# Care alternatives for pediatric chronic mechanical ventilation

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#### **Abstract**

**Objective:** To determine the impact of transferring a pediatric population to mechanical ventilator dependency units (MVDUs) or to home mechanical ventilation (HMV) on bed availability in the pediatric intensive care unit (ICU).

**Methods:** This is a longitudinal, retrospective study of hospitalized children who required prolonged mechanical ventilation at the MVDU located at the Hospital Auxiliar de Suzano, a secondary public hospital in São Paulo, Brazil. We calculated the number of days patients spent at MVDU and on HMV, and analyzed their survival rates with Kaplan-Meier estimator.

**Results:** Forty-one patients were admitted to the MVDU in 7.3 years. Median length of stay in this unit was 239 days (interquartile range = 102-479). Of these patients, 22 came from the ICU, where their transfer made available 8,643 bed-days (a mean of 14 new patients per month). HMV of eight patients made 4,022 bed-days available in the hospital in 4 years (a mean of 12 new patients per month in the ICU). Survival rates of patients at home were not significantly different from those observed in hospitalized patients.

**Conclusion:** A hospital unit for mechanical ventilator-dependent patients and HMV can improve bed availability in ICUs. Survival rates of patients who receive HMV are not significantly different from those of patients who remain hospitalized.

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#### Introduction

Mechanical ventilator-dependent children are a group of pediatric patients with complex care needs, due to continuous use of apparatuses for providing ventilation assistance and to prolonged hospitalizations. This population has been growing in recent years, 1 as a result of technological advances for treating severe chronic patients, as well as increased public access to medical resources.

Even when patients are clinically stable, many remain hospitalized in intensive care units (ICU) for periods that vary from few months to years.<sup>2</sup> This situation exposes patients and their families to problems associated with prolonged hospital stays, such as nosocomial infections, and also psychological<sup>3,4</sup> and relationship disturbances in the family. For the hospital, prolonged bed occupation in

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the ICU by stable patients impairs the capacity to receive new patients with severe conditions,<sup>5</sup> besides the fact that it increases expenditure.<sup>6</sup>

As an alternative to lengthy ICU stays, many patients have been transferred to services of lower complexity, such as mechanical ventilator dependency units (MVDUs).  $^{7-10}$  Patients who have favorable clinical and socioeconomic conditions may be indicated for home mechanical ventilation (HMV).  $^{7,11-18}$ 

There are no data available about bed occupation and length of stay associated with patients who require MVDU or HMV in developing countries. In Brazil, few services offer prolonged mechanical ventilation for pediatric patients.

In our study, we aimed to evaluate the impact that transferring this population to an MVDU and to HMV had on bed availability in a pediatric ICU.

## Materials and methods

This is a longitudinal, retrospective study that included hospitalized children who required prolonged mechanical ventilation at the MVDU provided by the Hospital Auxiliar de Suzano in São Paulo, Brazil. This hospital receives pediatric mechanical ventilator-dependent patients from Instituto da Criança proceeding from three sectors: ICU, nursery and step-down unit. Both institutions are state public hospitals and linked to Hospital das Clínicas of the Medical School of Universidade de São Paulo (USP). Beginning in 2001, care for pediatric patients who are clinically stable but still require prolonged ventilation has been provided by the MVDU. This unit has 14 beds, with an average monthly occupation rate of 100%. Three physicians are on duty during weekdays (each one for a period of 4 hours during the day), while one physician is in charge during night shifts and weekends. The criterion for a child to be considered as dependent of mechanical ventilation, and consequently being suitable for transfer from the ICU to MVDU, is the one adopted by the United Kingdom Working Party on Paediatric Long Term Ventilation: "any child who, when medically stable, continues to require a mechanical aid for breathing, after an acknowledged failure to wean, or a slow wean, 3 months after the institution of ventilation."19

In May of 2005, the Hospital Auxiliar de Suzano started a program that aimed to discharge patients who were hospitalized in the MVDU but were in a suitable condition to receive care at home. The criteria for patient eligibility were: 1) clinical stability; 2) suitable family conditions (education, habitation, socioeconomic situation); and 3) existing supportive local health care service (professional assistance, medical materials, transportation). The discharge procedures take place only if the patient (when intellectually able) and his/her family express the wish to go home and after receiving all necessary relevant information about HMV. In these cases, the hospital lends patients an apparatus

with bi-level ventilator (BiPAP®), energy manager, and a set of batteries. The apparatus is provided by a private company, which also offered maintenance and technical support both periodically and in emergency situations. The hospital expenses with this apparatus are posteriorly reimbursed by Brazilian public health care system - Sistema Único de Saúde (SUS). This reimbursement is due to specific legislation. <sup>20</sup> Before the patient is discharged, his/her family receives specific training for taking care of the patient, both in routine tasks and basic emergency procedures. The SUS, through the patient's local government health agency, provides staff to supervise the care. In case of an emergency, the public health care system is responsible for providing assistance as well.

Patients were included in this study according to the following criteria: 1) to be hospitalized in the pediatric unit of the Hospital Auxiliar de Suzano during the period between 5 February 2001 and 10 June 2008; and 2) to match the definition of prolonged ventilation by the United Kingdom Working Party on Paediatric Long Term Ventilation, as cited above.<sup>19</sup>

Data on hospitalization and the main diagnosis of each patient were obtained from patient charts provided by the hospital. Patients were classified according to preceding division (ICU, nursery, and step down unit) and then by disease group (neuromuscular, metabolic, hypoxicischemic encephalopathy, neurologic malformations, genetic syndromes, central nervous system tumors, and others). We calculated the length of stay for each patient in the MVDU. Next, we calculated the number of bed-days for groups of patients according to preceding division and disease group. Re-hospitalization was defined as any episode in which the patient needed a short hospitalization during the period when he/she was receiving care at home. Patients who needed to be re-hospitalized and were unable to return home shortly afterwards were no longer considered to be patients who were receiving care at home.

We proceeded to the survival analysis of the groups of patients who remained in the MVDU (group 1) and of those who were discharged with HMV (group 2). The Stata 11 software was employed to calculate the Kaplan-Meier estimator and other statistical data. We considered two situations: in the first one, we compared survival rate of group 1 to the survival rate of group 2. In order to control the groups of diseases as a possible confounding factor, in a second situation we modified group 1: we maintained in it only those patients who belonged to the same groups of diseases as the patients of group 2, and excluded those who did not fill this criterion. This group of patients was called group 1A. We assumed that there are groups of diseases whose patients tend to be more clinically stable than patients of other groups, a situation that would increase their chance of survival, as well as their chance of being discharged with HMV.

This study was approved by Ethics Committee for Research Projects Analysis of Hospital das Clínicas of the Medical School of USP.

#### Results

#### Patient characteristics

The total study period of patients in the MVDU was 2,682 days, which corresponds to 7.3 years. For patients in the HMV, the study period was 1,476 days, which corresponds to 4.0 years.

We identified 41 patients who matched our inclusion criteria. All 41 were included in the study. Twenty patients were males and 21 females. The mean age was  $5.4\pm5.0$  years. Among the patients included in this study, we identified 24 diseases of different etiologies. The number of cases per disease group is shown in Table 1.

Eight patients were discharged and received care at home. Of the 33 patients who remained hospitalized, 10 died before the HMV program was established, 14 had no clinical stability to be discharged to receive care at home safely (12 of them died), one patient was transferred to a hospital closer to her house (and was still alive at the end of data collection), six had inadequate family conditions (one died), and in two cases the local government health agency of the city of the patient was unable to be responsible for the home care of the patient.

## Data on hospitalization

The data on hospitalization are shown in Table 1.

The median of length of stay in the MVDU was 239 days (interquartile range = 102-479).

As for the patients on HMV, eight children represented 4,022 bed-days. The median of length of stay of patients on HMV was 330 days (interquartile range = 160-760).

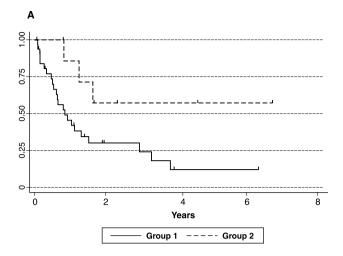
The estimated total time of re-hospitalization was 88 bed-days, which corresponds to 2.2% of the total bed-day time that patients remained at home. One of the patients was re-hospitalized and did not go back home due to clinical instability.

# Survival analysis

For the first part of survival analysis, we included 33 patients who remained in the MVDU in group 1, and eight patients who received HMV in group 2 (Figure 1A). Survival rate in group 1 after 6 years was 0.106±0.076, while in group 2 was  $0.552\pm0.195$  (p = 0.040). In the second part of analysis, we included 14 patients in group 1A, and group 2 was the same, with eight patients (Figure 1B). The groups of diseases found both in group 1A and in group 2 were: neuromuscular diseases (five patients in group 1A and 5 in group 2), metabolic diseases (five patients in group 1A and 2 in group 2), and malformations (four patients in group 1A and 1 in group 2). Survival rate in group 1A after 6 years was 0.264±0.146, and group 2 kept the same survival rate of  $0.552\pm0.195$  (p = 0.224). Other groups of diseases had no patients on HMV due to one of the following reasons: insufficient clinical stability, lack of adequate family conditions, or lack of adequate support from local health services.

Table 1 - Number of bed-days occupied by each group of diseases, according to patient's preceding unit

Group of diseases	Preceding unit							
	ICU		Nursery		Step-down unit		 Total	
	BD (%)	n (%)	BD (%)	n (%)	BD (%)	n (%)	BD (%)	n (%)
Neuromuscular	3,070 (17.4)	6 (14.6)	-	-	4,188 (23.7)	5 (12.2)	7,258 (41.2)	11 (26.9)
Metabolic	1,659 (9.4)	6 (14.6)	-	-	35 (0.2)	1 (2.4)	1,694 (9.6)	7 (17.0)
Neurologic malformations	1,689 (9.6)	2 (4.9)	518 (2.9)	3 (7.3)	-	-	2,207 (12.5)	5 (12.2)
HIE	806 (4.6)	3 (7.3)	2,151 (2.2)	3 (7.3)	1,595 (9.0)	2 (4.9)	4,552 (25.8)	8 (19.5)
Genetic syndrome	171 (1.0)	1 (2.4)	34 (2.0)	2 (4.9)	-	-	518 (2.9)	3 (7.3)
CNS tumors	479 (2.7)	1 (2.4)	-	-	102 (0.6)	1 (2.4)	581 (3.3)	2 (4.8)
Others	769 (4.4)	3 (7.3)	61 (0.3)	2 (4.9)	-	-	830 (4.7)	5 (12.2)
Total	8,643 (49.1)	22 (53.5)	3,077 (17.4)	10 (24.4)	5,920 (33.5)	9 (22.0)	17,640 (100)	41 (100)



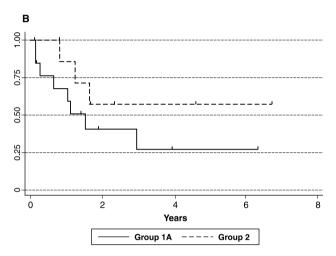


Figure 1 - A) Kaplan-Meier survival curves for children on longterm mechanical ventilation in the MVDU (group 1) and on HMV (group 2); B) Survival rates by Kaplan-Meier estimator of patients in the MVDU (group 1A) who had the same diagnosis as those who received HMV (group 2)

HMV = home mechanical ventilation; MVDU = mechanical ventilation dependency unit.

## Discussion

Table 1 shows that ICU was the division that referred patients to the MVDU the most. The transfer of 22 patients from the ICU to the MVDU made 8,643 bed-days available for new hospitalizations in the pediatric ICU. This corresponds to 98 bed-days per month. If we consider the mean length of stay in ICU as  $6.66\pm8.86$  days,  $^{21}$  these 8,643 bed-days may represent the hospitalization of 1,298 patients in the ICU in 7.3 years, or 14 new patients per month.

Likewise, patients transferred to the HMV made available 4,022 bed-days in the MVDU over 4 years. As the median of the length of stay of patients in this division is 239 days, this transfer of patients enabled hospitalization of 17 new patients in the MVDU. Indirectly, this could represent 604

hospitalizations in the ICU in 4 years, or 12 new patients per month.

The survival rate of the patients in HMV (group 2) was significantly higher compared to that of all those who remained in the hospital (group 1). The result was expected, as the patients who were able to receive care at home were more stable than those who remained hospitalized. When we considered in group 1A only those patients who belonged to the same groups of diseases as those of group 2, the difference between the survival rates was not significant. The groups 1A and 2 have some differences in the proportion of disease groups in their composition, a factor that may impair the comparison. Nevertheless, the absence of significant difference in survival rates may be due to clinical similarities between these patients.

It is noteworthy that the Kaplan-Meier estimator demonstrated that HMV did not impair the survival rate of patients receiving care at home. We believe that this can be explained not only by patient's clinical stability, but also by the skill of caregivers. We observed that the family caregivers acquire great knowledge about the patient's clinical condition and can successfully perform all the required tasks to their care with no major difficulties.

According to disease group, patients with neuromuscular diseases constituted the group that occupied most beds per day at the MVDU, with 7,258 bed-days (41.2%), followed by hypoxic-ischemic encephalopathy (25.8%) and malformations (12.5%).

Bed availability in pediatric ICUs is an important issue in Brazil's public health. Two of Brazil's greatest cities (São Paulo and Rio de Janeiro) have shortage of pediatric ICU beds in public hospitals, with an uneven distribution. <sup>22,23</sup> Around 80% of Brazilian population relies on public health services, <sup>24</sup> so this scarce and expensive resource must be used judiciously. Although the number of mechanical ventilator-dependent patients in our study is small, their lengthy stays represent a burden for ICUs, reducing bed availability. The implantation of MVDU and HMV services for mechanical ventilator-dependent patients may be a useful measure for optimizing pediatric public ICU bed occupation, without damage to patients' survival.

It is important to mention that the transference of a patient to a MVDU, and subsequently to HMV, has other important aspects for the hospital and for the patients' family as well. <sup>25,26</sup> For the hospital, this transference may represent a great reduction in economic costs, once many expensive resources available in the ICU are not needed in the MVDU. For the family, the caring activities bring not only an increased amount of workload to the caregivers, but also health, social, and economic burdens. However, there are also important positive aspects: the patient is relieved from the hospital stressful environment and from affective isolation, and regains his/her social links. The

parent who accompanies him/her (frequently the mother) can return home as well, restoring the family group. These aspects must be considered and discussed with the family before the discharge.

This study reports the experience of a single university hospital and was done considering a small number of patients. Here we showed that the transfer of stable patients who are under mechanical ventilation to a MVDU or to HMV leads to a greater number of beds available in the ICUs. This greater availability of beds enables the hospital to provide a better service to the community.

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