Home Mechanical Ventilation in Central Taiwan: Experiences at China Medical College Hospital

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Objective. To ascertain the outcome, benefits, and complications of patients using home care ventilation.

Methods. We reviewed the hospital charts and clinical records of all patients who had been admitted to our hospital and used a mechanical ventilator at home from 1991 through 1998. The starting point for data collection on survival was the date of discharge from the hospital. The end point was either the patient's death or the time when support using a mechanical ventilator was discontinued. The mortality rate was calculated. The cost data for the different types of ventilators were obtained from two local vendors. The cost of disposable respiratory care items (suction catheters; sterile water) was obtained by averaging the expenses from five patients. Nursing charges were surveyed for our community. Medications varied widely among patients and were not included in the estimated costs of care using a ventilator at home.

Results. Twenty-six adult and five children with chronic respiratory failure are enrolled; 18 (58%) of them had neuromuscular diseases (including central nervous system disorders), and four had injuries to the spinal cord. Three of the patients used non-invasive bi-level positive pressure ventilators and two used negative pressure ventilators. Among the 31 patients, four were eventually weaned from the ventilator, and 11 (36%) died at home or in the hospital due to disconnection from the ventilator or other complications. The mortality rate was greater for adults than for children. For the majority of the patients, the cost of management at home was significantly less than the cost of management in the hospital, depending largely on the level of nursing care required.

Conclusions. We suggest that mechanical ventilation at home is a reasonable alternative to prolonged hospitalization for medically stable ventilator-dependent patients, and non-invasive mechanical ventilation may be useful for some patients. **(Mid Taiwan J Med 2000;5:248-55)**

Key words

benefit, chronic ventilator dependent, complications, diagnosis, home care, mechanical ventilation

INTRODUCTION

Patients who require mechanical ventilation as a means of life support have been successfully managed at home for many years. Survivors of the poliomyelitis epidemics of the mid-twentieth century who have paralysis of respiratory muscles provide excellent examples of the effectiveness of home ventilator care [1,2]. There is an increasing interest in managing ventilator dependent patients outside of the traditional environment of the

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Table 1. Biographical data and ventilation equipment of 18 patients with neuromuscular disease and four patients with spinal cord injuries

Patient no.	Age at discharge (years)	Diagnosis	Time in hospital (months)	Length of home care	Equipment
Neuromuscular disease					
1	0.5	Spinal muscular atrophy	3	1.9 yr	PPV
2	1	Werdning-Hoffmann syndrome	10	1.1 yr	PPV
3	1	Werdning-Hoffmann syndrome	2	3.2 yr	PPV
4	9	Brain tumor S/P	7	3.3 yr	PPV
5	17	Becker's muscular dystrophy	1	10 mo; died	NIPPV
6	18	Becker's muscular dystrophy	4	1.2 yr	NPV
7	18	Cerebral palsy	1	1.5 yr; died	PPV
8	38	Spinal tumor	1.2	1.8 yr; died	PPV
9	31	Congenital muscular dystrophy	5	6 mo	PPV
10	38	Mitochondrial myopathy	2	3.3 yr	NPV
11	54	Amyotrophic lateral sclerosis	3	9 mo; died	PPV
12	56	Amyotrophic lateral sclerosis	3	11 mo; died	PPV
13	56	Polymotor neuropathy	3	2.8 yr; died	PPV
14	60	Brain stem infarction	1.5	2 mo; weaned	PPV
15	63	Amyotrophic lateral sclerosis	2	3.1 yr	PPV
16	65	Polymotor neuropathy	2	3.5 yr	PPV
17	71	Brain stem infarction	2	3 wk; weaned	NIPPV
18	72	Polymotor neuropathy	2	11 mo; died	PPV
Spinal cord injuries					
1	15	C-3 quadriplegia	5	8 mo	PPV
3	24	C-2 quadriplegia	2	11 mo	PPV
2	43	C-5 quadriplegia	3	6 mo; weaned	PPV
4	48	C-4 quadriplegia	4	6mo	PPV

PPV = positive pressure ventilator; NIPPV = non-invasive positive pressure ventilator; NPV = negative pressure ventilator.

hospital. Adults with chronic obstructed airway diseases, amyotrophic lateral sclerosis, poliomyelitis, and severe kyphoscoliosis with restrictive pulmonary disease have been treated at home using positive pressure ventilators [2,3]. A few pediatric patients have also been treated in the same manner. In recent years, there have been substantial improvements in technology and a proliferation of equipment companies to facilitate ventilator management outside the hospitals [1,3]. The goals of long-term ventilator care must include extending life, enhancing the quality of life, providing an environment which will enhance individual potential, reducing morbidity rates, improving physical and physiologic function, and reducing costs [1,2,4-7]. The aims of this study were to determine the advantages of mechanical ventilation at home, the prognosis with respect to longevity and ultimate weaning from the ventilator, the types of complications of mechanical ventilation which could arise at home, and the correlation with age and diagnosis.

MATERIALS AND METHODS

We reviewed the hospital charts and

Table 2. Biographical data and ventilation equipment of nine patients without neuromuscular disease but with spinal cord injuries

Patient no.	Age at discharge (years)	Diagnosis	Time in hospital (months)	Length of home care	Equipment
Chronic airway disease					
1	45	Bronchiectasis; S/P lobectomy	2	11 mo; died	PPV
2	68	DILD	2	2 mo; weaned	PPV
3	69	COPD	1.5	11 mo	NIPPV
4	78	COPD	3	1 mo; died	PPV
Cardiac disease					
1	76	DCM, CHF	3	12 days; died	PPV
2	78	Uremia, CHF	2	2 mo	PPV
Malignancy					
1	80	Oral cancer with upper airway obstruction	6	9 mo; died	PPV
Miscellaneous					
1	65	Central hypoventilation syndrome	4	7 mo	PPV
2	78	Central hypoventilation syndrome	4	5.6 yr	PPV

PPV = positive pressure ventilator; DILD = diffuse interstitial lung disease; COPD = chronic obstructive pulmonary disease; NIPPV = non-invasive positive pressure ventilator; DCM = dilated cardiomyopathy; CHF = congestive heart failure.

Table 3. Requirements for nursing care in chronic ventilator dependent patients with different diseases

Diagnosis	Total no. of patients	Family or friends	Assistant	Registered nurses	Nursing homes
Neuromuscular disease	18	12	1	0	5
Adult spinal cord injury	3	3	0	0	0
Pediatric spinal cord injury	1	1	0	0	0
Chronic airway disease	4	2	1	0	1
Cardiac disease	2	1	0	0	1
Malignancy	1	0	0	1	0
Miscellaneous	2	1	0	1	0

clinical records of all patients who had been admitted to our hospital and used a mechanical ventilator at home or a nursing home from 1991 through 1998. We collected data about 31 patients, 22 of them had neuromuscular diseases or spinal cord injuries (Table 1). We grouped the remaining nine patients who did not have spinal injury or neuromuscular diseases into four major diagnostic categories (Table 2).

The issuance of ventilation equipment was verified by patients and local vendors. The starting point for data collection on survival was the date of discharge from the hospital. The end point was either the patient's death or the time when the using of a mechanical ventilator was discontinued. The mortality rate was calculated. The data of expense for different types of ventilators were obtained from two local vendors. The cost of disposable respiratory care items (suction catheters, sterile water) was obtained by

averaging costs from five patients. Nursing charges were surveyed for our community, and estimated of range from new Taiwan dollar (NT$) 30/hr (NT$ 33 ≒ USD 1) to NT$ 200/hr. Medications varied widely among patients and were not included in the estimated costs of care using a ventilator at home.

RESULTS

Twenty-six adults and five children with chronic respiratory failure and mechanical ventilator dependency were enrolled. Eighteen (58%) of our patients had neuromuscular diseases. Four had injuries to the spinal cord (Table 1). All of the spinal cord injury patients were paralyzed at the level of the fifth or more superior cervical vertebra; one patient was less than 16 years of age at the time of discharge from the hospital.

Cardiac patients were all older than 16 years of age. Two of the eighteen patients with neuromuscular disease used negative-pressure ventilators (NPV-100 with pneumowrap) at home. One patient developed severe pneumonia with respiratory failure refractory to negative-pressure ventilation. Only three patients who had non-invasive positive pressure ventilators (BiPAP-S) and two patients who had negative pressure ventilator did not require nasogastrostomy tube and tracheostomy.

Discharge plans were arranged after requirements for equipment preparation, care-giver education, and family or patient's psychological condition preparation. Thus, we always consulted psychological and social experts as soon as possible after patients were evaluated and revealed medical conditions were stable.

Finally, 22 (71%) of the 31 patients were discharged from the hospital to homes. Two were discharged to rental houses and cared for by registered nurses. Seven patients were discharged to local nursing homes which provided nurse aides. Four patients were weaned from ventilation assistance while at home over periods ranging from 3 weeks to 6 months (Tables 1 and 2). Two of the four patients weaned had their tracheostomy closed with no further problems. Four of 31 patients with spinal cord injuries who used positive pressure ventilators were independent of their ventilator for at least 8 hours per day. Patients with spinal cord injuries varied in their degree of independence from the ventilator. However, even apneic quadriplegic patients were independent of the ventilator for at least 3 to 10 minutes per day.

Twenty-two (71%) of the 31 patients were cared for exclusively at home by friends, relatives, or nursing assistants (Table 3). Seven patients were discharged to nursing homes with nurse aides level of care. Only two patients received full-time care at home by a registered nurse.

The patients survived from 12 days to more than 5 years in homes and nursing homes using mechanical ventilators. Twelve patients (39%) survived for more than one year. Eleven patients died (Table 4), eight within one year of discharge from the hospital. Using life table analysis, overall 3-year survival was 19% (six of 31 patients). However, actual survival varied depending on age and diagnosis (Tables 4 and 5). Causes of death in the 11 patients who died at home or in the hospital were as follows: pneumonia, four; disconnection of ventilator, one; sepsis, three; congestive heart failure, two; and unknown, one. In the patient with unknown cause of

Table 4. Survival by diagnosis in chronic ventilator dependent patients with different diseases

Group	No. of patients	Deaths within first year	Total deaths
Neuromuscular diseases	18	4	7
Adult spinal cord injury	3	0	0
Pediatric spinal cord injury	1	0	0
Chronic airway disease	4	2	2
Cardiac disease	2	1	1
Malignancy	1	1	1
Miscellaneous	2	0	0

Table 5. Survivals with different ages in chronic ventilator dependent patients

Age (year)	No. of patients	Deaths within first year	Total deaths
0–10	4	0	0
11–15	1	0	0
16–40	7	1	3
40–65	10	3	4
>65	9	4	4

death there was no history of acute illness, but death occurred while attached to an apparently functioning mechanical ventilator.

Mechanical complications averaged less than one per patient-year. Generally, these were minor repairs to the ventilator that did not provoke inconvenience to the patients. In cases of failure of the ventilator and inability to provide replacement the same day, patients were hospitalized until necessary equipment could be obtained. Thus far, complications of prolonged tracheostomy have occurred in only two patients; one was a woman who developed severe tracheal stenosis requiring surgery and the other was a man who developed bleeding during his initial hospitalization.

Expenses for ventilation equipment varied in amount from NT$ 18,000/mo to NT$ 26,000/mo, depending on the vendor, the type of equipment, and whether the equipment was purchased or rented. Disposable respiratory care items averaged NT$ 2,976/mo (NT$ 1,800/mo to 8,000/mo). Patients requiring supplemental oxygen in addition to mechanical ventilation incurred additional expenses, which varied depending upon whether compressed gas or oxygen concentrators were used. Costs for supplemental oxygen (9 patients) ranged from NT$ 400/mo to NT$ 4,000/mo. Full-time care by a registered nurse, which was required by two of our patients, cost approximately NT$ 210,000/mo to NT$ 217,000/mo. Charges in our institution averaged NT$ 51,071/mo for a hospitalized ventilator-dependent patient but only NT$ 35,833/mo at home.

DISCUSSION

Since 1991, we have arranged home mechanical ventilation for 31 ventilator-dependent patients.

In general, we preferred negative-pressure ventilators to positive-pressure ventilators for use at home because of the simplicity of operation, cost-effectiveness, and the lack of necessity for a tracheostomy [6-8]. However, 26 of our 31 patients were unable to tolerate negative-pressure or non-invasive positive-pressure ventilators because they lacked swallowing coordination with aspiration required tracheostomy or severe scoliosis and deformity of the extremities prevented proper fit of negative-pressure devices. Quadriplegic patients, especially after traumatic spinal injury, generally required tracheostomy and positive-pressure ventilation.

The criteria for selection of patients for positive-pressure ventilation at home generally included etiology of patient who was ventilator dependence, medical condition, frequency of medical intervention, need for changes in ventilator settings, support systems in the home, abilities of patient and family, and finances available for home care [9]. These criteria have been discussed extensively but, in our opinion, are somewhat arbitrary [1,2]. We agree with the findings of previous reports that prospective candidates should have failed aggressive weaning attempts and received maximal treatment of any underlying congestive heart failure or airway obstruction before ventilation at home is considered. In addition, we believe that patients should no longer require positive end-expiratory pressure and prefer patients to be weaned from supplemental oxygen for reasons of safety and economy; however, nine of our 31 patients used supplemental oxygen at home [10]. Our "medically stable" criteria included documented appropriate gains in weight while in the hospital, a serum albumin level of more than 3.0 g/100 mL, stable major organ systems, absence of acute infection, acid-base and metabolic stability and ventilator

parameters readily achievable in the home (no large fluctuation in FiO_2, $FiO_2 \leq 0.40$, positive end-expiratory pressure ≤ 10 cm H_2O, avoidance of intermittent mandatory ventilation, and variation in peak pressure of ≤ 5 cm H_2O) [1] .

Discharge plans varied, but generally revolved around the following considerations; requirements for equipment, education of the care-givers, and psychological preparation of patients, their families, and care-givers [1,11]. Among these, fulfillment of requirements for equipment was generally the easiest to accomplish. Our ventilator-dependent patients were discharged and were provided with a volume-cycled ventilator (PLV-100, Bear-33), a BiPAP-S or a negative pressure ventilator (NPV-100) according to local availability and ventilator cost.

For the majority of our patients, a single ventilator was adequate. Volume ventilators (PLV-100 or Bear-33), pressure target ventilators (BiPAP-S) or negative pressure ventilators (NPV-100 with pneumowrap) were used, depending on the degree of patient's mobility, the amount of ventilation reserve, and accessibility to a local vendor for servicing of the ventilator. Two patients with neuromuscular diseases and one patient with chronic obstructive pulmonary disease used another type of non-invasive positive pressure ventilator; BiPAP-S, but the less expensive alternatives were usually equally satisfactory. Two of our patients with neuromuscular disease used negative-pressure ventilator (NPV-100 with pneumowrap). The patients had to use their own equipment in the hospital for at least one to two weeks prior to discharge, so that settings could be adjusted to assure adequate ventilation and comfort.

The psychosocial evaluation of respirator-dependent patients should begin as early as possible. When discharge to home on a ventilator seemed realistic, the team's recommendations were discussed with the patient and his or her family. Care-givers always expressed some fear of caring for a patient on a "life-support" system, which we viewed as a normal response. We generally found that as training progressed and as the demonstrated competency of the care-givers improved, their level of confidence increased. Seventy percent of our patients were cared for only by family members, friends or a hired non-nursing assistant after their discharge. Six percent of our patients required full-time nursing assistance at home. We generally supported this decision but occasionally found that health insurance did not cover such an arrangement.

The cost of continuous home mechanical ventilation varies greatly and depends on the need for home care personnel, the type of equipment, the type of supplies prescribed, the resources available to the patient, and the local economic factors. The major factor affecting the cost of home care was usually the need for a full-time registered nurse. Equipment was often an easier cost factor to manage. Negative pressure ventilators and non-invasive positive pressure ventilators were often the least expensive [6-10]. Non-disposable supplies were generally less expensive than disposable supplies, but the patients and family members must be trained in appropriate cleaning techniques. Hence, savings were very substantial if patients were cared for by family or friends, or part-time by nursing personnel. On the other hand, the cost of an around-the-clock home care by a registered nurse exceeded the cost of hospital care.

The patients' disease processes and medical status were of utmost importance in the selection process for home mechanical ventilation. There were specific medical conditions, such as neuromuscular disease, spinal cord injuries, and restrictive lung disease, which were likely to present fewer obstacles to successful home mechanical ventilation. Patients with chronic airway limiting diseases, such as bronchiectasis and chronic obstructive pulmonary disease, were not strongly recommended to use mechanical ventilators in the home [2,13-15].

Our intent was to show that mechanical

ventilation at home can be a reasonable alternative to prolonged hospitalization in patients of various ages and with various diseases. We share the concerns of others that long-term hospitalization has detrimental psychological effects on adults. These fears are magnified by the intensive care environment in which chronically ventilator-dependent patients must often live. This atmosphere is noisy and fosters a disregard for privacy, and the patients are subjected to frequent interruption of sleep cycles [6-8,10]. The most extreme example of depersonalization in the intensive care unit is the isolation of ventilator-dependent patients whose airways become colonized with nosocomial pathogens which are considered dangerous to other patients [16]. Coupled with these are the family problems of disrupted home life, time lost from work, and the stresses and economic burdens of daily commutes to the hospital. It was our impression at the beginning of this program that ventilator-dependent patients and their families would benefit from respiratory care at home. Although, mechanical ventilation at home is not without assuming some risks and expenses, we have been impressed with the overall results of home care in our adult and pediatric ventilator-dependent patients. Aided by a dedicated group of care-givers, mechanical ventilation at home can be emotionally, financially, and physically beneficial both to the patients and their families. We recommend that health insurance cover mechanical ventilation at home, so that more ventilator-dependent patients may benefit from such a program.

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慢性呼吸衰竭病患居家使用呼吸器：中國醫藥學院附設醫院的經驗

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目的 探討慢性呼吸衰竭病患居家使用呼吸器其診斷、效益、死亡原因及合併症等結果。

方法 我們回顧分析從1991至1998年所有曾在本院接受治療並在家中使用呼吸器的病患。存活時間由出院開始計算至病患死亡或撤機成功止。死亡率、併發症以及訓練使用居家呼吸器的時間亦列入探討。呼吸照護使用的消耗品耗費之金額計算，我們是抽出5位病患爲代表平均。護理照護的費用亦列入花費統計。藥物的使用，因病人疾病狀況不同，故不列入花費統計。

結果 病患中有18位(佔58%)爲神經肌肉疾病(包括中樞神經病症)，4例爲脊髓損傷，3位病患使用非侵犯型雙向正壓呼吸器，2位使用負壓呼吸器。在這31位病患中，有4位病患成功脫離呼吸器，有11位病人(佔36%)在家中或醫院因呼吸器管路脫離或併發其他合併症而死亡。成人的死亡率大於小孩。大多數這些需要依賴照顧並使用呼吸器的病患，在家中照顧所需的花費少於在醫院所需的花費。

結論 由以上結果我們建議一些生命徵候穩定，但需要長期使用侵犯型呼吸器或非侵犯型呼吸器的病人，可以選擇居家安養。（中台灣醫誌 2000;5:248-55）

關鍵詞

花費，慢性呼吸衰竭，併發症，診斷，居家照護，呼吸器

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