently when awake. 24 children were able to sustain adequate ventilation when awake and depended on nocturnal ventilation only. Three children required ventilatory support only episodically, mainly during respiratory tract infections. Additional technical home equipment consisted mainly of pulse-oximeters (23 of 32 children), suction devices (13 of 32 children) and humidifiers (21 of 32 children). 9 of the 32 patients received supplemental oxygen at home.

Table 5 shows that after institution of home mechanical ventilation, children returned to the hospital mainly for routine follow-up. Respiratory tract infection was the second most common cause for admission. Further reasons for admission to hospital were respite for parents, dehydration, elective surgery, orthopaedic disorders and gastrostomy feeding problems. When admitted from home, children were commonly being cared for in paediatric intensive care units (PICU) rather than in general wards. An exception to this trend was the location during follow-up, where some paediatric

clinics exclusively used the general ward, others only the PICU. Apart from their initial hospital stay to establish home ventilation, occupation of the PICUs was rarely for more than two weeks. Re-admission to hospital for longer than one month occurred in 4 children; twice for severe respiratory tract infections and twice for rehabilitation and adaptation of ventilation.

Children with CCHS who required ventilation from birth (n = 10) remained in hospital 6 to 14 months before home care became possible. Initiation of home ventilation was achieved much sooner in older children, especially when managed with non-invasive mask ventilation (usually within a few weeks). Of a total of 32 children, only two infants (both with CCHS) were still in hospital awaiting trained home care personnel or adaptation of their home environment. All other children lived at home with their families.

Home ventilation was primarily managed and followed in 22 of the 32 children by paediatric pulmonologists (or combined with paediatric intensivists) and in 10 children by adult pulmonologists. All children that were ventilated by tracheostomy were followed by paediatric pulmonologists and were managed by the paediatric centres. Children managed by adult pulmonologists were all ventilated by nasal mask and all were above 6 years of age. 19 children received professional home care support including all children with tracheostomies. Eleven children, all above 6 years of age, were cared for by their family without professional home support.

Table 4

Hours of daily ventilatory requirement of children supported by long-term ventilation in Switzerland.

| Hours of daily assisted ventilation | no. of children |
|-------------------------------------|-----------------|
| 24 h | 3 |
| 16-24 h (night and day time) | 2 |
| 8-12 h (nocturnal ventilation only) | 24 |
| Episodically (not every day) | 3 |

Table 5

Reasons for hospital admissions of children on home ventilation in 1999.

| Admitting Diagnosis | admissions (n = 40) | hospital site | |
|-----------------------------|------------------------|---------------------|--------------|
| | | intensive care unit | general ward |
| Follow-up | 26 | 19 | 7 |
| Respiratory tract infection | 7 | 5 | 2 |
| Other conditions* | 6 | 5 | 1 |
| Elective surgery | 1 | 1 | |

* Other conditions include dehydration, respite for parents and hospitalisation for specific problems associated with atopy, scoliosis and gastrostomy tube feeding

Discussion

Our survey, completed during the year 2000, provides the first national data on the group of children supported by long term ventilation in Switzerland. Whilst we cannot be certain that all

such children have been included, the data constitute the best available figures for this particular patient group. Our main findings were that long term ventilatory support is available to children in

Switzerland and is confined to a few diagnostic categories. The most encouraging finding was that most children lived with their parents at home and were supported by home care institutions.

Recent comparable surveys of children requiring long term ventilation documented 141 such cases in the United Kingdom and 82 in Canada [10, 11]. In these countries the numbers are somewhat lower in relation to total population than for Switzerland. In contrast, it seems that the number of children on home ventilation is higher in France. In 1992, the Association Nationale pour le Traitement a Domicile de l'Insuffisance Respiratoire chronique (ANTADIR) identified a total of 158 children who were started on home mechanical ventilation during this one year alone [12]. A recent survey in Japan identified 434 children ventilated for more than 3 months [13]. Of these 434 patients, only 61 were ventilated at home. This has been attributed to the lack of a system and regulations to support home ventilation in Japan. Unfortunately, further comparisons with other countries are impossible because such prevalence data is unavailable.

The most common indication for long term ventilatory support at home in children is chronic respiratory failure due to neuromuscular disorders. In the recent British and French survey, neuromuscular disorders accounted for nearly half of the paediatric patient population [10,12]. In the U.K., the remaining diagnostic spectrum was made up of CCHS (13%), spinal injury (12%), craniofacial syndrome (7%), bronchopulmonary dysplasia (4%) and a number of miscellaneous diagnoses accounting for 18% of all disorders. In contrast to the results of the British model survey, we found that ventilator-supported children with neuromuscular disorders did not outnumber the ones with CCHS in Switzerland (table 2). It remains unclear and only speculative from our small sample number, whether the lower proportion of children with neuromuscular disorders in our patient population reflects a true difference in societal and medical practice for initiating long term ventilation in these children compared to other countries. Our data, however, emphasise the need to discuss the option of long-term ventilation early with patients at high risk for respiratory failure and their families to avoid inappropriate avoidance or involuntary installation of ventilatory support due to misconception or inadequate expectations [14, 15]. The natural progression of neuromuscular disorders allows ample time to discuss options for long-term care early and prior to any acute respiratory catastrophe.

Prolonged hospitalisation after achievement of medical stability has been repeatedly identified as a common problem in the management of ventilator dependent children [16, 17]. Roughly one third of all children dependent on long term ventilation in the United Kingdom remain in hospital for undefined periods of time [10]. The most common obstacles to transferring children from hos-

pital to home care are: (i) failure to recruit qualified nursing staff to care for the child in the home environment, (ii) incomplete funding arrangements and (iii) unsuitable home conditions to meet the child's needs. In our survey, the proportion of home-treated versus hospitalised children is much more favourable. Only two of the 32 long term ventilator dependent children were waiting, for non-medical reasons, to return to their parents' home when the Swiss data were collected. However, all infants requiring ventilatory support from birth remained in hospital for long periods (up to 14 months) until home care was considered to be safe.

Looking at patient support at home, almost half (49%) of all British families with a child at home had to meet all their children's medical needs themselves [10]. Only 17% of these families had access to facilities which permitted respite care. In contrast, about two thirds of the families of children requiring home ventilation received professional home care support. In the remaining homes, parents relied on their own resources or on private help of relatives and friends. Our study was not designed to evaluate comprehensively quality and quantity aspects of home care in Switzerland. Whether the supportive care available is perceived as adequate or not by the individual families remains open for further investigations.

A shift of care from paediatric intensive care units (PICU) to less acute areas has been observed in the management of stable children on long-term ventilation in other countries [10]. This trend reflects efforts for the optimal use of logistical and financial health care resources. These efforts were initiated on the assumption that a high percentage of otherwise medically stable children could not be discharged and were „blocking“ much needed PICU beds [15]. The measures taken have been supported by a recent study on the safety of hospitalised ventilator-dependent children outside the PICU which demonstrated that the mortality rate and the risk of unexpected PICU transfer were not higher than in nonventilator-dependent inpatients [18]. According to our study, chronically ventilated Swiss children usually reside at home with their parents and occupy hospital facilities, mainly the PICUs, only for short periods of time when readmitted. The small number of patients would probably result in too little institutional experience of management of such children outside intensive care units and does not justify a change in current admitting procedures.

Of the increasing variety of methods for providing invasive and non-invasive ventilatory support at home, the ones applied in Swiss children were almost exclusively positive pressure ventilation via tracheostomy and nasal mask. In contrast, 6% of the children identified in the recent British survey were managed by negative pressure ventilation at home [10]. Although negative pressure ventilation has been used successfully in the past, non-invasive positive pressure ventilation has be-

come the favoured mode for patients with neuromuscular disorders. It provides stability for the upper airway and prevents upper airway obstructive events which may occur in REM sleep during negative pressure ventilation [19]. Negative pressure ventilation, however, has recently been recommended as an alternative for those children with slowly progressive neuromuscular disorders in whom nasal or face mask positive pressure support is not practical [20]. As reflected by our own cohort of long-term mechanically ventilated children, positive pressure ventilation with a nose mask is the common mode of support applied to patients with neuromuscular disorders. Exceptions to this practice are children who require full-time ventilation, or infants and young children who are unable to tolerate a mask device. Other concerns with using mask ventilation in infancy relate to the fear of respiratory deterioration during otherwise simple upper respiratory tract infections or to the development of mid-face deformity during growth. Hence, only two children in our study population were managed by non-invasive ventilation since infancy. In general, the choice of ventilatory support mechanism depends on age, diagnosis and ventilatory requirements, as well as on other factors not related to the child's needs, such as cost or local experience. The fact that no negative pressure device was used in any of the mechanically ventilated children can in part be attributed to the lack of commercial availability and lack of familiarity among clinicians with this mode of support.

The long-term prognosis of children supported by long-term ventilation depends heavily on the underlying disorder. Preliminary data and our own experience (J.H.) suggest that older patients with CCHS can be successfully switched from tracheostomy to non-invasive mask ventilation preventing stigmatisation and restrictions in social life [21]. With modern techniques for home ventilation, children with CCHS have a good long-term medical and psychosocial prognosis, and they will be offered the necessary therapeutic options without hesitation [22, 23]. The oldest patients with CCHS in our survey were two 12-year old girls who both attend regular school. Before ethical issues regarding prolonging life in patients with degenerative diseases can be considered, the quality of life with medical intervention must be delineated. Preliminary results suggest that there is also a role for assisted ventilation in patients with

slowly progressive forms of spinal muscular atrophy [24]. Many paediatricians in Japan have even actively prolonged the life of Werdnig-Hoffmann patients, from whom aggressive life-saving measures have been withheld in most Western countries [13]. Nevertheless, symptomatic ventilatory failure can be effectively palliated using non-invasive mechanical ventilation in patients with end-stage motor-neurone disease, but this benefit has to be carefully weighed against possible harmful effects, such as prolongation of life at the cost of increased disability.

The management of this heterogeneous group of ventilator-dependent children poses complex and unique ethical, medical, economic as well as psychological problems. It is likely that the size of this population of children will increase as medical technology advances and public views regarding life of quality on long-term ventilation change in our society. Having established minimum prevalence figures we conclude that there is a need for continuing data collection in this particular patient group to assess outcome, quality of home care support, clinical progress, changing incidence trends and economical aspects. We emphasise the importance of establishing a national database for children requiring home ventilation as a pre-requisite for improving the quality as well as for monitoring the long-term impact of this treatment.

We thank the following physicians for their contribution to our survey: PD Dr. K. Bloch (Department of Pulmonology at the University of Zurich), Dr. H. Hartmann (Kantonsspital Münsterlingen), Dr. B. Schwizer and Dr. C. Casaulta (University Children's Hospital, Inselspital Berne), Dr. B. Knecht (Affoltern a.A.), Dr. M. Baumberger (Paraplegikerzentrum Nottwil), Prof. J.W. Fitting, Dr. J. Cotting und Dr. J. Nielsen (CHUV, Lausanne). We also acknowledge the help of the Swiss Association against Tuberculosis and Lung Diseases, the "*Schweizerische Gesellschaft für Muskelkranke*" and the Swiss Disability Insurance. We thank PD Dr. B. Fowler (University Children's Hospital Basel) for help with the manuscript.

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