

# Discharge of Respiratory-Compromised Children after Respiratory Rehabilitation

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## Abstract

**Background:** There is a growing demand for respiratory rehabilitation services for children dependent on tracheostomy and/or chronic mechanical ventilation. Discharging these patients home following their rehabilitation can be an arduous process.

**Objectives:** To define the length of time required to rehabilitate and discharge these patients, and to identify predictors of a prolonged or failed discharge process.

**Methods:** We conducted a retrospective chart review of patients admitted to the Respiratory Rehabilitation Unit at Alyn Hospital, Jerusalem, over a 4 year period.

**Results:** Of the 48 patients identified, 31 (64.7%) were eventually discharged, 13 (27.1%) remained hospitalized long-term, and 4 (8.3%) died during their hospitalization. The median length of hospitalization was 10 months: 6 months for purposes of rehabilitation therapy, and 4 months thereafter to resolve the logistics of discharge. Specific family characteristics – an unemployed father (odds ratio = 4.6,  $P = 0.02$ ) and an additional family member with a disability (OR = 5.8,  $P = 0.03$ ) – as well as ongoing mechanical ventilation at the time of discharge (OR = 5.5,  $P < 0.01$ ) were found to positively correlate with a prolonged or failed discharge process.

**Conclusions:** Hospitalization in a pediatric respiratory rehabilitation unit may be prolonged for both medical and non-medical reasons, with the process of discharge home being particularly difficult in certain subsets of patients. A proactive discharge policy by hospitals, improved community support services, and legislation defining the rights of home-ventilated children may facilitate more efficient discharge home of these patients.

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Recent advances in neonatal and pediatric intensive care management have resulted in a growing number of children who successfully survive serious respiratory illness, but remain dependent on mechanical ventilation and/or a tracheostomy. Fraser and co-authors [1] reported that in England, children dependent on ongoing mechanical ventilation tend to remain hospitalized for prolonged periods even though home ventilation technology has advanced to the point at which children, and even neonates, can now be ventilated safely and effectively at home. This is of particular relevance in light of the finding by Fields et al. [2] that psychosocial development and quality of life for mechanically ventilated children is better in the home than in hospital settings. A survey by Jardine and colleagues [3] identified inadequate home-nursing services and difficult family socioeconomic circumstances as the major impediments

to successful home discharge of chronically ventilated children in England.

In Israel, a national pediatric Respiratory Rehabilitation Unit was established at Alyn Hospital in Jerusalem in January 2000 to provide respiratory rehabilitation services and general rehabilitation services for children with chronic respiratory difficulty. Respiratory rehabilitation in the unit comprises all modalities of rehabilitation therapy for the child as well as education and training of the parents in preparation for discharge of a child with chronic respiratory disease – often with the need for ongoing mechanical ventilation at home. Although the unit initially comprised 10 beds, due to a constant demand for pediatric respiratory rehabilitation services the unit almost doubled in size during the course of its first 4 years of existence. The length of time required to discharge patients after completion of their rehabilitation therapy, however, continued to strain the resources of the unit and impede its ability to accept new patients in need of rehabilitation. As a result, the current study was undertaken to determine the amount of time required to discharge pediatric patients after completion of respiratory rehabilitation, and to identify the factors that may be associated with a protracted or failed discharge process.

## Subjects and Methods

A retrospective chart review was performed to identify all patients less than 17 years old who were admitted to the Respiratory Rehabilitation Unit at Alyn Hospital in Jerusalem between January 2000 and December 2003, who needed at least one week of rehabilitation therapy and who were sufficiently stable to be discharged home upon completion of their rehabilitation program. For each patient, sociodemographic characteristics [Table 1], medical diagnoses, and the patient's respiratory condition upon admission were recorded. In addition, the source of referral, the outcome of the hospitalization, and a discharge timeline (the time from admission until a decision to discharge was taken and the time from the discharge decision until its actual implementation) was recorded for each patient. Frequency was calculated for discrete variables, the median and range were calculated for the discharge timeline variables, and mean and standard deviation were calculated for all other continuous variables. Associations between sociodemographic characteristics, ventilation characteristics and outcomes were calculated as odds ratios, using the chi-square test to determine the significance of associations. Differences in the length of time taken to implement a discharge

OR = odds ratio

once a decision to discharge had been taken were subjected to the Mann-Whitman U test, with a *P* value of < 0.05 considered significant.

## Results

Forty-eight patients were identified in the survey. Table 1 lists the demographic characteristics of the cohort. The mean age at the time of admission was 46 months. Although the ages of the patients at the time of admission ranged from 2 months to 17 years, approximately three-quarters of the group as a whole (73%), and all of the Moslem patients within the cohort, were under the age of 4 years. Ten percent of the children came from single-parent families. The number of family members ranged from 3 to 14, the most frequent number of children per family being 4. In 21% of the families there was an additional family member with significant physical disability. In over half the families, at least one parent was not generating a monthly income.

Only three of the patients had been referred for admission from home; the remaining 45 had been transferred from other hospitals. Referring diagnoses included complications of premature birth in 10 patients (23%), congenital neuromuscular disease in 22 (46%), and status post-trauma or severe infection necessitating ventilation in 16 (33%). Thirty-eight patients (79%) were tracheostomized and 28 (58%) were on full-time mechanical ventilation at the time of admission. It was also found that 31 of the children (65%) were being fed via a gastrostomy tube and 13 children (19%) exhibited severe neurologic deficit with minimal responsiveness to external stimulation.

Table 2 summarizes the discharge characteristics and outcome for the 48 patients in the cohort. The median time until a decision to discharge a patient was taken was 6 months (range 0–24 months). At the time of the decision to discharge, 7 of the initial 38 children (18.4%) with tracheostomies had undergone successful decannulation, while 4 of the initial 10 children who had not been admitted with tracheostomies required tracheostomy insertion during the course of their treatment. Consequently, when the decision to discharge was taken, 35 of the children (72.9%) had a tracheostomy *in situ*. In addition, 2 of the 28 children who were ventilated at the time of admission had been fully weaned from ventilation when the decision to discharge was taken, and a further 15 had been weaned to night-time ventilation only. Of the 20 patients who had not been ventilated initially, 7 began mechanical ventilation during the course of their hospitalization. Consequently, a total of 33 patients (69%) were receiving mechanical ventilatory support at the time that discharge was deemed feasible. Of these patients, 13 were on full-time ventilation and 20 were being ventilated only at night.

Once the decision to discharge a patient had been taken, the median time taken to implement discharge home was 4 months (range 0–17 months). Of the 48 subjects identified for inclusion in the study, 21 (43.8%) were successfully discharged home, 13 (27.1%) remained hospitalized in the Respiratory Rehabilitation Unit at Alyn Hospital on an ongoing basis despite their medical suitability for discharge home, 6 (12.5%) were transferred to long-term nursing facilities, 4 (8.3%) were transferred to the

**Table 1.** Sociodemographic characteristics (n=48)

	No.	%
Male	30	62.5
Female	18	37.5
Israeli-born	45	93.8
Born outside Israel	3	6.2
Jewish	37	77.1
Moslem	11	22.9
Single parent family	5	10.4
Additional disability in family	10	20.9
Unemployed father	16	33.5
Non-working mother	29	60.4

**Table 2.** Discharge characteristics and outcome (n=48)

Time elapsed	Median	Range
From admission until decision to discharge	6 months	0–24 months
From discharge decision until implementation	4 months	0–17 months

Respiratory status at time of decision to discharge	No.	%
Tracheostomy	35	72.9
Mechanical ventilation (13 fulltime; 20 only at night)	33	68.7
<b>Eventual outcome</b>		
Discharged home	21	43.8
Remained hospitalized in the unit	13	27.1
Transferred to chronic facility	6	12.5
Transferred to general rehabilitation ward	4	8.3
Died prior to discharge	4	8.3

**Table 3.** Predictors of ongoing hospitalization in the Respiratory Rehabilitation Unit (n=44)\*

Predictor	Remained		Discharged		<i>P</i>
	n=13	%	n=31	%	
Unemployed father	8	61.5	8	25.8	0.02
Additional disability in family	5	38.5	3	10.3	0.03
Ongoing mechanical ventilation	13	100	18	58.1	<0.01

\*Excludes four children who died during hospitalization.

general rehabilitation ward of Alyn Hospital, from which 3 were subsequently discharged home successfully, and 4 (8.3%) died prior to discharge.

In situations in which ongoing hospitalization was not medically necessary, we were able to identify several predictors of failure to discharge home [Table 3]. The single strongest predictor was the need for ongoing mechanical ventilation. As indicated above, while none of the 15 non-ventilated patients remained hospitalized long term, 13 of the 33 ventilated patients (39%) continued to be hospitalized on an ongoing basis (*P* < 0.01). The likelihood of a child remaining in the Respiratory Rehabilitation Unit on an ongoing basis was also significantly higher if the

**Table 4.** Predictors of a prolonged discharge process (n=31 successful discharges)

Predictor	N	Mean time from discharge decision until implementation	P (Mann- Whitney U)
		(mos ± SD)	
<b>Ventilation status</b>			
Ongoing ventilation	18	4.7 ± 5.3	0.04
No mechanical ventilation	13	2.5 ± 2.6	
<b>Paternal employment status</b>			
Unemployed father	8	5.7 ± 4.6	0.84
Employed father	23	3.6 ± 3.9	
<b>Additional disability in family</b>			
Additional disability	3	4.2 ± 4.1	0.3
No additional disability	28	0.6 ± 1.7	

father was unemployed (odds ratio = 4.6,  $P = 0.02$ ) or if there was an additional disability in the family (OR = 5.8,  $P = 0.03$ ).

In those cases in which discharge was eventually successful, the discharge process took significantly longer if the patient was still being ventilated, with a mean of 2.8 months longer than for non-ventilated patients ( $P = 0.04$ ). Unlike the findings for failed discharges, paternal unemployment or additional physical disability in the family did not significantly prolong the successful discharges. The number of successful discharges in cases of families with an additional physical disability, however, may be too small (n=3) to enable meaningful statistical analysis of this variable [Table 4].

## Discussion

Discharge of pediatric patients in need of respiratory rehabilitation can be arduous and time-consuming, and the failure rate is substantial. This study found that the need for ongoing mechanical ventilation, paternal unemployment, and the existence of additional physical disabilities in the family were predictors of failure to discharge a child who, from a medical point of view, could be managed at home.

Our finding that approximately one-quarter of patients remained hospitalized on an ongoing basis despite their suitability for discharge home is similar to those reported previously [4,5]. Community factors such as unsuitable housing and lack of financial support to cover the expense of maintaining a ventilated child at home have been cited as the primary impediments to discharging chronically ventilated children [6]. In a review of 18 families with home-ventilated children in the United States, Quint et al. [7] found that even when the patient's health insurance ostensibly covered the costs of home ventilation, the family labored under a heavy financial burden. In another study, parents of home-ventilated children identified the difficulty in obtaining funding for their ongoing ventilation-related expenses from their health services provider as a major source of distress [8]. Our observation that paternal unemployment increased the likelihood that the parents would be unable to take their child home corroborates these findings, as it highlights the financial burden entailed in supporting a child on chronic ventilation at home.

With regard to the successfully discharged patients, it was found that paternal unemployment, and possibly additional disability in the family, did not significantly prolong the process of discharge. This indicates that the process of discharging ventilated children home is lengthy not because of family economic stresses, but primarily because of bureaucratic issues. In our experience, delayed discharge home was generally caused by prolonged negotiations between parents and the health services provider over the nature and extent of the financial, nursing and technical support that the family would receive once they took their ventilated child home. Although a legal definition prescribing services for children ventilated at home would prevent the need for such negotiations, no such legislation exists in Israel at present. As a result, negotiations are often long and arduous, with unreasonable demands being made by both sides.

After recognizing that non-medical factors often prolong the discharge process, we at Alyn decided to begin to address the issue of discharge as soon as possible after the patient's admission to the Respiratory Rehabilitation Unit, rather than at the point at which a formal decision to discharge had been taken. This proactive process typically begins 2–4 weeks after admission. Early discharge planning not only allows the parents to prepare themselves emotionally and psychologically for the negotiations and challenges looming before them, but also brings them to an often startling realization: that their family life can be functional and meaningful despite their child's chronic disability. Our impression is that proactive and early discharge planning creates a positive mind-set in the parents, thus contributing to a successful outcome.

As the number of chronically ventilated children in Israel can be expected to continue to grow, and as the psychosocial development of these children is optimal in a home environment rather than an institution, there is a need for appropriate legislation defining the process of chronic pediatric home ventilation. In addition, families of low socioeconomic status due to unemployment, or families with additional disabled members, are at higher risk for being unable to care for their child at home and may benefit from more organized community support services. In order to minimize the delay in discharging patients who are ready for home ventilation and help parents navigate this challenging transition, we recommend that the initial steps towards discharging respiratory-compromised children be taken shortly after their admission and not deferred until completion of their rehabilitation program.

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